

29 October 2008



The Hon Nicola Roxon  
Minister for Health and Ageing  
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Parliament House  
Canberra ACT 2600

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## **Re: Neglect in Dietetic Services for People with Disabilities**

Dear Ms Roxon,

We write with concern regarding the neglect of nutrition problems in clients of disability services in Australia. The virtual absence of dietitians amongst the allied health services in the disability service sector places people with disabilities at risk of malnutrition. This is particularly so for children with developmental disabilities, and children and adults with swallowing difficulties (dysphagia). Dysphagia places the individual at risk of inadequate food and fluid intake due to reduced quantities of food and fluid consumed, extended time required to eat and drink, reduced energy density and reduced range of foods available when foods need to be modified in texture to manage dysphagia. These consequences increase the risk of malnutrition, nutrient deficiency, dehydration, growth retardation and poor health. With the recent injection of federal government funds into disability services, particularly in NSW, we are concerned that **none** of these funds have been used to address the dire gap in professional nutrition services.

The Dietitians Association of Australia (DAA) has conducted a survey to ascertain as far as we are able, the extent of dietetic services in the disability sector. The results provided below in this letter confirm that there is a serious gap in dietetic services and that, as a result, people with disabilities who do access services through the Commonwealth State/Territory Disability Agreement (CSTDA) funded services have virtually no access to funded dietetic services, extremely limited access to dietetic services situated in State health services, and that they therefore must pay for private practice dietitians if and when they recognize the need for and can find and afford such a service.

This situation is all the more unacceptable when there is ample evidence that the main causes of death among children and adults with disabilities in CSTDA funded accommodation services have been choking and respiratory disease linked to aspiration pneumonia. These life-ending events are very frequently considered to be caused by dysphagia, i.e. swallowing difficulties, a common issue amongst people with a developmental disability. This is not new information. The NSW Ombudsman, and in earlier years the NSW Community Services Commissioner, has brought down report after report that analyses the causes of death of people with disabilities in accommodation services in NSW<sup>1-7</sup>. These reports have repeatedly highlighted the

need for, amongst other things, dietetic services to ensure appropriate evaluation of feeding practices, nutritional assessment, implementation of medical nutritional therapy and monitoring of clients in coordination with other members of a dysphagia management team. Yet in NSW these reports have not led to the employment of dietitians in disability services except in the two large government run institutions. We believe this situation, which is little better in any other State or Territory of Australia, should not be allowed to continue as it is tantamount to providing a level of care that knowingly places people at risk of early death from potentially manageable causes.

**DAA wishes to request the Minister’s support in the following ways:**

1. Requiring the Australian States and Territories to take an adequate and consistent approach to dietetic services under the CSTDA.
2. Adoption of the following important principle in disability services in Australia: that wherever speech pathologists are employed in CSTDA funded services to assess clients with eating and drinking problems, that there is also a dietitian employed to work in coordination with the speech pathologist to ensure adequate nutrition. Further, that this principle be adopted in both adult and children’s CSTDA funded services.
3. The Department of Health and Ageing initiates a project that redefines “therapy services” under CSTDA funding, so it includes dietitians as part of the range of allied health professionals providing services for children with developmental disabilities. Adequate nutrition is a fundamental human right. Models of therapy for children with developmental disabilities need to be brought up to date so they strive for best practice in allied health services.
4. That State and Territory governments responsible for administration of CSTDA funded services are required under the CSTDA to implement a periodic planning process of broad-based consultation with services and the community that allows service gaps to be recognised and acted upon. We suggest a planning process similarly structured to that used for the Home and Community Services (HACC) Program is a process that could be considered.

**Background**

The Dietitians Association of Australia (DAA) is the National Association of the dietetic profession, with branches in each State and Territory. DAA represents over 3700 members. DAA is a leader in nutrition and advocates for better food, better health, and better living for all. Members working in a range of practice areas including disability and management contributed to the development of this submission. DAA is pleased to see that the Australian Government has set up the National People with Disabilities and Carers Council that will advise the Government on the development of the National Disability Strategy. DAA would welcome the opportunity to provide advice on nutrition issues and services to the Council.

**Accredited Practising Dietitians (APDs)** potentially have a strong role to play in disability services. APDs should be working along side other allied health professionals in the area of disability as APDs work with all age groups and across the entire continuum of care. APDs are the leading nutritional professionals with the qualifications and skills required to provide expert nutrition and dietary advice. APDs have sound university qualifications accredited by DAA, undertake ongoing training

and education and comply with the Association's guidelines for best practice. APDs are committed to the DAA Code of Professional Conduct and Statement of Ethical Practice, and to providing quality evidence based services.

With appropriate funding APDs could provide professional nutrition and dietetic services that will make a positive difference to the health of people with disabilities in each State and Territory of Australia.

