Human Rights and Technology

September 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 Human Rights and Technology Issues Paper by the Australian Human Rights Commission.

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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.

What types of technology raise particular human rights concerns?

There are two broad types of technology of concern to Accredited Practising Dietitians which raise human rights concerns. These relate to access to food and access to services.

Regarding access to food, enteral nutrition (also known as nutrition support) is a means of sustaining a person when they cannot consume enough food safely by eating and drinking normally, or where this is contraindicated because of dysfunction of one or more body systems. In this case, enteral nutrition support allows a person to consume food/formula through a feeding tube, commonly into the stomach via a Percutaneaous Endoscopic Gastrostomy (PEG). The person may require a feeding pump to deliver an appropriate formula through the feeding tube, or they may administer the formula by syringe or by gravity. Home enteral nutrition in this manner has allowed people to live in their home in the community for short periods related to an acute medical condition or for long periods of time related to a continuing functional impairment related to self-care activities of eating and drinking.

The second technology is telehealth whereby different media are used to connect a person with a professional, in this case an Accredited Practising Dietitian. For example, the connection may be through telephone, through Skype, or other means. The value of telehealth is the opportunity to improve access to services for some groups in the population. This addresses the human right to equitable access to reasonable and necessary services.

What opportunities and challenges currently exist for people with disability accessing technology?

Telehealth is frequently used in staff or territory funded health agencies to reach people living in rural or remote areas. Medicare in Australia reimburses medical practitioners in certain circumstances for services delivered by telehealth, but does not reimburse allied health professionals claiming Chronic Disease Management Items. Increasing access to services by telehealth under Medicare or private health insurance would be particularly relevant to people living in rural and remote areas where the prevalence of chronic disease is high but the access to services is low. Telehealth could also increase access to people living at home but who find it difficult to attend appointments outside of the home for reasons of mental illness or frailty. Conversely it would also enable allied health professionals such as Accredited Practising Dietitians who are located in rural or urban areas to meet the needs of clients at a distance.

In terms of challenges, access to home enteral nutrition has been inequitable for all the time the technology has been available in Australia. The Dietitians Association of Australia has advocated for a more equitable program across Australia but has not been successful. Implementation of the National Disability Insurance Scheme has disrupted some well-functioning state/territory programs leaving people with disability worse off than before. In some states provision of dietetic services and nutrition support products was free of charge, in other states there was a co-contribution paid. Sometimes it has been conditional upon being a public patient and not a private patient. A summary of nutrition support provision prior to the NDIA is provided in Appendix One.

How should Australian law protect human rights in the development, use and application of new technologies?

DAA notes the particular reference to new technologies. However, we raise the issue of established technologies and human rights, whereby access to particular technologies such as enteral nutrition is denied.

In the case of NDIS participants, people may be denied inclusion of Accredited Practising Dietitian services in their NDIS plan. The position of the Commonwealth Government is that food products, in this case enteral nutrition formula, are not funded except where the cost exceeds the cost of normal food. The cost of food products and the other consumables needed to deliver the food/formula can be a burden, particularly when the person experiences one or more other comorbidities which puts them in a difficult financial position. Changes in pricing of products with the implementation and change of supply arrangements, and inability to access some state tender pricing is causing hardship for tens, even hundreds of NDIS participants. In some cases, lack of access to nutrition support products at an affordable price threatens the food security of a person.

Even if nutrition support products (enteral formula) are included in NDIS plans, the exclusion of professional services puts the NDIS participant at risk of harm. Enteral nutrition is a unique situation in which the technology is interfacing with a person in a dynamic scenario and professional services are needed to support safety and quality. Without appropriate professional support, e.g. an Accredited Practising Dietitian, a person may experience difficulties which cannot be addressed by families or carers. This results in people having to attend emergency departments or being admitted to hospital.

