Submission
No 99

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

Name: Name suppressed

Date received: 16/08/2010

Inquiry into services provided or funded by the Department of Ageing, Disability and Home Care

A Submission to the Legislative Council Standing Committee on Social Issues

My employment background, whether paid or voluntary, is matched by lifelong experience as a person with disability, with family and friends with disability. As such I (and/or my family and friends) have been the recipient of ADHC funded disability services. Therefore, in commenting on ADHC services, policy and practice I have a foot in both camps – being able to speak as a policy officer/advocate and service recipient.

The Submission: Structure and Intent

My primary aim in writing this submission is to demonstrate the need for a paradigm shift within ADHC to equitably address unmet need. The current paradigm affects both the services ADHC funds and ADHC's direction as the lead agency in disability service delivery. I believe its basis in out of date legislation, the view of disability it portrays and the language used are all impediments to effective and equitable service delivery.

When considering the Inquiry's Terms of Reference, I am very grateful for the inclusion of "(g) any other matter". While I may touch on issues relevant to the initial six Terms of Reference, my main contention is to demonstrate a connection between ADHC services and the theoretical framework that underpins them. I have used examples of specific services and practice. When I have named someone in these examples, names have been changed to protect their identity. However, each of the examples is based on a real situation which I have encountered either as an advocate or person with disability.

The submission has been structured to separate theory from practice. I appreciate that, in the real world, they are intertwined, and one does not drive the other. However, for the sake of developing a coherent argument, they have been discussed as if theory ***should*** drive policy and practice. It is a belief that not all share. There are other drivers like political choice or sometimes political necessity. However, I maintain, that in an ideal world the two should segue.

Throughout the submission I have used the term *people with disability* rather than *people with **a** disability* or *people with disabilities.* The use of the term underpins the social model of disability. The recently released *National Disability Strategy* has chosen the term and acknowledges its basis in the social model. It is my contention that the other two terms sit more comfortably with other older models of disability and as such should be avoided. This for me is more than 'political correctness'. There is a link between the language people adopt and their view of reality.

Children (and some adults unfortunately) use terms like spastic to refer to a person that demonstrates any undesirable characteristic rather than spasticity. One individual, a Senior Policy Officer with ADHC still refers to people with intellectual disability as 'morons' claiming the term has a specific medical meaning. While she may be right her choice of terminology has a negative impact on society's acceptance of the people to whom she refers.

Current Discourse

The currency of any definition of disability must be viewed in the light of the society in which it arises. It has regularly been traced to a *medical model* where, with the birth of the hospital the aim moved from care to cure for people with impairments. It became a tragedy to be *disabled*. Some have contrast this medical model with a *managerialist model* where the aim of government and the non government sector is to manage the *disability*, its costs and consequences, providing services to people with disability but determining, with an eye on expenditure, what can and will be provided.

The *social model* of disability was developed in Britain, towards the end of the last century. It argues that *disability,* unlike impairment, is a consequence of the structure of society. Some will go so far as to argue that in a fully wheelchair accessible society, where every home and business is fully accessible, the person with paraplegia who uses a wheelchair for mobility, has an impairment but not disability. Others, wishing to extend rather than reject the social model, argue that, in addition to physical, social and economic barriers, disability also arises from attitudinal barriers.

Lesley Schwartz, a clinical psychologist from Africa, provides an example of the impact of attitudinal barriers in a reflective book on his upbringing - *Able Bodied: scenes from a curious life*. He relates the experience of his father who rose to high status in his working life, and was regularly playing golf, the game he loved, despite the impairments of deformed feet and hands. Using the social model's distinction, Swartz says that while the firm was run by a British company his father, who enjoyed the high esteem of colleagues as manager and golfing enthusiast, may have had an impairment but not disability. He then contrasts his father's experience when the firm was purchased by an American multinational, where squash replaced golf as the game of choice and corporate decisions were made at the squash centre, without reference to his father. Very slowly his father accepted that he no longer fitted the corporate profile. In effect, he was disabled by it.

