Inquiry into the implementation of the NDIS and the provision of disability services in NSW.

August 2018

The Dietitians Association of Australia (DAA) is the national association of the dietetic profession with over 6000 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 communities. DAA appreciates the opportunity to respond to the Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales by the NSW Legislative Council.

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DAA interest in this consultation

DAA supports the implementation of the NDIS and acknowledges the potential of the NDIS to improve the wellbeing of people with disability. DAA considers that the various nutrition needs of people with disability have not been well recognised in the past and that improved access to nutrition products and services through the implementation of the NDIS will enable people to reach their goals, to increase their social and economic participation, and to develop their capacity to actively take part in the community.

The Accredited Practising Dietitian (APD) program administered by DAA is the platform for self-regulation of the profession and provides an assurance of quality and safety to the public. APDs are food and nutrition experts who translate the science of nutrition into practical solutions for healthy living. APDs assist people with disability to make positive lifestyle changes tailored to their unique needs.

Key messages

DAA would like to see people with disability prosper under the NDIS. We would like to see

- More communication with peak professional bodies in building and implementing the NDIS.
- More work in developing policy which is translated clearly and consistently by planners and is clearly expressed in NDIA publications.
- Processes at the disability-health interface which resolve disputes quickly
- Registration processes which are genuinely risk proportionate, are simple and inexpensive
- Greater adherence to the principles of consumer choice and control in planning
- Monitoring of workforce and investment in workforce development in NSW and nationally.

Choice and control for people with disability

Frequent feedback from DAA members is that NDIS participants who request access to nutrition support products and APD services in their NDIS plans are not having their choice respected in these matters as planners do not include these

items in plans. This has occurred even when participants have previously been supported with APD services and nutrition support products by ADHC in New South Wales. The NDIA have stated in Senate Estimates of the Australian Parliament that decisions about access to services is made individually but there is evidence that this is a systemic high-level policy decision by the NDIA. For example, when asked if APD services and nutrition support products would be included in an Assistive Technology trial being run by the NDIA, we were told "no, due to the interface issues" i.e. interface between health and disability.

Some participants have requested reviews, and faced with unsatisfactory outcomes, they have applied to the Administrative Appeals Tribunal. It is commonly reported that the NDIA settles with participants before a judgement has been delivered, we assume to avoid a judgement being on record to form a precedent.

Experience of people with complex care and support needs

Many of the participants choosing to access APD services have complex care and support needs, often related to functional impairments of eating and drinking. APDs work with the participant, their family and support workers to increase their independence in functioning to enjoy social situations and to increase their participation in the community. However, participants are frequently denied APD services by the NDIA whose interpretation is that efforts to prevent choking and aspiration are preventing health events and therefore the responsibility of health services. We do not agree with this interpretation, which suggests that impairments related to eating and drinking as activities of self-care are considered differently to impairments related to mobility. This is despite the fact that all such impairments are described in the International Classification of Functioning, a document referenced by NDIS legislation.

An example of the experience of a participant was described in August 2018

> *"In one case I have had a client in a group home who paid for her annual (required by the home) dietetic consult out of her own pocket because her considerable NDIS funding did not cover health and wellbeing, and no health goals were stated, so improved daily living funding was also inaccessible. A request to update goals was submitted to NDIA, but the plan was re-written without consulting the client or the group home directly and the opportunity was missed for a second time."*

Another example from a different area was reported in December 2017.

> *"It is completely unacceptable for the NDIS to pull funding. Health cannot meet the needs of these people. A good example is the 30 people in the*

*XXX*Location supplied*XXX I look after living in group homes. Most have multiple diagnosis including cerebral palsy, extreme intellectual disability, extremes contractures. 1/3rd of them are on PEG feeds. At times they require input from me weekly as we make adjustments to feeding regimes following, for example episodes of vomiting, hospital admission and discharge on an extremely low rate of feed and minimal flushes."*

A further example is on record from January 2017

"I have a case study for you regarding an NDIS client with Huntingtons Disease who has been refused service by NSW Health dietitians (documented in emails to Speech Pathologist) and whom NDIS has also refused to fund dietetics. I have cc'd the case manager from XXXXorganisationXXX who has been liaising with NDIS and requested funding multiple times only to be denied again and again.

