



# **NDIS Act Review and Participant Service Guarantee (Tune Review)**

**October 2019**

The Dietitians Association of Australia (DAA) is the national association of the dietetic profession with over 7400 members in Australia and internationally. 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 NDIS Act Review and Participant Service Guarantee by the Australian Government Department of Social Services.



## **DAA interest in this consultation**

The Dietitians Association of Australia is the peak professional body for the nutrition and dietetic profession in Australia. DAA holds that all Australians should have access to food and services to support their health and wellbeing. The wide range of needs of people with disability has not been well recognised in the past, nor have people had equitable access to dietetic services and nutrition support products. The NDIS has the potential to improve this situation to empower people with disability to achieve improved social and economic participation in their community.

The Accredited Practising Dietitian (APD) program is the foundation of self-regulation of the dietetic profession. APDs are the experts qualified and credentialled in food and nutrition to support people with disability of all ages, their families and support workers. APDs contribute to team-based care in various settings, including people's homes, in supported accommodation and in health services.

## **Recommendations**

1. That the legislation is changed to enable amendments to be made to NDIS plans without triggering a full review.
2. That NDIS planners undertake comprehensive initial and ongoing training to increase their competency for the tasks of planning and supporting participants.
3. That the NDIA develop transparent methods to provide timely and evidence-based guidance for planners and other delegates.
4. That the NDIA engage appropriate experts to provide advice on professional issues, this could be modelled on the DVA professional adviser model.
5. That a cultural shift occurs such that the NDIA engages with peak professional bodies and people with disability to co-design policies, procedures and templates to increase fitness for purpose and to reduce red tape.
6. That early intervention for children should allow for team-based care or single discipline care according to the needs of the child.
7. That the NDIA ensure a participant has a single point of contact in whom they have confidence.

## Objectives and principles of the NDIS Act

While a satisfaction rating of 90% with the NDIS is quoted this is at odds with the backlog of reviews and the large underspend of the scheme overall. It appears that problems have arisen in the implementation of the NDIS because of the interpretation of the NDIS Act by NDIA delegates. Evidence for this is the highly variable experience of NDIS participants and APDs as NDIS providers since the beginning of the scheme.

Some NDIS participants have had their choice and control respected by the inclusion of APD hours and nutrition support products as requested and in accordance with professional reports by APDs. Others have not experienced this but have been told that these were matters for 'health'. Some NDIA planners continued to deny NDIS participants the APD hours and/or nutrition support products requested in plans, even after the COAG Disability Reform Council provided interim advice in late 2018 that dysphagia and mealtime management supports were in scope for NDIS participants, and then resolved issues at the health-disability interface at a meeting 28 June 2019.

## Experiences with administration and decision-making

### *Inconsistency*

We have mentioned the highly variable nature of decision making by NDIA delegates. One recent case in the ACT involved a case of a woman who requires APD hours and nutrition support products because she requires feeding through a gastrostomy. The participant had APD hours and nutrition support products included in her first plan, and yet these products were later denied. When a review of an unscheduled plan review was requested the NDIA delegate said "I have decided to confirm the earlier decision. This means that the NDIA will not review your plan at this time... I understand that this response may not be what you had hoped. If you would like to discuss these reasons, please contact the NDIA on the below numbers to make a time to do so. You may also apply to the Administrative Appeals Tribunal (AAT) within 28 days for a further, external review of the decision."

The reason for the decision was "In your request, you have asked for more supports, without showing us any change in circumstances or other reason to change your supports."

This case is problematic for several reasons. Firstly the supports should not have been denied. APDs have often reported that planners do not even read the expert reports they provide to the participant to take to their review meetings. Secondly the change in circumstances was created by the NDIA itself by denial of

reasonable and necessary supports. Thirdly the referral to the Administrative Appeals Tribunal seems to be a cavalier move for a family already dealing with the complexities of living with a disability when appropriate management of the case would have kept the matter away from the Tribunal. Finally, the referral to 1800 numbers and generic emails is very unhelpful and represents a careless and disrespectful way of dealing with people.

#### *Denial of reasonable and necessary reports*

DAA has had reports of scores of participants being denied nutrition supports which have left them at risk of harm and in financial hardship. The Productivity Commission report of 2011 noted that government welfare payments are intended to cover basic items i.e. rent, transport etc and not specialised products which are needed by people with disability. It is inconceivable how people can be denied nutrition support products which are the sole source of nutrition for some people.

#### *Fear of reviews*

Participants are loath to request reviews because they do not wish to come out with less than what they went in with. Since 1 October 2019 the NDIA has attempted to identify some participants who had been denied nutrition supports and put in place interim measures e.g. access to core supports. But these methods have not been adequate, for example there may not have been any core support budget available. Also, the measures assumed that people had been supported by health services prior to the transition to the NDIA but this was not the case for many people who were supported by disability funded services in Western Australia, Queensland, New South Wales and Australian Capital Territory.

#### *Early childhood supports*

Access to nutrition supports for children has been problematic from the outset of the NDIS. The NDIA refused to list APDs in the support guide for registration and yet a wide range of other professions were listed. It is hard to fathom why this would be given the fundamental importance of food and nutrition in the development and growth of children. Even in the cases where a participant did gain access the structure of early childhood supports works against team-based care and this is not in the interests of children and their families.

