

Submission
No 104

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

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**Services provided or funded by the Department of Ageing, Disability and Home
Care (ADHC) (Inquiry)**

Dear Ms Simpson,

I am writing to this inquiry as a long term client of Homecare, who is permanently confined to a wheelchair and, has been in receipt of various personal care services since 1987.¹ In general, Homecare has provided me with reliable services since that time. However, ADHC would appear, on some levels, to be an organisation resistant to change.

As a long term client, one has contributed to numerous internal and external reviews. One issue that is raised but has never been resolved is the question of a 24 hour emergency call service. Spending a university semester in Canberra during the mid-1990s, my personal care needs were met by Home Help ACT. This organisation had an after-hours pager held on rotation by one of its coordinators every night. If something went wrong, such as a carer not showing up, having an accident, or falling ill, there was a number you could call.

This was essential for me, particularly when I was in Canberra, while my family was based in Sydney. Fortunately, I only had to use the emergency number once, but it was reassuring to me and my family, to have the service in place. Further, when it was needed, I was able to have the supervisor come and get me out of bed, to start my day (if a little late) and, I was still able to meet my taxi to travel to that day's commitments.

There are many people, some of whom are known to me, who are heavily reliant on Homecare for multiple services during the day and evening. While most of these requirements are met regularly, there is no "fall back" procedure which can be accessed by either staff or clients when things do go wrong. Furthermore, as many Homecare services are delivered out of hours, you would think having a capacity to deal with problems outside business hours would be vital.

This has not happened. If a staff member cannot attend a client, they will need to ring the client and also try and find a colleague who can fill in for them. In my case, I am fortunate to have family who are able to help me, but family members as well as

¹ All observations and recommendations contained in this submission and supporting annexure are personal in nature. They do not represent the view of any other persons or agencies involved in the disability sector.

Homecare clients themselves, are ageing. Increasingly, families will not be able to fill in where service providers cannot deliver.

Recommendation 1: That Homecare establish an out of hours contact service, which can be accessed by staff and clients alike.

As a client, I have been around Homecare long enough to see the organisation amalgamate offices, devolve them again, declare staff should compile their own rosters, then declare coordinators will prepare service rosters; add to this a plan to have staff only work in fixed geographical areas and, a plan that only staff of a particular grade will work with particular high needs clients.

All of these ideas have their merits and look good on paper (and it may well be the same piece of paper from when the same idea was implemented, and then discontinued, several years previously). But clients, like staff, don't fit into neat boxes. Clients with high needs and the best qualified staff will not necessarily live in the same area. Equally, just because a client is formally "assessed" as needing one grade of care, won't mean that a staff member of a different grade is not perfectly capable of dealing with a person's needs. For example, while I have been advised that I am technically a Grade 3 'client', 'Grade 2' staff are quite capable of meeting my needs. This is because there is no need for elements of high needs 'Grade 3' care (such as catheterisation) in my daily routine.

It is also to my advantage that I am verbal and can give any new staff "on the job" training as required. Previously, this training was done by a second staff member who had experience with a client. However, in the last year or so, my personal observation is that this practice has not always been followed. Again, while the lack of an experienced staff member to train a recruit is not a major problem in my case, it could be confronting and problematic for a new carer and client alike, particularly if the latter has difficulty articulating their needs.

Recommendation 2: Departmental managers should be discouraged from restructuring the agency, unless there is a clear, direct benefit to service recipients. Otherwise, restructuring costs time and money and, causes uncertainty for staff and clients.

Finally, I wish to draw the Committee's attention to various difficulties experienced, after being assessed as eligible for ADHC's Attendant Care Program (ACP). While it is now the case that additional services have been provided via a brokerage agency, the difficulties experienced initially, should be of concern to this inquiry.

In particular, I was initially told that to access ACP funding, it would be necessary for me to give up my Homecare services and staff. As explained in my first submission to the Productivity Commission's inquiry into disability care, these services had consistently met my needs and, while prepared to discuss an augmentation of support, I was not prepared to be bullied into abandoning services which worked for me, nor give up

workers attuned and sensitive to my needs.² After all, it is worth remembering we are talking about intimate personal care needs.