DAA has had numerous reports from Accredited Practising Dietitians that NDIS participants are being denied Accredited Practising Dietitian services and/or nutrition support products in their plans, despite NDIS participants trying to exercise their right of choice and control by including these items in their plans. NDIS participants mare frequently told to obtain their products from health services. And some health services are refusing to supply products as they see the responsibility for supply lies with the NDIS. Some health services have policies in place which allow them to provide products but with minimal professional support. This can lead to poor clinical governance and risk to the NDIS participant where there are two professionals involved in the care of the person when only one is needed.

Another problem which arises from the provision of products by health services in a disconnected manner, is that the product may be technically appropriate but tender and pricing arrangements limit the options which are available to the NDIS participant needing the product. There may be other products which are more convenient to use because the food/formula comes ready mixed without the need to add additional components to increase the energy value of the product. Convenience is a reasonable factor to consider, for example when the mother supporting the child needing nutrition support is also working outside the home and has their own social and economic goals to achieve alongside those of their child.

In summary, DAA would like to see the human right of access to food and services respected. People may require support from professionals in the health or disability sector, and occasionally this need may be concurrent. Better approaches are needed at the national policy level, and at the local interface between health and disability to ensure peoples wellbeing, and participation in society is not put at risk. A statement by DAA is provided in Appendix Two related to this point.

Appendix One: Access to dietetic services and nutrition products prior to the NDIS

Long standing inequity

For over 15 years, the Dietitians Association of Australia (DAA) has advocated for equitable access to nutrition support products and services for all Australians, including people with disability. Advocacy has included repeated pre-budget submissions to the Australian Government Treasury and project work to bring this issue to the attention of the Australian government.

Other groups have also advocated for a better deal for people requiring nutrition support, for example in 2006 industry groups collaborated on a joint paper to the Standing Committee Inquiry into Health Funding[1]. In 2007 a report was published by the Greater Metropolitan Clinical Taskforce in New South Wales[2] which concluded that HEN (Home Enteral Nutrition, now termed nutrition support) services and supply were inadequate and inequitable in comparison to other states and overseas.

During 2009 and 2010 DAA members contributed to a jurisdictional working group under the Health Policy Priorities Principal Committee to prepare a common set of principles for Home Enteral Nutrition (HEN, more recently termed nutrition support) funding and service delivery, for presentation to the Australian Health Ministers Advisory Council. Progress halted at the last meeting in May 2010 when barriers were identified with the development of a national scheme i.e.

- the disparity in state and territory HEN services and funding models
- the lack of information and data on current HEN services
- the lack of capacity to resource a project from within jurisdictional health services.

Access at commencement of NDIS

In April 2018 DAA surveyed members working in disability to update information about nutrition support arrangements for people with disability at the time of the introduction of the NDIS. Key findings were that

- Policies regarding access to dietetic services and nutrition support products varied between, and even within, states and territories
- People with disability accessed dietetic services and nutrition support products to some extent through disability service and agencies (at least four states), health services, or through their own resources
- Payment for nutrition support products varied from no charge, to varying level of subsidy or access to jurisdiction tender prices, to paying market rates

- People who were treated in private hospitals, e.g. for tube insertion, had no professional support or access to reduced prices for nutrition support products when they returned to their community
- Private health funds did not provide rebates for products and provided only limited rebates for professional services.

Access through the Commonwealth government

Regarding access to nutrition support products or services through the Commonwealth government

- Service providers could claim an enteral nutrition supplement for older Australians in residential aged care or on high level home care packages.
- DVA clients could access formula, consumables and professional services of APDs. APDs could only claim the published DVA fees
- There was limited access to dietetic services through the Medicare Allied Health Chronic Disease Management Items. This provided for up to five allied health services in total per year, with each service being for a minimum of 20 minutes and rebated at $52.95. This falls far short of what is needed to provide comprehensive, integrated care to complex clients.

Cost and other disadvantage

In summary, at the time of the commencement of the NDIS there was no national nutrition support scheme for product supply or for dietetic services, except for limited items for older Australians through the Commonwealth government.

