Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Health care for people with cognitive disability

March 2020

The Dietitians Association of Australia (DAA) is the national association of the dietetic profession with over 7000 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 issues paper on 'Health care for people with cognitive disability', by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

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DAA interest in this consultation

DAA supports the rights(1, 2) of people with cognitive disability to access nutrition care and Accredited Practising Dietitian (APD) services to address their physical, mental and social wellbeing.(3)

People with cognitive disability have food and nutrition requirements related to function, in addition to requirements for growth and development, defence against infection, repair from injury, physical activity and mental health.(4, 5)

Access to healthy food, fluids and person-centred nutrition care are significant factors in promoting both the mental and physical health of people with cognitive disability.(6) Improved access to nutrition care and APD services through policy reform, care coordination, funding and education, will lead to improvements in the health and wellbeing of people with cognitive disability, reductions in preventable deaths(6) and increased social and economic participation.(7)

The 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 support people with cognitive disability to meet their unique food, fluid and nutrition needs and achieve their goals.

Key messages

People with cognitive disability may have physical, intellectual, sensory or psychosocial impairments leading to unique food, fluid and nutrition requirements.(5) It is the right of people with cognitive disability to access nutrition care that addresses their unique needs, to enable social and economic participation and achievement of the highest possible standard of health.(1, 2, 8)

Barriers to nutrition care for people with cognitive disability include:

- Inadequate access to Accredited Practising Dietitian services
- Limited availability of multidisciplinary community health teams for people with cognitive disability that include APDs
- Structural issues such as poor integration between disability and other sectors, lack of referral pathways to APDs and lack of a current National Nutrition Policy
- Inadequate management of nutrition and lifestyle-related health risks in disability services
- A health workforce lacking the skills and knowledge to support healthy eating and provide appropriate nutrition care for people with cognitive disability
- Inadequate funding for dietetic services
- Lack of accessible information regarding health eating and lifestyle for people with cognitive disability

Recommendations to overcome barriers to nutrition care:

- Fund positions for APDs in community health settings and establish referral pathways to APDs and other allied health professionals
- Update Australia's National Nutrition Policy to address the spectrum of food and nutrition issues. Also, support the development of organisation-specific policies to support access to healthy food, fluids and nutrition care in disability services
- Enforce better management of nutrition and lifestyle-related risks that lead to preventable deaths and chronic disease, among people with cognitive disability. Implement monitoring and accountability mechanisms to ensure risks are managed appropriately
- Develop the workforce and provide education to health professionals regarding food, fluids and nutrition, for all professionals involved in the care of people with cognitive disability
- Increase funding to ensure access to appropriate nutrition care and dietetic services for all people with cognitive disability
- Develop resources for people with cognitive disability to support healthy eating and physical activity
- Improve the consistency of access to nutrition supports and dietetic services through the NDIS

Response to questions posed by the Royal Commission

Quality of health care for people with cognitive disability (question 1)

People with cognitive disability have disproportionate rates of diet-related chronic disease and higher rates of mortality compared to the general population, reflecting a shortcoming in the quality of healthcare for people with disability.(4) Poor diet, obesity and lack of physical activity contribute to the health disparities.(5) Inadequate nutrition care practices have also been identified to contribute to both morbidity and mortality, including failure to refer to dietitians for the management of emerging and chronic health risks.(6)

Evidence of the shortcoming in quality of healthcare for people with cognitive disability is highlighted by a recent scoping review conducted by Troller and Salomon.(6) The review investigated the prevalence of, and factors contributing to the deaths of 901 people with disability, across Victoria, Queensland and New South Wales, spanning the period 2007-2018. Of relevance to the current Issues Paper, intellectual disability was either the primary or secondary cause of disability for 74 to 89% of people whose deaths were within the scope of the research.

The review found that both diet and lifestyle risks and sub-standard nutrition care practices were associated with several leading causes of death including respiratory deaths, choking, neoplasms and circulatory disease (Table 1).(6) The review also identified several nutrition care practices that contributed to the overarching issues across all jurisdictions. The findings highlight the need to raise the standard of nutrition care for people with cognitive disability in Australia.

