National Disability Agreement Review

August 2018

The Dietitians Association of Australia (DAA) is the national association of the dietetic profession with over 6400 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 provide feedback on the National Disability Agreement Review by the Productivity Commission.

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DAA interest in this consultation

DAA supports reforms which improve the wellbeing of people with disability in Australia. DAA considers that there has been unmet demand and poor recognition of the nutrition needs of people with disability in the past. Improved access to nutrition products and dietetic services through the implementation of the National Disability Insurance Scheme (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 dietetic 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.

Summary statement

More work needs to be done for the National Disability Agreement to achieve its stated aim of enhancing the quality of life of people with disability, their families and carers. In particular clarification at the disability-health interface at the highest Commonwealth level and at a local level to provide certainty in a timely manner for people with disability and for providers navigating a volatile and uncertain environment.

The experience of DAA members is that people with disability are being adversely affected by the denial of access to APD services and nutrition support products (including enteral nutrition products). High level policy work is needed to ensure that the responsibilities for health services and the NDIA are clear for all stakeholders to ensure the human rights of people with disability are respected. In addition, local mechanisms are needed to address individual situations which arise in the interpretation and application of legislation and guidelines in a timely manner.

Should the Commission aim to apply the same framework across all reviews of National Agreements?

DAA recommends that the Commission should apply the same framework across all reviews of National Agreements. The same principles should apply across all States and Territories. DAA considers that people with disability and service providers will do better with greater consistency in all of the arrangements in the

implementation of the NDIS and provision of disability services in mainstream services.

What should be the purpose of the NDA? Is it an effective accountability mechanism for government actions relating to disability.

DAA considers that at present there is a lack of effective accountability for government actions relating to disability with frequent tensions at the interfaces between the NDIA implementing the NDIS and other government agencies. Accounts given by people with disability and their families are evidence of the difficulties encountered. For example in a public forum convened by Senators Brodtmann and Brown, an NDIS participant said "It shouldn't be so hard".

APDs report that NDIS participants are being denied access to APD services and nutrition support products within NDIS participant plans which leaves NDIS participants worse off than they were previously. For example, in South Australia, many parts of New South Wales and the Australian Capital Territory, participants are not having their choice and control respected and are denied inclusion of APD services in their NDIS plans, even when they had access to these services in previous disability arrangements.

There are reports in New South Wales of service providers for people with disability in supported accommodation approaching health services for supply of nutrition support products for NDIS participants because products are not included in NDIS plans. Providers are told that health will not supply when the person is an NDIS participant.

Consequently people with disability are falling between the cracks.

Participants or their families can trigger NDIS plan reviews but we understand that there is a mountain of reviews with the NDIA with lengthy delays and uncertain outcomes. Where participants or their advocates are not happy with review outcomes, they may take their case to the Administrative Appeals Tribunal where it seems the NDIA prefer to settle before a judgement is made to avoid precedents being recorded. These are onerous processes for people with disability who should not have to work so very hard to exercise Choice and control to access reasonable and necessary supports.

What should be the scope of the NDA? Should it continue to cover all people with disability? What services should it cover (such as specialist disability services and/or mainstream services, including mental health, healthcare, aged care, education, transport, housing and justice)?

DAA recommends that the scope of the NDA should cover all people with disability. At present some people are falling through the cracks because specialist disability services and mainstream services are not working together

sufficiently nor consistently to enhance the quality of life of people with disability, their families and carers i.e. current arrangements are not adequate to resolve interface issues and provide seamless support to people who are at great risk of harm.

Should the roles and responsibilities of mainstream services to people with a disability be more clearly outlined in a national agreement?

DAA would like to see the roles and responsibilities of mainstream and NDIA services be more clearly outlined in a national agreement with a commitment from all agencies to interpreting the agreement to ensure the human rights of people with disability are respected and no one is worse off.

There should be mechanisms at local level to resolve issues at the interface quickly so as not to place the person with disability at risk. Rapid resolution of issues is also expected to reduced the overall cost to government agencies in the long term, and improve the quality of life of people with disability.

Where are the main gaps in services outside the NDIS? What are the problem areas?

DAA is concerned about gaps in services within the NDIS and outside the NDIS. DAA was advocating for a national program for home enteral nutrition long before the implementation of the NDIS. Although the relationships between nutrition, disability, and wellbeing are not well recognised at least there is reference to enteral nutrition and bowel management in NDIS legislation (see Appendix One), NDIS price guides reference nutrition support consumables, and provider registration guides reference APDs.

There are significant limitations of services available to people outside the NDIS e.g. health services may not have APDs on staff, APDS who are on staff may not have capacity in terms of number of staff or skill mix, and home visits are generally not available.

