Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability:

Group Homes

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 nations. DAA appreciates the opportunity to respond to the Group Homes Issues paper by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

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DAA interest in this inquiry

The Dietitians Association of Australia (DAA) supports the rights of people with disability living in group homes to access safe, healthy and affordable food, and the services of an Accredited Practising Dietitian (APD) to achieve their goals.

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 provide medical nutrition therapy services, advocacy and education for people with disability living in group homes and their support staff. APDs have an important role in supporting people with disability to achieve their goals and meet their unique food and nutrition needs.

APDs should be engaged to work alongside other allied health professionals and staff involved in the care of people with disability, as APDs work with all age groups across the entire continuum of care.

Food and nutrition issues in group homes

Access to adequate food, fluid and nutrition care to meet the unique needs of people with disability is a universal human right, enshrined in the Universal Declaration of Human Rights(1) and the Convention on the Rights of Persons with Disabilities.(2) However, it is the experience of our members that many people with disability living in group homes, experience neglect related to inadequate provision of food, fluids or nutrition care. While some group homes perform well in terms of meeting the needs of people with disability, in many situations this is not the case. More needs to be done to ensure equitable access to adequate food, fluids and nutrition care for all people with disability including those living in group homes.

People with disability may have physical, intellectual, sensory, psychiatric and/or psychosocial impairments that lead to unique food and nutrition requirements.(3) These requirements are in addition to general or age and sex-specific requirements for growth and development, repair from injury, defence against infection, physical activity and mental health.(4) Of the ~17,000 people with disability living in group homes, around 30% (n=5100) have mild intellectual disability.(5) Others may have moderate or severe intellectual disability or other types of disability such as acquired brain injury. Each person will have their own unique background and require access to food, fluids and nutrition care that is tailored to their individual needs and preferences. For instance, the food, fluid and nutrition requirements of a person with Down Syndrome and weight issues, will differ from a

person with cerebral palsy experiencing swallowing difficulties on a texture modified diet, or an individual with acquired brain injury requiring enteral nutrition (tube feeding).

Neglect in the provision of food, fluid and nutrition care, occurs on both an individual and systemic level. The quality, variety and nutritional adequacy of foods in group homes is often inadequate, and support to make informed food choices may be lacking. Our members advise that some homes have insufficient food to make meals and/or insufficient money to buy food, suggesting that food insecurity is an issue. Inadequate access to allied health and APD services increases the risk of adverse nutrition-related outcomes including poor physical, mental and psychosocial wellbeing and reduced quality of life.(6) Preventable deaths have been linked to inadequate nutrition care practices and poor management of diet and lifestyle-related risks.(7) Nutrition-related risk factors are also associated with leading causes of death of people with disability in receipt of disability services in Australia.(7) Appendix 1 outlines key nutrition-related risk factors and nutrition care practices associated with leading causes of death of people with disability, as identified by research conducted by Troller and Salomon.(7) While our members report hearing more about neglect than abuse or violence regarding food, the Royal Commission heard from a witness that food-related punishment is used in the group home setting.(8)(P-47) More research is needed to investigate the extent of these issues.

The impact of neglect in provision of food, fluids and nutrition care is well-documented. People with disability living in group homes, have disproportionate rates of diet-related chronic disease, poor nutrition-related quality of life and increased mortality.(7, 9) Access to APD services is inadequate, leaving many people with disability, living in group homes, without access to professional support to advocate for and address their nutrition care needs.

Access to adequate food, fluids and nutrition care is a universal right. Yet, issues of food and nutrition are commonly overlooked by policy makers and those involved in the care or support of people with disability. ***DAA considers this a longstanding and overlooked human rights issue and we call on the Royal Commission to make recommendations that address this problem and improve issues related to food, fluids and nutrition care, for people with disability living in group homes.***

Key recommendations

A range of solutions are needed to address the nutritional neglect of people with disability living in group homes.

