Submission
No 67

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

Organisation: Spinal Cord Injuries Australia

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Submission to the
New South Wales Parliament Legislative Council's Inquiry into
Services provided or funded by the Department of Ageing, Disability and Home Care

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Outline

1) Introduction

Spinal Cord Injuries Australia (SCIA) is Australia's leading community organisation supporting people catastrophically injured with a spinal cord injury (SCI) and similar conditions. Our organisation was established in Sydney in 1967 by a group of young men who had survived SCI resulting in quadriplegia to advocate for appropriate support services as none existed at the time. We have a long history of developing and providing services to people with SCI, their family, friends and carers and being a voice for their concerns both socially and to government.

The role that Ageing Disability and Homecare (ADHC) plays in the ongoing lives of people living in the community with spinal injuries, and indeed all people with a disability, can never be understated.

ADHC provides:

- Therapy Services
- Behaviour Support Services
- Respite
- Personal/Attendant Care
- Accommodation
- Home Modifications and the Home Maintenance Scheme
- Day Programs including The community Participation Program and Transition to Work.
- Case Work/Case Management
- Individual Advocacy Services
- Food Services including Meals on Wheels.

In providing comment on issues that our members have faced receiving services from ADHC we wish to say that we are overwhelmingly supportive of the positive intention that ADHC obviously has in its work with people with a disability.

Often when preparing submissions you need to focus on the negative, as that information provides the detail that can enable a service to learn and grow. In our conversations with members and even throughout the wider community of people living with a disability in NSW there are many that have only positive things to say about ADHC services.

It would be remiss of us to not acknowledge that fact.

For the purpose of this submission the use of the word **carers** applies solely to paid care staff whether ADHC provided or through a service provider.

2) 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.

3) Submission

Current levels of funding and unmet need

Our organisation deals primarily with people with a spinal cord injury and this means providing appropriate levels of support to individuals both in the hospital setting and the community. Where we are seeing gaps opening up in the provision of ADHC directly delivered services is in the transition between Hospital and home.

At present Hospital Social workers are tasked with navigating the bureaucracy of applications for services and then often, through their own, initiative cobbling together a package that will at least and in some part, satisfy the needs of that individual being existed to the community.

Where we are finding issue is in accessing the Attendant care program, appropriate Home modifications (Home mods) and access to case managers.

With the **Attendant Care Program** (ACP) we are continually finding that owing to a lack of available places people are being moved into the High Needs Pool (HNP) as a temporary remedy.

The HNP is not meant to be used this way and offers between 15 and 35 hours per week of pretty highly intensive care. This level of care can be detrimental to ensuring proper reintegration back into the community.

The ACP offers up to 35 hours per week and provides a more general care service with the aim of supporting positive community living. The ACP also has the provision to supply clients with a one of total funding package of $10,000 to assist the client move from hospital to home, purchase assistive devices that will make their home environment more OH&S friendly and provide for extra support services to see them through the transition. If no ACP places are available the HNP does not provide for this assistance. We have heard instances where carers have turned away form a client's service owing to OH&S worries over inappropriate or non existent equipment.

Home modifications can vary from the lowering of kitchen worktops through to the installation of access ramps, door widening and electrical PowerPoint and light switch relocation. These different modifications are grouped into three categories called levels, 1, 2 and 3 and are aligned to thresholds of funding. Level 3, for example, represents modifications in excess of $20,000.

The aim of home mods is to assist a person with a disability or elderly person remain in their own homes as opposed to some other form of setting. This has obvious benefits to the individual as opposed to the potential relocation to a facility far from family, social contacts, potential or actual employment and even a familiar environment.

Spinal cord Injuries Australia has been made aware over the last few months that there are funding issues for Levels 2 and 3 modifications with many applicants being advised of waiting times for funding varying from 5 months to 18 months (2 -6 pay cycles as home mods funding is provided in quarterly allotments). Interestingly whilst Level 3 deficiencies are more systemically represented across NSW Level 2 issues are more centred on specific offices.

In one reported case the local home mods provider could not give any guarantee as to when the modifications could be funded as they stated their annual projection for funding was actually spent within the first two months. In another case a provider stated that their entire annual allotment for 2009/2010 was allocated to their 2008/2009 applications this was even with some top up money being provided late in the year.

The current state funding level for home mods is $1,404,893 as declared during the 2009/2010 budget estimates hearing. There is an expectation that the organisations providing home modifications will prioritise their applications on a most 'needy' basis.

Surely all forms of modifications are 'needy'.