There are also limitations around the use of the Medicare Chronic Disease Management items which have a limit of five services in one year for all eligible allied health and reimbursement for minimum of 20 minutes, nothing like the time and remuneration to meet establish a therapeutic alliance between the APD and the person with disability, their family and their carers.

To what extent does the NDIS (for example, through the provision of ILC activities and Local Area Coordinators) cater to people outside the NDIS?

The experience of APDs working with people with disability for whom APD services are reasonable and necessary, is that Local Areas Coordinators and NDIS Planners and others have insufficient training about

- functional impairments which impact on eating, drinking and nutrition that affect the health and wellbeing of people with disability.
- the role of Accredited Practising Dietitians as the professionals qualified and credentialed to support people with disability, and
- where appropriate supports can be obtained within or outside the NDIS
- the harm which may be experienced by people with disability who are not appropriately supported.

An example of this was provided by a member who described the advice given by a planner for a client with complex needs. The advice ignored the wishes of the person with disability and their family to include an APD in their plan, was poorly structured and inappropriately directed where referral was made to a home economist, nutritionist and others not qualified and credentialed in medical nutrition therapy and food related behaviour management.

I would really love to share with you a response from a planner that we received today dietetic involvement request for a client under a therapy package. We asked the planner for consent to be involved as they did not identify meal time and dietary difficulties on the clients' plan despite the family discussing it at a planning meeting. I actually can't even believe how far they are trying to go to not have dietetics involved under NDIS. There is just so much wrong with their response below. I have de-identified for confidentiality. The client is a young lady who is growth faltering with ASD and anxiety diagnoses:

"… What I would suggest is that:

- *Therapists address a letter to GP outlining concerns and the situation, stating that a referral to a dietician is needed. Psychologists and other supports to assist with appointment attendance/liaising with medical specialists and drilling down to the crux of the issue(s).*
- *Support from NDIS funded supports to help X implement this at home, school and in the community, based on these recommendations. Referral to other mainstream supports (even via the Home Economics Teacher/mentorship from the school and even parent support groups e.g. holistic approach). For instance, meal-time management plan development and behavioural support, as well as parental support groups for mum.*
- *Transdisciplinary team to support the family to implement this at home*
- *Other mainstream healthy eating programs such as food education through https://www.foodbankwa.org.au/food-sensations/ as an example*
- *If you have concerns regarding an eating disorder, I would be contacting the Children's Hospital (via the GP/concerns expressed in your letter) and then having a full review undertaken by a specialist clinic at the hospital*
- *They can then decide on the best approach to implement, from a medical standpoint*
- *Through core supports, the family can have ongoing support with mentorship/meal preparation and so on.*

There will most likely be a root cause behind her diet and eating patterns, possibly even some health related deficiencies (low in iron/some minerals/other issues so she may need blood tests etc) and/or this may be related to mental health conditions, which is also where mainstream supports can assist. A suggest course of action may be:

Allied health professional provides information to GP
GP to do dietician/nutritionist based referral AND/mental healthcare plan
Hospital/ dietician/nutritionist initial provide treatment
NDIS funded supports and mainstream supports to assist with meal-time management and behavioural intervention to promote a balanced diet and lifestyle
Continue to liaise with GP/specialists to report ongoing issues/progress
If one GP/dietician does not provide sufficient support/have that specialist knowledge base, allied health professionals and other supports can assist with researching alternative options. Usually within these health based plans there are some choices that can be made. Some GP's specialise in female adolescent health and there's no reason why X's family can't change GP's or other health providers if they wish to do so.?"

To what extent has the performance framework of the NDA supported improved outcomes for people with disability, their families and carers? Has it influenced government policy?

DAA finds that the performance framework of the NDIA has not supported improved outcomes for people with disability, their families and carers to any great extent. It has not sufficiently influenced government policy to address interface issues between health and disability.

DAA understands that some people with disability are satisfied with their NDIS plans and have had excellent outcomes. But more often we hear of denial of reasonable and necessary supports and adverse outcomes such as admissions to hospital or delays in discharge from hospital because of problems in accessing appropriate supports. Some participants achieve their goals with the support of APDs in their plans, and are devastated when their choice and control is not respected for continuation of that support in following NDIS plans. Denial of services not only impacts on the person in terms of their capacity to undertake self care on a daily basis, but also on their self esteem and confidence in self-determination.

