

Submission
No 42

**INQUIRY INTO SERVICES PROVIDED OR FUNDED OR
THE DEPARTMENT OF AGEING, DISABILITY AND
HOME CARE**

Name: Mr Greg Killeen

Date received: 06/08/2010

Submission to the Inquiry into services provided or funded by the
NSW Department of Ageing, Disability and Home Care (ADHC)

Date: August 6, 2010

Greg Killeen

The Director
Standing Committee on Social Issues
Parliament House
Macquarie St
Sydney NSW 2000
Fax: (02) 9230 2981

Dear Director and Standing Committee on Social Issues,

Thank you for providing the opportunity to make this submission into the inquiry of services provided or funded by the NSW Ageing, Disability and Home Care.

Background:

As a person with quadriplegia for many years, I have not only been a user of services and programs provided and/or funded by the NSW Ageing, Disability and Home Care inclusive (ADHC), I am also an employee at a non-government disability organisation and an active committee member of a number of community and disability organisations as well as State and Local Government departments. One of the community organisations is funded by Ageing, Disability and Home Care and other NSW and Federal Government departments to provide numerous services and programs for frail older people and people with disability. However, I provide this submission from a service user's perspective.

I am currently a regular recipient of Personal Care Support provided by NSW Home Care, Respite Service provided by Sunnyfield, Home Modification and Maintenance Scheme provided by Inner-City Home Modifications, Emergency Nursing Service provided by Spinal Cord Injuries Australia, Community Health Services including Community Nursing and Occupational Therapy provided through Prince of Wales Hospital and previously used food services from the South East Neighbourhood Centre.

Government funded and/or provided services and programs are essential to enable people with disability to live in the community as we would simply not survive without them. Appropriately funded, administered and coordinated services and programs, that are also flexible and affordable for people with disability, generally have an ongoing positive impact on the quality of life of people with disability, including their families and carers, enabling them to participate in the community as active members of society. Not providing appropriate government funding for such services and programs is false economy!

Fee-For-Service:

ADHC requires people with disability and their families to pay a fee-for-service to access the majority of the government funded services and programs. Although such fees might be considered relatively small and affordable from the perspective of ADHC or the service or program provider, for people with disability who need to access numerous services and programs, it can be relatively costly in conjunction with all the extra unavoidable costs of having a disability. There seems to be no uniformity or equity in relation to what services or programs people are required to pay for and how much they pay. This arbitrary decision is being left to the organisations providing the service or program. People with disability who are accessing the Attendant Care Program of up to 34 hours per week of personal care support do not pay any fees, however, people with disability with equivalent (or less) service from the ADHC High Needs Pool are required to pay a monthly fee - hardly equitable and I would like to suggest that people with disability be exempt from paying to access the High Needs Pool.

Out of Hours Backup Service:

People with disability, particularly people with spinal cord injury and similar conditions, generally have complex care needs and require access to services at least twice a day for tasks that include showering, toileting, dressing, transferring between bed and wheelchair/shower chair, food preparation for breakfast, lunch and dinner and assistance to bed in the evenings to name a few.

NSW Home Care Service is funded by ADHC and the local area branches generally have office administration hours of 8:30 AM-4:30 PM, Monday to Friday. However, many people with disability have services outside of the office administration hours and of course on weekends, including public holidays, and there is currently no appropriately funded and coordinated "Out of Office Hours" backup service when there is a breakdown in the service delivery, particularly when there is a breakdown of service at very short notice due to a care worker not being available for various reasons e.g. being unwell, vehicle breaks down or traffic accident, poor coordination of the service by the Service Coordinator etc.

The Randwick/Botany Home Care Branch is the only branch with any type of coordinated "Out Of Office Hours" back up service. This service has been in operation for many years and is being coordinated by one of the regular personal care workers, however, it is less than ideal as this personal care worker does not have the authority of a Service Coordinator to request and/or direct the other personal care workers to cover the services where there has been a breakdown. Also, the person does not have access to the Home Care Service database that provides the personal care worker scheduled roster and contact details that would approve the effectiveness and efficiency of the backup service. The NSW Home Care Service database is now web-based and can be accessed from any computer with internet access.

