



**Carers NSW and Carers Victoria joint submission on the
NDIS Code of Conduct Discussion Paper**

29 June 2017

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

Introduction

The National Network of Carer Associations would like to thank the Department of Social Services for the opportunity for early consultations and for incorporating feedback to include carers in the NDIS Code of Conduct Discussion Paper. Carers NSW and Carers Victoria have taken the opportunity to make a joint submission in response to the Discussion Paper. This submission will refer to implications for family and friend carers of people with disability.

Carers NSW and Carers Victoria are the peak non-government organisations for carers in their respective states and are members of the National Network of Carer Associations. Our vision is an Australia that values and supports all carers and our goals are to work with carers to improve their health, wellbeing, resilience and financial security; and to have caring recognised as a shared responsibility of family, community, and government.

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Background

A carer is anyone who provides informal care and support to a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or who is frail aged. The person receiving care may be a parent, child, spouse/partner, grandparent, other relative or friend.

Care relationships are multifaceted and dynamic. Carers advocate for the health, safety, wellbeing, dignity and inclusion of the person living with a disability to ensure they meet their potential and lead a life of purpose and meaning. However, this often comes at a personal cost to the carer.

Caring can have negative effects on a carer's own financial situation, retirement security, physical and emotional health, housing arrangements, social networks and career trajectory. The impact is particularly pronounced for carers of people who have complex chronic health conditions as well as functional and cognitive impairment.

In a report prepared for Carers Australia by Deloitte Access Economics it was estimated that informal carers in the Australian community provided 1.9 billion hours of care in 2015. Deloitte Access Economics conservatively estimates it would cost \$60.3 billion per year if all informal community care was delivered through formal care systems.¹

Compliance

Carers NSW and Carers Victoria believe there remains insufficient detail on the regulatory corrective mechanisms available to the Commission for non-compliance. It is imperative the Commission has sufficient power to enforce compliance.

Furthermore, it should be considered how the proposed system will interact with existing complaints mechanisms, such as the Commonwealth Ombudsman and State and Territory government complaints bodies, and whether they will retain any jurisdiction, especially if complainants are dissatisfied with the outcome achieved by the Commission.

Consistency

Carers NSW and Carers Victoria note that the fourteen elements identified in the NDIS Quality and Safeguarding Framework² that could constitute a code of conduct have been reduced to nine. While some elements have been integrated into other elements, some have been removed altogether. Carers NSW and Carers Victoria believe the following elements should be reinstated:

- a) *Communicate in a form, language and manner that enables the participant to understand the information provided and make known their preferences*

This element has been integrated into another element, 'promote individual rights, etc'; however, effective communication is essential to planning required services and supports for people with disability and carers and should be a key component of the code of conduct.

Communication should be respectful of the role of carers and families. It should also be inclusive and address the diverse communication styles, needs and limitations of its audience. Communication should be defined in the same manner as Article 2 of the UNCPRD 2006:

Communication includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.³

This should include providing access to an Auslan or LOTE interpreter when required.

- b) *Offer reasonable supervision and take reasonable steps to ensure staff are competent and supported to perform their role*

In the proposed code of conduct 'appropriate staff supervision and training' is seen as a component of the element 'actively prevent all forms of violence, exploitation, neglect and abuse'. However, there is much more involved in staff competence and supervision than 'do no harm'. The code of conduct should promote best practice in safe service delivery which exceeds compliance and achieves positive outcomes for

people with disability and emphasises the importance of self-determination, choice and control and freedom of expression.⁴

c) *Display the code of conduct or make it available to participants*

Carers NSW and Carers Victoria believe the code of conduct should be displayed in all organisations providing disability services in an area visible to clients. An Easy English version of the code should also be on display if clients include people with cognitive disability. People with disability and carers should be aware of the obligations of workers who support them. Furthermore, Carers NSW and Carers Victoria recommend the NDIA should release the final document with a comprehensive funded communications strategy to inform participants and carers of what they should expect from disability services and their right to complain when these services fall short of expectations.