Nutrition care practices associated with deaths of people with disability, identified by Troller and Salomon(6) included:

- Lack of proactive support for preventative health care including lack of allied health referrals
- Lack of accessible dental care. Poor oral health is associated with risk of choking, aspiration pneumonia and cardiovascular risk
- Limited use of communication plans and other communication accommodations
- Failure to proactively manage emerging and chronic health risks, such as obesity
- Staff not confident about, or aware of, best practice standards for responding to a medical emergency such as an epileptic seizure or a choking event.

Table 1. Leading causes of death of people with disability in Victoria, New South Wales and Queensland between 2007-2018, and the associated food and nutrition-related risk factors and nutrition care practices(6)[1]

Respiratory deaths[2]	
Food and nutrition-related risk factors	High rates of problematic feeding behaviours that increase aspiration risk such as gorging or pica
	Higher rates of dysphagia
	Higher rates of GORD
	Higher rates of percutaneous endoscopic gastronomy (PEG) to receive nutrition
	Dental problems and gum disease
Nutrition care practice issues	Lack of comprehensive nutrition and swallowing assessment in at-risk groups
	Safe mealtime guidelines not being adhered to or being disregarded all together
External causes of death – choking	
Food and nutrition-related risk factors	Dysphagia
	Risky food behaviours such as gorging and pica
	Gastro-oesophageal reflux disease (GORD)
	Poor oral health
Nutrition care practice issues	Expert advice provided by a dietitian or speech pathologist about mealtime management not being adhered to
	Failure of service providers to proactively reduce the risk of choking
Deaths due to neoplasms and circulatory disease	
Food and nutrition-related risk factors	Obesity
	Low or unknown levels of physical activity
	Hypertension
	Diabetes
Nutrition care practice issues	Poor management of lifestyle related risks
	Lack of staff awareness or compliance with lifestyle policies in residential care
	Lack of care co-ordination between services to address identified risk factors
	High rates of psychotropic prescriptions and polypharmacy

[1]The other leading cause of death was epilepsy. This is not included in the table as food and nutrition-related factors weren't identified as contributing to epilepsy-related deaths

[2]Risk factors related to aspiration pneumonia

Barriers to nutrition care (question 2b)

Inadequate access to Accredited Practising Dietitian services

Inadequate access to APD services is an ongoing issue for people with cognitive disability.(6, 9) During the NDIS rollout, DAA heard from members that many people with cognitive disability were denied access to nutrition support products and APD services, despite the need for these supports to achieve the highest attainable standard of health. Appendix 1 provides examples of real cases of people with cognitive disability who were denied access to APD services during the NDIS rollout. DAA has been informed that most of these participants have since been granted access to APD services and some APDs report that access has improved since the 28 June 2019 Disability Reform Council meeting.

However, despite these improvements, DAA continues to receive reports that people with cognitive disability are denied access to APD services by NDIS planners or that significant time and effort is required to advocate for the inclusion of dietetics in NDIS plans. This is due to poor understanding and knowledge of planners regarding the importance of nutrition care and dietetics to the mental and physical health of people with cognitive disability.(10, 11)

There are multiple barriers to access of APD services including lack of policy to support healthy eating,(12) health system interface problems,(7) inadequate management of nutrition and lifestyle risks,(6) workforce and educational issues,(7) physical location,(13) lack of accessible information and funding issues.(14)

DAA recommendations

Improve access to APDs through a range of measures including those listed below and highlighted in following parts of this report:

- Employ APDs in community services
- Integrate dietetic services into multidisciplinary health care teams for people with cognitive disability, such as the Specialised Intellectual Disability Health teams, based in Sydney, funded by the NSW government
- Subsidise dietetic services
- Increase the number and duration of Medicare items for dietetic services
- Upskill and educate the disability health workforce regarding the role of food, fluids and nutrition care in health and disability, and the role of APDs

Structural barriers

Structural issues such as limited availability of multidisciplinary community-based healthcare teams, remote physical location and poorly coordinated health systems, present barriers to nutrition care for people with cognitive disability. Examples include:

- Limited availability and access to community-based health teams for people with cognitive disability, which include APDs within the multidisciplinary team.
- Australia does not have an up-to-date National Nutrition Policy to address that nation's food and nutrition issues and growing diet-related health concerns.(15) A National Nutrition Policy would bring together evidence on the role of food and nutrition in health and provide a framework for translating the evidence into action in prevention and treatment of physical and mental health issues for all people including those with cognitive disability.(12, 16)
- Lack of organisation-specific policy to support healthy eating and nutrition care in disability services, such as group homes.(9)
- Fragmented healthcare systems with poor integration between disability and other sectors including aged care and mental health. This issue was highlighted in multiple submissions to the Aged Care Royal Commission, by organisations representing people with disability.(17-20) These issues may be exacerbated for people with cognitive disability or communication issues.
- Interface issues between mainstream health and NDIS services including challenges transitioning people from Health to NDIS providers. For example, the parallel cessation of government healthcare services, with implementation of the NDIS, resulted in people with cognitive disability losing access to nutrition care services, without clear pathways of access to APDs.
- Referral pathways to APDs are poorly established or non-existent, making it difficult for health professionals and health services to identify and refer to APDs.
- General Practitioners may refer to APDs but Medicare provides limited support for comprehensive healthcare for people with cognitive disability.(14) Medicare Chronic Disease Management items do not provide enough items or items of long enough duration, to work with people with complex needs including individuals with cognitive disability. Further detail of the issues regarding Medicare are outlined in a recent DAA submission.(14)
- Individuals who live in rural or remote locations may have difficulty accessing APD services due to workforce shortages and travel limitations.
- For some people living in rural or remote locations, telehealth services could provide a means to access APDs but these services are poorly established and inadequately funded.(7, 13, 14, 21)

- People with cognitive disability may not have a computer or internet access and will have varying capacity to use telehealth services. Further, Medicare does not cover telehealth services and there are few accessible and affordable telehealth facilities.(14)

DAA recommendations

Specialised community-based health teams for people with cognitive disability

- Fund the development of specialised cognitive disability health services. Include APDs and other allied health professionals in the multidisciplinary teams.(5)
- The Specialised Intellectual Disability Health teams based in Sydney, recently funded by the NSW government, should be expanded to fund positions for APDs and other allied health professionals.

Establish referral pathways

- Referral pathways to APDs and other allied health professionals should be established and readily available to health professionals.(21)

Nutrition policy

- Update Australia's National Nutrition Policy.(12, 15, 16) The rationale and evidence for a National Nutrition Policy are outlined in the '*Joint Statement: Towards a National Nutrition Policy for Australia'*,(12) and associated background paper,(16) endorsed by DAA, the Public Health Association of Australia, Nutrition Australia and the National Heart Foundation of Australia.
- Develop food, fluid, nutrition and lifestyle policies for specific settings, such as group homes(9, 22) and schools, to improve equity of access to healthy food and nutrition care for people with cognitive disability. These policies will serve to create supportive food environments but also create systems and accountability mechanisms, to ensure people are provided with the appropriate support to address emerging and chronic health diet-related risks, such as obesity.(6) These policies should address supported decision making and referral pathways to APDs and other health professionals needed to manage food, fluid, nutrition and lifestyle-related issues.

Coordination and integration of disability and other sectors

- An overarching policy framework is needed to integrate healthcare sectors to improve the quality of health and nutrition care provision for all people including people with cognitive disability. This includes integrated systems for physical and mental healthcare and may require the co-location of services.