I originally saw this lady under a Medicare Plan where I bulk-billed a home visit as a favour to a colleague who was extremely concerned about this lady's wellbeing. This lady has deteriorating swallowing function and is at high risk of aspiration. She is currently being considered for enteral feeding. She lives with her elderly stepfather who provides most of her care as well as support staff who visit daily. I have had 2 other cases that I can remember of clients with the same diagnosis and risks who were funded for dietetics without question. The only difference I can see is the lack of capacity of the stepfather to advocate on her behalf due to his own failing health."

The accessibility of early intervention supports for children

DAA highlights the anomalies which exist in accessing APD services for children younger than seven years. Children with plans managed by the NDIA are denied access to APD services because of unwarranted limits published in the NDIS Provider Registration Guide to Suitability. Dietitians have inexplicably been omitted from the Early Childhood category, and editions published from June 2017 onwards state dietitians and others are only able to register for Therapy Supports for participants aged seven years or older.

Children whose plans are self-managed have no trouble including APDs in their plans according to the principle of choice and control. Children whose Early Childhood Partner employs an APD in their team, can access an APD. (although we note that not nearly enough APDs are employed by Early Childhood Partners)

DAA has taken this matter up with the NDIA which acknowledges some children might access Accredited Practising Dietitians but they have not changed their written advice in the Registration Guide. The NDIA's most recent advice to DAA

was to take the matter up with the NDIS Quality and Safeguards Commission since the Commission now has responsibility for registration in NSW.

The provision of support services, including accommodation services

APDs report that participants who previously were supported under ADHC in NSW are not being supported in their NDIS plans for similar supports.

The adequacy of current regulations and oversight mechanisms

Current oversight mechanisms are not adequate to resolve issues at the health-disability interface. We have heard accounts of adverse outcomes for participants for example where they experience extended stays in hospital because adequate arrangements cannot be made for their discharge into the community.

Workforce issues impacting on the delivery of disability services

The uncertainty in the market and frequent changes in administrative requirements working in the NDIA environment are barriers to entry to the workforce for APDs.

DAA is concerned that there will be limited opportunities for dietetic students to have exposure to disability as an area of practice, as the private practice environment is not currently set up for student placements. Also, there is a shortage nationally of post-graduate training and mentoring for dietitians in disability although DAA provides some training at DAA National Conferences, and through DAA sponsored webinars.

Concerns about sustaining the workforce were expressed by an APD as follows

> *"Workforce pressures worry me the most. When we see the pressure put on staff to achieve billable hours targets then client outcomes are affected. Quantity becomes more important than quality. Staff wellbeing is also affected. A highly casualised workforce is not going to attract more dietitians. There's no one to train them now anyway because we don't have time for students anymore and there is no clinical supervision framework within the NGOs for dietitians. This affects career progression opportunities and hence staff retention."*

DAA is also concerned about the limited skills and knowledge of support workers in disability. Even workers who have completed Certificate III or IV may not have studied basic nutrition and may lack basic skills in food purchasing, preparation and storage. This puts the worker and participants at a disadvantage, given the prevalence of food and nutrition-related disorders experienced by people with disability. Feedback from service providers who are employers of support workers is that the funding provided by the NDIS is not sufficient for service delivery and training of staff.

Challenges facing disability service providers and their sustainability

APD providers report many challenges in the NDIA environment. There is a large administrative burden carried to satisfy NDIA processes, for example a change recently to invoice requirements means three invoices must now be generated where one was previously sufficient. Changes are made at short notice without consultation with providers.

Providers must satisfy registration processes which introduce more costs and a burden in terms of presenting documents. This is despite the extremely low record of problems presented by allied health providers. So low in fact that not very long ago health ministers around Australia decided not to register a number of mainstream professions (dietetics, speech pathology, social work and others) because of the low risk presented to the public.

Policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services

We would like to see much greater efforts being made to resolution of issues at the health-disability interface for individual cases, and at the higher level such that better policy interpretations can guide good practice.

We would also like to see much greater consultation with professional peak bodies by the NDIA, and even better would be genuine co-design.