**National Disability Insurance Scheme Quality and Safeguarding Framework**

**April 2015**

The Dietitians Association of Australia (DAA) is the national association of the dietetic profession with over 5800 members, and branches in each state and territory. DAA is a leader in nutrition and advocates for food and nutrition for healthier people and healthier nations. DAA appreciates the opportunity to provide feedback on the proposal for a National Disability Insurance Scheme Quality and Safeguarding Framework.


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## DAA interest in this consultation

The Dietitians Association of Australia (DAA) advocates for the basic human rights of people with disability to a standard of living adequate for their health and well-being, including food.

The Accredited Practising Dietitian (APD) program is the foundation for self regulation of the profession, and a public assurance of safety and quality. APDs provide medical nutrition therapy to people with a disability and their families to achieve personal goals. APDs also work with other stakeholders in the disability sector to support individuals and groups of people with disability to achieve well being and quality of life.

## Discussion

### Need for a quality and safeguarding framework

DAA considers a framework is essential to manage the risks to which people with permanent and significant disability, their families and carers will be exposed as states and territories retreat from existing disability arrangements and the NDIS is progressively implemented to provide individualised support.

Some of this risk will be managed by existing safety and quality mechanisms, such as professional regulation, Australian Consumer Law, and the National Disability Standards. The proposal identifies where further mechanisms might need to be developed.

However there is insufficient attention for the risk to people with disability who fall between the cracks of the NDIS and other government departments such as health. Families are already being denied services as state agencies close down services before the full implementation of the NDIS across Australia.

### Principles to guide the development of a quality and safeguarding framework

DAA generally agrees with the principles to guide the development of a Quality and Safeguarding framework for the NDIS. The principle of *Presumption of capacity* presents challenges to implementation however for people who are profoundly disabled and less able to determine and express their choices. It will be important that the framework addresses how family, friends and other stakeholders are to interpret the wishes of this vulnerable group of NDIS participants.

**Managing the risk of poor quality**

*Information is essential*

The risk of receiving poor quality supports is correctly identified. DAA considers this risk can be managed in part by ensuring that participants and NDIA Local Area Coordinators and Planners are well informed so that they can assist participants to identify and articulate their needs, to understand what services will meet these needs and how to access services.

Before the NDIS, there was poor recognition that lack of nutrition has an impact on the growth and development of children with disability, and the quality of life of adults with disability. The NDIS has the potential to improve access to dietetic services to enable people with disability to achieve better quality of life, but NDIA planners will need to be well informed if they are to support participants.

*Practice must be based on evidence*

The risk that people with disability might be harmed can be managed in part by ensuring that models of care and service delivery are based on solid evidence. New models such as the proposed early intervention with 'transdisciplinary approaches' or 'key workers' [1] should be based on interventions which demonstrate that the model benefits participants and does no harm. DAA has knowledge of a case of a key worker not recognising the nutrition needs of a child with Downs Syndrome even though the child was 'skeletal', and 'coughing after feeding' suggesting aspiration.

*Access to services*

DAA identifies another risk i.e. that people with disability cannot access services which they both need and want through the NDIS, Commonwealth or state or territory government agencies. DAA members report that this is already happening in trial sites and beyond as illustrated in this case study

> *Child with cerebral palsy, epilepsy, global developmental delay. Not able to take food safely orally and requiring all nutrition requirements through gastrostomy feeding. This patient was previously being seen at a state health facility and was receiving Home Enteral Nutrition (HEN). The outpatient service has recently closed and the child's family have been informed that she can no longer access HEN pricing at state government contract prices as she has been discharged from the state service. Referred to an APD as a private client under a Medicare Chronic Disease Management Item. The family is very concerned as they are on a disability carer pension and are unable to afford the cost of the HEN formula which is over double the price they were previously paying.*

While there are some people with disability for whom the Medicare Chronic Disease Management Items are appropriate, for people with complex needs the five visits

available under the CDM item are not sufficient to facilitate access to the variety of practitioners required annually. Not all allied health practitioners bulk bill, so families may be out of pocket.

