



**Carers Victoria submission
Proposal for a National Disability Insurance Scheme Quality and
Safeguarding Framework
Consultation Paper released February 2015**

Carers Victoria

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About Carers Victoria

Carers Victoria is the state-wide peak organisation representing those who provide care. We represent more than 700,000 family carers across Victoria – people caring for a person with a disability, mental illness, chronic health issue or someone with an age-related condition. The people being cared for could be a parent, child, spouse, grandparent or a friend.

Carers Victoria is a member of the National Network of Carers Associations, as well as the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership-based organisation. Our members primarily consist of family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

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Introduction

Carers Victoria welcomes the opportunity to provide input to the Department of Social Services (DSS) in response to the consultation paper 'Proposal for a National Disability Insurance Scheme Quality and Safeguarding Framework' released in February 2015.

The consultation paper presents a proposal for the NDIS Quality and Safeguarding Framework (the Framework) with five specific elements:

1. NDIA provider registration
2. Systems for handling complaints
3. Ensuring staff are safe to work with participants
4. Safeguards for participants who manage their own plans
5. Reducing and eliminating restrictive practices in NDIS funded supports

As outlined in Carers Victoria's submission to the NDIS discussion paper on the policy parameters for Information, Linkages and Capacity Building (available on Carers Victoria website www.carersvictoria.org.au), the comments from Carers Victoria in this submission are presented in the context that rollout and transition plans for full implementation of the NDIS in Victoria are not yet publicly available.

In addition, DSS is currently designing an Integrated Carer Support Model for all carers regardless of the age and condition of the person they are caring for, but the design details have not been made available by DSS. Carers Victoria is therefore unable to comment about the integration of these various programmes and plans in conjunction with the proposal for a NDIS Quality and Safeguarding Framework without further detail being publicly available.

Background – carers and the role of Carers Victoria

Carers¹ provide unpaid care and support to a family member or friend needing assistance with a disability, mental illness, chronic health condition or age-related frailty. Carers come from all walks of life, across all age groups and all cultures. Not all carers identify themselves as carers, and may instead identify themselves in terms of their family and friend relationships.

There are an estimated 773,400 informal carers in Victoria, which is 13.6% of the Victorian population. Of these, 217,800 (3.8% of the Victorian population) are primary carers, defined as providing the majority of ongoing care to the person requiring assistance². Women are more likely to be carers than men, with 70 per cent of primary carers being women.

Carers Victoria supports caring families through information, online and face to face training and education programs, respite support, counselling and systemic advocacy. Carers Victoria had 28,545 interactions with carers through our carer advisory line, counselling and other support services during 2013-14.

The cost of providing care

In a report prepared for Carers Australia by Access Economics, it was estimated that in 2010 informal carers in the community provided 1.32 billion hours of care in Australia. Access Economics conservatively estimates it would cost \$40.9 billion per year if all informal community care was delivered through formal care systems³.

Caring can have negative effects on the carers' own financial situation, retirement security, physical and emotional health, social networks and career. The impact is particularly severe for carers of people who have complex chronic health conditions and both functional and cognitive impairments.

¹ The terms 'carers', 'family carers' and 'caring family/ies' used in this submission includes the diverse range of people in care relationships, including carers and people receiving care in same-sex families, 'families of choice', friends and others who provide unpaid care.

² Australian Bureau of Statistics (2013) *2012 Survey of Disability, Ageing and Carers*, Cat. No. 4430.0.

³ Access Economics (2010) *The Economic Value of Informal Care in 2010*, Carers Australia.

Recommendations

Recommendation 1: That the Quality and Safeguarding Framework acknowledges and respects the role of families, carers and other significant persons in the lives of people with disability.

Recommendation 2: That the Quality and Safeguarding Framework acknowledges people with disability can have a significant caring role.

Recommendation 3: That the Quality and Safeguarding Framework addresses the support needs of carers in order to realise the potential economic effects and economic/social benefits of the NDIS for carers.

Recommendation 4: That the Quality and Safeguarding Framework acknowledges that assessment of the vulnerability of a person with disability must include consideration of the role and support of families and carers, and the support needs of carers in order to maintain and sustain care relationships.

Recommendation 5: That the NDIS information system component of the Quality and Safeguarding Framework meets the need for carer specific information, and assists carers to support the person they care for to source, access and interpret information regarding the NDIS and NDIS services and supports.

Recommendation 6: That appropriate supports such as information, counselling, validation and emotional support be provided to carers while they are supporting people with disability during a complaints investigation process.