- Integrate food and nutrition education, and skill development, into VET courses, undergraduate degrees and continuing education for all staff and health professionals involved in the care of people with disability living in group homes
- Build awareness and knowledge of the role of APDs in addressing the physical, mental and psycho-social needs of people with disability
- Develop legislation and policy to support healthy eating and supported decision making in group homes
- Develop legislation and policy to address interface issues between mental health, ageing and the disability sectors
- Engage with the DAA to address the spectrum of food and nutrition issues
- Provide accountability mechanisms to ensure that staff, health professionals and other people involved in the care of people with disability in group homes provide appropriate support for healthy eating and managing nutrition and lifestyle-related risks according to best practice standards of care
- Provide more funding for people to engage with an APD through individual and block funding
- Develop innovative methods to improve access to APD services in rural and remote regions, such as through better use of telehealth technology and by building workforce capacity
- Employ more APDs in disability services and community settings
- Routinely employ APDs to work alongside speech pathologists to assess eating and drinking issues for people with disability
- Improve the NDIS planning and review processes to ensure consistency in access to APDs. This will involve educating NDIS planners on the role of food, fluids and nutrition in health and disability, and the role of the APDs
- Invest in research to assess the needs, barriers/facilitators to access of food, fluids and nutrition care, and health of people with disability
- Invest in research to investigate the extent of abuse and neglect of food, fluids and nutrition care of people with disability living in group homes.

Quality of life for people with disability living in a group home (question 2)

When a person's food, fluid and/or nutritional needs are not met, their physical, mental and psycho-social wellbeing may be compromised, and quality of life reduced.(6, 10)

Examples of how food, fluid and nutrition-related issues impact quality of life:

- The physical burden of diet-related chronic disease may lead to mental ill-health and social exclusion.(10) For instance, obesity may lead to social withdrawal(11) and sedentary behaviour in individuals with psychosocial disability(12)
- Poor food quality and lack of food variety may reduce the enjoyment of eating and the mealtime experience, both important dimensions of quality of life
- Lack of choice and control over food and activities, such as meal planning and food preparation, impacts social participation and reduces quality of life(13)$^{(P-125)}$
- Lack of support to make informed food choices may lead to frustration, poor mealtime experiences and exacerbation of diet-related concerns such as obesity(14)$^{(P-162)}$(13)$^{(P-125)}$
- Insufficient food and/or lack of money to buy food impacts both nutrition status and food-related quality of life. One of our members reported observing this over the last 15 years, during the transition from institutional care to group homes in Victoria. APDs have addressed this issue by approaching management to advocate for money or food for residents of the home.

Violence, abuse, neglect or exploitation of people with disability in group homes (question 3)

DAA advocacy to address longstanding issues of neglect of food, fluids and nutrition care of people with disability

DAA has long advocated for the rights of people with disability to healthy food, fluids and nutrition care.(6, 15, 16) (17, 18)

We draw attention to a letter addressed to the Hon Nicola Roxon and further communicated to Rhonda Galbally and several State Ministers(19)(Attachment 1). In the letter, dated 29th October 2008, we express our concern regarding the neglect of nutrition problems in clients of disability accommodation services in Australia. The letter raises our concern regarding preventable deaths of

people with disability. We highlight the absence of dietitians amongst allied health services in the disability sector and the failure of states and territories to act on the findings of the NSW Ombudsman regarding *'the need for, among other things, dietetic services to ensure appropriate evaluation of feeding practices, nutritional assessment, implementation of medical nutrition therapy and monitoring of clients in coordination with other members of a dysphagia management team*."(19)[(p. 1)]

It is unacceptable that despite the ongoing work of the NSW Ombudsman, DAA and others to advocate for better management of these problems, these issues remain unaddressed and people continue to die from potentially preventable causes.

Neglect of food, fluids and nutrition care

The physical, social and mental health needs of people with disability living in group homes have long been neglected. Below we highlight several areas of neglect of the food, fluids and nutrition care needs of people with disability living in group homes.

