

25 January 2013

Committee Secretary  
Senate Standing Committees on Community Affairs  
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Dear Senator Moore and committee members,

**Submission to Senate Committee Inquiry into the  
National Disability Insurance Scheme Bill 2012**

I have had a long-term involvement in the disability sector as a person with a disability and also as the mother of a young man with disability. Therefore I believe a national framework to address a broken and dysfunctional disability system is long overdue. I commend the Federal Government for bringing it before the Australian people at long last. It will make a positive difference in my life and will drastically alleviate major concerns I've been having about my son's future.

I hope you will positively consider the points I have included in my submission. I believe their inclusion will help strengthen the legislation.

Thank you for the opportunity to make a submission into the inquiry into the NDIS legislation.

Kind regards  
Heidi Forrest

## ***Summary of Recommendations***

### **Recommendation 1**

That the principles and objects make an explicit reference to the primacy of people with disability to the NDIS

### **Recommendation 2**

That the NDIS legislation more comprehensively adopts the principles expressed in the *Convention on the Rights of Persons with Disabilities (CRPD)*, particularly Article 8 Awareness Raising; Article 12 Equality Before the Law; Article 19 Living Independently in the Community; Article 20 Personal Mobility and Article 26 Habilitation and Rehabilitation.

### **Recommendation 3**

That the legislation makes a provision for the inclusion of a presumption that people with disability have decision-making capacity and places primacy on the role of supported decision making.

### **Recommendation 4**

That gender equity firmly be firmly embedded throughout the legislation

### **Recommendation 5**

That the legislation adopts prescriptive language such as 'must' and 'will'

### **Recommendation 6**

That the legislation provides greater clarification about the role of plan nominees by detailing, for instance, the principles governing their operation

### **Recommendation 7**

That the legislation make specific reference to the significant role that Disabled Peoples Organisations can play in the Scheme

That the legislation make provision for establishment an independent monitoring scheme, this would include a method such as the Community Visitor Scheme

### **Recommendation 8**

That the legislation makes provision for a 'cooling off' period to make the transition smoother when moving from NDIS to the aged care system

## ***Objects and Principles***

1. The Objects and Principles should incorporate the purpose of the legislation. It should specifically refer to the citizenship and human rights of people with disability and the fundamental objective of supporting people to achieve their goals, aspirations and the basic human right to lead an 'ordinary' life.

2. S 3 (1) (a) this subclause should also include a reference to the primacy of people with disability within the NDIS.
3. S 3 (1) (h) – this section should make explicit reference to specific articles within the CRPD; particularly article 8 –awareness raising; article 12 equality before the law; article 19 living independently and being included in the community; article 20 personal mobility and article 26 habilitation and rehabilitation.
4. S 3 (1) – the principles section should also include a presumption that people with disability have decision-making capacity.
5. S 3 (2) a whole of government approach is a very positive requirement, but there should be a practical obligation applicable to all government departments to report on disability access and inclusion. Whole of government reporting is not only a practical outcome, but it will also boost awareness and action around disability access and supports in mainstream services and infrastructure.
6. S 3 (3) – I commend the government for the inclusion of the concept of progressive realisation. I believe this will address inherent societal angst about the financial impact of the NDIS.

### ***General Principles under the Act***

1. S 4 (4) – add in the least restrictive way.
2. S 4 (7) – this subclause should be further elaborated to add “that anyone who raises a complaint or seeks to review a decision in respect of this Act should not be disadvantaged as a result of exercising that right.”
3. S 4 (8) – this subclause also needs to make specific reference to article 12 in CRPD, Equal recognition before the law.
4. S4 (11) – a new sub clause (a) needs to be added outlining that people with disability must be able to exercise their rights as citizens, particularly the rights highlighted in the CRPD.
5. S 4 (11) – needs an addition. Should now read “to maximise their independence *and quality of life*”.
6. S 4 (12) – This sub clause makes specific reference to the role of families, carers and significant others in the life of people with disability’ and highlights that they need to be acknowledged and respected. Whilst I welcome the addition of this sub clause, where is there an equivalent reference to the centrality of people with disability in the NDIS? I would like to see explicit reference to a clause like s60CA in the *Family Law Act* that provides for the paramountcy of the child.