In Australia, many senior staff in disability organisations participate in the debate and its relevance to defining the policy agenda. By comparison ADHC continues to develop policy for *people with a disability*, without considering the link between the term and the model it imputes.

In using the term *people with a disability* (like *people with disabilities*) ADHC treats disability as a synonym of impairment. It references a personal trait, and conveys no suggestion that disability is acknowledged as a social construct.

ADHCs definition of disability stems from the major legislation underpinning its service delivery model, the Disability Service Act (1993) (DSA) and it is to legislation and its drawbacks I now turn my attention.

Legislation and Disability

No Australian legislation to date has been based on the social model of disability. Progress has been made to expand/extend the cohort captured by legislation however the definition of disability in legislation is still based on impairment.

In 1981 the Anti Discrimination Act (1977) (ADA) was amended to include *physical disability* as a further basis for discrimination covered under the Act and *intellectual disability* in 1982. The definition of these terms was spurious and fraught with difficulties. Physical disability was seen as a disability *arising in the body* and intellectual disability as a disability *arising in the brain*. The consequence was that people with brain injury, epilepsy or cerebral Palsy were covered as people with intellectual disability, regardless of the educational qualifications, social status or IQ.

The definition of disability provided in the DSA was a clear improvement on that used by the ADA. However, disability was still confused with impairment. It is also noteworthy that the Act does not include people with psychiatric disability, issues affecting people with mental illness being viewed as falling within the portfolio of the Minister for Health.

The world has moved on and the definition of disability used in the ADA has been changed to include people with psychiatric disability, in alignment with the wider definition of the Disability Discrimination Act (1992). However, the DSA remains without change.

Impact of legislative restrictions

In a recent meeting of the Advocacy Network (advocacy services funded by ADHC) an advocate complained that to open the doors to complaints from people with psychiatric disability would extend their client base. It was argued, that as an ADHC funded service, the organisation was funded to comply with the DSA and people with psychiatric disability were not covered by that Act. The ADHC staff member present agreed even though the representative of another service noted that ADHC also requires funded services to report against the Minimum Data Set (MDS) - and this includes the percentage of clients seen who have psychiatric disability.

The inappropriateness of the restriction of ADHC's coverage to the cohort defined in the DSA is increased by review of the composition of the Disability Council of NSW, the official adviser to the NSW Government reporting to the Minister for Disability Services. The initial Council included a woman with psychiatric disability. The same woman has been its past Chairperson, the Executive Officer of the Mental Health Co-ordinating Council and a member of the Mental Health Tribunal. Her substantial expertise in the field of psychiatric disability has informed previous Ministers for Disability Services and ADHC Directors-General. She is not the only person with psychiatric disability appointed by the Governor-General of NSW on the advice of Parliament. However, the Minister responsible for ADHC, the main recipient of advice, does not include people with psychiatric disability within his portfolio.

It is my contention that ADHC should cover people with psychiatric disability among the group to which it provides services. This view may be strengthened by a government adviser being a person with psychiatric disability. It is also consistent with the Australian decision to adopt a National Disability Strategy based on the social model of disability. To do otherwise leaves ADHC using criteria inconsistent with the future direction of Australian Government policy.

Distinguishing psychiatric disability from mental illness

This submission is not forwarding the view that NSW Health is the inappropriate department to address the needs of people with mental illness. However, at present, NSW Health, not only addresses their health needs but funds advocacy services that address issues of discrimination, tenancy rights and much more.

The stigma associated with mental illness, the discrimination and rights abuses are (under the social model) aspects of disability: the structure of society failing to address this group's need for equitable treatment. It is not a consequence of illness.

Addressing such disability should be the role of ADHC – not NSW Health.

Managerialism, Tragedy and ADHC service delivery

ADHC policy should be based on client needs. That is the view underpinning *Stronger Together*. At the moment most service delivery addresses clients as people in tragic circumstances whose disability must be managed to improve their lot. This argument can best be demonstrated by examples.