Overcoming issues related to physical location

- Build the allied health workforce in remote and rural locations. This should include supporting health workers to upskill in the area of cognitive disability.
- Funding is required to develop appropriate technology, and other solutions, to enhance access to APDs and allied health professionals, for people with cognitive disability living in remote and rural locations. MBS items should be expanded to include telehealth, to increase access to services.(14)
- Funding for travel is needed for people with disability to access APD services, or for APDs to travel to clients in remote and rural locations.(13)

Inadequate management of nutrition and lifestyle risks

The scoping review by Troller and Salomon(6) identified several nutrition care practices associated with the deaths of people with disability in Victoria, NSW and Queensland between 2007 and 2018, of which a high proportion were people with cognitive disability. As detailed by the researchers(6) and highlighted in Table 1, these issues include:

- Lack of comprehensive nutrition and swallowing assessment in at-risk groups
- Safe mealtime guidelines not being adhered to or being disregarded all together. DAA further notes that safe mealtime guidelines may be absent altogether
- Expert advice provided by a dietitian or speech pathologist about mealtime management were not adhered to
- Failure of service providers to reduce prior identified risks of choking
- Poor management of lifestyle related risks
- Lack of staff awareness or compliance with lifestyle policies
- Lack of care co-ordination between services to address identified risk factors
- High rates of psychotropic prescriptions and polypharmacy

The case study presented Appendix 2 provides an example of the impact of poorly managed eating practices on the weight status of people with disability living in residential facilities in NSW, and the benefits of involving a dietitian to address these issues. In this case, the benefits of dietetic involvement were improved weight outcomes for residents, improved management of dysphagia and the associated nutritional risks, and State-wide recommendations to improve dysphagia management practices. This case relates to a submission to the Disability Royal Commission by dietitian Lyn Stewart.

DAA recommendations

- Better management of nutrition and lifestyle risks is required to promote the mental and physical health of people with cognitive disability, and reduce preventable deaths.(6) This

will require increased referral to APDs to address diet-related issues, training and education of all staff on appropriate management of diet and lifestyle risk, and monitoring and evaluation practices to ensure lifestyle risks are identified and managed appropriately.

- We recommend the Royal Commission take special note of the extensive list of food and nutrition-related recommendations provided by Troller and Salomon, to reduce respiratory and choking related deaths and reduce lifestyle risks, of people with disability in receipt of disability services.(23)
- Collaborate with the Dietitians Association of Australia and other relevant organisations, to create food and nutrition policy and systems to support the physical and mental health of people with disability.

Workforce and educational barriers

A skilled and knowledgeable workforce is required to address the nutrition care needs of people with cognitive disability. Nutrition knowledge and skills are needed across the range of professions including APDs but also planners, local area coordinators, support workers and health professionals.

Key education and workforce issues include:

- Lack of knowledge and education of staff and health professionals regarding:
    - The connection between physical health and mental health(7)
    - The role of food, fluids and nutrition in health and disability(4, 5)
    - The role of APDs in addressing the physical, mental and social needs of people with cognitive disability, and when to refer to an APD(7)
    - Healthy eating through supported decision making
    - Cognitive, language and behavioural considerations when supporting people with cognitive disability
- Not enough opportunity for student dietitians and other health professionals to gain experience working with people with cognitive disability prior to graduation
- Lack of opportunity for dietitians and other health professionals to extend their skills and update their knowledge post-graduation
- Lack of community services providing multidisciplinary care for people with cognitive disability that include APD services
- Too few APDs employed by large disability service providers

DAA recommendations

- There should be core education and training regarding food, fluids and nutrition for all staff and health professionals involved in the care of people with cognitive disability

- Education should also be directed to other individuals who influence food choices including family members
- Increase the number of dietitians working in the community setting.

Funding barriers

There are multiple funding barriers to access of APD services including:

- Not enough funded positions for APDs in community services for people with cognitive disability
- Insufficient duration and number of MBS rebated sessions for APDs and other allied health professionals. Current funding only entitles eligible individuals to 5 sessions per year, shared across all eligible allied health professions. This is insufficient to deliver evidence-based care for people with cognitive disability, to support building relationships, communication and incremental behaviour change.(14)
- Lack of funding from Australian, States and Territory governments to build the capacity of the dietetic and allied health workforce, to support the needs of people with disability
- Individuals with NDIS funding may be denied access to funding for APD services or provided inadequate hours with the APD to address their individual goals
- People with cognitive disability may have lower income,(24) which may limit their access to healthy food, fluids, and APD services
- Limited funding for people with disability to travel to access APD services or for APDs to travel to their clients.(13)

DAA recommendations

- Fund dedicated APD positions in community-based multidisciplinary teams and other health services for people with cognitive disability
- Ensure people with cognitive disability have enough funding, through NDIS or other sources, to access APD services
- Address financial barriers, such as low income, that limit access to healthy food, fluids and nutrition care
- Increase the duration and number of MBS items for APDs services, to enable effective dietary consultation with people with cognitive disability.(14)

Lack of accessible information

There is a lack of accessible resources to support people with cognitive disability to make healthy food choices and lifestyle change.