The denial of timely home mods has both an economic and social impact on all people with a disability, in this instance spinal cord injured people, as well as the NSW government. Anecdotally we hear of people who remain in NSW state funded hospital spinal units awaiting discharge back into their own homes who are essentially forced to remain and block access to expensive acute care beds for up coming patients. We understand this can cost in excess of $2000 per night. If they are discharged they will usually end up in the Weemelah, Berala or Ferguson Lodge facilities essentially just waiting for their homes to be made more accessible. These waits are now calculated as a personal cost of around 80% of the Disability Support Pension (Maximum accommodation payment of around $515.35 per fortnight). That is obviously under the belief that their application for the Disability Support Pension has gone through without any glitches.

The point we are trying to make is that often, the cost of not providing essential home mods in a timely fashion can often end up costing either, or both the Government and the individual, more than the costs of the completed modifications.

In terms of 'ideal' budget and given the lack of access to information regarding waiting lists which ADHC have declared they do not keep, they sit with the local modification providers and ADHC do not ask for them it could be difficult to pose an ideal funding figure. With some providers being approximately 12 months behind orders and others going from having waiting lists of 5 – 18 months it may be fair to theorise that a 100% increase in budget should assist the program address much of the need. Whether this would need to be ongoing or could be reduced after a potential 2 year period it is also difficult to say.

Case Managers are very difficult to get access to. We hear from people in the community that waiting times can be 6 months or more, despite an increase in number under Stronger Together.
The role of the case manager is pivotal in ensuring that a person gets access to appropriate services. They are the glue that holds together the services that enable a person to live a decent life in the community.

Case Managers are not only required to help set up services for a person at the beginning. They are needed to assist on an ongoing basis with changing needs and requirements of the individual. When people are waiting for long periods of time trying to get access to a case manager their issue can compound leading to worse outcomes for the individual in the community.

Variations in service delivery and program quality between metropolitan Sydney and Regional NSW

People in the regions of NSW living with a disability have for a very long time experienced differing levels of service with their metropolitan based counterparts. Issues that affect Sydney based individuals are often more acute in the regions.

This can be for a variety of reasons such as the sheer size of regional NSW meaning that carers can often have to drive long distances between clients with a greater chance of being late for a scheduled time. This distance can also mean that a carer can do fewer jobs per day than their Sydney based counterparts.

The actual cost of care will be higher when you add in Kilometre costs and greater wear and tear on vehicles.

There is also a limited pool of care providing agencies leaving the individual with little 'real' choice as to who they use for their care. Particularly when faced with issues such as faulty rostering by some coordinators. We have heard of consumers being sent care workers untrained in bowel management on toileting days, workers not showing up for regular service or two workers rostered for the same shift.

A further example of this was demonstrated to us by one of our organisations regional officers. A major issue / deficit in the Northern Rivers are carers just not turning up for their rostered times, therefore leaving clients sitting in their wheelchairs for long times and very late at night. An example of this was a client (quadriplegia) was expecting Home Care to provide service between 7pm and 9pm, which happens 7 days per week. The carer did not turn up for a shift, leaving the client in their chair, without dinner or drinks. At 10pm the client managed to use the vital call service which then got an ex-partner to drive 30 minutes to feed them and get them into bed. There was no apology from Homecare, just "oh well, we can't do anything about it if a carer doesn't turn up". This is not an isolated case in this region. There is a lack of suitably trained care staff in the regional areas.

Ongoing Issues around carer availability and hiring new carers is certainly difficult in metropolitan Sydney and is definitely more acute in the regions. This is recognised by ADHC in providing funding for a limited campaign administered by National Disability Services (NDS) with the aim of increasing interest in being a carer as a career.

In recognising the issues that exist in regional NSW and the sheer difficulty in getting service to individuals It seems almost bizarre that ADHC have provided further issues of their own making to compound peoples problems in the regions. This has led to the perception of a two tiered service structure in NSW with the regions coming off worse.

ADHC Staff have an over the top OH&S focus, when they go into homes they focus on Risk Assessments instead of on providing a quality service for the consumer, we have heard of consumers spending extreme amounts on additional equipment like ceiling and portable hoists and matrasses because of a perceived risk reported by homecare staff and on the other hand we have also heard of consumers who have had a Occupational Therapist assessment to have a hoist installed after sustaining a shoulder injury and then not being able to utilise the equipment because homecare workers are forbidden from using equipment until homecare have made there own Occupational Therapist assessment and therefore risking further shoulder injury due to being made to transfer themselves.

We have heard of consumers getting turned away from SCOPE and being told not to bother trying to apply for funding because funding allocations for the year have been spent. Consumers were offered no assistance to access the service waiting list and no information on the application process. For many consumers this means extended stays in hospitals and transitional respite facilities and for many inappropriate placements into aged care facilities until modifications can be done. If family used a private builder personal care services can be refused if mods are not completed to standard.