Food quality and food access issues

Poor food quality and inadequate access to nutritious food, fluids and nutrition support products, contribute to reduced quality of life, malnutrition and diet-related complications in people with disability living in group homes.(7, 18)

Many people living in group homes rely on disability support workers to assist with making food choices, preparing meals, budgeting, food shopping, food handling and texture modification of foods. However, support workers typically have minimal nutrition knowledge and may lack the practical skills needed to support healthy eating. Too often, the food habits and attitudes of untrained staff become the standard adopted in the group home in which they work. This may lead to inadequate supply of healthy food, poor dietary habits and adverse health outcomes.(14)[(P-162)]

Food insecurity is an issue. Our members advise that some group homes have insufficient food to make meals and/or insufficient money to buy food. APDs have reported advocating for food and/or money for residents to address food shortages.

Management of nutrition and lifestyle-related risks

Inadequate management of nutrition and lifestyle-related risks contributes to preventable deaths of people with disability. Troller and Salomon(7) investigated the prevalence and causes of deaths of people with disability in receipt of specialist disability supports and services, between 2007 and 2018, in Victoria, NSW and Qld. The research identified several nutrition care practices associated with leading causes of death (respiratory, choking, neoplasms and cardiovascular), including:

- *Lack of comprehensive nutrition and swallowing assessment in at-risk groups*
- *Increased risk of aspiration related to safe mealtime guidelines not consistently adhered to or sometimes being disregarded all together. DAA further notes that safe mealtime guidelines may be absent altogether.*
- *Failure by service providers to proactively reduce the risk 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 (7)*

Further examples of neglect of the management of nutrition and lifestyle-related risks are briefly outlined below.

Poor diet

Suboptimal diet is a key modifiable risk factor for non-communicable disease and mortality.(20) Like many Australians, research shows that many people with disability do not eat enough fruit and vegetables for optimum health and wellbeing, and do less physical activity than recommended.(21) Recent Australian data shows that people with disability consume more sugar sweetened beverages and diet drinks daily, compared to people without disability.(22)

People with disability represent a diverse population and the nutritional quality of diets will vary between groups. Research is needed to identify and address the nutritional issues of different groups of people with disability.

Dysphagia, choking and aspiration pneumonia

Aspiration pneumonia and choking are leading causes of death in people with disability living in group homes. Inadequate nutrition care practices are associated with these deaths and the surrounding nutritional problems.(7)(Appendix 1)

This problem is not new. The NSW Ombudsman has investigated the causes of death of people with disabilities in NSW accommodation services over many years.(9, 23-28) Amongst other issues, the Ombudsman has repeatedly raised the problem of deaths due to choking and aspiration pneumonia, and the need for dietetic services. DAA has also advocated for better management of these issues. The Ministerial response to our written communication in 2008 was inadequate,(Attachment 2) with no responsibility or proactive action taken to address the issue we raised regarding neglect of nutritional care and dietetic services. This is reflected systemically by the poor outcomes and preventable deaths that emerge year after year.

A recent submission to the Royal Commission by dietitian Lyn Stewart (Appendix 2), highlighted work that has been done by dietitians to aid better management of dysphagia, risk of choking and aspiration pneumonia. However, despite the combined efforts of dietitians, DAA, the NSW Ombudsman and others, these issues remain largely unaddressed. Part of the solution is to ensure that both APDs and speech pathologists are routinely employed in a team approach to manage feeding, food, fluid and nutrition issues for people with disability, including those living in group homes.

Overweight, obesity and cardiometabolic risk factors

Overweight, obesity, type-2 diabetes, hypertension and cardiometabolic disease risk factors are prevalent among people with disability living in group homes.(7, 9) Poor diet is a risk factor in all of these conditions;(20, 29) however, research suggests that diet and lifestyle-related risks are poorly managed by support staff and health professionals.(7)

The 2018 NSW Ombudsman's *report of reviewable deaths of people with disability in residential care(9)* emphasises the need for greater action to address weight issues for people living in group homes:

> *"…our reviews continue to identify the need for proactive efforts by disability services, health providers, and population health programs to help people with disability in residential care to address their critical weight issues."(9)[p. 47]*

The report also highlights the lack of professional support and team-based care in the context of obesity management:

> *"There is insufficient evidence of health practitioners and disability services working together, and with the person, to help them to address their obesity. A range of reviews identified individuals whose weight was adversely affecting their health, such as their respiratory function. However, other than recording the significant risks for the person and telling them they needed to lose weight, no support was provided. In some cases, we did not see an attempt to adopt a coordinated and person-centred approach to helping the person to address their weight risks, even when their obesity was noted to be limiting the treatment options for their chronic conditions."(9)[p. 47]*

DAA observes that lack of support for healthy eating, inadequate access to healthy food and fluids, unsupportive food environments and lack of referral to allied health professionals including APDs are some of the factors that contribute to this issue.