**Important features of an NDIS information system for participants**

The information system should be

- supported by technology to facilitate access across participant abilities, geographical, age and socioeconomic gradients
- comprehensive to include the full range of services which meet the needs of people with disability, with connections to service providers
- easy to navigate so that participants are not sent from agency to agency, provider to provider to access the services they need, whether funded under an NDIS package or not
- be continuously updated
- be informed by trained staff and updating online and other resources.

**Developmental domain**

*Building capacity important*

DAA agrees that it will be critical to build the capacity of participants for self direction and self advocacy. The approaches suggested in the consultation document are appropriate. This will be especially important for individuals and families who are refused services or can obtain limited services from the NDIA and other agencies, and who must piece together the services they need from various providers.

*Duty of care*

DAA considers additional measures will be needed for people who are profoundly disabled and who are more reliant on family, friends, or carers to interpret their needs, to assess risks and manage risks on matters related to their health and wellbeing on a daily and ongoing basis. Stakeholders should be aware that participants of the NDIS have rights as stated in the United Nations Conventions for disability[2] and universal human rights[3] *“Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food...”*.

Staff employed in various government agencies operate within guidelines addressing duty of care[4]. Anecdotal reports from DAA members indicate that the perception of duty of care held by carers for participants in trial sites may not be consistent with guidelines which were in effect prior to the trial. This is illustrated by the following case which places the client at risk.

> *A profoundly disabled client was prescribed a diet by a medical practitioner. This was supported by the dietitian working with the participant given there was sufficient evidence for implementing the diet and potential benefits for the client. The client did not have the capacity to give consent. The carer disagreed and chose not to implement the diet.*

Carers, NDIA Planners, NDIA Local Area Coordinators, service providers and other stakeholders must participate in training to implement appropriate strategies for interpreting the needs of NDIS participants who have very limited capacity for self determination.

**Preventive domain**

DAA agrees that preventive measures must be in place to prevent harm to people with disability.

*Service level safeguards*

The service level safeguards described in the Framework on page 20 are generally appropriate. DAA considers that it will be important for practice to be evidence based. New models for service delivery should be based on relevant research, involve key stakeholders and be evaluated thoroughly before full implementation in the NDIS. DAA has concerns about the evidence base for the model of early childhood intervention being implemented in some NDIS trial sites, and that the model is being implemented without rigorously evaluation. DAA will be participating in the forthcoming workshops for the ECIA project for the development of practice guidelines but is concerned about the potential for harm to NDIS participants who receive therapy from practitioners operating outside of their scope of practice.

*Lack of coordinating functions*

While DAA supports the principle of individual choice, the implementation of this through the funding of individual packages for specific service providers means there is no coordinating function for the individual. Some participants will have the capacity to work with the various providers, but others will find this challenging. In previous models this might have been addressed by multidisciplinary and interdisciplinary team models of care involving practitioners from one agency, and also through case managers. These functions are not evident in the NDIS model to date where Planners are not to be case managers. Consequently, DAA is concerned that even with capacity building, participants with complex needs and their families will be challenged by having to coordinate their own care.

*Safeguards related to NDIA processes*

Risk assessment and risk management must be built into NDIA processes to minimise risks to participants. When drafting the *Support Clusters and Associated Pricing* for the trials of the NDIA, the NDIA sought advice on the risks of reusing 'single use only' enteral nutrition giving sets for some participants eligible for Home Enteral Nutrition. DAA is surprised that the NDIA considered it reasonable that participants carry the risk of food borne illness related to reusing giving sets as a result of participants being able to access 75% of the giving sets they require annually through the NDIA. If participants do not wish to accept this risk they must purchase additional feeding sets. Alternatively they may request these through their NDIA Planner, but participant and planners may not know there is the flexibility to do this.