Another issue for early childhood services is that team-based care is permitted but not single discipline care.

### **Current NDIA operational reforms**

DAA has repeatedly approached the NDIA offering to work collaboratively to ensure that policies and procedures are fit for purpose and served the needs of NDIS participants. Engagement has been limited despite the open offer of assistance, and when asked about their source of dietetic advice the NDIA

responded that they have sought 'legal advice' and 'subject matter experts'. It is apparent that the advice the NDIA has comes from other professionals acting out of scope, not suitably experienced APDs.

The problems in decision-making by NDIA delegates appears to be related to employment of people without relevant skills and knowledge, lack of appropriate initial and ongoing training of employers, poor design and dissemination of policies and procedures and limited requirement of planners to follow direction. This doesn't seem to have improved with current NDIA operational reforms.

DAA members have observed that when participants have their choice and control respected and are able to access the support they need in their plans, they can do very well. For example, with the support of an APD, an adolescent with autism was able to improve his bowel function such that he was able to attend school thus increasing his social participation. He also learned to manage his anxiety without the need for restrictive practices to prevent him from eating a jar of peanut paste in one sitting. These are important achievements for this lad to facilitate greater social participation in his community.

## **Feedback on consultation questions**

### *Principles*

DAA agrees with the principles outlined in the Discussion Paper for NDIA service standards. Embedding these would advance participants and other stakeholders. DAA does not consider that other principles should be added until the benefits of these current principles are realised.

The principle of Connected is important. Peak professional bodies such as DAA have a genuine interest in seeing better outcomes for NDIS participants. DAA considers that this can be achieved by collaboration and codesign with professionals, participants and other stakeholders.

The principle of Expert is especially salient. Not only should NDIA staff have greater knowledge about the range of issues experience by people with disability, they should also know how to work with the expert advice provided by professionals engaged by participants.

The principle of Valued is also important and DAA is pleased to see that this includes participants and others knowing where to go if they need further assistance that is welcoming and does not require an 1800 number.

### *Measures of principles*

DAA suggests various measures could be used to gauge how well the NDIA has delivered on the principles

- Amount of scheme underspend, generally and in specific areas
- Number of Administrative Appeals Tribunal cases
- Time taken in planning
- Number of reviews requested
- Number of disability related avoidable admissions to hospitals
- Number of deaths of people with disability related to denial of supports

### *Planning process*

One of the challenges faced by NDIS participants in the planning process include planners not reading the reports provided by experts to support the choice of the participants, reading but disregarding the advice contained in the reports or not acting on all of the advice e.g. but rather reducing the hours of service requested by a participant.

The templates provided by the NDIA are not always appropriate to the supports needed by the participant and may require the provider to present information which adds no value, takes time for the planner to work through and is burdensome to complete on the part of the provider. DAA advocates for codesign of templates to ensure that they are fit for purpose and minimise red tape.

### *Challenges in using supports*

DAA members continue to raise issues in relation to participant plans where dietitian hours and/or nutrition support products could reasonably be expected. The NDIA has attempted some approaches from 1 October 2019 to fix plans for participants who had been denied dietitian hours and nutrition support products but these have not all worked. Problems include

- No core supports budget in the plan
- Core supports budget has already been spent
- Core supports are all allocated to other service bookings
- Core supports budget is itemised in the background so that the participant is unable to use it for other items such as dietitian hours and/or nutrition support products
- There is lack of alignment between dietitian hours and/or nutrition support products in plans, price guides/support categories and the portal
- Dietitians are not allowed to contact planners on behalf of a participant via the generic email portal or national hotline (and no current budget is available for this time, all non-billable)
- Planners not abiding by the resolutions for Nutrition Supports agreed at the 28 June 2019 meeting of the Disability Reform Council e.g. a planner recommended referral to Medicare Chronic Disease management items to access an APD despite a clinical report which outlined the link to the

person's disability. The planner put only stated supports in the 'Improved Daily Living' budget so that it couldn't be used for dietetics

- Planners with minimal knowledge of the nutrition issues experienced by people with disability and the role of APDs in supporting participants resulting in a planner saying that a participant is not allowed to have dietetics in a plan unless the client has an eating disorder.

### *Challenges in reviewing plans*

Getting plans right in the first place will reduce the need for reviews and Administrative Appeals Tribunal cases.

- APDs report various issues related to plan reviews including the following
- Planners calling planning meetings up to four months early. Families being given only 1-2 weeks' notice and APD providers not given any notice (unless a proactive participant/family notifies the APD provider)
- No clear process for seeking plan reviews for participants with no current budget
- Caregivers being burnt out so they cannot face a plan review
- Caregivers not wanting to risk losing other funding in their plan so avoiding plan review
- Caregivers have already raised plan reviews for other reasons so have used all their changes at plan review.

### *Appealing a decision by the NDIA*

The NDIA could improve the decision review process by entering a process of genuine cooperation and intention to resolve issue with participants and providers.