Submission
No 78

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

Organisation: State Spinal Cord Injury Service

Name: Professor James Middleton

Position: Director and Chair

Date received: 6/08/2010

ACI NSW Agency for Clinical Innovation

3 August 2010 Our Ref:

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

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

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
The State Spinal Cord Injury Service (SSCIS) represents a network of specialised spinal cord injury services at the Prince of Wales Hospital, the Royal North Shore Hospital, the Royal Rehabilitation Centre Sydney, the Spinal Outreach and Rural Services and the Hunter Spinal Cord Injury Service. These specialist services provide a coordinated multidisciplinary model of service delivery in inpatient and non-inpatient settings across acute, subacute, rehabilitation, outpatient and outreach service environments to individuals who have acquired a persistent spinal cord injury as the result of trauma or from a non-progressive disease condition. The multidisciplinary team works with the individual and their families / significant others during the acute and rehabilitation inpatient phases of the person's post injury recovery to prepare them for return to independent self directed community living with the appropriate support and care services to allow them to achieve this goal.

SSCIS works in partnership with key stakeholders involved in the provision of support services for people with spinal cord injury, including in government the Lifetime Care and Support Authority, EnableNSW, ADHC, Dept of Housing, and Non-government organisations such as ParaQuad NSW, Spinal Cord Injuries Australia and Northcott Paediatric Spinal Outreach Services. These services play an ongoing role in supporting the individual with spinal cord injury following their return to community living.

This submission includes input from only some of the services listed above. It is our understanding that a number of these services will be making separate submissions.

Issues for consideration by the Committee
The issues we raise in this submission are in relation to points 1a) and c) of the Terms of Reference of this Inquiry, relating to *'level of funding and unmet need'* and *'flexibility in client funding arrangements and client focused service delivery'*

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1. Timely access to attendant care packages and/or home modifications

Over a number of years now, SSCIS has repeatedly drawn attention to the continuing difficulties being experienced by our subacute inpatient services in relation to the timely discharge of spinal cord injured patients from hospital due to delays in access to attendant care packages, home modifications and appropriate housing. Most recently this issue has been raised in a brief prepared by NSW Health Statewide Services Development Branch for the Senior Officers Interagency Group in May 2009. As a result of this, we are pleased to have been invited to participate in and contribute to an interagency working party currently reviewing and developing pathways for traumatic brain injury (TBI) clients, as a significant number of SCI population sustain a comorbid TBI (up to 40%) at time of injury. As well as many similarities existing in the discharge planning, service providers and community support issues for complex clients.

Attention was drawn to the recommendations made in relation to these issues in the July 2007 in a report of the Spinal Cord Injury Community Participation Project, Motor Accidents Authority of NSW. Since completion of the NSW Community Participation Project there is little evidence of significant improvement in coordinated approaches, collaboration and communication between government agencies. Clinicians struggle to gain timely responses from the various agencies in addressing the complex discharge needs of the spinal cord injured patients resulting in extended hospital lengths of stay, limiting access to specialised beds and reducing efficiency of the spinal cord injury units through exits blockage.

For example, a review of data for Interagency Brief of patients with SCI discharged in 2006, 2007 and 2008 showed that there continued to be:

- Extended lengths of stay with significant discharge delays in 15-20% of patients following completion of rehabilitation goals, particularly for persons with tetraplegia and complex housing or equipment/support needs, as follows
    - 2006: n=16, range 9-94 days, median 28 days, total=544 days;
    - 2007: n=10, range 15-263 days, median 39 days; total=755 days;
    - 2008: n=15, range 6-125 days, median 15 days, total=460 days.

  (Nb. 11 of these subsequently were transferred to other hospitals and further 5 to Weemala (on-site at Royal Rehabilitation Centre Sydney) for varying periods prior to eventual return home).
- Delays in the provision of attendant care packages, and delayed recruitment and training of attendant care staff (n=16).
- Extended waiting times for major (Level 2 & 3) home modifications (n=11), which in some cases is taking up to 12 months or so to complete.
- Lack of suitable accessible accommodation (n=6).
- Awaiting provision of specialised equipment (n=3).

In addition, a research report commissioned by Disability Services Queensland was released in June 2008, after evaluation by Griffith University of effectiveness of an initiative called the Spinal Cord Injuries Response (SCIR) which followed allocation in 2005/06 of $1.5 million in recurrent funding to enable service providers to respond to the needs of people with SCI transitioning from hospital to the community. SCIR demonstrated positive outcomes in three main areas, namely client outcomes, service delivery methods and inter-agency integration. Shorter lengths of hospital stay with safe and efficient transitions were achieved through establishing improved processes with clearly defined roles and lines of responsibility, standardised procedures, written protocols and effective communication strategies allowing better information-sharing, collaborative problem-solving and resolving conflicts between agencies. For clients discharged in the 2006/07 financial year a net saving of $681,786 was estimated. Further details of results and recommendations that may provide useful additional information about strategies, policy directives and service delivery models can be found in Executive Summary (pages 7-20) of GARP Report (Griffiths Abilities Research Program

(June 2008) Review of the Spinal Cord Injuries Response (SCIR) – Disability Services Queensland, Griffith University, CRICOS 00233E).