Unintentional weight loss and underweight

Our members report that underweight and unintentional weight loss, in people with disability living in group homes, are poorly managed.

For people with limited mobility, loss of fat and/or muscle may lead to weight loss, which contributes to further loss of mobility and potentially loss of independence or access to the community. Underweight and unintentional weight loss can also lead to compromised skin integrity, which can be an issue for non-ambulant people. Skin breakdown potentially reduces a person's ability to participate in the community, reduces quality of life and is expensive to treat.

The submission to the Royal Commission by dietitian Lyn Stewart (Appendix 2) highlighted several problematic feeding issues and nutrition care practices responsible for underweight in people living in residential facilities. Among them, a belief that underweight is normal and poor feeding practices (eg. force feeding), contributed to the problem of underweight residents. Again, lack of education and training of support staff in identifying and addressing underweight and its etiological dietary factors contributes to these issues.

Bowel management and constipation

Our members suggest that many people with disability living in group homes experience issues with bowel function and constipation. When a person with a disability is dependent on another person to provide them with adequate fluid intake, there is a risk that insufficient fluids are provided. Insufficient fluid intake leads to constipation and reduced quality of life.

Appropriate nutrition care is required to ensure that food and fluids are delivered in a timely manner and address individual requirements. Our members report that the fluid, food and/or nutritional aspects of bowel management and constipation are poorly addressed in both the medical context and group home setting. This is reflected by witness accounts to the Royal Commission.(30)[(P-47 – P-49)]

DAA does not have data on the extent of this issue but our members suggest this is a problem. Further research is needed to investigate the extent to which this issue impacts people with disability living in group homes.

<u>Inadequate access to Accredited Practising Dietitians</u>

Many people with disability living in group homes have complex nutritional needs and live in complex social situations requiring adequate time with an APD to achieve their goals. However, access to APD services is often inadequate, for reasons such as lack of money or funding, uneducated management and lack of support from disability support workers, staff and health professionals.(6, 9, 31)

> *"… our reviews of deaths in 2014-2017 identified low rates of access to dietitians for people who were overweight, obese or severely obese."(9)*[(p. 47)]

People living in group homes have frequently been denied APD services by the NDIA or NDIS planners. For NDIS participants with access to an APD services, there is often not enough hours in the NDIS plan for the participant to achieve their goals. This seems to have improved since the June 28, 2019 decision by Disability Reform Council, but some dietitians still report NDIS Planners provide inadequate hours for dietetic support or remove hours for the APD upon plan review, despite the ongoing need for this service.

DAA also notes that during the transition to the NDIS, many people went without access to an APD or continued to engage with an APD in the mainstream setting, as community health services discharged residents to the care of NDIS providers.

Funding may be limited or NDIS planners may not recognise the importance of involving an APD in the NDIS plan or the time required for effective support. Our members report that working with people with disability in group homes takes longer due to travel, administration, communication requirements and care coordination activities that are often required to support people with disability and their support staff.

People living in group homes located in isolated, remote or rural locations may have difficulty accessing the services of an APD. Further, allied health professionals, including APDs, are ineligible for telehealth services under the Medicare Chronic Disease management program, making it even more difficult for people to access APD services through Medicare.(31)

Inappropriate environmental and behavioural support for diet, physical activity and lifestyle change

Disability support staff, family and health professionals have been observed promoting unhealthy food behaviours such as encouraging consumption of take away foods or providing energy-dense nutrient poor snacks, such as chocolate, as food rewards.

