Provision of services under the NDIS Early Childhood Early Intervention Approach

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The Dietitians Association of Australia (DAA) is the national association of the dietetic profession with over 6000 members. DAA is a leader in nutrition and advocates for food and nutrition for healthier people and healthier nations. DAA appreciates the opportunity to provide feedback on the Provision of services under the *NDIS Early Childhood Early Intervention Approach* by the Joint Standing Committee on the National Di9sability Insurance Scheme.

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DAA interest in this consultation

DAA supports the implementation of the NDIS and acknowledges the potential of the NDIS to greatly 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 achieve their goals, to increase their social and economic participation and to developo 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.

Key messages

Many children with disability have food and nutrition issues which are integral to their disability. APDs providing early intervention services to children and their families can help children with disability achieve a safe and adequate intake of nutritious food and fluids which are essential for children to grow, develop, learn, live and play.

DAA recommends that the NDIA include APDs alongside other allied health professions in the Early Supports for Early Intervention Professional Registration Group (Provider Toolkit Module 4).

Pricing should be reviewed for travel arrangements for APDs providing services to children with disability and their families who live in rural and remote areas to allow better access to the family's choice of practitioner.

Feedback on selected Terms of Reference

b. The service needs of NDIS participants receiving support under the ECEI pathway

Children with disability may experience a variety of nutrition problems according to their disability. Underweight or overweight, food behaviours, food sensory issues, bowel problems, food allergies or intolerances are commonly encountered. Helping families to manage these issues can greatly enhance the child's development, interaction at home and at school, and engagement in community activities. (More information is available in references 1 and 2.)

When children receive the supports they need, they have the opportunity to do well, as demonstrated in the early NDIA Newsletter report of Harrison, aged 3 years from Loxton in South Australia who was able to make greater progress with access to a dietitian. (see Appendix)

DAA has received a number of reports from APDs that NDIS participants have been denied inclusion of nutrition services from APDs in their packages, despite nutrition care being reasonable and necessary for participant wellbeing. An example of a NDIS participant, i.e. child with developmental delay, is described in the case below from an APD working in Victoria. DAA is aware of similar cases in South Australia and New South Wales.

> *I am a Paediatric Dietitian who has been working with* [redacted] *and his foster carer to improve his nutritional status. Child Protection referred* [redacted] *to me after an assessment by "* [redacted] *Clinic at* [redacted] *Hospital with concerns about his nutritional status and growth faltering. NAME's growth had been well under what would be expected for a typically developing child. NAME was diagnosed with Developmental Delay; extreme anxiety linked to Post Traumatic Stress Disorder and Selective Mutism. On assessment NAME was a very pale and frail looking little boy who appeared to be very anxious. On assessment it became apparent that* [redacted] *has a very poor feeding history with dependence on bottles of chocolate milk until he was two years six months of age. NAME missed those important developmental steps of transition from a totally milk based diet to food at 4 to 6 months and then progressing to more textured family foods by the age of 12 months. Children who miss these vital developmental steps often have issues with the development of speech and ongoing oral motor issues that can affect their eating for years.*
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> [redacted] *under the care of his foster parents has had been able to transition to a more age appropriate diet however he still has issues with some textures and his poor growth continued.* [redacted] *severe anxiety would cause him to have periods of severe anorexia when his oral intake would be minimal.* [redacted] *was unable to consume adequate amounts of nutrients at other times to compensate for his episodes of anorexia.* [redacted] *malnutrition was influencing his energy levels, which meant he could not engage in adequate amounts of therapy activities to assist with his cognitive and physical development.* [redacted] *would have also been lacking in most vitamins and minerals, which meant he could not reach his full developmental, cognitive, emotional and physical potential.*

Another barrier to access of nutrition services in the 0 – 6 years age group is the inexplicable exclusion of APDs from the Early Supports for Early Intervention Professional Registration Group (Provider Toolkit Module 4). For many years APDs have worked with other disciplines such as speech pathologists, occupational therapists, physiotherapists etc in teams supporting families. Consistent with best practice, DAA advocates 'Nutrition services should be provided throughout life in a manner that is interdisciplinary, family-centered, community based, and culturally competent'[1].

DAA has advocated to the NDIA for inclusion of APDs in Early Intervention Professional Registration, but so far without success.

DAA is aware that few service providers employ APDs in their teams of allied health professionals to deliver early childhood services. This might be because APDs are not included in the Early Intervention Professional Group, or it may be lack of awareness. A phone check of service providers in 2015 in the ACT demonstrated that none employed APDs. The phone check indicated that providers did not understand that nutrition is important to the wellbeing of many people with disability and that APDs have the skills to assist people with disability.

When APDs are excluded from Early Childhood teams, they can be included in NDIS plans as a separate item. However, this is usually discovered after the participant plan has been signed off. Consequently, nutrition care is delayed until plan review or is not accessed leading to incomplete team care for the participant and their family.

