

30 April 2015

NDIS Quality and Safeguards Framework Consultation Team

Department of Social Services

NDISqualitysafeguards@dss.gov.au

NDIS Quality and Safeguarding Framework

Dear Sir/Madam,

Carers NSW welcomes the opportunity to provide a submission in relation to the NDIS Quality and Safeguarding Framework.

Carers NSW is an organisation for people who provide 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. Carers NSW supports and advocates for carers in NSW, and is the only state-wide organisation that has all carers as its primary focus. Carers NSW is also part of the national Network of Carers Associations, which works collaboratively to lead change and action for carers.

Our submission focuses on the role of informal carers as natural safeguards and stakeholders in service quality. It addresses the topics of building capacity, determining quality, making complaints, self-management and restrictive practices.

Thank you for accepting our submission. For further information, please contact Sarah Judd, Policy and Development Officer, on (02) 9290 4744 or email sarahj@carersnsw.org.au.

Yours sincerely,



Elena Katrakis

CEO

Carers NSW

Carers NSW submission in relation to the NDIS Quality and Safeguarding Framework

Background

The National Disability Insurance Scheme (NDIA)'s document *A national quality and safeguarding framework* observes that:

“A person who has a network of family and community support, understands how the system works, and has a sound knowledge of their rights will always be better protected by these natural safeguards than they would by any safety-net built by governments.”¹

This principle forms a key part of the developmental domain addressed by the framework. While not all people with disability have informal carers, most do.² Recognising and supporting informal carers is therefore critical in preventing neglect and abuse, as well as other problems people with disability may experience when using disability supports.

Informal carers generally know the people they care for well and have a personal interest in their safety and wellbeing. The 2012 Survey of Disability, Ageing and Carers indicated that the majority of informal carers are family members³ and the Carers NSW 2014 Carer Survey found that more than half of informal carer respondents were caring because they wanted to.⁴ As a result, informal carers generally have the person's best interests at heart, are experienced in communicating with the person, see them regularly enough to notice any problems and are likely to have their trust and be called upon in a time of need.⁵ Informal carers can also be key sources of information and often play the role of advocate for the person they care for.

However, informal carers cannot effectively fulfil the role of natural safeguard without adequate, ongoing information and support that takes into account the caring arrangement. The pressures that can be associated with the caring role can sometimes cause the relationship to deteriorate. If an informal carer is not coping in their role, they may be less likely to notice, report or appropriately deal with risks or problems. Worse still, other risks to the safety of the person with disability may arise due to, for example, parental mental health or family dysfunction.⁶

In order to be effective natural safeguards, informal carers need adequate information and support, both in relation to their role as safeguards and in relation to their caring role in general. As an association for informal carers in NSW, in this submission Carers NSW seeks to address how informal carers can best be strengthened and supported as natural safeguards. It focuses on building capacity, determining quality, making complaints, self-management and restrictive practices.

Building capacity

In many cases, building the capacity of informal carers is just as important as building the capacity of people with disability. Informal carers who understand the rights of the people they care for and how to navigate the service system can play an important role in safeguarding, especially where the cognitive capacity of a person with disability is limited. Informal carers should therefore be provided with information and training opportunities that strengthen them in this role.

Information and training should, as the draft framework suggests, cover rights and responsibilities, self-advocacy and decision making skills and guidance on navigating the system and how to choose support types and service providers. Information and training should not be restricted to passive formats such as fact sheets, but should also involve interactive components, such as online learning modules and face-to-face learning and peer support opportunities.

Information must also be accessible to diverse groups of informal carers. While it is important for the NDIS to be flexible and innovative in delivering information through emerging technologies, it should also be remembered that some people do not have compatible devices, computer skills or internet access. For example, 53% of respondents to our 2014 Carer Survey did not use online support at all.⁷ Care should therefore be taken to deliver all information in a variety of modes: online, in print form, over the phone and in person. Language should be clear, simple and free of jargon and available in other languages where appropriate, with any translated material written at an appropriate level of language for the intended audience.

Determining quality

The NDIS prioritises the choice and control of participants and their families and carers. Determining the quality of disability supports should therefore heavily reflect the preferences and experiences of these service users. Any registration or accreditation processes should avoid more conventional, institution-based ‘tick the box’ approaches and instead place a strong emphasis on the feedback of people with disability and informal carers. Outcomes measures should take into account their experiences and ratings. People with disability and their carers should also be encouraged to share their feedback with their peers in public fora to support others to exercise informed choice and control.

Providers should be held accountable to certain basic quality and safeguarding principles and procedures, but should also be encouraged to go above and beyond in their staff vetting and training, for example through a star rating system. This could also act as an incentive for small, non-traditional or mainstream providers by adding commercial value and avoiding onerous accreditation or reporting requirements that do not line up with their core business. Small, non-traditional and mainstream providers need to be encouraged to become NDIS providers to maximise choice and control and community engagement for participants and their informal carers.

In contexts where there is a limited market, for example in rural and regional areas, there may be a disincentive for providers to maintain a high standard of service due to a lack of competition. This could compromise service quality for participants and leave carers to fill the gaps. Mechanisms for ensuring quality services in such situations, and providing incentives for ongoing quality improvement, will therefore be important.

