



Review of the NDIS Act  
Ernst & Young  
GPO Box 281  
Canberra ACT 2601

**Re: Submission to the Independent Review of the Operation of the *National Disability Insurance Scheme Act 2013 (Cth)***

Carers Australia welcomes the opportunity to provide a submission to Ernst & Young (EY) on the Independent Review of the Operation of the *National Disability Insurance Scheme Act 2013 (Cth)*.

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a disability, mental illness, chronic condition, terminal illness, drug or alcohol problem, or those who are frail aged.

Carers Australia acknowledges that both the NDIS Act and the NDIS Rules provide strong recognition of the important role that unpaid carers play in the lives of people with disability. This recognition is greatly valued by carers of people with disability and is critical to providing clear direction on where carers are placed within the NDIS.

This submission provides a range of recommendations about potential changes to the NDIS Act and the NDIS Rules, but does not directly answer each of the discussion questions outlined in the EY Discussion Paper.

Carers Australia sees this independent review as a positive opportunity to achieve consistency across the legislative framework, the Operational Guidelines and other communications materials developed by the NDIA and the Department of Social Services in relation to carers under the NDIS. We hope that any changes to the legislation as an outcome of this review will not only promote further consistency in NDIS engagement with carers, but will provide carers with greater assurance and clarity of how the NDIS recognises, respects and supports their caring role.

Yours sincerely

A handwritten signature in black ink that reads "Areswell".

ARA CRESSWELL  
Chief Executive Officer

9 October 2015



**Carers Australia**

**Submission to the Independent Review of the  
Operation of the *National Disability Insurance  
Scheme Act 2013 (Cth)***

**October 2015**

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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## Introduction

Overall the NDIS Act and the NDIS Rules contain a strong recognition of carers and their role in supporting people with disability. This recognition is important in ensuring that NDIA staff understand the caring relationship and how the NDIS can strengthen it.

Much of the feedback received by Carers Australia about the NDIS from carers of participants is related more to operational issues than to the legislative framework specifically. However, some of the issues raised by carers as well as those identified by Carers Australia and the state and territory Carers Associations may be attributable, in part, to a lack of clarity in the legislation about where carers stand in the NDIS.

## Comments on the NDIS Act

### Inconsistencies in terminology:

There are inconsistencies in how carers are described throughout the Act (and the NDIS Rules). Terms include families, informal supports, informal community supports and supportive relationships. Carers Australia recommends that whenever carers are inferred, that the word carer is explicitly used. This would help both NDIA staff and carers to understand their rights within the legislative framework.

### Inconsistencies around describing caring relationships:

There are inconsistencies in how the relationships between carers and participants are described in the Act. For example,

- Part 2, Section 4, (12) “The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected”. (Emphasis added)
- Part 2, Section 5 (e) “the supportive relationships, friendships and connections with others of people with disability should be recognised”. (Emphasis added)
- Part 2, Section 5 (f) (iii) “strengthen, preserve and promote positive relationships between the child and the child’s parents, family members and other people who are significant in the life of the child”. (Emphasis added)

Carers Australia believes there should be greater consistency in how the Act outlines the way that the relationship between carers and those they care for is supported through the NDIS. As the NDIS Act currently references the *Carer Recognition Act 2010*, there is value in achieving consistency between the two pieces of legislation. The Carer Recognition Act states that “The relationship between carers and the persons for whom they care should be recognised and respected”.<sup>1</sup>

### Nominees:

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<sup>1</sup> *Carer Recognition Act 2010*, Schedule 1.6

Carers Australia has received feedback from the network of Carers Associations that:

- Both carers and representatives from carer associations have experienced difficulties accessing any detailed information about the nominee process including exactly how the NDIA determines whether someone should become a nominee.
- Some carers are confused about how the nominee process works when the person with disability for whom they care doesn't have the capacity to identify a nominee.
- There is some dislike of the term 'nominee' on the grounds that it doesn't reflect the range of decision making capacity of people with disability.
- There is support for the terms recommended by Australian Law Reform Commission (ALRC) including 'supporters' and 'representatives'.<sup>2</sup>
- There is support for greater consistency in the nominee process across the aged care and disability systems. This is particularly important for those who care for both an older person and someone with a disability.