Recommendation 7: That any system of complaints within the NDIS Quality and Safeguarding Framework develops clear information in plain English about the steps that will be followed after a complaint is made, including how and when feedback will be provided to the person with disability and their carers.

Recommendation 8: That service providers recognise the importance of the participant's significant relationships, including care relationships.

Recommendation 9: That service providers have appropriate policies and procedures regarding planning and implementation of significant service delivery changes.

Recommendation 10: That any capacity building strategy for front line staff will include training to build capacity to respect, respond, support and value the participant's care relationships. Carers Victoria is well equipped to assist with this training.

Recommendation 11: That the NDIA considers a capacity building strategy for NDIA planners including training to build capacity to respect, respond, support and value the participant's care relationships. Carers Victoria is well equipped to assist with this training.

Recommendation 12: That the NDIA publicly reports additional data in their quarterly reports to COAG on the amount of time carers devote to assisting NDIS participants to self-manage their plan, where there is a care relationship.

Section One: Overarching Comments

Acknowledge the role of carers in the lives of people with disability

The Framework rightly places emphasis on the presumption that all people with disability have the capacity to make decisions and exercise choice and control. As has been identified in the consultation document, people with disability often rely on the support of people they trust to make important decisions about their lives (consultation paper, page 15).

Carers Victoria believes that the Framework fails to adequately reflect the significant role that families and carers can have in the lives of people with disability, including supporting people with disability to make decisions. This is an important consideration for any NDIS framework, particularly as the vast majority of people with disability live in the family home, whether by choice or necessity⁴, and challenges the statement in the consultation paper (page 15) that 'many adult participants in NDIS trial sites are not well connected with family'. The Framework also fails to acknowledge that providing support and care to people with disability can come at financial, emotional and social cost for the family and carers.

In addition, while it is acknowledged that many people with disability have little experience in identifying their own goals and aspirations and exercising choice and control (consultation paper page 15) the consultation paper fails to acknowledge that families and carers will also have limited experience in supporting people with this new requirement as part of the NDIS.

By failing to acknowledge and respect the role of families, carers and other significant persons in the lives of people with disability, as required under Section 4 (12) of the *National Disability Insurance Scheme Act 2013* (the Act), the Framework does not adequately provide for specific carer and family supports. These specific supports can assist carers and families in providing natural safeguards for people with disability, as well as supporting them to make important decisions about their lives.

Recommendation 1: *That the Quality and Safeguarding Framework acknowledges and respects the role of families, carers and other significant persons in the lives of people with disability.*

Acknowledge people with disability can have significant caring roles

The Framework also fails to acknowledge and adequately address the fact that people with disability can themselves have a significant caring role. In Australia around one-third of primary carers⁵ have a disability (37%), compared with 16% of people living in households who are not in a caring role⁶.

Recommendation 2: *That the Quality and Safeguarding Framework acknowledges people with disability can have a significant caring role.*

⁴ AIHW (2008) *Disability in Australia: trends in prevalence, education, employment and community living*, AIHW Bulletin 61.

⁵ Primary carers are carers aged 15 years and over who provide the majority of ongoing informal assistance to a person with disability

⁶ Australian Bureau of Statistics (2013) *2012 Survey of Disability, Ageing and Carers*, Cat. No. 4430.0.

Support to realise the potential benefits of the NDIS for carers

The Productivity Commission report '*Disability Care and Support*' released in August 2011 identified that the NDIS can deliver wellbeing gains for carers⁷. The economic effects are estimated by the Productivity Commission as increasing GDP by around \$750 million annually, with the effects taking some time to occur. The Productivity Commission also states that this is likely to underestimate the true labour supply response by carers.

The economic benefits for carers outlined by the Productivity Commission will arise from the better utilisation of some carers' skills by enabling carers with skills and qualifications to return to occupations where their productivity is higher. Some carers cannot access employment commensurate with their skills and qualifications because they require flexible work arrangements to fulfil their caring role. If carers who are already working but have reduced their workload return to higher productivity occupations, it is estimated there will be a further increase in GDP of \$800 million (Productivity Commission, page 966). This means there is a potential \$1.55 billion annual increase in GDP to be realised if the support needs of carers of people with disability are appropriately considered and met within the development of NDIS frameworks and policies. To realise these gains for the Australian economy, as well as for the lives of carers and the people they care for, the NDIS must take into account the support needs of carers.