Clarifying the level of risk for particular individuals throughout the planning and review processes, in consultation with their informal carers, will also be an important safeguard in the NDIS. In this way, decisions about self-management and choice of registered or unregistered providers can be tailored to individual need and preference. In all cases, however, the risks of various courses of action should be clearly and appropriately communicated to the participant and their informal carers so that they are able to make informed choices and take appropriate action if problems arise.

Making complaints

It is often an informal carer that discloses a problem or makes a complaint with or on behalf of a person with disability. Sometimes barriers can prevent this from happening in a timely and appropriate manner. Barriers can include a lack of information or support about rights and avenues for complaint, physically or otherwise inaccessible offices, communication challenges and uninformed or prejudicial attitudes on the part of the informal carer and/or the service provider.⁸ Care should be taken to eliminate such barriers wherever possible.

Informal carers should also be able to make complaints and challenge decisions in their own right. This is vital given that any shortcomings in the decision process and resulting plan and package will often negatively impact on the informal carer as well as on the person with a disability. For example a carer may be unhappy with the level and nature of the caring responsibilities they are providing, the level of support provided to them in their caring role, or treatment of them by a service provider. An inadequate individual plan, funding package or service may lead to serious negative impacts on an informal carer's health and wellbeing, withdrawal from education or employment, and neglect of other responsibilities, including to other family members. In some cases, the impacts on the carer can be highly significant and long term and affect their ability to support the person they care for.

Self-management

In a self-managed plan, risk is transferred to the participant in addition to greater choice and control. This also affects informal carers, placing more of an onus on them to identify and mitigate any risks that might arise for the person they care for. This increased level of responsibility must be accompanied by adequate information and support so that they can perform this role confidently. Support must be given to carers to ensure they know what is required of them and are confident that they can deliver or seek further support where required.

Informal carers involved in the provision or coordination of NDIS supports should be duly consulted if the planner and participant are considering self-management. In cases where self-management is the preferred arrangement, planners should work as a team with the participant and any informal carers who will be involved to help them understand the risks involved and to build their capacity to manage these risks.⁹ Appropriate, accessible information, resources and training opportunities to assist the participant and their informal carers to make wise decisions should be freely available. Informal carers should also have access to planners to provide feedback, ask for support or voice their concerns, and planners should seek to liaise with informal carers wherever possible to ensure that safeguards are adequate.

Restrictive practices

In line with current industry practice, Carers NSW believes that restrictive practices should be avoided wherever possible. However, decisions about any kind of behaviour management should always involve consultation with a participant's informal carers. This should not be limited to primary carers or formally appointed decision makers, but should include, where appropriate, any informal carers contributing to the provision, management or coordination of supports.

Informal carers are likely to have specialist knowledge of the participant's behaviour that can assist with planning, and also need to be informed and supported to implement agreed principles of behaviour support in their own care for the participant. In addition to consultation, informal carers may also require ongoing, and sometimes intensive, support to manage the participant's challenging behaviours in their own caring role, especially as challenging behaviours often cause distress and may pose significant risks to the health and wellbeing of informal carers.

Conclusion

Quality in the NDIS should be ultimately judged by participants and their informal carers – those who are choosing and using disability supports. While formal frameworks need to be in place, DSS and the NDIA should place a high priority on consulting not only participants but also informal carers in the design of these frameworks. Policies and practices around safeguarding should acknowledge the

important role that informal carers play as natural safeguards and adequately inform and support informal carers to fulfil this role effectively.

¹ National Disability Insurance Agency (2015) *A national quality and safeguarding framework*, p.2

² Australian Bureau of Statistics (2013) *Disability, Ageing and Carers, Australia: Summary of Findings, 2012*, Disability tables, Catalogue no. 4430.0. The 2012 Survey of Disability, Ageing and Carers indicated that 81 per cent of people with disability needing assistance received support from informal carers. For those with a profound or severe core activity limitation (that is, needing help with self-care, mobility and/or communication), 91 per cent received informal support.

³ ABS (2013) *Disability, Ageing and Carers, Australia: Summary of Findings, 2012*, Carer tables, Table 39, Catalogue no. 4430.0.

⁴ Carers NSW (2014) *Carers NSW 2014 Carer Survey: Main report*, Carers NSW, Sydney NSW, p. 21. The Carers NSW 2014 Carer Survey is the most recent of our biennial surveys of carers in New South Wales. The survey was completed by 1,684 carers.

⁵ Disability Services Commission (2014) *Disability Services Commission Position Paper: Individual safeguarding*, Government of Western Australia, Perth; Mental Health Commission (2013) *Draft safeguards framework for individualised support and funding*, Government of Western Australia, Perth WA; NSPCC (2014) *'We have the right to be safe': Protecting disabled children from abuse. Main Report*, NSPCC.

⁶ NSPCC (2014); Office for Standards in Education, Children's Services and Skills (2012) *Protecting disabled children*, Ofsted, Manchester, UK.

⁷ Carers NSW 2014 Carer Survey, unpublished data.

⁸ Department of Family and Community Services (2013) *Prevention of abuse and safeguarding mechanisms in ADHC*, Prepared by KPMG; NSPCC (2014).

⁹ Local Government Association (2013) *Making safeguarding personal*, Local Government Association, London; Mental Health Commission (2013);