> *"In this instance, the house staff do not follow the behavioural support strategies provided by clinicians. There has been little oversight of the house staff by the service provider. And despite numerous complaints being made about the quality and behaviour of support staff, no improvements have occurred. Staff in this home have repeatedly refused to assist the client to cook, despite the client wishing to learn to cook. Instead, support staff have facilitated the client eating takeaway food constantly. This client has gained a large amount of weight accordingly."(14)*[(P-162)]

The NSW Ombudsman found that disability support staff often neglect to provide appropriate support to address weight issues, eating habits and physical activity, and some practices contribute to health problems.

> *"…people with disability in residential care need assistance to be able to reduce their weight and lead a more active lifestyle. Among other things, most of the elements that affect their weight – including the food they eat, and the physical activity they can be involved in – are typically heavily in the control of disability support staff. However, our reviews of the deaths of people who were obese have rarely identified a proactive approach to helping the person to reach a healthy weight. Some practices by disability services – such as community access outings that comprise a meal at a fast food outlet – promote the opposite."(9)*[(p. 47)]

Staff may have little consideration for the need for access to food, involvement in cooking and a functional kitchen to prepare food and drinks.

> *"They put in a second sink so the residents in the wheelchairs could access the sink and help with meal preparation and clean up and things. That was fantastic but when they put the sink they put a big fascia board across the front, so there's no access for wheelchairs to that second sink. But somehow, somebody has signed off on that and when I keep asking what's happening, what's happening, it's like there is – it has come back there will be no more work done on this house, the money has been spent, that's the end of it. And, like, well, it's completely useless and it's a blatant misuse of funds as well, if nothing else. So yes, none of those residents get to actually help with meals in their own home."(13)*[(P-148)]

Lack of choice and control over food

People living in group homes may lack choice and control over food. The Disability Royal Commission asked Dr Pearce, Office of the Public Advocate, if there were features of the group home model that need to be addressed for group homes to support independent living and human rights, in relation to choice and dignity. Dr Pearce stated that, amongst other things, choice and control over food and mealtimes was often lacking:

> *"Now, the five of you are going to live together. You're going to share the one bathroom. You've going to have meals at the same time. You're going to go to bed at the same time. You're going to eat the same kinds of food. Well, I mean, how is that reflective of human dignity and choice? So it's the one size fits all model that is one of the contributing factors to violence and abuse in group homes. I mean, wouldn't you be frustrated? I would really struggle with that, not to have choice about what kinds of food I ate, who I lived with, when I could use the bathroom, when I could go to bed."(13)*[(P-125)]

Causes and solutions to neglect in group homes (question 4)

Lack of skills, knowledge and education regarding food, fluids and nutrition and the role of APDs

NDIS planners, disability support staff, family, health professionals and others involved in the care of people with disability often have poor knowledge of the role of food, fluids and nutrition in health and disability. Staff may also lack practical skills and knowledge to support healthy eating through menu planning, budgeting and shopping, safe food handling, food preparation, cooking or texture modification of foods and drinks.

There is also limited awareness of the role that APDs play in supporting people with disability to achieve their physical, social and economic goals.

Lack of skills, knowledge and education contributes to neglect of the food, fluid and nutrition care needs of people with disability living in group homes, and the systemic failure to identify and address nutrition-related health concerns, promote healthy eating environments and refer to APD services.(7, 9)

There is an ongoing risk of adverse nutrition-related health outcomes for people with disability living in group homes if the skills, knowledge and educational needs of the workforce are not addressed.

DAA Recommendations

- Integrate food and nutrition education, and skills development, into VET courses, undergraduate degrees and continuing education for all staff and health professionals involved in the care of people with disability
- Building awareness and knowledge of the role of APDs in addressing the physical, mental and psycho-social needs of people with disability.

Lack of legislation and policy

Legislation governing food provision in group homes varies between states and territories and the NDIS Rules don't stipulate requirements for healthy food provision for providers of specialist disability accommodation. Further, the general nature of the National Standards for Disability Services(32) means that food and nutrition systems are not adequately addressed. This failure on the part of the national, state and territory governments to implement policy regarding food and nutrition has led to inadequate access to healthy food in group homes and as described throughout

this submission, poor nutrition care practices. This is particularly problematic for residents who are more dependent on staff and the existing support system to provide meals and beverages or support for healthy eating.