Home Care Services are provided to clients at the convenience of ADHC staff with inappropriate consequences for the person with disability whose needs they are to address.
This can be demonstrated by reference to Susan's circumstances.

> *Due to Susan's impairment she is unable to change her clothes, bathe, or transfer to bed without assistance. Her husband provided support until their separation. Susan thereafter needed support of Homecare staff.*
> *Susan has been on various advisory boards to both Commonwealth and State Governments. She has travelled internationally as an adviser on disability services and is well respected for her expertise by Ministers and Directors-General of several Government departments.*
> *Home Care can only provide assistance within prescribed hours so Susan is assisted to bed before sunset and must work from her bed if she continues to work after sunset.*

Susan's treatment does not demonstrate that ADHC is committed to her right to equal participation in the community and deprives Government of her expertise in hours when she would normally be more functional as advocate and adviser.

The *Home Maintenance and Modifications Service* (HMMS) is funded by ADHC. According to senior staff of ADHC the aim of the program is to keep people out of hospital (where, in their homes, they are less cost to Government). It is often used by people with disability to ensure their homes are accessible and subsidises the cost of home modifications.

There is an argument that people with disability (who require home modification) are financially disadvantaged by the fact that when applying for a home loan they must demonstrate they have the amount required to finance a home loan *and modify their home*.

In Britain this is acknowledged and modifications made to homes at no cost to the person with disability. HMMS often subsidises these necessary modifications, dependant on cost and the income of the service recipient. When modifications are costly the waiting period between application and approval will mean that alternative support mechanisms must be adopted if the home is to become the residence of the person with disability. Further, between application and approval the needs of the person requiring the modifications is determined by an occupational therapist (OT) and the modifications made determined by the service (not the individual requiring them).

The following example demonstrates the impact of these restrictions.

Jean uses a wheelchair for mobility. She and her husband Simon purchased a villa and applied to HMMS to assist in modifying the home. Three months after the application an OT arrived to assess Jean's requirements. On receipt of her report the local HMMS team assessed the cost of the modifications required and negotiated with Jean and Simon (based on their combined income) what percentage of costs they would be required to pay for modifications. Due to the high cost of modifications the decision was escalated to a regional body for approval.

Work began on modifications nine months post application. In this time Simon lifted Jean to and from the inaccessible bath (or over the shower hob) and up and down the front steps.

As access was difficult from the front Jean and Simon agreed that access should be provided through the rear kitchen door. However the HMMS assessor decided that the laundry door would provide less costly access.

Jean and Simon pointed out that due to Jean's short stature and the narrow wheelchair Jean was capable of accessing the house from the laundry even though her friends in larger wheelchairs could not. Further, for Jean to get to the laundry door a path would be needed the length of the house and if it was not covered Jean would be soaked in heavy rain.

After negotiations it was decided (by HMMS) that a lift from the garage to the kitchen was needed. This necessitated the loss of a car space in the tandem garage and Jean and Simon are required to pay for annual maintenance of the lift.

The bathroom also required modification. The shower hob was removed and non-slip tiles replaced the old tiles in the shower. Jean pointed out that she would rather have one set of tiles across the floor and that non-slip tiles were unnecessary as she used a shower chair. She agreed to pay additional costs to ensure the bathroom met her requirements but the new tiles were only applied in the shower area.

As a concession to the couple the entire bathroom was tiled (rather than just the shower). A mirror was provided to suit Jean's height. Simon noted it was too low for him to use. The argument from the builder was that the bathroom was modified for Jean, not him.

A handrail was needed so that Jean could transfer to the toilet. The builder placed it where the OT had determined it should go based on the Australian Standard. Jean pointed out that she could not reach the handrail due to her short stature but the OT had to be called before the builder would adjust the rail to a height she could use.

Because a lift was installed through the garage and there is a step from the rear of the garage to the back yard Jean can still not access the yard herself. HMMS provided a portable ramp that Simon could lay down when his wife needed to access the yard – no means were provided for Jean to access the yard independently.