Without APDs contributing to team care for children and their families, children do not have the help they need with food or nutrition issues. For example, a child with cerebral palsy may not have the energy to respond to other therapies, nor have the energy to respond to classroom or playground activities, or to participate in family and social activities.

f. The evidence of the effectiveness of the ECEI Approach

There is no plausible reason for the exclusion of APDs from the Early Supports for Early Intervention Professional Registration Group.

We surmise it is the result of using an incomplete evidence base to build the initial ECEI model, i.e. the evidence comes largely from education and welfare settings. DAA expressed concern about this at the time of consultations by Early Childhood Intervention Australia on the ECEI model behalf of the NDIA. However, the model was already being introduced in Victoria.

h. The adequacy of information for potential ECEI participants and other stakeholders

Planners are the gatekeepers in the NDIA. However, the performance of planners is highly variable. It seems planners often have poor knowledge of the importance of nutrition across the spectrum of disability, or the role of APDs. We suggest that more investment in training of planners is needed. Having APDs on the NDIA staff to act as a resource for planners and other NDIA decision makers would be helpful.

With inadequate or incorrect information from planners, NDIS participants have frequently been told that they should access an APD from a health service or under Medicare Chronic Disease Management items. However, health services

may never have provided the service required and may not have the number of staff or the skill mix to meet the needs of children with disability. Even health services that have provided services in the past may now refuse services believing that people with disability can access services through the NDIS.

The suggestion that children or adults with disability should use Chronic Disease Management items is done in ignorance of the complex needs of the person with disability which require sufficient time and frequency of service from a suitably skilled practitioner. Medicare Chronic Disease Management items are capped at five consultations per year across all eligible allied health providers. The remuneration is far less than market rates and is for a minimum of 20 minutes. This is not a suitable consultation scenario for quality service provision by a practitioner with experience in disability.

We also hear that some NDIS participants are advised to use Medicare before they use allied health services in their plan, or to use their NDIS funding to pay the gap between the Medicare bulk billing rate and the price charged by the APD. We understand that this practice is not allowed under Medicare rules but it seems that planners have not been informed.

i. The accessibility of the ECEI Approach, including in rural and remote areas

The issue of access to APDs in NDIS participant plans is hard enough in metropolitan areas, and more so in rural and remote areas. APDs relate that the limitations of travel under NDIS rules makes it difficult to recoup travel costs for NDIS participants to access experienced APD practitioners who are unable.

We hear in some cases that people with disability are denied the practitioner of their choice, and a practitioner geographically closer to them is included albeit without the same level of experience in disability.

j. The principle of choice of ECEI providers

APDs relate that planners may not include the APD of the NDIS participant's choice in their package. The following case comes from an APD in Victoria.

> *I have had several clients who have specifically asked to see a dietitian and were told that diet is a "health issue" and they could access Dietitian at community health or at their hospital. Number of problems with this, hospital Dietitians will only see people who have a UR number. Community Dietitians often won't see clients who are eligible for Early Intervention, others won't see them because they don't have any expertise in Disability…..*
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> *In my public service job in early intervention I often had joint appointments with the SP,PT or OT. This is no longer happening because the client doesn't want to pay for 2 therapists. This is very disappointing as I worked closely*

with the SP/PT and OT with children complex feeding issues and children going through tube weaning. These children are now been disadvantaged under the NDIS.

I could go on forever but I thought I would just send these through to you and maybe send more when I get time.

k. The application of current research and innovation in the identification of conditions covered by the ECEI Approach, and in the delivery of ECEI services.

Research of the services which have been accessed by NDIS participants would be a helpful first step to building a stronger NDIS platform for the future. This would identify patterns of service provision which could be compared with evidence based guidelines for practice.

References

1. Ptomey LT, Wittenbrook W. 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
2. Dietetic Core Standards for Disability. NSW Government Family and Community Services and Cerebral Pasly Allinace 2016. https://daa.asn.au/resource/dieteit-core-standards-for-disability Accessed 9 August 2017

Appendix: Example of an early NDIS participant who did will with an APD in his team care

National disabilityinsurance Scheme

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Open section menu

Walking, talking Harrison

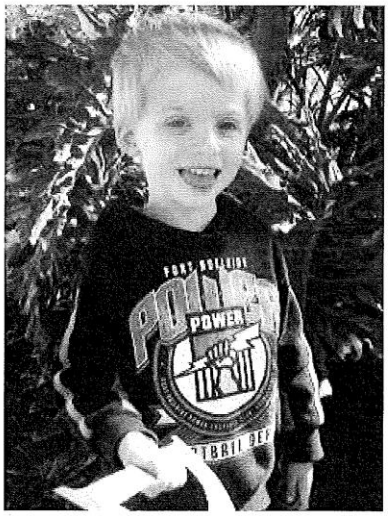
Rachel and Karl Klose might live some distance from Adelaide's National Disability Insurance Scheme (NDIS) trial site, but are grateful to be an active part of the South Australian Scheme.