ADHC funded service and program providers are required to provide a 24/7 backup service, however, as the NSW Home Care Service is one of the largest service providers across NSW it needs to practice what it preaches and implement an appropriately funded an "Out Of Office Hours" backup service with proper coordination and administration by Branch Service Coordinators.

NSW Home Care Service Branch Coordinators should be assigned the responsibility to undertake the backup service on a rotating roster. They would be provided with a mobile phone (with the branch number diverting to the mobile phone when the office is closed) and a laptop computer with internet access providing access to the NSW Home Care Service Branch database. The Home Care Service is an essential service that is greatly valued by service users, particularly people with severe physical disability, and it deserves nothing less than to provide an appropriately funded and coordinated backup service.

Specialist out of Hours Emergency and Backup Service:

Spinal Cord Injuries Australia (SCIA) has been operating the ADHC funded "Emergency Service" which operates each day between 11 AM-3 PM and 9 PM-5 AM. This is a fantastic and much-needed service that is currently operating in the Randwick/Botany Local Government Areas providing support to people with physical disability in their own homes. This is an on-call service supporting many people with a spinal cord injury (quadriplegia and paraplegia) or similar condition, often in an emergency or crisis situation, which they can assist with without the need of the ambulance or paramedic services and the hospital emergency services. It provides peace of mind to people with spinal cord injury, particularly overnight between 9 PM-5 AM, when they know that if they experience a problem such as a bowel accident or specifically if they get a blocked catheter (that can trigger Autonomic Dysreflexia causing extreme high blood pressure that can cause a brain haemorrhage or heart attack which can be potentially fatal).

I believe there is urgent need for ADHC provide funding for the SCIA "Emergency Service" to be expanded to other areas. It may not need to be operated by SCIA but would make common sense to mirror this existing service in other areas using the expertise of SCIA's Emergency Service.

Community Transport Services:

Community Transport is funded by ADHC through the Home and Community Care (HACC) program which is generally provided by non-government organisations or local councils. Community transport services are generally limited to 9 AM-5 PM, Monday to Friday and not available to transport people to and/or from employment, education or training. Community transport generally provides transport for social group outings, as well as individual transport, including hospital and medical appointments.

However, for people living in rural areas, transport services, facilities and infrastructure are often very limited in comparison to major towns and cities as many of the country train stations have been closed and train services replaced with bus services, plus there may be no, or a small number of, wheelchair accessible taxis. For people with physical disability, particularly those using a wheelchair or mobility device, community transport is often the only form of transport but it can be very limited, inflexible or inaccessible to wheelchair users and often their only accessible transport option is to purchase their own vehicle to either drive or be transported as a passenger or in some circumstances they may only be able to access their local area in a wheelchair mobility advice.

As community transport is a vital part of the transport options and that all community transport vehicles should be accessible to meet the needs of wheelchair users. If the community transport service provider currently does not have accessible vehicles, it should implement an accessible vehicle when replacing an inaccessible vehicle.

Whole of Government Approach to Service and Program Provision:

Although this is an inquiry into ADHC funded or provided services and programs, I would like to bring to the committee's attention that there is an urgent need for all services for people with disability that are funded or provided by different government and non-government services to be coordinated with a whole of government approach.

As previously mentioned, people with disability require a variety of government funded or provided services and programs to enable them to live in the community including accessible accommodation, personal care support, respite, community health, equipment, aids and appliances, home modification and maintenance, day programs and post-school options, education, training and employment and accessible transport, etc.

People that acquire a physical disability, who are awaiting discharge from hospital, will generally require accessible accommodation (either through Department of Housing or home modifications of their own property or a private rental property), personal care support, mobility equipment and other assistive technology and communication devices. Although these people would be trying to come to terms with the physical, emotional and financial impact of acquiring a disability, as are their families, friends and associates, the lack of appropriate funding or provision of these services and programs can cause a delay to being discharged from hospital into the community which can have an ongoing detrimental effect on them.