The kitchen was not modified to meet Jean's need. The bathroom leaked and needed repair (as did the lift following a breakdown).

The example cited suggests the HMMS service is not designed to meet client need. The HMMS service (and the OT) made the decisions – not Simon and Jean. This might be due to underfunding of the service. However, the treatment of Jean suggests the view that it is not accepted that she is a citizen with the right to access her home. She did not determine how she should access her home, what floor tiles were needed and the decision to provide a mirror for her use suggests the HMMS failed to consider the bathroom was to be accessible to the couple (not just Jean). The scheme is designed, not to ensure her home meets her needs, but to keep her out of hospital.

The Home Maintenance Clearing House, funded by ADHC and functioning from the University of Sydney's Lidcombe campus, is used extensively in Australia and overseas. It gives up to date detailed information to builders on the best tiles, hand rails and modifications available. It explains how the HMMS works. It might also be a valuable service to register complaints – a task it does not yet do.

If Jean and Susan (and others in similar circumstances) were acknowledged as citizens with rights to equitable treatment the services received would see their needs as paramount – not costs. Decisions as to when services were provided (and what services) would be up to them and not ADHC service providers.

ENABLENSW and AIDAS

EnableNSW is responsible for the administration of the NSW Health disability support programs including the Program of Appliances for Disabled People (PADP). This includes provision of aids/equipment services to residents of ADHC funded services operated by a Non Government service providers.

Information on EnableNSW and its services are publicly available via the NSW Health website, including equipment covered, the application process and grievance mechanisms.

Aids for Individuals in DADHC funded Accommodation Services (AIDAS) provides aids/equipment to residents of ADHC owned and operated group homes. Information on AIDAS is not publicly available but is treated by ADHC as internal policy. Review of AIDAS policy documents shows several dissimilarities with those of EnableNSW resulting in differing aids/equipment able to be sourced, different methods of determining client contribution to costs, different grievance mechanisms.

My primary concern is that AIDAS policy is not publicly available. Parents and siblings of people in ADHC funded and operated group homes are unaware of entitlements, costs or grievance procedures.

People with disability can move between group homes so that an individual may be entitled to AIDAS in one group home and covered by EnableNSW in the next. The differences in entitlements and transparency suggest the possibility of inequitable treatment.

There is a need to review the very existence of AIDAS. It seems to duplicate service delivery and, as details are not in the public domain, it lacks transparency.

Home and Community Care (HACC)

The HACC Program is a jointly funded Australian Government and State and Territory initiative established under the Home and Community Care Act 1985. The program aims to prevent premature or inappropriate admission to long term residential care by providing funding for community support services for frail older people, people with disability and their carers.

The Program forms part of a broader framework of community care services. In NSW, ADHC is responsible for the administration of the program, in partnership with NSW Health and NSW Transport and Infrastructure. NSW Health receives approximately $75 million per annum in HACC funding. Services provided are predominantly community nursing, allied health and centre based day care.

Home Care is provided with consideration of the carer, their health and safety: the service having OHS obligations to its employees. If a person requires assistance in toileting, showering, dressing or being moved to and from their bed, Home Care will ensure the processes are checked to ensure they can be done safely by staff.

The employer has no legal obligation to the carer of a person requiring their assistance: only their staff. If a process (e.g. getting a person from bed) is judged unsafe, and service refused, to continue to get from bed the individual needing the assistance will need to rely on their unpaid carer.

It is questionable whether the assessments consider practicalities, being based on theory rather than the lived experience of the person with disability.

Diana has high lesion quadriplegia. She has required assistance in daily living (including getting to and from bed) since her accident 35 years ago. Her husband Dave, for the past 35 years, has been lifting Diana to and from bed, dressing, bathing her and attending to her daily needs. As they have aged Dave and Diana have had to revise the process to ensure Dave can continue to lift his wife safely. Dave is in his late 60s and still lifting Diana to and from bed using a method he has devised over years, without self injury.