The arrangements at state or territory level were highly variable with some access to disability services and agencies or health services or neither, and no identified default provider. People with disability and their families were frequently disadvantaged by cost, by services provided only in inpatient or outpatient settings not in their own environment, and by the time needed to negotiate the system operating in their jurisdiction.

A more equitable future

The NDIS Rules state that the NDIS represents a “fundamental change to how supports for people with disability are funded and delivered across Australia. The NDIS is designed to produce major benefits for people with disability, their families and the broader community.” The NDIA has also stated that no one with disability will be worse off under the NDIS. The Disability Nutrition Support Network would like to see that people with disability have the opportunity to live ordinary lives and experience more equitable access to the products and services they need with the establishment of the NDIS.

References

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2. HEN supply and delivery models in Australia and Overseas 2007 https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0004/154669/hen_report_2007.pdf

NDIS participant access to Accredited Practising Dietitian services and nutrition support products

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DAA statement on Accredited Practising Dietitian services and nutrition support products for NDIS participants

The Dietitians Association of Australia (DAA) supports the rights[1-3] of people with disability to access nutrition support products and Accredited Practising Dietitian services which meet their unique needs to promote physical, mental and social wellbeing.

The following principles focus on National Disability Insurance Scheme[4] (NDIS) participants in Australia. NDIS participants experience physical, intellectual, sensory or psychiatric impairments that lead to unique and complex food and nutrition needs.

People with a disability have food and nutrition needs related to function, which are in addition to those for growth and development, defence against infection, repair of injury, physical activity, maintenance, and mental health.[5]

The inclusion of the services of Accredited Practising Dietitians (APDs) as qualified and credentialed nutrition professionals 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 participation. The National Disability Insurance Agency is on record in the Australian Parliament as stating that allied health and dietary supports are considered on an individual basis in the planning process (Appendix One).[6]

Key Principles

1. Many NDIS participants have complex nutritional needs and live in complex social situations requiring more time to work with an APD. NDIS Plans should include sufficient APD hours to undertake activities which will enable the participant to realise their goals and aspirations, whether the participant is living independently, with family or friends, or in supported accommodation.
2. NDIS participants living in rural or remote locations should be able to access APD services and nutrition products to achieve good life outcomes.[7]
3. Consistent with the principle of self-determination, the NDIS participant should be free to choose an APD provider with the skills and experience relevant to the NDIS participant goals and aspirations to maximise their independent lifestyle and full inclusion in the community. Choice is important in building participant self-esteem and a strong working relationship between participant and an APD.

The use of Medicare Chronic Disease Management items[8] to access dietetic services will rarely meet the complex functional needs of NDIS participants. Health agencies may not have the resources to meet NDIS participant needs. NDIS participants may not be able to access an APD to achieve their goals and aspirations if APD services and nutrition support products are not included in their NDIS plan.

4. Access to APD services may be needed by NDIS participants of any age but is particularly important for NDIS participants aged 0-7 years with global developmental delay or disability including Autism Spectrum Disorder (ASD). Early intervention supports should allow for inclusion of APDs in a collaborative team approach.[5]

5. NDIS participants should have access to affordable nutrition support products (including tube feeds, consumables, oral supplements, fluid and food thickeners). Access to food is a human right[1]. NDIS participants with complex needs should be food secure i.e. the cost of nutrition support products in an unregulated market should not place them at risk of food insecurity[9].

6. NDIS participants should be empowered with NDIS plan set up and review processes which identify necessary supports, are timely and do not place them at risk of harm[10] or compromise their activities of daily living, social inclusion and functional wellbeing.

7. APDs are food and nutrition professionals who are qualified and credentialed to work with NDIS participants, families, support staff, professionals and others. APDs must meet regulatory and professional standards including the DAA Code of Professional Conduct, the DAA Statement of Ethical Practice[11] and DAA Scope of Practice Framework[12] (Appendix Two). APDs work within an evidence-based paradigm and use relevant guidelines, including the Dietetic Core Standards for Disability[13].