Legislation and policy change are needed to address interface issues between mental health, ageing and disability sectors, to ensure equity of access to food, fluids and nutrition care for all people with disability living in group homes. For example, many people with disability over 65 years of age are not entitled to NDIS funding, despite the need for disability-related health supports. Legislation and policy are needed to overcome structural and systemic barriers, to ensure equity of access to supports for all people with disability.

DAA Recommendations

- Assess existing policies and services to identify where inequities in access to adequate food, fluids and nutrition care exist. Address these gaps to ensure Australia is meeting its international human rights obligations
- Develop legislation and policy to support healthy eating and supported-decision making in group homes
- Develop legislation and policy to address interface issues between mental health, ageing and disability sectors, to ensure equity of access to food, fluids and nutrition care for all people with disability
- Provide accountability mechanisms to ensure that people with disability living in group homes are provided with appropriate support for healthy eating and nutrition care
- Provide funding for government departments or APDs to assess if group homes meet food standards set out in policies or legislation and provide funding to train staff to meet food standards, policies and legislation.

An example of best practice in policy and support for healthy eating in group homes

The legislation: In Qld, supported accommodation services that provide accommodation for 4 or more residents, are required to comply with the *Residential Services (Accreditation) Act, 2002* and the *Residential Services (Accreditation) Regulation, 2018*. The Act and Regulations stipulate requirements for food service provision, for level 2 and 3 supported accommodation providers. The 'levels' of accommodation refer to the degree of support residents receive with Level 3 pertaining to high-intensity care.

The initiative to improve food and nutrition in group homes: To support residents in meeting these requirements, Queensland Health community nutritionists (dietitians), in partnership with supported accommodation providers, developed the '*…toolkit for healthy eating in supported accommodation. A best practice guide'*.(33)

The aim of the toolkit is to help supported accommodation providers meet requirements outlined in the Regulation:

> ***2.1 Food and Nutrition*** *• Residents are provided with food and nutrition complying with the best practice guide of healthy eating in supported accommodation published by the health department on the website of the Metro South Hospital and Health Service.*
>
> ***2.2 Kitchens*** *• The kitchen facilities comply with the service provider's accredited food safety program, if any, or the Food Standards Code, standard 3.2.3.*
>
> ***2.3 Food Handling and Storage*** *• Procedures are in place to ensure the safe delivery and storage of food. • Persons preparing and serving food observe personal hygiene and cleanliness practices, take reasonable action to minimise the risk of food contamination, and comply with the service provider's accredited food safety program, if any, or the Food Standards Code, standard 3.2.2.(33)*[(p. 1)]

Implementation of the toolkit was supported through a series of face to face staff training sessions. Free interactive online training modules are now available to all Qld staff working in supported accommodation.

Through consultation with accommodation providers and the Qld government, the community nutritionists also played a role in updating the accompanying legislation and training government staff to assess if providers meet the legislation.

The outcome: The nutritionists informed DAA that the project has led to improvements to food supply and healthy eating within Level 2 and 3 supported accommodation and that support staff feel better equipped to support healthy eating.

One of the issues identified by the team is that there is more scrutiny, follow up and enforcement of the legislation of Level 3 providers than Level 2 providers, despite the technical requirement for both levels to meet the same food standards. More needs to be done to support accommodation providers to meet policy, legislation and standards regarding food and nutrition. More legislation and policy are needed to ensure all people with disability living in group homes have equitable access to healthy food, fluids and nutrition care, regardless of their housing situation.

Inadequate funding

NDIS funding for APD services is often insufficient for the participant to realise their full goals. However, we hear from members that this has improved since the 28 June 2019, Disability Reform Council meeting.

Medicare Chronic Disease Management items will rarely meet the needs of people with disability who may need more time with an APD to address complex functional needs, including time to establish rapport and communication.(31)

NDIS funding provides insufficient payment to cover APD travel costs to and from group homes situated in rural and remote locations. Likewise, there is insufficient funding for people with disability to travel to seek the services of an APD.(34)

With the introduction of the NDIS, block funding is no longer available. This makes it difficult for an APD to address food and nutrition issues associated with the broader group home setting such as group nutrition education and staff training.