Dave has to travel interstate for family reasons and asks Home Care to assist his wife. The transfer method Dave has been using is determined to be unsafe and the recommendation made for a new hoist and modification to the bedroom. Dave and Diana can't afford either.

After an unsuccessful appeal to Home Care, Dave has no option but to cancel the trip to continue to assist his wife.

It is appreciated that Home Care has no legal obligation to Dave. However I cannot fathom how his method of assisting his wife is deemed (even after appeal) to be unsafe when he is in his late 60s and able to do the task safely.

To facilitate a strategic, long term approach to planning for the HACC Program, three-year planning was introduced in 2008 culminating in the development of the *2008-11 HACC Triennial Plan*.

As an outcome of the *National Health and Hospitals Network Agreement*, COAG has established the Australian Government as the level of government with full funding, policy, management and delivery responsibility for a national aged care system. These reforms include a transfer to the Commonwealth of current resourcing for aged care services including the component of the HACC program that provides services to those over the age of 65.

To inform negotiations with the Commonwealth in the devolution of the HACC program and to ensure community care services to people with disability are appropriately funded the following will need to be determined:

- the cohort of HACC clients with disability (under 65 and 50 for people who are Aboriginal)
- anticipated fluctuations in this figure;
- the proportion of funding service usage pattern in supporting these clients (who may require costlier services due to differing need).

To my knowledge ADHC has not yet begun to collect such figures. They may be elemental in negotiations re future funding. Underestimation will negatively affect service delivery.

ADHC Services and Commercial Considerations

ADHC funded services often complain of the need for adequate equipment to provide services safely (e.g. hoists). ADHC has funded *equipment pools* that can be utilised. This seems inappropriate if the services are viewed as businesses deriving profits from their services. It would be more in keeping with normal business practices for services to calculate costs of equipment in service delivery charges. The current process suggests the services are charitable services to tragic victims. The method may reduce costs of service provision (or profits from it). My local grocer does not ask for aid in purchasing shelving to safely store commodities. The cost is absorbed by the business. I am uncertain as to why ADHC does not see its services in the same light.

Some of the services seeking such assistance are in the position of a monopoly. In rural NSW some are so large they provide almost all local services. They therefore are able to dictate what services will be provided and at what cost. Such an organisation can still ask for subsidies and select what services it provides. ADHC may have an obligation to service users to ensure competition exists (and people with disability – or older people are able to get the services required).

It is elemental to compliance with the Disability Service Standards that services funded by ADHC are located in fully wheelchair accessible premises. Some are not. ADHC has an obligation to ensure they are, even when their client base is people with intellectual disability. It is arguable that the NSW and Australian Governments should not fund services that are inaccessible. Access is not only required by service clients but people with disability seeking employment. The continued funding of inaccessible services discriminates against people with disability both in employment and service delivery.

Conclusion

I have not listed recommendations ahead of this submission. Instead, in conclusion, I would suggest some things the Committee might consider in determining its recommendations.

The submission has sought to demonstrate:

- a review and update of legislation, and language is consistent with the social model of disability, is necessary if NSW (and Australia) is to adequately address issues affecting people with disability;
- the current restrictions of the DSA (excluding people with psychiatric disability should be addressed if ADHC is to be the lead agency addressing disability in NSW;

- the view of people with disability promoted by Government needs to be as citizens with equal rights rather than social burdens with needs that must be managed effectively;
- services are needed which put the aims and needs of the service recipient above costs or preferences of the service provider;
- services offered to one group of people with disability (e.g. those offered through EnableNSW) should be equally available to all people with disability (regardless of their residential status);
- planning is needed to ensure future changes to service delivery (arising from COAG decisions) do not reduce service effectiveness in NSW;
- services should be seen as commercial ventures with obligations under discrimination law (e.g. to provide accessible services) and not protected from commercial realities as protectionism suggests their client base are less than citizens with rights to equity and choice.

I hope the above submission will provide food for thought for the Committee members.