8. APDs advocate for the rights of individual NDIS participants. APDs have the right to speak out against situations that discriminate against people with a disability and may compromise NDIS participant well-being.

References

1. Universal Declaration of Human Rights
   http://www.ohchr.org/EN/UDHR/Documents/UDHR_Translations/eng.pdf
2. United Nations Convention on the Rights of Persons with Disabilities
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3. Convention on the Rights of the Child
   https://www.humanrights.gov.au/convention-rights-child
4. National Disability Insurance Scheme Act 2013
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5. 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
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8. Chronic Disease Management - Individual Allied Health Services under Medicare – Provider Information
   http://www.health.gov.au/internet/main/publishing.nsf/content/health-medicare-health_pro-gp-pdf-allied-cnt.htm
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    United Nations General Assembly resolution A/RES/70/1, Transforming our world: the 2030 Agenda for Sustainable Development
11. DAA Code of Conduct and Statement of Ethical Practice
    https://daa.asn.au/maintaining-professional-standards/professional-standards/
12. DAA Scope of Practice
    https://daa.asn.au/maintaining-professional-standards/dietitian-scope-of-practice/
13. Dietetic Core Standards for Disability 2017
    https://daa.asn.au/resource/dietetic-core-standards-for-disability/

Appendix One

Senate Community Affairs Committee

ANSWERS TO ESTIMATES QUESTIONS ON NOTICE

SOCIAL SERVICES PORTFOLIO

2017-18 Additional Estimates Hearings

Outcome: National Disability Insurance Agency **Question No:** NDIA SQ18-000032

Topic: Dietetic Services under the NDIS

Hansard Page: Written

Senator Steele-John asked:

The exclusion of dietetic services from the NDIS seems to be in direct contrast to the intent of the NDIS to 'enhance outcomes and maximise the social and economic participation of people with disability'. The exclusion increases the risk of harm to children and their families who wish to exercise choice and control by including a Dietitian in their NDIS plan but cannot access services. This is particularly so for children with complex disability and socioeconomic profiles. Can you explain the reasoning behind the exclusion of dietitians?

Answer:

Allied health and dietary supports are considered on an individual basis in the planning process.

Appendix Two

About the Dietitians Association of Australia

- DAA is the leading body for nutrition professionals and the national association of the dietetic profession with branches in each State/Territory. It has been nationally organised since 1976. DAA is a member of the National Alliance of Self Regulating Health Professions and Allied Health Professions Australia.
- The Association has over 6000 members constituting approximately 80 percent of the dietetic workforce in Australia.
- DAA was approved in 1999 by the Australian Government Department of Employment Training and Youth Affairs as the assessing authority for dietitians trained in other countries, and prior to this advised the Australian Government on recognition of dietitians trained overseas.
- DAA has accredited dietetic training courses in Australian universities since 1984.
- The interests of dietitians are broad and derive from training in three dominant areas of practice i.e. individual case management of medical nutrition therapy (clinical care), community and public health nutrition, and food service management.

About the Accredited Practising Dietitian (APD) program

- The Accredited Practising Dietitian (APD) program is the foundation of DAA as a self-regulated profession with over 98 percent of eligible members participating in the program.
- The APD credential is recognised by the NDIS, Medicare, the Department of Veterans Affairs, private health funds and for access to the Healthcare Identifiers Service.
- The APD program meets the requirements of the National Alliance of Self Regulating Health Professions and has similar requirements to professions regulated under the Australian Health Practitioner Regulation Agency, including
    - Work within scope of practice framework
    - Subject to code of conduct
    - Compliance and disciplinary processes in place
    - Minimum annual continuing professional development required, and subject to audit
    - Resumption of practice requirement
- APDs work in diverse settings including disability, aged care, hospitals, mental health, private practice, public health, community health, food service, food industry, research and teaching.
- APDs will often work extensively in one area and develop high level skills and experience in that area e.g. APDs that work with people with a disability.

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