The scope of APD services should include:

- Assessment, nutritional care planning and provision of medical nutrition therapy to individuals
- Training and supporting staff in disability services to screen clients for nutrition risk factors including obesity and malnutrition.
- Provision of enteral nutrition therapy (tube feeding) when indicated
- Working with other allied health professionals, particularly speech pathologists and occupational therapists regarding assessment, planning and management of dysphagia (swallowing difficulties).
- Providing consultation and expert advice in menu design and food preparation within accommodation services (both in institutional and community settings) to ensure that nutritional requirements of clients are provided.
- Providing education and training on food, nutritional requirements and nutritional care to families, carers and staff in disability services.
- Preventative education, including counselling to promote the long term nutritional health of people with disabilities.
- Contributing to the development and implementation of nutrition policy and procedures in disability services.

### **Reasons for the current gap in services**

There appear to be several reasons why the gap in nutrition and dietetic services has not been addressed. We believe they include the following:

1. Nutrition and dietetic services are not seen as part of the traditional "therapy" services provided under CSTDA funded services. Perhaps this is because 'therapy' is not specified in terms of the professional services it could, or should, encompass. The lack of comprehensive guidelines describing the objectives and methods of 'therapy' services continues to limit the scope and development of these services. Therapy models have been used to exclude dietitians or deny the need for dietetic services.

2. An adequate diet has never been specified as integral to care provision under CSTDA funded services. Perhaps this is because an adequate diet is a human right and thus has been assumed as a basic standard of care. However, it is a mistake, even in a country as wealthy and educationally advanced as Australia, to assume that an adequate diet is always provided, let alone always consumed by individuals with swallowing difficulties or by other individuals with disabilities.

3. NSW is the only Australian State or Territory which has a nutrition policy in disability services<sup>8</sup>. Despite increased awareness about the nutrition risks in clients of CSTDA funded services this has not led to the employment of dietitians in disability services other than in institutional care. There has been an incorrect assumption in the

Department of Aging, Disability and Home Care (DADHC) that NSW Health will provide adequate and appropriate dietetic services for people with disabilities. Neither has a working relationship between DADHC and NSW Health been developed in order to provide dietetic services to clients of CSTDA funded services.

4. The professional inter-relationship between speech pathology and dietetics in the assessment and management of dysphagia (swallowing difficulties) has not generally been recognised in the recruitment of both professional groups into disability services although it is well established in health services. This has led to a lack of professional coordination in dysphagia management plans for clients in CSTDA funded accommodation services and community dwelling clients receiving these services. Hence the person with dysphagia may fail to meet micro and macronutrient requirements and/or hydration needs when the dietitian's input to the plan is missing.

5. The Home and Community Care (HACC) Program provides for an "allied health-dietetic" service type. There are no such allied health service type descriptions under CSTDA funded disability support services. This has led to wide variances between States and Territories in the provision of allied health services for people with disabilities.

6. The States and Territories do not lead a widely consultative periodic planning process for disability support services. This may partially explain why service gaps, such as in dietetic services, have not been recognised in disability service development plans.

### **The risks of nutritional neglect**

The near absence of dietetic services within CSTDA funded services in Australia places people with disabilities at risk of neglect of their nutritional welfare. This is a lamentable situation for adults with disabilities who are able to access a range of other allied health professionals employed under CSTDA funding. However for children with developmental disabilities the situation is worse. There are virtually no dietetic services for children with disabilities outside of those employed by State and Territory health departments within the children's hospitals. This means that nutritional status is not assessed by early intervention services, developmental disability assessment services or in school-based therapy services. The one exception is in those very limited early intervention services in Victoria as indicated by our survey in the table below. This gap in dietetic services applies across Australia in both metropolitan and rural areas.

People with significant dysphagia are at risk of an inadequate and/or imbalanced food consumption, developing malnutrition, poor immunity to infection, choking and aspiration pneumonia, and, in children, a risk of not meeting their growth potential. These consequences have been identified in the Ombudsman's reports as referenced at the end of this letter. Dysphagia should be assessed by professionals working in collaboration, and preferably in a team<sup>9</sup>. The core professionals in this process are speech pathologist, dietitian, occupational therapist, physiotherapist, and, as possible, nurse and doctor. The speech pathologist assesses and diagnoses swallowing disorders of an oropharyngeal origin. The speech pathologist makes recommendations as to safe

food textures and consistencies of beverages. Using these recommendations the dietitian conducts a nutritional assessment and implements a nutritional care plan by liaising with and educating family and carers about the preparation of food and drinks at recommended consistencies and textures. He/she advises on meals and menus to meet the person's nutritional requirements . When the dietitian's input is missing it means the speech pathologist's recommendations may not be interpreted into an adequate diet for the client, particularly when food and fluid consistencies are substantially changed. This can substantially increase the risk of inadequate energy and nutrient intake which can contribute to malnutrition, nutrient deficiencies, dehydration and, growth retardation in children, .

### **Current state of nutrition services targeted for people with disabilities**

DAA has recently surveyed dietitians who work in the disability sector to ascertain, as far as we are able, the extent to which dietetic services are currently provided across the country. The following information summarises our findings to date.