DAA Recommendation

- Improve the NDIA travel rules to cover the cost of travel to and from the APD providers office to the NDIS participant living in a group home
- Provide more funding for people to engage with an APD through individual and block funding.

Physical location of group homes

People living in group homes in remote and rural locations typically have poor access to APD services and there may be additional barriers regarding supply of healthy foods to remote and rural locations. There is limited support for people living in group homes to travel to seek the services of an APD and there is limited funding to cover the transport costs of APDs to and from group homes.(34)

DAA Recommendations

- Facilitate better access to APDs for people with disability living in group homes including those living in rural and remote locations
- Find innovative methods to improve access to APD services such as through better use of telehealth technology and building workforce capacity in rural and remote locations.

Workforce issues

There are a range of workforce issues that contribute to neglect of people with disability living in group homes. These include:

- Lack of education and training of staff, support workers and health professionals regarding:
    - The role of food, fluids and nutrition in health and disability
    - How to support healthy eating through supported decision making
    - The role of APDs and when to refer to an APD
- APDs are not routinely employed to assess eating and drinking issues for people with disability living in group homes
- APDs are also not employed to work alongside speech pathologists when assessing eating and drinking issues. This leads to under diagnosis of nutrition-related problems that frequently co-occur with eating and drinking or swallowing difficulties (see Appendix 2 for case study)
- Not enough funded APD positions in services that support the needs of people with disability living in group homes, such as large disability service providers
- Inconsistent staff in group homes and the high turnover of staff impacts the implementation of policy and procedures including nutrition care
- Lack of policy in disability organisations to support healthy eating and engage APDs to support the food, fluid and nutrition care needs of people with disability.

DAA Recommendations

- Address the education, training and skills development needs of staff and health professionals who support people with disability living in group homes
- Employ more APDs to work in disability services and community settings
- Routinely employ APDs to work alongside speech pathologists to assess the eating and drinking issues of people with disability
- Support disability organisations to develop policy to support healthy eating and refer to APDs to address the food, fluid and nutrition care needs of their clients

NDIS issues

There have been ongoing issues with the NDIS including inconsistent planning and review processes that provide unreliable access to APD services and nutrition support products. Many people with disability, including those living in group homes, have been denied nutrition support products and APD services, despite these being both reasonable and necessary components of support. These issues have in-part been resolved recently with the availability of disability-related health supports to purchase with NDIS funding. However, APDs still report a lack of consistency in the planning and decision-making process regarding the inclusion of APD services in NDIS plans.

DAA Recommendations

- Improve the NDIS planning and review processes to ensure consistency in access to APDs. This will involve education for NDIS planners regarding the role of food, fluids and nutrition in health and disability, and the role of the APDs
- Also address educational, policy, funding and workforce issues as described above.

Differences in the experience of neglect for particular groups of people with disability (question 5)

Vulnerable groups may experience greater disadvantage and poorer access to healthy food and APD services. This may be the case in particular for culturally and linguistically diverse populations, Aboriginal and Torres Strait Islander communities and older Australians. Targeted measures are needed to ensure that access to food, fluids and nutrition care is culturally appropriate and meets the unique needs of culturally and linguistically diverse communities and First Nations people.

Research is needed to understand the unique needs of different groups of people with disability living in group homes.

Continuing role for group homes in providing accommodation for people with disability (question 6)

DAA acknowledges that group homes are an important source of accommodation for people with disability. However, more needs to be done to ensure access to healthy food, fluids and nutrition care.

Restrictive practices in group homes and what needs to change to eliminate their use (question 7)

Environmental restraint is a form of restrictive practice involving food and beverages in group homes.(35) In some cases, restrictive practices are used appropriately, with strategies in place to ensure appropriate access to food for other residents in the group home. For example, there may be locks placed on cupboards to limit access to food for a person with Prader-Willi Syndrome because of their increased appetite, decreased perception of satiety and obsessive and compulsive behaviour towards food. Measures may be implemented alongside the restrictive practice to enable other residents to access food and beverages.