Room for improvement

Specific feedback on elements of the code of conduct which Carers NSW and Carers Victoria believe require further development is provided below.

a) *Promote individual rights to freedom of expression, self-determination and decision making*

We believe this element should include the requirement to act in accordance with applicable Australian laws, for example the *Racial Discrimination Act 1975* and always act in the interests of the NDIS participant. Furthermore, the following should be included: service providers must not intimidate or coerce any person in any way including but not limited to: undue pressure; physical threats; manipulation of anxieties; depriving a person of food, sleep, or basic needs; bullying; harassment; financial exploitation and threats of disallowing visits from family members or friends. This element should also include the requirement for any fees charged to be aligned with the NDIS pricing guide.

b) *Actively prevent all forms of violence, exploitation, neglect and abuse*

We note the following recommendation made by the Senate Community Affairs Reference Committee: "...the establishment of a national system for reporting and investigating and eliminating violence, abuse and neglect of people with a disability which should at a minimum cover all disability workers, organisations and people with disability without being restricted to NDIS participants".⁵ As such, Carers NSW and Carers Victoria believe the code of conduct should be expanded to include all disability workers (NDIS registered and NDIS non-registered as proposed) and all workers delivering non-NDIS funded disability supports, rather than just NDIS funded supports.

c) Act with integrity, honesty and transparency

While this element raises potential conflicts of interest, it should be expanded to include service providers who provide both plan management and disability supports to have mechanisms in place to deal with conflicts of interest as set out in Rule 3.15 of the *National Disability Insurance Scheme (Registered Providers of Supports) Rules 2013*.

d) Provide supports in a safe and ethical manner with care and skill

The code of conduct should include *National Disability Insurance Scheme (Registered Providers of Supports) Rules 3.12 and 3.13* which relate to the qualifications, approvals, capacity and experience of the service provider.

e) Raise and act on concerns about matters that may impact on the quality and safety supports provided to people with disability

This element refers to service providers having in-house complaints processes. The advocacy and safeguarding role of carers in raising concerns and reporting complaints is critical; however, carers are not always supported in this role. Carers do not always feel included in the complaints process.

Some carers who have raised complaints regarding the person they share a care relationship with have felt they did not receive adequate communication and information throughout the complaint process. Further, the additional psychological distress placed on the carer going through the complaints process is seldom acknowledged. As such, in-house complaints processes should always include ways to recognise, respect and support carers. While the code of conduct specifies that 'People with disability need to feel safe to make a complaint or provide negative feedback without fear of adverse consequences or loss of service', the same should apply to carers who often experience adverse consequences of advocating for the person they care for, such as disrespectful treatment and exclusion from decision-making.

Further, service providers should be required to respond properly to a complaint by a person (whether the person is a NDIS participant or not) about the work or services carried out by themselves or their employee. This element should also include direction to service providers that they must submit all documentation required by the Commission within a specified time frame when investigating a complaint.

f) Respect the privacy of people with disability

Service providers are expected not to "...disclose and personal details about a

person with disability without consent'. This includes referring to participants, their disability or support they are receiving in any marketing or communication materials without consent. Carers should have the same right to privacy, especially as the record does not belong to the carer, but stores important and personal information regarding the carer and their relationship with the person with disability.

This element should include reasonable steps to prevent unauthorised access to protected information and should prohibit offering protected information to third parties. It should also refer to: privacy contained in Part 2 of the *NDIS Act 2013 (Cth)*; and the 11 information privacy principles contained within the *Privacy Act 1988 (Cth)*. For services provided in Victoria, this section should also include Part 3 regarding privacy of health information of the *Health Records Act 2001 (Vic)* and the Health Privacy Principles set out in Schedule 1 of this Act.

Regard should also be had for the fine line between protecting the privacy of a person with disability and putting them at risk by limiting the information available to individuals, such as carers who are supporting their decision-making. Recent amendments to the NSW *Mental Health Act 2007* provide good examples for how these principles can be balanced in the storage and dissemination of health information.