To get increased personal care service hours the consumer had to be reassessed by the homecare assessment team. When the service agreement comes back the consumer who asked for 1.5hours personal care and 0.5hour domestic assistance per day was shocked to see she was getting 1 hour domestic and 0.5 hour personal care and to adjust the hours another assessment had to be done. The additional cost is just a pure waste of funds when the first assessment should be conducted with thoroughness to ensure a correct application of hours.

Another issue occurs when clients are discharged from another states hospital they are not registered or assessed for or by ADHC. This situation commonly occurs near to state borders where it is far safer and logical to transfer an individual to the nearest spinal centre, if you live near Lismore that may be in Brisbane. We have clients being assessed 3 – 5 years after hospital discharge

that have been born and raised and worked in NSW. This means they have been missing out on services all that time. The only service they can get access to is personal care. The Occupational Therapist who is conducting these late assessments (we have completed one to date with more to come) told me that they are doing an audit of all people with a disability? And will be assessing many clients over the next few months.

In including community Transport we have been made aware of a Molong consumer who has expressed concerns after being told the local Community Transport HACC funding guidelines apparently stipulate that the service exists primarily for the Aged, not for people with disabilities.

Disability Service Standards and Disability Services Act compliance issues for ADHC directly delivered services.

As an organisation that provides an Advocacy service we are consistently being made aware of some rather negative situations that people with a disability currently experience living in the community when in receipt of ADHC directly delivered services. Despite the positive wording of both the Disability Services Standards (DSS) and the Disability Services Act (DSA) there seems to be a breakdown between positively written, centrally created, ADHC policies and local management directing front line staff.

An example of this would be out of ADHC office hours contact support (support required between 1600 and 0830). Up until recently the procedure was if a carer had not turned up then you were pretty marginalised for that evening.

This could be spending the night in a wheelchair which is sadly quite a common occurrence or even spending the night with your toileting not dealt with leading to a heightened risk of infection through skin deterioration owing to prolonged exposure to moisture.

If you required emergency support in the night for an event such as a blocked catheter then you needed to call an ambulance. ADHC had not planned to provide a telephone number for staff to call to report that they were unwell and unable to fill a shift outside of hours or for people receiving service to telephone the non turn up of a carer. Strangely enough ADHC funded services are required to provide this service.

As this is a growing issue local management are now endorsing an 'Option B' model. This is basically that you need to have a friend on standby as ADHC cannot guarantee service. The question is then what if you have no friends or relatives, as sadly many isolated people in the community do not? 'Option B' is no option for many people.

In terms of compliance with the DSA this case shows breach under 3 (a), 3 (b) (i), (ii), (iii) and 3 (c) 3(e) and 3(f). Under the disability service standards we see a breach under (2), (3), (4), (5), (6), (8), and (10).

We recognise that often with the provision of services to a diverse group of people that there may well be operational issues or budgetary concerns. Nobody expects government to be perfect yet an enforced requirement that all ADHC funded services are compliant with the DSS and DSA seems to go unheard of for many ADHC provided services.
This is one illustrated example of a case of non compliance with standards.

There also seems to be a growing gulf between the application of policy in Metropolitan Sydney and Regional NSW. New or even existing policies are being incorrectly interpreted in the regions into whatever works best for them all of this, generally, to the detriment of the client.

Often a simple telephone call to ADHC will turn up the real policy that is often met with non belief by regional operators. Individuals receiving service are justifiably worried by getting engaged with overturning what their carer has told them they now need to do. As an individual is reliant on their carer many do not question and just received a locally inspired variation on their service.

Complaints against staff, providers and ADHC rarely seem to go answered when delivered by an individual. It is our thinking that complaints are healthy as they allow service development to happen. An advocate fulfils a very important role in driving quality service.

ADHC funded advocacy service providers are faced with a clear dilemma in advocating effectively for clients against the funding body.

There are around 73 state funded advocacy organisations throughout NSW providing much needed supports to people both living independently in the community, in supported accommodation and in medical settings. They are generally small in nature with a few 'super sized' advocacy organisations being supported by the state government to provide services both in Sydney and throughout NSW.

Currently funding to support these organisations is provided directly by ADHC with ADHC contract managers supervising the provision of services and attempting to ensure compliance with the Disability Service Standards (DSS).

As has been detailed in this submissions introduction such are the array of services provided by ADHC that the large majority of people living with a disability in NSW will in some way be touched by ADHC services. Often, as an organisation that has individual and systemic advocates, we see cases of complaints against ADHC operations or failings in direct service delivery.