Their son Harrison, 3, was born with cerebral palsy and it's been an adventurous road for the couple to find the right supports. The Kloses live in Loxton, 170km north east of Adelaide.

Thankfully now, as NDIS participants, they have more access to physiotherapy, occupational and speech therapy and, as a result, Harrison is blossoming.

"We've been with the NDIS about a year now, and being able to get more supports has meant Harrison is progressing so much faster now," Rachel said.

"With his plan we are actually able to access way more therapy than ever before and as a family we are enjoying the flexibility of choosing therapists to meet Harrison's unique needs.



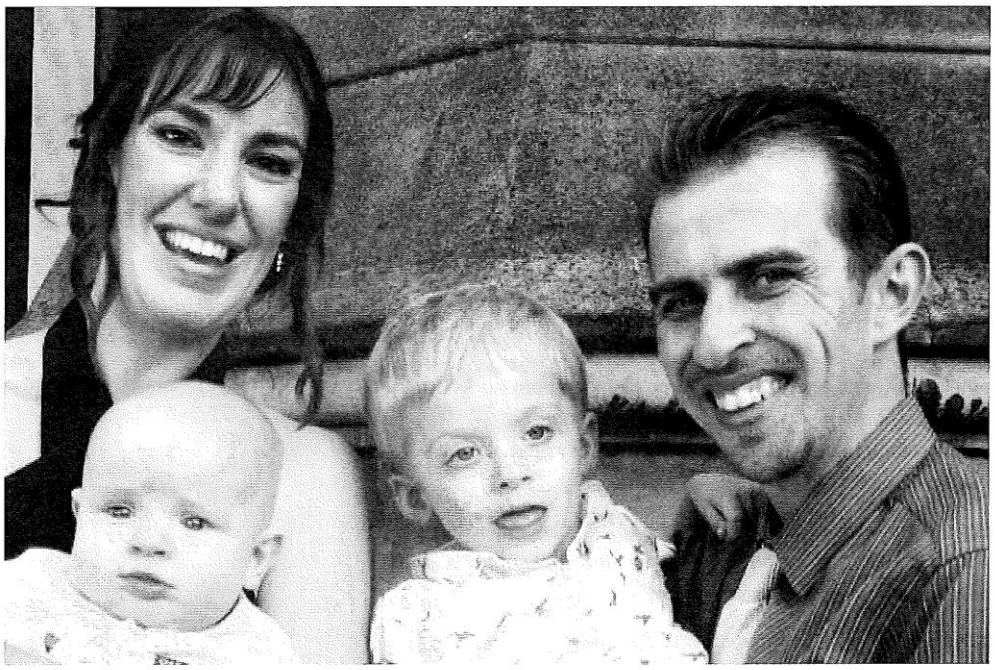
Unstoppable... Harrison Klose, 3, is now chatty and full of energy.

"Now Novita Children's Services visits us on a regular basis and provide Harrison with therapy, a toy-borrowing system and specialised equipment, like orthotics.

"All of Harrison's supports have been fantastic and they are definitely the reason he has progressed so much in the last year."

Rachel said this time last year Harrison was a "bottom shuffler".

"He wasn't able to walk yet, and by November last year he just caught up and started walking one day, and he hasn't looked back. Now I've had to baby proof the house," she says with a laugh.



Accessing more, better supports... Mum Rachel, dad Karl, Harrison and baby Joshua.

"Harrison has a younger brother, Joshua, 10 months, who he adores. Amazingly Harrison started walking a week before Joshua was born, so it was perfect timing."

Through Harrison's plan, Rachel and Karl were also able to access an intensive feeding program in Adelaide called Lively Eaters – 255km from their home in the Riverland.

"Lively Eaters has been one of the best things," Rachel said.

"Ever since Harrison started on solid foods he's had all sorts of difficulties – basically he wasn't eating, so we had quite a few appointments with Lively Eaters first, via Skype, due to our distance. We also had an additional assessment as well with them and they recommended one of their feeding programs.

"As part of that program we were also able to stay in Adelaide for a week so Lively Eaters staff could visit us during meal times. We saw a dietician, an occupational therapist and a speech therapist during those times and they were able to give us lots of tips and ideas on how to get our little boy eating.

"One of the tips was rather than just cutting up a strawberry and giving it to him, mash it with a potato masher first and then it was in a state where he was able to swallow it easier. Now Harrison is enjoying all the foods everyone else gets to enjoy and he's not missing out on all of those beautiful flavours.

"He's also been a lot healthier since the program because he is eating more of a varied diet."

Rachel says Harrison has also impressed them with his communication skills.

"When he was two he was only really verbally saying mum, dad and car. He was signing some words but now he's impossible to keep quiet," she said with a laugh. "He's really blossoming."

The NDIS helps people with disabilities and their families, delivering long-term community benefits.