The NDIA were asked in Senate Estimates of the Australian Parliament about access to APDs. Their response was that decisions are made on an individual basis. This is at odds with member reports that senior staff (names not provided here, but available on request) direct NDIA planners and others that APD services and

nutrition support products are the responsibility of health. The Director of Assistive Technology in the NDIA has twice said in meetings with Allied Health Professions Australia that nutrition support is not being included in a current NDIA project to trial improved Assistive Technology arrangements "because of the interface issues between disability and health".

We note that there has never been a universal default provider for nutrition support products in Australia. Also, that enteral feeding (referred to more recently as nutrition support) was an area which would reasonably be covered by the NDIS. The Productivity Commission noted in its 20111 report

> "Enteral or PEG feeding One area where living costs are higher for people with disability is in regard to medically necessary diets (subs. 569, 376). In particular, enteral or Percutaneous Endoscopic Gastrostomy (PEG) feeding is likely to lead to higher food costs than would otherwise be necessary. Northcott Disability Services argued that:
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> … the scheme should not fund general lifestyle needs (eg food) but should fund these needs if they would not have existed in the absence of a disability (eg. specialised food /formula required for a person who is PEG fed). (sub. 376, p. 17)
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> The Commission considers that the NDIS should cover the additional costs associated with PEG feeding, and had noted this in its draft report. This was generally welcomed by participants (subs. DR868 and DR783)."

To what extent has a coherent national performance reporting system been achieved

DAA finds that a coherent national performance reporting system has not been achieved. The NDIA reports on number of people entering into plans and positive survey outcomes about NDIS participant experience. However, there is a lack of transparency about

- causes of dissatisfaction
- the services and products provided under the NDIS and the services and products denied under the NDIS
- Avoidable hospital admissions arising from inadequate supports provided to NDIS participants under the NDIS
- Delayed discharge from hospitals because of lack of agreement about supports for NDIS participants returning to the community

Are there gaps in what data are collected (for example, in relation to the disability workforce)?

There are gaps in the data collected in relation to the disability workforce. This is in relation to allied health professions generally, and particularly regarding self-regulated professions such as Accredited Practising Dietitians.

References

1. Productivity Commission 2011, Disability Care and Support, Report no. 54, Canberra

Appendices

1. **The *National Disability Insurance Scheme (Quality Indicators) Guidelines 2018* *Part 3 – Module 1: High Intensity Daily Personal Activities***

Attachment

1. Dietitians Association of Australia. NDIS participant access to Accredited Practising Dietitian services and nutrition support products. July 2018

Appendix One - Accredited Practising Dietitians have unique skills and knowledge to support people with disability regarding bowel management and enteral nutrition (nutrition support).

National Disability Insurance Scheme (Quality Indicators) Guidelines 2018

The *National Disability Insurance Scheme (Quality Indicators) Guidelines 2018* *Part 3 – Module 1: High Intensity Daily Personal Activities has the following information:*

29 Complex Bowel Care

Outcome: Each Participant requiring complex bowel care receives appropriate support relevant (proportionate) to their individual needs.

To achieve this outcome, the following indicators should be demonstrated:

(1) Each participant is involved in the assessment and development of the plan for their complex bowel care management. With their consent, the participant's health status is subject to regular and timely review by an appropriately qualified health practitioner. The plan identifies how risks, incidents and emergencies will be managed, including required actions and escalation to ensure participant wellbeing.

(2) Appropriate policies and procedures are in place, including a training plan for workers, that relate to the support provided to each participant receiving complex bowel care.

(3) All workers working with a participant requiring complex bowel care have received training, relating specifically to each participant's needs, type of complex bowel care and high intensity support skills descriptor for providing complex bowel care, delivered by an appropriately qualified health practitioner or person that meets the high intensity support skills descriptor for complex bowel care.

30 Enteral (Naso-Gastric Tube – Jejunum or Duodenum) Feeding and Management

Outcome: Each participant requiring enteral feeding and management receives appropriate nutrition, fluids and medication, relevant and proportionate to their individual needs.

To achieve this outcome, the following indicators should be demonstrated:

(1) Each participant is involved in the assessment and development of the plan for their enteral feeding and management. With their consent, the participant's health status is subject to regular and timely review by an appropriately qualified health practitioner. The plan identifies how risks, incidents and emergencies will be managed, including required actions and escalation to ensure participant wellbeing.

(2) Appropriate policies and procedures are in place, including a training plan for workers, that relate to the support provided to each participant who has enteral feeding needs.

(3) All workers working with a participant who requires enteral feeding have completed training, relating specifically to each participant's needs, type and method of enteral feeding and regime, and high intensity support skills descriptor for enteral feeding, delivered by an appropriately qualified health practitioner or person that meets the high intensity support skills descriptor for enteral feeding.