We wish to highlight that there is a clear potential for ADHC funded advocacy service providers to not 'bite the hand that feeds them' (whether real or at least perceived) at the expense of a clients ADHC related issue leading to a conflict of interest. In fact in advocacy circles it is quite widely discussed as

standard that funding may be at risk if you are too adversarial with ADHC. We feel that direct funding through ADHC of advocacy service providers does not lead necessarily to better outcomes.

We are not criticising State based advocates who many do the best that they can only that the system for funding has created a perception of doubt in ensuring that a client with a disabilities rights are upheld.

A potential solution for these issues would be to fund NSW state funded advocacy service providers through the state attorney generals department. Although still not ideal as funding is being provided by the present government it is a way at least of recognising that fair access to services and supports for people with a disability have some fundamental rights grounding.

State based ADHC funded advocacy service providers need to report on an annual basis on the throughput of individual advocacy cases.

Achieving advocacy results is something that benefits everyone. From the client whose situation is resolved though to an organisation or department. These may have been advocated against but they can now grow and make policy amendments or whatever the amendment is required to be better at what they do.

Advocacy helps everyone.

Where there is a potential issue is in the reporting of advocacy statistics to ADHC. There is no clear way of identifying an individual case to ensure that the advocate has been properly supportive and that the clients issue was resolved within a 12 month period. Obviously there may be cases that last longer than this period but they are the few.

We recognise the absolute need to provide client anonymity and so propose ADHC created reference numbers working in conjunction with regular polling of client satisfaction. These numbers can be provided in block to advocacy service providers for use to identify clients. Reporting against these numbers can help form part of standard reporting. This protects the client and ensures that ADHC can, rather easily, track individual case resolution. Polling clients, once exited is a great way to show that yes throughput of cases has happened and that those cases that have been resolved a cross section of clients are satisfied.

Accreditation for advocates

Currently in NSW there is little governmental emphasis on ensuring that state funded service providers have staff than are qualified to do the job.

Many advocates come to the job from a diverse array of former careers wishing to do well for individuals and be of some support. That is good and certainly it brings different skills into an area where diverse thinking can be of use to the client. Yet we believe that with some form of common accreditation for advocates clients may feel surer that the advocacy service provider they choose is capable of doing the job. In addition the client can feel that they will be dealt with in a professional standard manner.

A possible way to provide accreditation for NSW funded advocacy organisations and advocates would be to look at what current training packages are in place at the moment, what the needs are of advocates and more importantly what clients would like form their advocates. A training package could be created leading to accredited advocates in NSW.

4) Summary of recommendations

1) The ACP needs more places and for a published waiting list to be created providing assistance to ACP planners and potential service recipients.

2) We require that the NSW government provide a 100% increase in funding for the home modifications scheme with a view to clear the existing waiting list. This increase to be implemented as a priority

3) We require the set up of a formal waiting list to better inform HACC and Home modifications planners on an appropriate level of ongoing funding to meet the recognised need in the community.

4) A Commitment by ADHC and the NSW government to a study tasked with investigating financial waste across directly delivered services to the community. We are aware that often the resolution isn't gained solely through an application of new funding. Resolutions can sometimes be better achieved by ensuring that what is in place at present operates efficiently and for the benefits of the program or service recipients. This study could also look at the budgetary impacts of cost creation on one department by another department not satisfying immediate need.

5) We require the NSW Government to investigate case loads for current case managers where there are areas of excessive wait in NSW and apply more case managers to those areas.

6) We require the NSW government to formally open a waiting list for individuals attempting to access case managers.

7) Funding should not be given according to population only. There are many consumers moving back to the cities in order to receive a service because more money is spent where there are more people. The NSW government should be supporting people to the same level throughout NSW.

8) There should be a way to monitor how an ADHC funded service services their regions and any future applications for funding projects they should be assessed on how well they are currently running existing contracts. This assessment should also have a focus on quality of life with the service. Basically how has the service contributed to the individual's wellbeing?

9) There should be a way to accurately record unmet need and manage waiting lists for services as the same person might be on the waiting list for 10 providers that provide the same service type.

10) ADHC provided services need to be compliant with all current Disability Service Standards and the Disability Services Act. We recommend that an independent auditor is appointed to conduct an assessment both at

ADHC head office and in each of the regional offices. This assessment should also include service recipients' experiences.

11) ADHC funded advocates should have their funding moved to the NSW Attorney Generals department to assist with real or perceived conflict of interest.

12) As part of an annual Advocacy service provider contract there should be a requirement to report on individual case numbers to demonstrate throughout of clients.

13) The NSW government should work with state funded advocacy organisations and advocates to develop a common training package leading to accreditation in NSW. This will bring common standards up.

SCIA would like to take the opportunity to thank you for this opportunity to provide feedback on the operations of Ageing Disability and Homecare and anticipates the content will be given favourable consideration.