7. S 4 - I believe another sub clause is needed in the General Principles under s 4 (15) that addresses the need for infrastructure and all mainstream services to become fully accessible, thereby enabling the ultimate aim of social and economic participation to be realised.
8. S 4 – as a general principle I believe the legislation should also include a specific to the importance of addressing gender equity throughout the text similar to article 6 in the CRPD, women with disabilities. Furthermore, I feel there should be a specific reference to the importance of independent advocacy.
9. I would also like to see the inclusion of a few other General Principles that were recommended in the submission to the Senate Inquiry from the Victorian Disability Services Commissioner:
  - a. People with disability have the right to access information and communicate in a manner appropriate to their communication and cultural needs;
  - b. People with disability have the right to access supports and services which supports social and economic participation as well as maximises their quality of life;
  - c. The Agency and registered service providers should have regard for any potential increased disadvantage which may be experienced by people with disability as a result of their gender, language, sexuality, cultural and indigenous background or location.

### ***General Principles Guiding the Actions of Others***

1. S 5 (a) needs to add '*and supported*' ie (a) people with disability should be involved *and supported* in decision making processes. The reality is that for many people with disability to be able to be fully involved in decision making processes they need to be supported to enable them to make an informed choice. Furthermore, being involved in, doesn't always translated as be included – it reminds me of the concept of parallel segregation.
2. S 5 (b) needs to be expanded so that it not only encourages community participation, but that it also requires the community to become accessible (subject to the concept of progressive realisation). This would promote the removal of barriers to participation.
3. S 5 (d) – I would like to see the inclusion of the word '*respected*'. So that the sub clause reads "cultural and linguistic circumstances of people with disability should be acknowledged, *respected* and taken into consideration. I am concerned that only a reference to '*taken into account*' might limit this requirement. It could also mean that cultural and linguistic factors are heard, but not listened to or seriously considered.
4. S 5 (e) needs to be expanded so that supportive relationships, friendships and connections should be recognised and *respected*. My concern is that if this clause is

not elaborated these fundamental informal relationships may be merely recognised but not respected.

### ***Simplified Outline***

1. S 8 – in relation to agency functions, there should also be a subclause (c) stipulating that the agency will also will be facilitating greater community inclusion of people with disability by promoting accessibility to generic services as well as to infrastructure.

### ***Definitions***

1. S 9 specifically highlights that ‘carers’ are informal supports providing care, support and assistance. The term ‘*Carer*’ needs to be rephrased to read *family, friends and informal support*. The use of the word ‘carer, particularly in relation to informal situations reinforces a charity model of disability where people with disability are positioned as the victim or passive member of the relationship. If the NDIS is to be in line with the tone of the CRPD, people with disability must be perceived as equal partners in all relationships. This legislation should use language that promotes a positive image of people with disability. Furthermore, as the mother of a young man with disability, I don’t like being referred to as his ‘carer’, I am his mother. I support my daughter (who does not have a disability) too, but I’m not called her carer. I feel the term carer denigrates my relationship with my son. I would much prefer the descriptor to be ‘family, friends and other informal supports’ rather than ‘carer’.
2. Cognitive development does not adequately cover *developmental delay*. It should read cognitive, adaptive and social development. A person with disability may develop cognitively but not socially. I note the Bill refers to social interaction, but that is not the same as social development.
3. The legislation needs to include a definition of disability.
4. References to ‘mental’ should use terminology accepted by the sector ie psychosocial.
5. There needs to be a definition of ‘person’ especially as ‘person is specifically referred to, but not defined. Unless ‘person’ is explicitly defined, this will remain highly problematic and unduly invasive.
6. This section must include a definition on safeguards, particularly as safeguards play a key role in protecting people’s rights under the NDIS. It is critical that safeguards are addressed throughout the legislation and that this definition is not narrowly interpreted. The rules must make further elaboration re safeguards. It is important safeguards include protections, monitoring and approvals not only in relation to abuse and neglect, but also in relation to restrictive practices and critical incidents.

