Supported Independent Living Submission 5



National Disability Insurance Scheme (NDIS) Supported Independent Living

September 2019

The Dietitians Association of Australia is the national association of the dietetic profession with over 7,000 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 to the Joint Standing Committee on the National Disability Insurance Scheme for the inquiry into NDIS Supported Independent Living.

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DAA interest in this consultation

The Dietitians Association of Australia (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 requiring support to live more independently in their own home, in group or shared accommodation.

Improved access to nutrition products and dietetic services through the funding of Supported Independent Living (SIL) under 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 in SIL environments.

Summary statement

More work needs to be done for the NDIS to improve the wellbeing of people with disability, their families and carers. The experience of DAA members is that people with disability are being adversely affected by the denial of access to Accredited Practising Dietitian services and nutrition support products.

DAA considers it vital that:

- funding of Supported Independent Living in the NDIS Plans of NDIS
 participants includes appropriate supports such as nutrition support
 management, mealtime management and dysphagia management, so as to
 increase NDIS participant enjoyment and reduce the risk of harm associated
 with functional impairments of eating and drinking.
- people with disability living in supported accommodation have assistance through dietetic hours to build their own capacity as individuals and that of support workers with respect to food and nutrition skills. This is needed to address the high prevalence of co-morbidities in people living with disability, co-morbidities which shorten lives but can be favourably influenced by access to professional services (including APD services), healthy food choices and physical activity. More specifically, NDIS participants living in supported accommodation must be able to access APDs through the NDIA Price Guide categories of 'Improved Health and Wellbeing' and 'Improved Daily Living' for

wellbeing and capacity building of food and nutrition skills for residents and staff.

DAA would also like to see much greater consultation with professional peak bodies by the NDIA. As a peak body, DAA has both national and local connections to issues which affect both NDIS participants and providers. Genuine consultation and co-design has the potential to generate stronger systems for the future, built on a more comprehensive knowledge of issues affecting NDIS participants and NDIS providers.

Responses to selected terms of reference for the_inquiry into Supported Independent Living (SIL) under the NDIS are provided.

a) the approval process for access to SIL:

DAA is not in a position to comment on the approval process for access to SIL as such. However, there is every indication that NDIS participants who are funded for SIL will have even less access to APD services than ever, contrary to the expectations of improvements under the NDIS.

Reports by the NSW Ombudsman, the Victorian Disability Services Commissioner and the Queensland Office of the Public Advocate clearly demonstrate that people with disability living in supported accommodation experience poorer health outcomes, many of which are directly related to food and nutrition.

For many years, people with disability have experienced poor access to dietetic services to prevent and manage nutrition concerns, such as dysphagia, lifestyle related chronic disease, food intolerance/food allergy, and special dietary requirements, for a very long time. The implementation of the NDIS has the potential to improve access to APD services and nutrition support products, but thus far the evidence is of a worsening of access, not improvement.

As an example, there was some access to APD services through disability funded services in New South Wales and Victoria prior to the implementation of the NDIS. That access has disappeared, with very few NDIS participants having APD hours funded in their NDIS plans. DAA learnt this week that none of the service providers taking over the 500 or so homes from the Victorian government employ dietitians. DAA sees this reduced access to services as a human rights issue.

b) process, including its management and costs:

The inclusion of APD services and nutrition support products in NDIS participant plans is reasonable and necessary for participants to realise their goals and aspirations, and to increase their social and economic participation¹. Yet DAA members who work in the disability field report that many planners do not understand why food and nutrition is important across the breadth of disability. Nor do planners understand the important role that APDs play in working with people with disability to manage food and nutrition related functional impairment, to ultimately improve wellbeing and increase the opportunity to participate in society.

APDs who work with people with disability have seen great outcomes in terms of empowerment and improved health and wellbeing, leading to greater social and economic participation. NDIS Participants who have been able to include APD services in their NDIS Plans have been able to build their skills and independence and have increased their enjoyment of social and economic opportunities. In some cases this may lead to reduced needs for NDIS funding in the future. One example came from an APD this week of a young man living in supported accommodation who worked with his APD to lose weight. He is now able to wear more trendy clothing, participate in social activities to a greater extent and he is proud to have a girlfriend.

