DAA Submission

Towards Solutions for Assistive Technology – Discussion Paper

February 2015

The Dietitians Association of Australia (DAA) is the national association of the dietetic profession with over 5800 members, and branches in each state and territory. DAA is a leader in nutrition and advocates for better food, better health, and wellbeing for all. DAA appreciates the opportunity to provide feedback on the Towards Solutions for Assistive Technology – Discussion Paper by the National Disability Insurance Agency.

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DAA interest in this consultation

DAA supports the principles of the NDIS, including that people with disability have choice and control in their life, and a right to expect safe and accurate advice. DAA is particularly concerned that people with a disability are supported to optimise their nutritional status to achieve individual goals of well being and independence.

The DAA Accredited Practising Dietitian (APD) program is the foundation of self regulation for dietitians in Australia. APD is the credential which can be used by people with disability, their families and carers to identify health professionals who will provide safe and accurate nutrition advice.

In terms of nutrition, assistive technology (AT) under the NDIS relates to home enteral nutrition which enables people to take in food and fluids when they are unable to safely chew and swallow adequate food and fluids. Meeting personal nutrition goals through home enteral nutrition enables growth and development, achievement of individual potential, supports maximum response to other interventions, supplies energy to participate fully in essential and recreational activities, and promotes a feeling of well being and improved quality of life.

Specialised formula is needed to meet the nutritional requirements of the child or adult with disability using home enteral nutrition. The person may use various methods to deliver the formula through their feeding tube, e.g. bolus method using syringe, bolus method using a container and tubing (giving set), or continuous delivery using a pump with container and tubing.

Recommendations

- Solutions for assistive technology should ensure that safeguards are in place and that risks related to the technology are adequately addressed
- The participant capacity building framework should be trialled and evaluated before full implementation
- Expert advisors must be appropriately qualified and credentialed, for example APDs are the expert advisors for people with disability for AT related to home enteral nutrition.

Discussion

It is important that people with a disability receive safe and accurate advice around home enteral nutrition. If home enteral nutrition is not delivered appropriately serious health outcomes can result including cognitive and physical decline which can reduce independence and quality of life for people with a disability.

"The physiotherapists are beside themselves because they can't do any therapy with the child because they (i.e. the child) are exhausted all the time and (the child) has limited muscle mass" (quote from APD in an NDIA trial site on harm arising from inadequate home enteral nutrition)

1. *Do you think the participant capacity building framework will help participants reach their own decisions and give them better control over choices about assistive technology solutions?*

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DAA considers that the framework has potential and recommends that it is trialled and evaluated. It will be important to observe how well the framework functions for individuals, and families at different points of the spectrum of capacity, from those with high capacity to those with least capacity, to reach their own decisions. Evaluation should also consider the role of planners, care workers and others to build better frameworks in the future, and also to ensure that the wishes, interests and well being of the participant are the principal drivers in decision making.

There are a number of positive features to the framework that will assist participants to make decisions and have a sense of control. This includes allied health professional and peer mentor support. Recognition of participant 'expertise' is a positive aspect of this framework and some consideration needs to be given to situations where the participant has an unrealistic and limited understanding of their needs or the issues. Participants may 'not know what they don't know'. Careful consideration will need to be given to the determination of participant capacity to self-assess where safety is concerned.

Planners, allied health professionals, peer mentors and others should receive ongoing training related to assistive technology, and related to client centred decision making.

2. *How useful would it be to have access to peer support people, such as Assistive Technology Mentors?*

Peer support people/mentors have a role in relating to the lived experience. The practical advice mentors could share from real life experiences would assist participants in making decisions and understanding new AT devises, provided this experience is placed within a broader framework.

Mentor experience may be limited, and they may not have encountered the same issues as their mentee. So mentors may supplement but not replace expert advisors who would have a comprehensive understanding of issues related to any particular AT.

Mentors would need clear guidelines on scope of practice to make sure they did not give advice on issues they are not qualified to answer. Training for AT Mentors would enable them to be confident about their scope of practice, and to know when to refer, and to whom.

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3. *How important do you think "expert advisers" will be in assisting with assistive technology solutions and decision-making? What are the main skills and attributes you think they should have?*

In the absence of a definition of 'expert advisers' DAA interpretation of an expert adviser is someone who is appropriately qualified and credentialed in the topic on which they are advising, e.g. Accredited Practising Dietitian for advice on Home Enteral Nutrition.

The term 'expert advisor' should be defined. Expert advisors as DAA understands the term, should possess

- Appropriate qualifications and credentials
- Clear understanding of their scope of practice
- Solid understanding of the key NDIA principles, i.e. choice and control, reasonable and necessary, person centred practice.

4. *Provide suggestions for processes and/or activities to ensure that assistive technology solutions are identified correctly, with minimal error, and are effective in supporting participants to achieve their goals.*

For home enteral nutrition, an APD should always be consulted to work with the participant and their family or carers to ensure appropriate formula and equipment is used, and that the feeding regimen enables the participant to meet their personal nutrition goals. Regular review (as determined by the APD and the participant) should also be included to ensure the formula type, formula volume, rate of delivery, and equipment etc used is meeting the participant goals.

5. *What do you think of the acquisition and procurement approach (including having a third party entity manage the pricing sourcing and procurement arrangements and contracted supply agreements)?*

DAA generally supports the acquisition and procurement approach to leverage pricing for off-the-shelf mass produced products. State jurisdictions and others already practice this when procuring nutrition products. In terms of stimulating the Australian market, there are limits to what can be expected as most enteral nutrition products are sourced from outside of Australia because the Australian market is relatively small.

Panels developing specifications and assessing tenders for procurement could include consumer representatives with relevant experience of the technology being acquired.

Home enteral nutrition products are generally off-the-shelf and readily available through specialist suppliers, and so are suitable for acquisition and procurement in this way. In fact, DAA is aware that a number of NDIA participants in New South Wales are being disadvantaged by not being able to access home enteral nutrition products at state tender prices.

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"(Client) Was receiving dietetic services and registered on HNEH (home enteral nutrition) service for supply of enteral formula. Was receiving formula at government contract pricing and was also receiving a 33% subsidy. Due to client now being an NDIS participant they have been transitioned to a NDIS private dietitian. They also now need to source their formula privately, which unfortunately means an increase in cost."

If a third party entity was managing acquisition and procurement there would need to be sufficient flexibility to ensure that the individual needs of the participant can be met i.e. if the needs of the participant cannot be met by standard formula on procurement, then an alternative must be sourced to meet their needs.

6. *What do you think about the use of refurbished items (assuming that all appropriate health and safety procedures and necessary safeguards will be in place)?*

DAA supports the provision of equipment which functions safely and is fit for the purpose intended. Whether items are new or refurbished is not important provided the item functions to enable the participant to meet their personal nutrition goals.

Safety and quality should be an abiding concern in the implementation of the NDIS. DAA remains concerned that pricing schedules promote re-use of single use only giving sets for participants using home enteral nutrition.

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