## ***Participants and their plans***

1. There needs to be an explicit provision ensuring that the Agency includes complaints and monitoring processes that are independent of the Agency. These must then be further elaborated in the rules.
2. S 13 (2) (b) where the definition of general support is “an activity engaged in by the agency in relation to a person”. This section could end at the full stop. I think that specificities such as coordination and referral would be better addressed and further elaborated in the rules.
3. 19 - There needs to be the inclusion of an additional point addressing the importance of the nominee being local to the participant.
4. S 19 (a) – how is decision-making at a local level going to happen? How is delegation going to be exercised? This must be in the rules?
5. I understand the Productivity Commission Report outlines that if a person with a disability is in the system when they reach 65, they shall have the option of staying with the NDIS or transferring to the Age Care system. Moving to a new care system is extremely traumatic, but it creates even more stress and anxiety for many people ie people on the autism spectrum. To address potential problems associated with moving from NDIS to the aged care system, I recommend the introduction of a ‘cooling off’ period, especially for the first few years. I am concerned about people that have opted to change systems only to realise it was a bad choice. Furthermore, will there be a mechanism for independent review? Will the agency play a role in supporting, informing and monitoring this transition? If so, then this must be elaborated in the rules.
6. Currently the draft bill, 24(d) states: “A person meets the disability requirements if: (d) the impairment or impairments affect the person’s capacity for social and economic participation’. My interpretation of this section is that it only refers to "economic and social" - whereas it should read "economic and/or social". As it currently reads, disability must affect you both economically and socially to be eligible. This discounts anyone who is unemployed, as well as anyone who is only struggling at work, but is not affected socially. The "social impact "of a disability is a fairly broad requirement. The wording of the draft needs to be changed to read "economic and/or social participation".
7. S 24 (2) – How is permanent defined? Where does this leave people who cross over into early intervention?
8. Information about the NDIS refers to tier 1 and tier 2? What are the disability requirements for tier 2?

## ***Participant Plans***

1. S 31 (d) - This clause should be extended to strengthen and build capacity of families and other informal supports even when participants are not children ie in families that include developmentally delayed adults.
2. The principles in relation to participant's plans also need to include a reference to the requirement for independent review, monitoring and a grievance mechanism. These mechanisms need to be put in place to ensure that the choices being made in the plan reflect the goals and aspirations of the participant and not simply programs or activities offered by the service provider. This is because there is a widely held concern that individual plans invariably reflect what a service provider can offer and not what the participant actually wants.
3. What happens for a "participant" who cannot prepare their own "statement" of "goals, objectives and aspirations"? I would suggest the need for Disabled Persons Organisations (DPOs) to help address this gap, through the provision of informal supports in areas such as goal setting and in supporting participants to express their aspirations before they meet with the Agency staff. This initiative would also promote individual empowerment.
4. Furthermore, I am concerned that particularly people with cognitive disability and Aboriginal people with disability who have a fear of government or semi government departments that this may miss out unnecessarily. This could be redressed by the inclusion of a new s 32 (3) indicating that "the CEO may provide assistance to enable people with disability to prepare a plan".
5. S 33 (2) (c) - Does stipulating a date for review limit the review to that timeframe, rather than offer flexibility so that the plan can be reviewed as required? This section must also stipulate the requirement for an independent review.
6. S 36 (2) (b) - If the CEO requires the participant to undergo an assessment for further information, it must be about more than getting a label. The assessment must address how the participant is to be supported ie what their capacities are in relation to how they want to live. The rules must stipulate requirements for additional information and establish ground rules such as relevance to the plan ie assessments need to be compatible with determining social and economic capacity. They also must include the importance of positive language ie it was very demoralising for an orthopaedic surgeon to begin a report about me stating 'Heidi is an unfortunate women'.
7. S 34 (c) – what does "value for money" mean? How will this be determined? As it reads it's very subjective.
8. S 34 (d) – this subclause should be expanded to include not only best practice models but also to trial innovative types of supports and activities
9. S 34 (e) – Currently this sub clause seems to make a subjective judgement about what families and other informal networks can and will provide. This doesn't

consider the individual circumstances of families. For example I have a physical disability and my son is on the autism spectrum. What I can provide in the way of supports is entirely different to the circumstances of another family.