Also, when people are well enough to be discharged from hospital, but are unable to do so, it may also prevent other people from being admitted to hospital exacerbating hospital waiting lists.

Although Australians are fortunate to have access to a variety of government funded services and programs for people with disability, often the positive benefits from accessing one service or program can exclude people with disability from accessing another service or program due to the eligibility criteria, particularly with the government services and programs that are using the Disability Support Pension (DSP) Concession Card as the eligibility criteria.

Some people with disability are accessing appropriate levels of personal care support services that would enable them to re-enter the workforce, however, the Howard Government implemented the "Welfare to Work" reform in 2006. This reform meant that people with disability being assessed for the DSP will only receive it and the DSP Concession Card if they are only be capable of working up to 15 hours per week. Any people with disability assessed to be capable of working more than 15 hours per week, or wanting to work more than 15 hours per week, will not be eligible for the DSP Concession Card.

EnableNSW, a department that sits within NSW Health, is responsible for administering and coordinating a number of disability related services and programs including the Home Oxygen Service, Artificial Limb Service, Home Ventilation Program for people using ventilators and the Program of Appliances for Disabled People (PADP). The PADP is aimed at supporting people with permanent or lifelong disability to live in community which also helps with their ability to re-enter the workforce.

The PADP is extremely important and highly valued by people with disability, however, the PADP eligibility criteria requires applicants to have the DSP Concession Card which is a major disincentive for people with disability to seek employment beyond 15 hours per week and to pursue a career path—plus there are very few employment opportunities that are less than 15 hours a week. In contrast to this, with the introduction of the Lifetime Care and Support Scheme (LTCS) in 2007, eligible recipients of this program are provided with all of their mobility equipment, aids and assistive technology to meet their needs but are not required to have the DSP Concession Card to be eligible. LTCS participants not only have access to appropriately funded services and programs that provide essential support services and equipment, they do not face the same disincentive to seek employment as the LTCS does not require the DSP Concession Card to access the equipment programs and services.

In regard to the above-mentioned information I call on the NSW Government to provide services and programs to people with disability with a whole of government approach and to immediately change the eligibility criteria do not require the PADP applicant to have the DSP Concession Card.

Again, thank you for providing the opportunity to make a submission to this very important and timely inquiry and I trust that the committee will make appropriate recommendations to address any issues. I would also be happy to appear as a witness in person to answer questions and/or provide additional information not included in this submission.

Yours sincerely,

Greg Killeen

INQUIRY TERMS OF REFERENCE

1. That the Standing Committee on Social Issues inquire into and report on the quality, effectiveness and delivery of services provided or funded by the Department of Ageing, Disability and Home Care (ADHC), and in particular:
 - (a) the historical and current level of funding and extent of unmet need,
 - (b) variations in service delivery, waiting lists and program quality between:
 - (i) services provided, or funded, by ADHC,
 - (ii) ADHC Regional Areas,
 - (c) flexibility in client funding arrangements and client focused service delivery,
 - (d) compliance with Disability Service Standards,
 - (e) adequacy of complaint handling, grievance mechanisms and ADHC funded advocacy services,
 - (f) internal and external program evaluation including program auditing and achievement of program performance indicators review, and
 - (g) any other matters.
2. That the committee report by 30 September 2010.

PARLIAMENTARY INQUIRY COMMITTEE MEMBERS

Hon Ian West MLC (Chair) Australian Labor Party
Hon Trevor Khan MLC (Deputy Chair) The Nationals
Hon Greg Donnelly MLC Australian Labor Party
Hon Marie Ficarra MLC Liberal Party
Dr John Kaye MLC The Greens
Hon Helen Westwood MLC Australian Labor Party

Further information is available by contacting the committee Secretariat:

Primary contact: Rachel Callinan

Phone: (02) 9230 2976

E-Mail: socialissues@parliament.nsw.gov.au

Assistant Council Officer: Lynn Race

Phone: (02) 9230 3504

E-Mail: socialissues@parliament.nsw.gov.au