Feedback to APDs working in the SIL environment demonstrates that support worker capacity is increased through training and professional guidance. Management capacity for clinical governance is enhanced by APDs guiding the development and implementation of food and nutrition policies to support safe quality care. Chronic disease risk is reduced in NDIS participants in group living situations where APDs assist in the empowerment of individuals, support workers and the organisation though nutrition and health promotion activities².

However, even where service providers recognise the food and nutrition related risks (many do not), the transition from block funding to individual funding makes it difficult to implement changes in the SIL environment. This makes it even more important for NDIS participants to have nutrition support included in their NDIS plans, yet this is frequently denied.

c) the funding of SIL:

Reports published by the NSW Ombudsman³ recommend that people with disability living in supported accommodation have assistance as individuals and for workers to build their capacity with respect to food and nutrition skills. This is because of the high prevalence of co-morbidities in this group of people, co-morbidities which shorten lives but can be favourably influenced by access to professional services (including APD dietetic/nutrition services), healthy food choices and physical activity.

Therefore, DAA considers it important to allow for capacity building of food and nutrition skills for residents and staff in the funding of SIL under the NDIS. More specifically, NDIS participants living in supported accommodation must be able to access APDs through the NDIA Price Guide categories of *'Improved Health and* Wellbeing' and 'Improved Daily Living' for wellbeing and capacity building of food and nutrition skills for residents and staff.

Funding of SIL should also address the risk of harm to NDIS participants from lack of access to services and poor quality of care from support workers who lack training and are expected to operate without sufficient policy guidance. NDIS participants may also be exposed to disproportionate risk of harm if they are not supported by a skilled carer workforce guided by APDs and Speech Pathologists. Choking, aspiration pneumonia and death for people with intellectual disability in supported accommodation were identified as problems by the NSW Ombudsman³ when procedures are not in place to support mealtime management and dysphagia. In an annual review of disability service provision to Victorians who have died while in receipt of disability services⁴, swallowing and choking risks were also highlighted as a major issue. Likewise, a review of the deaths in care of people with disability in Queensland⁵ found that of the five people in the sample who died due to choking/food asphyxia, swallowing assessments had been conducted and mealtime management plans developed for only three. Notably, there appeared to be a lack of compliance with those plans.

As such, DAA considers it important that funding of SIL in the NDIS Plans of NDIS participants includes support for nutrition management, mealtime management and dysphagia (swallowing problems) management, so as to increase participant enjoyment and reduce the risk of harm associated with eating and drinking. APDs and Speech Pathologists play a vital role in the management of dysphagia to reduce the risk of choking, aspiration pneumonia, weight loss and malnutrition.

The change to individual funding provides benefits for individuals who have greater choice and control over their circumstances. However the move away from block funding is problematic because the development and implementation of policies and procedures to ensure safety and quality across an organisation is no longer assured. Service providers are expected to provide training and quality assurance activities across the whole facility, but the remuneration from individuals in a supported living situation may not be sufficient to ensure this is in place for food and nutrition systems in supported accommodation.

References:

- Position of the Academy of Nutrition and Dietetics: Nutrition Services for Individuals with Intellectual and Developmental Disabilities and Special Health Care Needs. J Acad Nutr Diet. 2015;115:593-608. Available from: <u>https://jandonline.org/article/S2212-2672(15)00121-5/fulltext</u>
- 2. A Community Health Dietetic Service for Group Homes: Review and Reflections. Prepared and presented by Ju-Lin Lee (APD) and Michelle Livy

Supported Independent Living Submission 5

(APD) at the Dietitians Association of Australia national conference, May 2018. [Please refer to attached presentation provided as part of this submission]

- 3. NSW Ombudsman. Report of Reviewable Deaths in 2012 and 2013. Volume 2: Deaths of people with disability in residential care June 2015. Available from: https://www.ombo.nsw.gov.au/news-and-publications/publications/annualreports/reviewable-deaths-vol-1/report-of-reviewable-deaths-in-2012-and-2013volume-2-deaths-of-people-with-disabilities-in-care
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