DAA is not aware of the extent of unlawful use of restrictive practices in the group home setting. APDs have reported that disability support workers sometimes inappropriately label dietary advice given by APDs as a restrictive practice. A contrary view is that not providing opportunities for people to eat food or drink fluids to meet their individual health needs is an avoidance of duty of care and an abuse of human rights. The underlying factors here are likely to be poor understanding of the health and nutrition needs of people with disability and poor skills in supportive decision making.

The Disability Royal Commission identified cases of harmful application of restrictive practices including support workers restricting mealtimes as a form of punishment for undesirable behaviour.

> *"Oh, yes. Look, she couldn't win. It was. It was. There was no way she could win because what would happen was the staff that was on first thing in the morning if my daughter didn't behave, then there was – there was a consequence of that which might have meant she wasn't allowed to have her meals with the other residents, etcetera. And it was a cumulative thing. When the next person came on duty, they added to that. Then the next person came on duty; they added to that."(8)[P-47]*

There was also a report of poorly managed restrictive practices regarding food impacting all residents in the group home, rather than just the individual targeted for intervention.

> *"… Just where one person in the home might have some issues where the food has to be excluded and locked away, so it's locked away for everybody. Or where that one person may need a door locked, so it's locked for everybody. Or where a person routinely might be in their room and they're not allowed out because of other issues of compatibility. Those are matters which seem to be acceptable within homes and when they come to our attention we clearly point out they're not. And often, you know, notices to take action or notices of advice about training for staff around those matters because they're just not acceptable, even though they've become acceptable and normal for the home."(14)*[(P-197)]

DAA recommendations

- Build awareness and education regarding what constitutes environmental restraint, where they apply and how they can be managed
- Provide greater consistency in the use, authorisation and reporting of restrictive practices
- Provide education for support staff and health professionals on use of positive behaviour change strategies
- Provide education for all people involved in the care of people with disability, around enabling choice while meeting the food, fluid and nutritional needs of the people with disability
- Develop tools and guidelines for practice.

Barriers and obstacles to identifying, disclosing or reporting incidents of neglect (question 8)

Barriers to disclosing and reporting incidents of abuse and neglect regarding food and nutrition

- Fear of the consequences and bullying associated with disclosing and reporting information
- Cultural differences in consumer complaint behaviour lead to different approaches to disclosing and reporting incidents of abuse and neglect. Culturally appropriate strategies are required so people feel safe disclosing and reporting incidents of abuse and neglect.
- Lack of awareness that access to food, fluid and nutrition care is a human right
- Lack of appropriate channels of communication to raise issues regarding food, fluids and nutrition.

DAA recommendations

- The solutions will involve addressing the spectrum of issues leading to neglect of the food, fluid and nutrition care needs of people with disability
- Culturally appropriate strategies should be developed to enable people to feel safe in disclosing information
- Clarity around who is responsible for addressing the issues is needed, so that appropriate complaint channels can be established.

Addressing staffing in group homes to better support the choices and potential of people with disability (question 9)

- Workforce issues should be addressed including education of staff and health professionals regarding the importance of food, fluids and nutrition in health and disability, and the role of APDs
- Legislation, policies and procedures should be established to assist staff in providing and maintaining a healthy food environment and supporting healthy dietary behaviours. Policies regarding food and nutrition should be established at the level of government but also for individual group homes to support healthy eating and food provision in group homes.
- VET sector qualifications should include food and nutrition as compulsory content. Other topics that should be covered include supported decision making, substitute decision

making, and restrictive practice generally and specifically in relation to food. Education and training should also be directed to upskill existing staff and students.

Appendix 1. Leading causes of death of people with disability in receipt of disability supports and services in Victoria, New South Wales and Queensland between 2007-2018, and the associated food and nutrition-related risk factors and nutrition care practices(7)[1]

Respiratory deaths	
Food and nutrition-related contributing 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 contributing 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 were not adhered to
	Failure of service providers to reduce prior identified risks of choking
Deaths due to neoplasms and circulatory disease	
Food and nutrition-related contributing 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
	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

Appendix 4. 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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