10. S 36 (3) – I feel this section implies that the CEO, not the participant owns the plan. I was of the belief that the participant and not the CEO own the plan.
11. S 40 (3) – This sub clause should also include the same provision that is in s 40 (2) (a) “if the CEO is satisfied that it is appropriate for the grace period to be longer”. The rules must provide guidance about what circumstances this may entail, rather than risking an arbitrary decision.
12. S 45(2) and s 46 (2) re payment and acquittal of NDIS amounts. Any reference to the content of the NDIS must use prescriptive language. Both sections should read ‘must’ not ‘may’.

### ***Reviewing and Changing Participants Plans***

1. S 48 should also make provision for the requirement of an independent review.
2. S 48 (2) - What are the reasons the CEO can refuse to conduct the review? This must be elaborated in the rules.
3. S 48 (4) – what are the reasons the CEO can opt to review a plan? These reasons must be elaborated in the NDIS rules.

### ***Administration***

1. S 52 (2) - This section must prescribe that written notification from the CEO must be provided in a format that is accessible to the participant. Alternatively the legislation may include an interpretive article where the requirement to provide notices and other documentation must be in a format that is accessible to the participant (possibly s 7). There is a concern that if this requirement remains implicit rather than explicit that information may be provide in accessible formats, but not formats that are accessible to the participant.

### ***Privacy***

1. S 60 (1) – this section allows for a ‘person’ to obtain protected information, but there is no definition for ‘person’ in the legislation. The section must provide clarity about who that person is.
2. S 60 (2)
  - a) must include safeguards to ensure the information is protected;



- b) Must specify who 'any person' is, as otherwise this could pose a severe privacy issue and even be in breach of section 62 and other privacy laws. It also must add the requirement 'with written permission from the participant';
  - c) What is meant by 'otherwise use such information'? The NDIS rules must prescribe what situations might necessitate this.
3. S 60 (3) – Also needs to include protections to individual privacy.
4. S 66 - This section must include a requirement that the CEO notify a participant of a decision to disclose information, thereby providing the person with the opportunity to agree to the disclosure.
5. S 66 (1) (b) - In what circumstances can the CEO disclose protected information to other government bodies? If the CEO is empowered to disclose protected information, then there must be safeguards to ensure this information goes no further.
6. S 67 (a) – If the CEO is certified to disclose protected information in the public interest, then the NDIS rules 'must' not 'may' elaborate what type of situations this covers.

### ***Registered Providers of Supports***

1. S 69 (2) – add an extra sub clause (c), it's important to explicitly refer to accessible formats whenever applications are required. Unless it's explicitly addressed within the Act, lawyers and other professionals can interpret that it's not a requirement.
2. S 70 – new (4) it's essential that the rules address the rules for registered service providers to meet the National standards and associated quality framework.
3. S 73 (1) and (2) – amend the wording, the rules 'must not 'may'. The legislation must use more prescriptive language such as 'must' and 'will', not passive terms such as 'may'.
4. S 73 – this section must include the provision of a reference to safeguards (in s 9 definitions). There must be a provision for safeguards particularly in relation to abuse and neglect, restrictive practices and critical incidents. Furthermore, the rules must further prescribe the requirement that registered service providers to provide information to participants on complaints and appeals mechanisms.

### ***Children***

1. Consistent with terms used in the *Family Law Act 1975 (Cth)*, the child's best interest should be the paramount consideration and any views expressed by the child must be taken into consideration. In relation to decision-making the Court gives weight to any views expressed by the child and any factors (such as the child's maturity or level

of understanding) that the court thinks are relevant to the weight it should give to the child's views.

2. S 74 - If the CEO is empowered to appoint someone in the event of joint parental responsibility, then this person should be independent. The Family Court appoints an independent children's lawyer- s 68L *Family Law Act*.
3. The NDIS rules should stipulate how the CEO will make a determination whether or not the child is capable of making decisions themselves.
4. S 74 (6) – must expressly state what the NDIS rules must prescribe. Does the child have a right of review if there's an adverse finding?
5. S 75 (2) – does this mean that the CEO can override a decision of the Family Court?
6. S 75 (3) again there must be provision for the appointment of an independent person or child's advocate.
7. S 75 (4) - The NDIS rules must stipulate how the CEO will make a determination whether or not the child is capable of making decisions themselves. The legislation must use prescriptive language when referring to criteria that needs to be elaborated in the NDIS rules.
8. S 76 (4) - The legislation must use prescriptive language when referring to criteria that needs to be elaborated in the NDIS rules.