DAA recommendations

- Fund the development of accessible resources to support people with cognitive disability to make healthy diet and lifestyle choices.

Problems that people with cognitive disability have with the NDIS and accessing health care (question 3)

The NDIS represents an opportunity for people with cognitive disability to access supports and services to address their nutrition care needs. However, several issues remain.

- Even in 2020, subsequent to the NDIS guidelines changing in June 2019, NDIS planners deny access to APD services in NDIS plans or provide fewer hours than necessary for the participant to achieve their goals.
- Plan review processes are inconsistent. Access to APDs may be denied upon plan review to the detriment of the person with cognitive disability.
- Participants have often been told to use Medicare Chronic Disease Management items (CDM) to access APD services rather than NDIS funding. However, CDM items are unsuitable to support effective treatment in clients with complex care needs and people with cognitive disability. These participants often require more time with the APD for initial and follow-up dietary assessment compared to what is provided through the CDM items.
- NDIS Planners often lack awareness and knowledge regarding the role of food, fluids and nutrition and APD services in addressing the physical, mental and social needs of people with cognitive disability. This lack of awareness means that people with cognitive disability are still denied access to nutrition care in NDIS plans.
- For people living in rural and remote locations without local access to an APD, there is limited funding for travel to seek the services of APDs. Telehealth services are an option but the infrastructure to support telehealth is poorly established and many people with disability lack the appropriate technology and support to access services in this way.
- Services to APDs are currently disrupted due to the current COVID-19 pandemic and associated closure of services or reduction in face-to-face clinical consultations. Whilst the NDIS allows for telehealth consultations, many people with cognitive disability lack the appropriate technology and supports to utilise telehealth to connect with an APD. Further, APDs have varying capacity to deliver telehealth services to people with cognitive disability.

DAA recommendations

- All staff and health professionals involved in the care of people with cognitive disability should be educated and trained, as per the recommendations provided in question 4

- NDIS planners should be guided by recommendations from the APD regarding the appropriate number of hours to meet the participant's needs
- The NDIS planning and review process should provide greater consistency and ensure that reasonable and necessary nutrition supports (products and APD services) are identified and included in plans
- NDIS should provide funding to cover travel costs associated with delivering nutrition care(13)
- Funding should be directed to build the capacity of the workforce to deliver telehealth services, and to support people with cognitive disability to access and use telehealth technology.

Experiences of neglect in health care different for First Nations and culturally and linguistically diverse people with cognitive disability (question 7)

There is a long history of violence, abuse, neglect and exploitation of Aboriginal and Torres Strait Islander peoples, leading to many of the health inequities observed today.(25, 26) The life expectancy gap for Aboriginal and Torres Strait Islander peoples is 8.6 years for males and 7.8 years for women(27) and diet-related chronic disease is a major contributor to the mortality gap.(28, 29)

It is reported that 8% of Aboriginal and Torres Strait Islander peoples between the age of 12 and 24 years 'have problems of psychological development', which is around double the general population.(30)[(p. 307)] Aboriginal and Torres Strait Islander peoples experience the spectrum of cognitive disability experienced by the broader population. However, there is concern that the prevalence of some conditions may be increasing.(30) The prevalence of intellectual disability among Aboriginal and Torres Strait Islander peoples is higher than the general population and the rate of intellectual disability is reported to increase across the lifespan.(30, 31) Some conditions, such as Autism Spectrum Disorder, may be under- or misdiagnosed, due to language and cultural barriers or difficulty obtaining an accurate history.(30)

This data suggests that the prevalence of cognitive disability is disproportionate among the Aboriginal and Torres Strait Islander population. Cognitive disability may exacerbate existing disadvantage experienced by Aboriginal and Torres Strait Islander populations such as lack of physical or economic access to adequate, safe and nutritious food and fluid, and access to culturally appropriate nutrition care.(29, 32)

Other culturally and linguistically diverse (CALD) populations may face their own challenges and compounding issues that impact food and nutrition, such as communication barriers, poor integration of services (eg disability and aged care) and a workforce unequipped to work with a CALD population.