### **Carer rights to support:**

Part 2, Section 31, (d) and (da) of the Act outlines that NDIS plans should "where possible, strengthen and build capacity of families and carers to support participants who are children" and for adult participants "if the participant and the participant's carers agree- strengthen and build the capacity of families and carers to support the participant in adult life".

Carers Australia recognises that the Act makes a distinction between carers of adults who are NDIS participants and carers of children who are participants. This is important to protect the rights of people with disability under the scheme to determine who is involved in the development and implementation of their NDIS plan.

While the Act appropriately gives participants the right to determine whether their carer is supported through their NDIS package of supports, Carers Australia is of the view that those who provide significant unpaid support to an NDIS participant should, at a minimum, be referred to supports for themselves outside the NDIS. This would help to ensure the sustainability of the caring relationship of those who care for someone with limited decision making capacity (and who therefore can't give permission) and those who care for someone who doesn't want carer supports included in their plan.

In Section 3.3 (c), the NDIS Act states that regard is to be had to the *Carer Recognition Act 2010*. The Carer Recognition Act (Part 4, Schedule 1) states that "Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education" and that "Support for carers should be timely, responsive, appropriate and accessible". There may be a need for greater clarity around how the rights afforded under these two pieces of legislation inter-relate.

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<sup>2</sup> Australian Law Reform Commission 2014, 'Equality, Capacity and Disability in Commonwealth Laws,' ALRC Report 124 <https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>

## Access Criteria:

Carers Australia shares the concerns of other groups in the mental health sector around the use of the term 'permanency' as an access criteria for the NDIS.

- The term 'permanent impairment' doesn't reflect the reality of everyone with a severe disability who should receive support through the NDIS.
- It is unclear what 'permanent' means in the context of mental illness. Most people with psychosocial disability have needs (and impairments) that fluctuate in severity and in nature over their lifetimes, and it is often difficult or impossible to predict which people will need long-term support and who will exit the 'system'.<sup>3</sup>
- Requiring individuals with a severe mental illness to obtain a diagnosis of 'permanent impairment' in order to access the NDIS may be problematic from a diagnostic perspective if it is unclear how long the condition will last.
- The requirement to be labelled as 'permanently disabled' acts as a barrier for some people to engage in help-seeking behaviour and is not consistent with the notion of 'recovery' which is promoted in the mental health sector.<sup>4</sup>

## Comments on the NDIS Rules

### Determining reasonable carer support:

#### NDIS (Supports for Participants) Rules 2013

Part 3.4 of this Rule outlines what the CEO is to consider in determining 'reasonable family, carer and other support'.

Carers Australia supports the current inclusions of factors such as the age and capacity of the carer, the intensity and type of support required, and the extent of any risks to the long term wellbeing of the carer.

Carers Australia believes that any additional caring responsibilities - other than for the NDIS participant- should also be taken into consideration when determining what a 'reasonable' level of informal care is. This goes to both those who care for more than one person with a disability, mental illness, chronic condition, terminal illness, drug or alcohol problem or someone who is frail aged, as well as those who have other dependents without disability.

Carers Australia recommends the following statement be added as an additional factor in both sections (a) and (b) of Part 3.4: *'and the extent of any other caring responsibilities'*.

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<sup>3</sup> Mental Health Australia 2013, 'Mental Health and the National Disability Insurance Scheme: Position Paper', [http://mhaustralia.org/sites/default/files/docs/mhca\\_position\\_paper\\_-\\_ndis.pdf](http://mhaustralia.org/sites/default/files/docs/mhca_position_paper_-_ndis.pdf)

<sup>4</sup> Psychiatric Disability Services of Victoria 2015, 'Learn and Build in Barwon: The impact of the National Disability Insurance Scheme on the provision of Mental Health Services in the Barwon Launch site.'

## General criteria for supports:

### NDIS (Supports for Participants) Rules 2013

Part 5.1 (a) of this Rule states that a support will not be provided or funded under the NDIS if “it is likely to cause harm to the participant or pose a risk to others”. Carers Australia recommends that the following addition be included;

*“or negatively impacts on the sustainability of informal care”.*

## Other considerations for inclusion in the legislative framework

Several of the NDIS Operational Guidelines<sup>5</sup> contain more detail about how carers of NDIS participants should be involved and supported through the NDIS. These Guidelines aren't enforceable however and feedback seems to indicate a wide variance in both knowledge of NDIA staff about the Guidelines as well as their interpretation in practice.