The rationale for this requirement was that ACP funding came from a separate pool of money, other than that which supported Homecare. Thus, despite both programs being funded and administered by ADHC, no ADHC client could mix or match elements of both, to achieve a support package which truly suited them. Yet, as emphasised to the Productivity Commission, the language used throughout the process was one of choice; despite the fact that, as I outline in the document, there were times when one felt at the wrong end of Departmental ultimatums. To address this power imbalance, people with disabilities (or their guardians/family) should have the option to contract staff and related services directly, perhaps alongside ADHC

Recommendation 3: In light of what has been said above, the Committee's attention is drawn to the first three recommendations contained in Annexure A,³ with the suggestion that such reforms be implemented regardless of the outcome of the Productivity Commission inquiry.

Subsequently giving evidence to the Productivity Commission, my aim was to draw attention to the level of control government service providers, like ADHC, have over the lives of people with disabilities.⁴ My experience with ACP has also made me reticent about proposals for a national disability insurance scheme, because this may prompt agencies like ADHC to conclude that more direct service delivery is the responsibility of Canberra rather than the States.

This is a theme I take up in my second submission to the Productivity Commission. I submit that this Committee should note this possibility of a State to Federal cost shift, while recommending the movement of all disability services to a PLAN Canada, or similar model.⁵ We must put people with disabilities and their families in control of decisions that relate to them, not government bureaucrats.⁶

Achieving such reforms requires ADHC direct service delivery and, funding of third party service delivery agencies to be completely separated.⁷ While there might be

² See Annexure A, pp. 1 - 4; pp. 16 - 20.

³ See *ibid*, p.4; p.5; p.10

⁴ See Disability Care and Support - Public hearings, Sydney, Tuesday, 20 July 2010, at 9.31 AM, <http://www.pc.gov.au/data/assets/pdf_file/0018/100674/20100720-sydney.pdf> pp. 759 - 763, as at 4 August 2010

⁵ See Annexure B, pp. 7 - 8

⁶ See Disability Care and Support n 3, pp. 759 - 760, where I note the regulatory burden placed on people with disabilities, as well as others in need. Another example of the regulatory burden on many people is the Federal Job Seeker Compliance system: see my submission on this issue at

<<http://www.deewr.gov.au/Employment/ComplianceReview/Documents/AdamJohnstonSubReviewFinal.pdf>> as at 5 August 2010

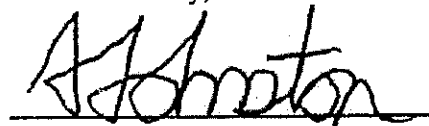
⁷ While I am a recipient of ADHC services and am on the board of a non-government service provider, my personal view is that ADHC is an organisation in a perpetual conflict of interest; as both a service provider and funding body. Equally, for service providers dependent on government funding for a large slice of their budgets, it has to be asked just how much flexibility and choice these organisations can truly give their

structural separations within ADHC now, my view is that some of these work against end users (refer to my experience with the ACP, discussed above), while others require non-government organisations to take on bureaucratic-type rigidities of process. I recommend the use of an independent panel of service providers, clients and family members, as well as other experts in disability services be appointed by the Governor, to make funding and grant allocations. The panel's funding decisions, as well as the reasons for these decisions and supporting documentation should be published, to demonstrate the independence and fairness of the process.

Recommendation 4: That all of ADAC's functions become contestable, so that more PLAN-type organisations can develop.

Recommendation 5: An independent panel be appointed to make all funding decisions currently made by ADHC.

Yours faithfully,



Adam Johnston

August 5, 2010

clients, as a consequence of the financial relationship with (dependence on) government. For a discussion on this matter, see Peter Saunders, *Supping with the Devil: Government Contracts and the Non-Profit Sector*, Centre for Independent Studies, 09 August 2009, publication details <<http://www.cis.org.au/publications/policy-forum/article/1215>> as at 5 August 2010. I further draw your attention to comments made by the founder of PLAN Canada: "If government gives you money, they have a certain amount of control, and there may be a fear of advocating there. If we earned our own money, we could advocate and hold government accountable." – Arthur Mudry, PLAN founder.