Work is needed to synthesis existing data, to characterise the unique food, fluid and nutrition care challenges of Aboriginal and Torres Strait Islander and CALD populations. A skilled and educated workforce, with cross-cultural competency and appropriate communication skills is also required to deliver effective nutrition care.(29) Strategies to build workforce capacity (33) include:

- Core training of non-Indigenous health professionals should include an Aboriginal and Torres Strait Islander curriculum framework
- Food and nutrition units integrated into core Aboriginal Health Worker primary health care training
- Opportunities for Aboriginal and Torres Strait Islander peoples to participate in tertiary training in food and nutrition
- Fostering partnerships between Aboriginal and Torres Strait Islander peoples, CALD populations and health professionals to deliver key nutrition messages
- Dedicated nutrition and dietetic positions for Aboriginal and Torres Strait Islander peoples and people from CALD backgrounds.

DAA recommendations

- Commission research to understand the unique food, fluid and nutrition issues facing Aboriginal and Torres Strait Islander peoples with disability and CALD communities
- Fund the development of culturally appropriate services
- Address issues of inequitable physical and economic access to safe and adequate food, fluids and nutrition care
- Develop workforce capacity, as per strategies outlined above
- Interpreting services should be made accessible in the private practice setting and better subsidised to ensure equity of access to services.

Helping people to feel safe when accessing health care (question 8)

Addressing the spectrum of issues and barriers to nutrition care is required for people to feel safe when accessing care. Addressing the person with disability as a unique individual and using appropriate language and communication strategies is important. It is also important that healthcare professionals are appropriately educated and trained to deliver culturally appropriate support for people with cognitive disability.

A suitably qualified and experienced support person advocating for the person with a cognitive disability would be a useful resource when endeavouring to access health services of every kind.

Appendix 1. Examples of people with cognitive disability denied access to nutrition support products or APD services during the rollout of the NDIS

Pseudonym	Date of APD report	Participant age (years)	Living situation	Disability	Functional impairment which impacts on food and nutrition	Nutrition and dietetic support requirements
Danielle	June 2019	35	Small group home; Brisbane	▪ Cerebral palsy ▪ Intellectual disability ▪ Epilepsy	▪ No swallow ▪ High risk of vomiting and dumping syndrome ▪ Sensitive to dehydration	▪ Continuous pump feeding to meet all nutrition requirements ▪ Nutrition support to maintain bowel function, fluid intake and achieve correct feeding technique
Frederick	June 2019	37	Brisbane	▪ Cerebral palsy ▪ Quadriplegia ▪ Epilepsy ▪ Contractures ▪ Non-verbal communication	▪ Unable to swallow safely (causing aspiration pneumonia) ▪ Risk of dumping syndrome	▪ 100% nutrition through PEG ▪ Bolus through syringe
Henderson	June 2019	62	Supported accommodation; Brisbane	▪ Intellectual disability ▪ Physical disability ▪ Epilepsy	▪ Full support for meal preparation and feeding ▪ History chronic constipation ▪ Unintended weight loss ▪ Sporadic food refusal ▪ Risk of nutrient deficiency ▪ Continuous movement of upper body increases energy requirement	▪ 100% nutrition and hydration requirements through food and supplements
Gregory	June 2019	58	Brisbane	▪ Down's syndrome	▪ Dysphagia ▪ Reliant on care team. ▪ History unplanned weight loss. ▪ Periods of food refusal.	▪ Thickened fluids ▪ Texture modified diet ▪ Nutrition supplements in addition to meals
Philip	June 2019	37	Supported group home; Brisbane	▪ Intellectual impairment ▪ Anxiety ▪ Autism	▪ Dysphagia ▪ Underweight ▪ Difficulty consuming adequate food and energy to maintain weight	▪ Thickened fluids ▪ Texture modified diet