While not everything covered in these Guidelines should be included in the legislation, there is merit in seeing some of the key points incorporated into the legislative framework. This would not only give carers a greater sense of assurance about their role in the NDIS, but would also provide better guidance to NDIA staff on the ground about how they can engage with and support carers.

### **Key points about carers covered in the Operational Guidelines that should be considered for inclusion in the NDIS Rules:**

#### Operational Guideline- Planning and Assessment- Supports in the Plan- Supports for Sustaining informal Supports<sup>6</sup>

**s.9** The ongoing capacity of family and carers is critical to the wellbeing of participants. Support loads and other factors such as illness and ageing can place carers' wellbeing at risk and compromise their capacity to continue in the caring role.

**s.12** Consideration of the participant's family context, living arrangements and informal support draws on discussions with the participants and their family and carers, and will take account of the carer's circumstances, capacity and future plans relevant to their caring roles, and the sustainability of caring arrangements. The NDIA will work to make informal caring arrangements sustainable, and provide certainty to carers that the person they are caring for will get reasonable and necessary support into the future.

**s.13** Through the planning and assessment conversation the delegate should:

- c.** Establish the impact of providing this informal support on the carer and their capacity to continue to provide this level of support, now and for the duration of the planning period.

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<sup>5</sup> Operational Guideline – Planning and Assessment- Supports in the Plan- Supports for Sustaining Informal Supports <http://www.ndis.gov.au/operational-guideline-planning-and-ass-6> and Operational Guideline- General Conduct- Communicating with Participants and Others [http://www.ndis.gov.au/sites/default/files/documents/operational\\_guideline%20\\_general\\_conduct\\_communicating\\_participants\\_others.pdf](http://www.ndis.gov.au/sites/default/files/documents/operational_guideline%20_general_conduct_communicating_participants_others.pdf) and Operational Guideline- General Conduct- Providing Support and Assistance [http://www.ndis.gov.au/sites/default/files/documents/operational\\_guideline%20\\_general\\_conduct\\_providing\\_support\\_assistance.pdf](http://www.ndis.gov.au/sites/default/files/documents/operational_guideline%20_general_conduct_providing_support_assistance.pdf)

<sup>6</sup> Operational Guideline – Planning and Assessment- Supports in the Plan- Supports for Sustaining Informal Supports <http://www.ndis.gov.au/operational-guideline-planning-and-ass-6>

This may, in some circumstances, need to be discussed in a separate conversation with the carer.

### **The Carer Statement:**

Since the development of the NDIS legislative framework and the Operational Guidelines, Carers Australia has learned of the option for carers to submit a Carer Statement to the NDIA as part of the planning process for the participant. Correspondence from the NDIA and the Department of Social Services has informed us that the Carer Statement can be in written or verbal form and may cover the following information:

- Carer goals which impact on their informal care provision and sustainability of informal care for the participant.
- Current capacity and any limitations with providing care or support to the participant.
- Other informal support networks available to the participant (e.g. other family members or friends who also provide support).

There is currently no reference to the Carer Statement in either the NDIS Act, the NDIS Rules or any of the Operational Guidelines. Feedback from carers of NDIS participants has illustrated that knowledge of the Carer Statement is very limited. Including a reference to the Carer Statement in the NDIS Rules would promote greater consistency across NDIA staff in their dealings with carers, and would also help to better inform carers of their rights under the NDIS.

## **Conclusion**

Over the last 2 years since the NDIS was introduced, the role that carers play within the scheme has changed. These changes have been reflected in both the introduction of certain Operational Guidelines and in the official communications of both the previous Minister and the Chair of the NDIA Board. Carers Australia has greatly welcomed these developments, but continues to see inconsistencies in the messages about carers rights under the NDIS.

Carers Australia sees this independent review as a new opportunity to achieve consistency across the legislative framework, the Operational Guidelines and other communications materials developed by the NDIA and the Department of Social Services in relation to carers. We hope that any changes to the legislation as an outcome of this review will not only promote further consistency in NDIS engagement with carers, but will provide carers with greater assurance and clarity of how the NDIS recognises, respects and supports their caring role.