In this context, Carers Victoria believes that to realise the potential economic effects along with the economic and wellbeing benefits of the NDIS for carers as estimated by the Productivity Commission, the support needs of carers must be fully addressed. This means that carers receive the information, services and support they need at the right time and in the right way to allow them to develop, maintain and support their role in a caring relationship without detracting from their own health; wellbeing; capacity; financial security and resilience. For carers who are already in the workforce, or would like to enter the workforce, it would mean supported them to balance their work responsibilities with their caring role.

Recommendation 3: *That the Quality and Safeguarding Framework addresses the support needs of carers in order to realise the potential economic effects and economic/social benefits of the NDIS for carers.*

A proportional safeguarding framework

The Disability Complaints Commissioners group has produced⁸ agreed minimum safeguards that should form part of a National Quality and Safeguards Framework for people with disability under the NDIS. Carers Victoria agrees with the approach taken by the Disability Complaints Commissioners group that recognises each person with disability faces different risks and different levels of vulnerability. Therefore, any national safeguards system must take a sophisticated and proportionate approach to managing risk.

This approach acknowledges that not all people with disability will require the same level or type of protection, and a person's level of vulnerability may vary from setting to setting or change over time. Carers Victoria builds on this approach to acknowledge

⁷ Identified as 'informal carers' in the Productivity Commission report

⁸ Published 11/2014 ISBN: 978-1-925061-23-9.

that carers of people with disability will also require varying levels of support and assistance depending on their circumstances, and that these may change over time. Any assessment of the vulnerability of a person with disability must include consideration of the role and support of families and carers, and include assessment of the support needs of carers to maintain and sustain care relationships.

Recommendation 4: *That the Quality and Safeguarding Framework acknowledges that assessment of the vulnerability of a person with disability must include consideration of the role and support of families and carers, and the support needs of carers in order to maintain and sustain care relationships.*

Section Two: Specific comments

Carers Victoria has provided specific comments on aspects of the proposed quality and safeguarding framework for the NDIS most relevant to carers in Section Two of this submission.

1. Providing information for participants

The proposed Quality and Safeguarding Framework discusses the NDIS information system from the perspective of the participant. As outlined above in the introductory comments for this submission, Carers Victoria's position is that carers, family members and other significant people hold a key role in the lives of people with disability. As part of their role in supporting people with disability, carers may assist the person they care for to source, access and interpret information about the NDIS and NDIS services and supports.

In addition to their supportive role, carers will have their own information needs. Carers need to be able to access and receive information in a variety of ways. Research undertaken by Quantum Market Research for Carers Victoria⁹ found that carers who are at the start of their caring journey prefer to receive information face-to-face. The information needs of carers may then change throughout their caring role as situations can change quite rapidly. Occasionally carers may return to 'the beginning' with regards to information needs.

The Quantum research also found that parents of children with disability must continually search for new and relevant information as their child grows, reaches new milestones, and as their support needs change. Parents reported that both online and face-to-face learning formats were appealing to them as means for receiving information.

In light of these research findings, Carers Victoria provides information to carers, including carers of people with disability, through a range of different formats. These include face-to-face workshops, eLearning modules available on the Carers Victoria website for registered users, and a telephone advisory line.

Carers Victoria believes the most important features of an NDIS information system are:

⁹ Quantum Market Research for Carers Victoria (2012) *Caring Families Research Report*.

- Information is available that meets the needs of both participants and their family members and carers.
- Information is available in a variety of formats for both participants and their family members and carers.
- Information is available across the lifecourse, and recognises that situations and needs change and evolve for both the participant and carers.
- If telephone advisory lines are used to provide information to participants and carers, these lines can meet any needs they may have when they call, including the need for emotional support.
- Carer specific information is available that complements information for participants.
- Carer specific information is available for carers to assist them to support the person they care for to source, access and interpret information regarding the NDIS and NDIS services and supports.

Recommendation 5: *That the NDIS information system component of the Quality and Safeguarding Framework meets the need for carer specific information, and assists carers to support the person they care for to source, access and interpret information regarding the NDIS and NDIS services and supports.*

2. Systems for handling complaints

The Victorian Disability Services Commission¹⁰ (DSC) believes many people with a disability and their families are still afraid to voice their concerns about disability services, due to fear of retribution and loss of services or relationships. This finding reflects the concerns raised by carers with Carers Victoria.

Carers Victoria believes there should be an independent body or bodies with responsibility for oversight of the NDIS, with powers to investigate and handle complaints. Any independent body must be able to receive and investigate complaints made by carers on behalf of the person with disability who they care for, and provide appropriate supports to carers to assist them in their role as ‘support person’ to the person with disability during the complaints investigation process. This is imperative during investigations of serious incidents.

