



Submission on the Proposal for a National Disability Insurance Scheme Quality and Safeguarding framework

April 2015

The NSW Agency for Clinical Innovation (ACI) is part of the NSW Health System. We work with health professionals, consumers and managers to design and promote better healthcare for NSW. We do this through our Clinical Networks, Institutes and Taskforces.

The Nutrition Network aims to improve nutrition care and food standards in NSW hospitals and to improve Home Enteral Nutrition (HEN) services across NSW.

The ACI Nutrition Network appreciates the opportunity to contribute to the consultation about the National Disability Insurance Scheme (NDIS) Quality and Safeguarding framework and invites the NDIA to consider the attached information in relation to HEN and implementing the NDIS.

For more details please contact

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Summary

HEN can support people to participate effectively in activities, perform tasks and maintain and/or improve their quality of life. To ensure quality of care and safety for people with disability needing HEN services, the Framework should address the following:

- Nutrition as a fundamental component of general health and wellbeing for all participants.
- Care coordination and oversight
- Support for planners and Local Area Coordinators via access to health professionals including Dietitians, Nurses and Speech Pathologists for advice, training and guidance.
- Safe and appropriate provider registration
- Professional supervision and development for providers
- Adequate, consistent and equitable access to equipment and enteral nutrition products
- A strong interface and sharing of information between all care providers, including between NDIS and other agencies such as Health.
- Obtaining the Participant experience in a way that supports service improvement.

Background

What is HEN?

Home Enteral Nutrition (HEN) is the delivery of nutrition support via the gastrointestinal tract for people in the home setting. Nutrition support is used to help people that cannot eat and/or drink enough to meet their nutritional needs.

Oral nutrition support (e.g. special supplement drinks) and enteral tube feeding (e.g. using nasogastric tubes, gastrostomy feeding devices) are both forms of HEN. HEN may be used as a temporary measure, but it is often needed permanently for people with disability.

Who needs HEN?

People of all ages may need HEN and there are many situations where a person may not be able to eat or drink enough to maintain adequate nutrition and hydration. This may include, but is not limited to:

- Impaired ability to ingest and/or absorb nutrients
- Swallowing disorders
- Increased or specialised nutrition requirements

For example, the need for HEN could be as a result of stroke, cerebral palsy, cystic fibrosis, brain injury or trauma, or motor neurone disease.

Why is HEN important?

HEN can support people to participate effectively in activities, perform tasks and maintain and/or improve their quality of life. The primary goals of long term HEN are to:

- maintain body weight or facilitate weight gain (where appropriate)
- correct nutritional deficiencies and maintain good nutrition status
- maintain adequate hydration
- promote growth in children with growth faltering.

If a person needs HEN, what do they require in terms of support and equipment?

People needing HEN can be safely supported in the community if appropriate services are provided.

The care of people needing HEN is best provided by a coordinated team. This team should include at least the treating physician, a dietitian, a nurse (for people that need tube feeding) and a speech pathologist (for people with dysphagia). The team does not need to be located within the same service, but all members of the team should communicate, work together and engage the person needing HEN and their carer/family in all aspects of care.

People that need HEN require

- access to timely and coordinated care and support by skilled health professionals
- ongoing monitoring and support
- adequate communication, collaboration, information and resources
- involvement in their own care.

People needing HEN may require commercial nutrition supplements and special equipment such as feeding tubes, giving sets, feeding pumps and physical positioning aids.

Comments on the Proposal for a NDIS Quality and Safeguarding framework

NDIS Information system

- It is important to obtain feedback from participants on the care they receive from providers to help improve the quality of care. There are benefits and risks of enabling participants to share information about NDIS providers
 - o BENEFIT: Providers will have access to information from the participant perspective and the opportunity to improve services.
 - o RISKS
 - There may be times that participants do not agree with the professional opinion of the provider, despite it being appropriate and reasonable, and give negative feedback which could impact the provider's reputation.
 - The participant may not know how to distinguish the difference between high quality and low quality care.
 - The feedback may be influenced by the personal relationship between the participant and the provider, instead of the quality of the care.

Building capacity through plan development

- The role of the planner will be crucial to the health and well-being of many participants. In order for planners to respond to questions and assist participants to develop and make changes to their plans in relation to HEN, it is essential that NDIS planners are aware of the importance of nutrition in disability, and the roles of health professionals in supporting the person with disability. This could be addressed by:
 - o Training and guidelines about nutrition and disability
 - o Ongoing access to qualified health professionals such as Dietitians, Nurses and Speech Pathologists for advice and guidance.
 - o Nutrition as a part of a key set of services for each participant.
 - o Service coordination between multiple service providers

Building capacity through Local Area Coordinators (LAC's)

- LACs will need to have the skills and knowledge to help people with disability connect to HEN providers, including providers of mainstream supports such as community and health services. This could be addressed by:
 - o Training and guidelines about nutrition and disability
 - o Ongoing support for LACs via access to qualified health professionals such as Dietitians, Nurses and Speech Pathologists for advice and guidance.

- Information and education for LAC's about the different professional bodies, including how and when to make a complaint about a provider.
- Local HEN Service Directories.

Service level safeguards — support for service level capacity building

- To ensure providers have the capacity to provide ongoing high quality services for people needing HEN a number of strategies should be in place for providers. For example:
 - A requirement for ongoing professional supervision
 - Support for, and access to, continuing professional development
 - Strong and transparent communication processes and sharing of information
 - Links to professional bodies.
- It is likely that there will be many sole practitioners providing care for people needing HEN under NDIS. It is even more important for these practitioners that the strategies above are in place.
- Service providers also need access to local/state HEN equipment programs (e.g. the NSW State contract for HEN and EnableNSW).

NDIA provider registration

- People needing HEN can be safely supported in the community if appropriate services are provided.
- The need for HEN, and especially enteral tube feeding, can be confronting, challenging and overwhelming for the person, their family and carers. It is important that the health professionals involved have the knowledge and skills to provide safe and appropriate care.
- It is therefore important that there is strong governance and a safe and appropriate registration process for NDIS providers and practitioners. This requires a thorough process for the review of applications and assessment of suitability and level of experience against specific criteria – for both large service providers and sole practitioners.
- Structures for clinical governance should be established to ensure safe and appropriate care is provided. This will help avoid duplication of care and ensure providers are working within their professional scope.
- Suggested resources are listed at the end of this submission.

Safeguards for participants who manage their own plans

- Nutrition is fundamental to good health and general well-being. It is therefore important that people with disability have access to appropriate nutrition care at all times. Nutrition needs should be assessed and form part of a key set of services for each participant.

Additional comments in relation to HEN

- It is important that there is adequate and equitable access to enteral nutrition products and equipment for all people with disability that need HEN across Australia. Participants should have access to 100% of their equipment requirements to meet their health and safety needs.
- Privacy of information is very important. However, there needs to be a system for sharing information between NGOs/NDIS and other care providers such as GPs and state health services because people with disability that need HEN may require input from several service providers. This will help everyone to provide safe and appropriate care and help ensure people with disability continue to get the support they need.

Relevant Documents

NSW Agency for Clinical Innovation, 2012. *Guidelines for Home Enteral Nutrition (HEN) Services, 2nd edition*. Chatswood, NSW. www.aci.health.nsw.gov.au

NSW Agency for Clinical Innovation, 2014. *A Clinician's Guide: Caring for people with gastrostomy tubes and devices*. Chatswood, NSW. www.aci.health.nsw.gov.au

Dietitians Association of Australia, 2014. *Role Statement for Accredited Practising Dietitians practising in the area of Disability*. www.daa.asn.au [accessed 24.4.15]