Steven	June 2019	7	Brisbane	▪ Acquired brain injury Non-verbal	▪ Dysphagia ▪ Weak swallow ▪ Oral intake inadequate to maintain weight ▪ Constipation ▪ Diarrhoea ▪ Bloating ▪ Reflux and vomiting ▪ High muscle tone (increase energy requirements and makes it difficult to maintain weight)	▪ Tube feeding ▪ Advice on types and amounts of feeds to meet nutrition requirements
Melissa	May 2019	10	Lives with family; Regional QLD	▪ Autism ▪ Developmental delay	▪ Significant food aversions	▪ Requires nutrition support product orally to grow but told nutrition support product cannot be included in NDIS plan
Trent	Nov 2017	45	Supported accommodation; Perth	▪ Acquired brain injury	▪ Progressive dysphagia ▪ Weight loss ▪ Constipation ▪ Dehydration	▪ Nutrition support (PEG) ▪ Dysphagia management

Appendix 2. Case Study: Nutrition project leads to improved weight and nutrition of severely underweight people in large residential services run by NSW Department of Community Services

The problem

In 1993/1994 Dr Beange, a part-time medical officer at Stockton Centre, identified that residents in four of the wards at Stockton Centre, with severe to profound disability, were very underweight. Dr Beange consulted with the CEO and requested dietary assessment to identify nutrition problems.

The dietitian (Lyn Stewart) identified the following issues:

- Inadequate food intake by residents who were fully dependent on being hand-fed by nursing staff
- Many of the residents had dysphagia (difficulty eating, chewing and swallowing)
- Inadequate time to feed residents
- Lack of understanding by staff regarding how the person should be carefully and safely fed
- Staff belief that residents were naturally underweight and that nothing could be done to address the underweight. "They had tried and failed many times"

Following this work, in 1994/1995, Lyn was commissioned by the NSW Department of Community Services, to consult on the issue of underweight across all government disability residential facilities in NSW. Dietary assessment identified the following issues contributing to underweight among residents:

- Cultural beliefs that operated amongst staff members that severely underweight residents were naturally underweight and that this condition was normal for them
- Inadequate time allowed to feed people. Staffing was typically one person hand-feeding eight fully dependent residents in one hour
- Inappropriate feeding practices (eg. forcing food into the mouth of a struggling person thus predisposing them to choke; failure to support the head of a person with uncontrolled movement while they were being hand fed; not allowing sufficient time for swallowing between mouthfuls of food)
- Lack of understanding about dysphagia and its nutritional consequences and respiratory consequences
- Staff feeding practices led to significant malnutrition (insufficient food) among residents

The outcome

- Project renourish was implemented at Stockton to address underweight residents. Two part-time dietitians were employed and began working with a speech pathologist who had expertise in dysphagia. Over the following several years, residents responded to the improved care at mealtimes and were fed more food. Some severely underweight residents in their 20's resumed growing, began to menstruate, and gained weight towards a healthy weight range.
- In 1998, the Nutrition Project, funded by the Department of Community Services was implemented, with the following outputs:
    - 'Nutrition and Swallowing Checklist' (a risk assessment tool for nutrition and for dysphagia)
    - 'Nutrition in Practice Manual' (the guide to using the Nutrition and Swallowing Checklist)
    - 'Food Service Manual' (a manual for large accommodation facilities)
- In 2001 the checklist and manuals were introduced with a training program in disability services in NSW. The checklist may have also been rolled out in both government-run and non-government services in NSW.
- Other versions of the checklist derived from this original work have since been utilised in disability services in Victoria, Western Australia, the ACT and South Australia. FACS in NSW also have a nutrition and swallowing checklist that was developed after this original work by Lyn Stewart and her project team.

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