#### **1. Dietitians employed under CSTDA funded disability support services.**

<b>State / Territory</b>	<b>Dietitians employed by government disability services (ie. under CSDA-funded services)</b>	<b>Dietitians employed by non-government disability services (ie., under CSDA-funded services)</b>
NSW	4 in government institutional services.	0
VIC	2 plus 2.6 in early intervention services in three regions	1 in early intervention services
SA	2	3
QLD	0	0
WA	1	0.4
NT	0	0
ACT	unknown	unknown
TAS	0.4 temporarily for one year on work of limited scope	0

#### **2. Dietitians in private practice**

The number of APDs in private practice across Australia who provide services in the practice area of disability is small. In NSW (15); QLD (4); VIC(6), ACT(1), WA(1) and SA, NT and TAS have nil. These figures are from 'Find an APD' accessed via [www.daa.asn.au](http://www.daa.asn.au) on 8 September 2008. These APDs accept referrals (but not exclusively) for people with a disability.

#### **3. Dietitians employed by State health department services for specialty work with people with disabilities**

In NSW, two in hospital-based specialty clinics (once/week) (Kogarah, Katoomba, and Penrith) and one in a multi-disciplinary dysphagia clinic (once/month clinic) at the Children's Hospital and Westmead. In QLD, Halwyn Centre at Red Hill has a visiting dietitian service from Royal Brisbane Hospital. Jacana acquired brain injury

service has a dietitian service from QLD Health. In Victoria, Yarra Valley Community Health support a dietitian's clinic every six weeks at a local special school. In WA Princess Margaret Hospital provides a multidisciplinary dysphagia clinic for children, Sir Charles Gardiner provides a clinic for adults with cerebral palsy and Royal Perth Hospital provides a late effects of disability clinic for adults.

These statistics together show the current nutrition and dietetic services available to people with disabilities are piece-meal, very inadequate and are certainly inequitable. The CSTDA funding should provide a base level of dietetic service within disability service teams (preferably multi-disciplinary teams) so that nutrition services are comprehensive and included in diagnostic and assessment services, community support/resource services, school-based "therapy" services, and in early intervention services.

In conclusion, DAA argues that APDs have a strong role to play in disability services and the current disability services program requires change to achieve best health outcomes for Australians. We request the Minister's early attention to the four requests we have made, which are in summary

1. an adequate and consistent approach to dietetic services under the CSTDA.
2. establish the principle that where a speech pathologists is employed assessing people with dysphagia that there is also a dietitian employed
3. redefine "therapy services" so as to include dietitians
4. that planning processes for CSTDA funded services are consultative and broad-based

DAA would welcome an opportunity to discuss these matters with you or your delegates so that the matters we raise in this letter can be progressed.

Yours sincerely,



President  
Dietitians Association of Australia

Cc:

RHONDA GALBALLY, Chair, National People with Disabilities and Carers Council  
KATY GALLAGHER MLA, Minister for Disability & Community Services, Health and for Women.

PAUL LYNCH MP, Minister for Ageing, Disability Services and Aboriginal Affairs  
JENNY MACKLIN MP, Minister for Families, Housing, Community Services and Indigenous Affairs

GAIL MULCAIR, CEO, Speech Pathology Australia

LINDY NELSON-CARR MP, Minister for Communities, Disability Services, Aboriginal and Torres Strait Islander Partnerships, Multicultural Affairs, Seniors and Youth

LISA NEVILLE MP, Minister for Mental Health, Community Services and Senior Victorians

SIMON O'BRIEN MLC, Minister for Transport and Disability Services

JENNIFER RANKINE MP, Minister for Families & Communities, Ageing and Disability

BILL SHORTEN MP, Parliamentary Secretary for Disabilities and Children's Services

LIN THORP MLC, Minister for Human Services

## References

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2. Food for thought... A report card on nutritional and mealtime practices in accommodation services for people with disabilities -1997 to 2002. Community Services Commission , April 2002.
3. Young Deaths- Children with Disabilities in Care. A review of the deaths of eight children and young people at the Mannix Children's Centre. Community Services Commission , February 2001.
4. Reviewable Deaths Annual Report 2003-2004. NSW Ombudsman, December 2004
5. Reviewable Deaths Annual Report 2004. NSW Ombudsman December 2005
6. Report of Reviewable Deaths in 2005. Volume 1. Deaths of people with disabilities in care. NSW Ombudsman November 2006
7. Report of Reviewable Deaths in 2006. Volume 1. Deaths of people with disabilities in care. NSW Ombudsman November 2007
8. Ensuring Good Nutrition, a policy for services for people with a disability funded or directly provided by the Department of Ageing, Disability and Home Care (DADHC), particularly accommodation and centre-based respite services. DADHC 2003.
9. The role of dietitian and other allied health professionals has been described in the Nutrition in Practice Manual, Department of Ageing, Disability and Home Care, October 2003.