*Safeguards related to meeting common needs of groups of people with disability*

There is a high likelihood that people moving from large state run facilities to supported small group houses will not have their common needs met because their packages are determined on an individual basis and there is no mechanism to recognise the common needs. For example, people with special dietary needs in a large facility would expect to receive food and beverages prepared by trained staff according to accepted standards to meet their nutrition needs. DAA believes it is essential that standards of support for group homes are developed, implemented and monitored; that carers receive ongoing training to meet the food and nutrition needs of residents of group homes, and that ongoing funding is available to support these functions. Failure to address this issue places people with disability at risk of reducing their capacity to live a productive and happy life.

**Corrective domain**

Australian Consumer Law, the National Disability Standards and existing professional regulation will provide some protection for people with disability but more is needed.

*Independent oversight body for the NDIS*

DAA supports elements of the *Oversight* functions described in the paper but is concerned about the potential for people with disability to be harmed or experience financial hardship where services are limited or denied under the NDIA and state and territory government services. The case study provided earlier illustrates that this is happening already before the full roll out of the NDIS.

Some of the established bodies referred to in the consultation document can investigate cases in the Commonwealth, or at the state and territory level, but it will

be important for an independent oversight body for the NDIS to address cases which are falling between the jurisdictions.

**NDIA provider registration**

DAA considers that service providers should be able to provide participants of the NDIS with safety and quality assurances. Robustly self regulated professions can demonstrate this already e.g. the Accredited Practising Dietitian program is recognised by Medicare, Department of Veterans Affairs and private health funds. Health facilities that require health professionals to be credentialed and qualified use existing programs of this type for safety and quality assurance rather than reinventing additional credentialing systems. DAA recommends a similar approach for recognition of self regulated and registered health professionals for the NDIA to minimise the red tape burden on providers.

Where service providers are not already regulated in this way, DAA recommends that systems be implemented for quality and safety assurance purposes.

**Providing assurance while letting people make their own choices**

The issue of balancing the provision of assurance with letting people make their own choice is complex as discussed earlier in this document. Training and education for all stakeholders will be important as a foundation, also ongoing discussions in public forums, and investigation of cases of documented harm to NDIS participants.

**Systems for handling complaints**

Part of the capacity building for participants will be education on how to approach agencies or service providers who have not met participant expectations. Professional regulators such as the Dietitians Association of Australia already have systems for handling complaints which are supported by a code of conduct and statement of ethical practice. DAA considers it is important that there are mechanisms to deal with complaints for service providers who are not registered or robustly self regulated.

There must also be mechanisms for complaints against the NDIA.

**Ensuring staff are safe to work with participants**

DAA supports measures which ensure staff are safe to work with participants. The measures required should be similar to those required already in health and state disability services and should address risk management by employers, a requirement for referee checks for all roles and police checks for certain employee roles, working with vulnerable people clearances, and a national barred persons list.

Risk management by employers should include employing staff who are already professionally registered or self regulated, and ensuring staff with vocational qualifications or industry experience are appropriately trained and supervised to assure participants of safety and quality.

**Safeguards for participants who manage their own plans**

People who manage their own plans should be required to choose providers who can meet NDIA agreed quality and safety requirements. DAA considers that the NDIS have a duty of care to ensure that all providers are safe and competent, and practice within scope of practice.

**References**


1. Early Intervention Best Practice discussion paper. Early Childhood Intervention Australia NSW Chapter October 2014. Available from http://www.ecia.org.au/advocacy/best-practice-development-project Accessed on 30 April 2015
2. UN Convention on the Rights of Persons with Disabilities. Available from http://www.un.org/disabilities/convention/conventionfull.shtml Accessed 30 April 2015
3. Universal Declaration of Human Rights Available from http://www.un.org/en/documents/udhr/ Accessed 30 April 2015
4. Accommodation Policy and Development Directorate. Nutrition and Swallowing Policy and Procedures 2012. Available from http://www.adhc.nsw.gov.au/publications/policies/policies_a-z?result_237652_result_page=N Accessed 30 April 2015