Carers NSW and Carers Victoria believe the code of conduct should refer to the obligations of nominees representing NDIS participants, as the existing procedures and principles regarding appointment of, and communication with, nominees is currently unclear and inconsistent, raising issues for participants and nominees alike.

g) Not engage in sexual misconduct

Carers NSW and Carers Victoria believe this element should be expanded to include sexual relations between service providers and participants, both consensual and non-consensual, expressly dealing with the power differential in such relationships. This was contained in the indicative elements of an NDIS code of conduct developed in the Framework, but has since been omitted in the proposed NDIS code of conduct.

h) Keep appropriate records

This element should include that records can be made available for inspection by the Commission.

General comments

a) *Code of conduct awareness raising*

Carers NSW and Carers Victoria support the code of conduct applying to both registered and non-registered NDIS service providers and services funded for ILC activities. However, carers and participants already have increased administrative responsibilities with regards to the following aspects of the NDIS:

- Planning
- Arranging proof of disability documentation through clinicians (if required)
- Finding suitable services
- Arranging service delivery
- Developing service agreements with registered providers
- Nominee duties (if applicable)
- Reviews and;
- Complaints.

Participants and carers who have elected to self-manage the funding for supports under the participant's plan are also required to manage budgets, have an understanding of employment law, set up payroll systems⁶ and provide information on the code of conduct and its obligations to any unregistered providers they engage.⁷

Carers NSW and Carers Victoria believe it should be the responsibility of the NDIS Quality and Safeguards Commission to ensure providers are familiar with the code of conduct, to assist with familiarity and compliance, rather than placing additional administrative responsibilities on participants and carers.

b) *Compulsory online orientation module*

Non-registered NDIS service providers are currently not required to undertake the compulsory online orientation module which will explain the code of conduct. Carers NSW and Carers Victoria believe all service providers, registered and non-registered, should complete the orientation module.

c) *'No wrong door' policy for complaints*

Our associations are supportive of the 'no wrong door' policy, meaning that any complaints outside the scope of the Quality and Safeguarding Commission will be referred to the relevant agency. Inter-agency collaboration delivers a much better and more user-friendly system. A central complaints referral gateway would have the additional benefit of a central data collection point on complaints made to the Commission as well as other authorities, services and agencies.

Carers NSW and Carers Victoria also support the statement that anyone can be a complainant about NDIS-funded supports. Carers are a natural safeguard for NDIS

participants and should be able to make a complaint when necessary. Therefore, complaints data should capture complaints made by carers to enable the relevant authority to provide information on available carer support services, which carers may not be currently accessing. This is especially important if the nature of the complaint is psychologically distressing, as carer support services provide funded counselling and emotional support for carers.

This is consistent with two principles in the statement for Australia's carers defined in the *Carer Recognition Act 2010 (Cth)*:

- *the relationship between carers and the persons for whom they care should be recognised and respected*
- *carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.*

Carers NSW and Carers Victoria would like to see the enabling legislation for the Commission include data collection and reporting on: the reporting of complaints made specifically by carers; the referral of complaints; the outcomes of complaints; and corrective actions undertaken. Furthermore, complaints made by carers should trigger the inclusion of information on carer support services in future correspondence with the complainant.

¹ Deloitte Access Economics, (2015), The economic value of informal care in Australia, 2015, p iii

² DSS, (2016), NDIS Quality and Safeguarding Framework, p96.

³ UNCPRD, (2006), Article 2, available from

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-2-definitions.html>

⁴ DSS, (2013), National Standards for Disability Services: Evidence Guide, p 15.

⁵ Senate Community Affairs References Committee, (2015), Violence, abuse and neglect against people with disability in institutional and residential settings, p xv.

⁶ DSS, (2016), *NDIS Quality and Safeguarding Framework*, p24.

⁷ DSS, (2017), *NDIS Code of Conduct*, p 10.