

July 27, 2010

Sirs,

I wish to make a submission on disability services.

I represent no organization. I am a quadriplegic of 52 years, C5/6 complete, which means I have survived many moons as a severely disabled person. I think that is all I have to say about myself.

I need carers to keep me going with the many activities I engage in, some at a senior level. My wife is developing arthritis in her spine and leg and is finding it increasingly difficult to do the things for me that my carers do not do.

I have two sets of carers, mornings and nights. The night carers provide about 8 hours of care per week including two-three bowel care nights. The service is provided by *Ability Focus*, and financed under the Northern Territory's Individualised Funding. The morning carers provide 'getting-up' care every morning, through *Red Cross Home Care Service*, approximately eleven hours per week, plus an hour cleaning. It is funded through *HAACC* the Commonwealth funding agency; and that is the problem.

*HAACC* funding is provided to the care service, out of which my funding is provided, in my case it goes to *RCHCS*. I have been supported by many years by such service. There have been times where I have had to suffer whatever this service provided or otherwise, quality care or otherwise, the ups and downs. There was no option, whatever this service provided, good and bad, and all in between, I had to wear it; I was in effect held hostage because I dare not depart for fear of losing funding support.

There were times I became despondent. I do not intend to illustrate specific instances of bad care or good care. The fact is, I was held virtual hostage to one service because of *HAACC* being the nature it is, not supporting portability. All the 'motherhood' statements and averments in disability legislation and service slogans of excellence has no allayed the fears held by me; one has to live the life to experience such down-sides. I'm not saying there are no up-sides of course there are, but that only points to the problems in this system. On many occasions I would have changed services seeking better standards of care applying at the time. But the non-portability of *HAACC* funds prevented me from taking the risk.

**My question is; why can't the money required for my *HAACC* care, plus a sum for administration, be calculated and detached from that service, so one can apply to other services for similar care. I cannot rationalize why this should be so hard; in fact it should be a relatively straightforward matter. I believe the inability of portable funding under *HAACC* is based on serving the interests of organisations and not necessarily the recipients of such care.**

I'm not criticizing *RCHCS* standing alone, because the bad parts are probably out-weighted by good care, as I experience generally 5 days a week in recent weeks, for example. And I am aware of other commonwealth schemes, like *EACH*, which also run alongside the one I have been reliant upon. I have investigated in depth the latter scheme but it has flaws which if anything are worse than *HAACC*.

There are other issues which concern me, but this one has been and continues to stymie any true independence, and is sufficiently general to warrant a submission of its own. I respectfully submit that this scheme could be improved by portability, despite certain opposition from care services.

Sincerely,  
Ted Dunstan