Recommendation 6: *Appropriate supports such as information, counselling, validation and emotional support be provided to carers while they are supporting people with disability during a complaints investigation process.*

Carers Victoria believes that carers can be required to hold an important role in safeguarding the people they care for; however carers do not always have the right, or may believe that they do not have the right, to complain about services being delivered for the person they are caring for.

The Victorian Disability Services Commissioner and the Victorian Mental Health Complaints Commissioner provide good practice examples of complaints services that allow carers (among others) to make complaints on behalf of the person they are caring for.

¹⁰ Disability Services Commissioner (2014) *Families and service providers working together*, Learning from Complaints, Occasional Paper No. 2.

Some carers who have made complaints in the past directly to service providers have not always feel included in the complaints process. Carers Victoria is aware that some carers who have raised complaints regarding the person they care for felt they did not receive adequate communication and information throughout the complaint process and in some cases believed that key information was concealed. Some carers who have raised complaints with service providers have felt unacknowledged or dismissed as overly paternalistic or 'overprotective', or felt coerced into accepting what they believe is an unsatisfactory outcome.

Recommendation 7: Any system of complaints within the NDIS Quality and Safeguarding Framework develops clear information in plain English about the steps that will be followed after a complaint is made; including how and when feedback will be provided to the person with disability and their carers.

3. High quality support services

The Consultation Paper (page 20) identifies that the most important relationship in the NDIS is between participants and providers. Carers Victoria believes the important relationships for people with disability are the significant relationships in their own lives, including their relationships with family and carers. This would then mean reorientating the wording in the Consultation Paper so that the most important relationship in the NDIS is between the participant, their family, carers and other significant relationships, and the providers.

With reference to existing service delivery for people with disability, carers have raised with Carers Victoria their concerns regarding issues of staff changes, turnover, inadequate staff training and inappropriate staff recruitment. Carers have told Carers Victoria that they believe service providers have too much scope and freedom to make these kinds of significant changes to service delivery (e.g. reductions in staff, service hours or transport assistance), and are not required to justify these changes to clients, their families and governing bodies. These service changes can affect both the person with disability and their carer, with resulting impacts flowing through to the carer's caring role.

The impact of poor quality supports can have significant, profound and long-lasting impact for carers, and lead to deep distrust of providers. Carers Victoria believes that high quality supports that respect and value significant relationships, including care relationships, are required as part of the Quality and Safeguarding Framework.

Recommendation 8: That service providers recognise the importance of the participant's significant relationships, including care relationships.

Recommendation 9: That service providers have appropriate policies and procedures regarding planning and implementation of significant service delivery changes.

Recommendation 10: That any capacity building strategy for front line staff will include training to build capacity to respect, respond, support and value the participant's care relationships. Carers Victoria is well equipped to assist with this training.

4. NDIA staff and planners

The staff of the NDIA, particularly NDIA planners, will have significant roles in the lives of people with disability and their families and carers. Carers Victoria has previously provided input and information to the NDIA concerning the carer experience as part of the planning process, and is encouraged that the NDIA has recognised the need for carer involvement in planning.

However, anecdotal evidence from carers is that the skills and capacities of NDIA planners vary considerably. As the Consultation document acknowledges (page 19), it is expected that NDIA staff will work together with participants to identify risks and safeguards and then work with participants to put in place supports to reduce these risks. This planning process must acknowledge and respect the participant's care relationship and include carers in the process, particularly when they are expected to have a significant role in providing natural safeguards.

Recommendation 11: *That the NDIA considers a capacity building strategy for NDIA planners that includes training to build capacity to respect, respond, support and value the participant's care relationships. Carers Victoria is well equipped to assist with this training.*

5. Self-management

Self-management in the NDIS context is likely in most cases to involve both the participant and their carer, where there is a care relationship. Currently there is no publicly available data on the role and potential burden placed on carers who are caring for a person with disability who is a NDIS participant and self-managing their plan. Carers Victoria is aware that potentially carers are significantly involved in the process of self-management, including organising appointments, budgeting etc.

Carers Victoria strongly encourages the NDIA to publicly report additional data in their quarterly reports to COAG on the amount of time carers devote to assisting participants to self-manage their plan for those NDIS participants who are self-managing, and where there is a care relationship.

Recommendation 12: *That the NDIA publicly reports additional data in their quarterly reports to COAG on the amount of time carers devote to assisting NDIS participants to self-manage their plan, where there is a care relationship.*