In summary, novel pilot initiatives in NSW (MAA CPP) and Queensland (SCIR), specifically targeting people with SCI, identified many of the same issues and have highlighted the critical need to develop strategies to strengthen relationships/working agreements between services, delineating roles and responsibilities, developing pathways/guidelines, improving communication and modifying existing and developing new processes for finding solutions between and among key stakeholders. Consideration should be given to establishing a predetermined number of ACP places matched to predicted SCI incidence and/or allocate funding to support 'transition' until permanent ACP funding and/or completion of home modifications or appropriate housing available.

2. Inequity of access to services for 'older' persons with SCI

Several broad case scenarios are provided to highlight problems commonly encountered by SSCIS services when making application to the ADHC funded program the Home Care High Needs Pool.

Significant difficulty is experienced in obtaining care and support for the return to community living for people with a spinal cord injury aged 60 years and over, and in particular those between the ages of 60 and 65 years, resulting in inequalities both in access and financial cost, in the provision of support services to this age group. For example;

A person aged 60 years or older suffers a spinal cord injury resulting in a tetraplegia (commonly known as quadriplegia) and therefore has high support needs. Prior to injury the person was independent and living with their family and therefore wishes to return to live with their family in the community with the appropriate support and care in place. The person, though physically disabled, is able to adequately direct the management of their care.

For the person aged under 65 years, they are eligible to apply for the ADHC Home Care High Needs Pool. Our services have been informed by ADHC that these clients are not given priority over those applying for the Attendant Care Scheme. However, should the person who is under 65 years old require residential care and support, they are not eligible to be assessed by the Aged Care Assessment Team (ACAT) or if assessed, their application will not be supported due to their age as per the Commonwealth guidelines for ACAT approvals.

For a person who is aged over 65 years, the only option for support to return to community living available to them is an EACH (Extended Aged Care at Home) Package as they are not considered by ADHC for the Home Care High Needs Pool. However, the waiting period for an EACH package can be up to a year, there are a limited number of available packages, and the assessment for this package must take place either in the later stages of their inpatient rehabilitation (delaying their name being placed on the waiting list for the package) or once they have been discharged to the community. As the person is unable to be discharged to the community without the support, this requirement is impossible to achieve leaving the person with no other option but to consider placement in a nursing home.

A number of such case scenarios have been discussed on a case by case basis with ADHC without resolution. The negative impact on the individual and their families is considerable as they struggle to secure the necessary support services to allow them to return to community living and to achieve a positive adjustment to the spinal cord injury and the resulting disability.

Sixty five years of age being the upper cut off point for ADHC support and the lower cut off point for Commonwealth aged care support services, the apparent reluctance of the ADHC program to support those between 60 and 65 years, and the limited availability of aged care support services for those over 65 years, leads to extended negotiations for, and delays in, the provision of support services to allow the return of the individual to community living.

The delay in discharge from hospital not only has a negative impact on the individual and their families, but also has a serious impact on the availability of both acute and rehabilitation hospital beds.

Additional inequalities in ADHC programs for people with a spinal cord injury are the following:

- The financial impact on the individual who has to pay a fee for the Home Care High Needs Pool but no fees are required for aged care packages.
- Access to respite care – respite is available for carers. However, the individual with a spinal cord injury who is able to live independently but who occasionally may require additional support (eg. if they require a period on bed rest for pressure sore or other illness management, but do not have the support to remain on bed rest) or respite care, they are ineligible for respite support as they do not have a carer. The only options available to this individual are either to not remain on bed rest, resulting in a further deterioration of their illness or pressure sore, or to present to the emergency department for admission. Access to respite or in home support would prevent both the deterioration and need for a hospital admission.

Recommendation

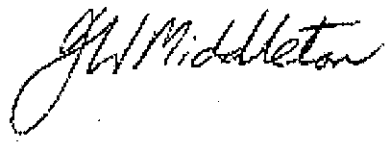
Consideration should be given to the following:

- Providing greater flexibility and communication across government organisations for the age group between 60 and 65 years of age.
- Creating fairer access to services provided by ADHC for people with a SCI aged over 65 years. This group should not be disadvantaged by their age and made to compete for very limited services under the aged care programs which do not cater for people with disabilities who require high care living in the community.
- Making respite or additional support hours available to individuals to allow recovery at home and avoid deterioration of health and unnecessary hospital admission.

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.

SSCIS would be pleased to provide any further details needed or to clarify the issues raised in this submission.

Yours sincerely,



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