### **Nominees**

1. S 78 must make provisions for supported decision making and specifically refer to Article 12 of the CRPD. This is particularly important as currently this section reads weaker than Guardianship Legislation. The NDIS legislation must provide greater clarity regarding the role of nominees. It needs to include protections outlining, when how and by whom different tasks are done.
2. S 78 (5) – Do the NDIS rules prescribe when the CEO can appoint a plan nominee on their initiative? Also when can the nominee determine that a participant isn't capable of doing thing themselves – s 78 (5) (c)?
3. S 79 - Why is there a differentiation between plan nominee and correspondence nominee? The positions overlap, if there's a separation of task it's imperative that these nominees work together and regularly communicate. This needs to be prescribed in the rules.
4. S 80 (4) – NDIS rules 'must', not rules 'may' prescribe other duties of nominee. I also think part of the function of a nominee should be to empower participants so that they are fully informed and have an opportunity to participate in every step of the decision making process.

5. S 81 - should include provision for correspondence nominee to inform and consult with participant of all notices, particularly as s 82 (1) states that notice has been taken to be given to the participant and that the participant is taken to have failed if the nominee fails to comply.

### ***Appointment, Cancellation or Suspension of Appointment***

1. S 86 – Is there a fixed term for this appointment with a provision for renewal? If the CEO is empowered to make the appointment, do the rules address the criteria? If not, this must be addressed in the rules. Will local issues also be addressed or will it be a centralised decision? If it is centralised, then the rules must include pathways to addressing local level issues.
2. S 91 - why only suspend a nominee if they have caused severe physical, mental or financial harm? Shouldn't they be removed - especially if the NDIS espouses to free people with disability from abuse and neglect. If they are not removed this decision must be subject to independent review with in a tribunal.
3. 91 (3) what if there's abuse and the participant is unable or unwilling (possible coercion etc) to provide a written statement cancelling the appointment?
4. S 91 (5) – is the CEO's decision not to cancel the appointment after the suspension ends appealable? If so, it must be to a body independent of the Agency.
5. S 93 – NDIS must prescribe NOT 'may' prescribe requirements. Furthermore, there should be provisions for the decision to be appealed to an independent body.

### ***Review of Reviewable Decisions***

1. Consistent with other sections within the legislation, this section should make reference of a timeframe.
2. S 100 (2) – Reviewable decisions must be subject to independent appeal external to the agency.
3. S 100 (2) and (3) – who can make this request?
4. S 103 - this section should also include a provision for external mediation or other forms of alternative dispute resolution. The AAT only deals with administration, what about issues between people with disability and service providers?

### ***NDIS Agency***

1. S 118 – *Functions of the agency* – add (i) re promoting/advocating that generic services and infrastructure become accessible so that the ultimate aim of economic and social participation can be fully realised. Or alternatively elaborate (d) to include

the need not only to build community awareness but also facilitating greater community inclusion of people with disability by promoting accessibility to generic services as well as to infrastructure.

### ***Board***

2. Will there a board for each agency? Or will there be one board for them all?
3. S 127 (2) – must include a majority of people with disability. Similarly people with disability must be involved in recruitment during appointment process of Agency Staff, the Board and the independent Advisory Council.
4. S 127 (6) Balance of skills and experiences on the Board and IAC should also include gender equity.
5. S 128 – should term of appointment include an option/s for extra term of 3 years?
6. S 136 - his section must also make provisions for people with disability on the board to enable them to fully participate in proceedings.
7. S 142 (1) (c) – should read consult not inform
8. Should the board also (along with the IAC s 152 and s 153) be required to provide written notice of all interests to avoid conflicts of interest?

### ***Independent Advisory Council***

1. S 146 – must provide for a majority of members to be people with disability.
2. S 147 - people with disability must be involved in the appointment process.
3. S 148 – will there be an option to renew?

### ***CEO and Staff***

S 160 – will there be an option to renew?

S 167 (a) – must define and/or elaborate on the meaning of misbehaves.