

THE RHETORIC IN DISABILITY SERVICES IN AUSTRALIA

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I would like to thank the Senate for taking an interest in the failed disability support system.

To use my own example with disability services in Australia - I am a severely physically disabled person, suffering from a disease called Friedreich's Ataxia. I was diagnosed with the onset of Friedreich's Ataxia at the age of 14, and I am now aged 44.

This is a progressive disease that causes impairment through a failure of timely muscle reaction to messages sent from the brain (the slow reaction to the stimulus of neurotransmitters). It also affects muscular growth, giving rise to severe medical deformities, limitations and other problems (for example, severe scoliosis and cardiomyopathy), and had me in a wheelchair by the age of 23.

The progress of my disability has left me vulnerable, but not inadequate.

My vulnerability is due to a lack of assistance with my disability.

HomeFirst is a program run by the Department of Human Services Victoria. It incorporates the In-Home Accommodation Support program, which provides a range of home and community based support.

This program provides people with disabilities with essential goods and equipment to enable them to live independently and not in residential accommodation, such as nursing homes or hospital style accommodation.

It allows many people with disabilities to remain living in their own home, while increasing or maintaining independence.

HomeFirst is a program that can help certain people with disabilities move to a more independent style of living arrangement that more equitably provides for access to community activities and facilities.

The HomeFirst program can provide up to 34 hours a week of care and or support, and can include up to \$150 of additional support from Linkages.

Until January 2005, Linkages was the major administrator of my care needs. Linkages is a care/support program funded through the Department of Human Services as part of the HACC program. Linkages is budgeted to provide a maximum of 16 hours care/support a week, compared with HomeFirst's 34 hours of care/support a week.

Linkages clientele are believed to require less frequent care/support assistance. Linkages is budgeted to deal with the provision of support for the elderly, and not the complex support needs of people with profound disabilities. I have been a recipient of Linkages care and support services for over seven years, and I presently receive **Support & Choice** funding for 24 hours a week, which is far less than what I need and would be provided by Homefirst.

In November 2002, in response to my application for the HomeFirst program, *I was informed by mail that I was on the urgent list.*

To support my application, I produced a detailed account of my need for additional assistance, with the backing of references from people who are leaders in their respective fields.

Despite being on the urgent list, I have not as yet been accepted into the HomeFirst program.

Any correspondence I have had with, or through, the Department about my need for the HomeFirst program is answered by the cliché about the government department having no money.

This is a first indication that the rhetoric of Disability services in Australia, generally.

This failure to provide adequate care/support has significant implications for my wellbeing and quality of life. There is no known medical cure for Friedrich's Ataxia: however, there are forms of therapy, mostly medical, that may provide some easing of the pain, or an adequate type of solution to many of the inherent side effects and problems carried by the disease.

Most of these treatments can be provided by a trained carer, including physiotherapists, occupational therapists, masseurs, and speech therapists.

Presently I cannot take on any of these options due to the limited time I may spend with carers/support staff. This would only be possible through HomeFirst.

This further throws into question the stated claims of the State Disability Plan to provide for human rights, dignity and self-determination, when individuals are denied access to programs that have as their goal the improvement of quality of life.

In terms of the emphasis on balancing rights and responsibilities, I contend that I fulfill my obligations to society, and as such the denial of my access to HomeFirst can not be based on ideas of mutual obligation.

I have been studying at a post-secondary level since the age of 23. I completed an Associate Diploma in Business Studies (Accounting) at the age of 27. After this I attended Monash University for ten years, being awarded with a Bachelor of Arts, a Bachelor of Business (Accounting), and a Master of Arts.

My last academic association was with the University of Melbourne, where I completed a PhD in December 2005. I believe I am certainly fulfilling my obligation to contribute to society.

In addition to undertaking an ambitious and successful course of study, I have lived independently on my own in Victoria for the past 16 years. This has allowed me to develop social skills that have dramatically impacted on my life, allowing me to take responsibility for my actions.

However, the ability to maintain my life has progressively become harder, as I become older, less agile and more susceptible to pain and physical injuries.

These are caused by the inadequate factors of care/support, such as those previously outlined that are involved with the performance of most of my daily activities.

This unwarranted stress and hardship would be alleviated, to a certain degree, by the extra care/support that would be granted to me under the HomeFirst package.

Since I was allocated the 24 hours a week care and support from Support & Choice my disease and care needs have progressed and my ability to live independently without adequate assistance has progressively diminished.

This provision of care, which has not been responsive to my changing needs and life circumstances, again reveals significant problems in attaining the goals of the State Disability Plan in the context of the everyday lives of people with disabilities.

It is a long way from the stated goal of the State Disability Plan to “focus on supporting people with a disability in flexible ways, based on their individual needs, so that each person can live the lifestyle they want to lead.

In conclusion, I would argue the problem with disability services is structured on power relations based on economics, which drives a vision of social policy closely aligned to the neo-liberal view that social supports are burdensome to marketised economies, and to the ultimate goals of delivering budgetary surpluses.

As a result, today it appears rational to reduce social spending.

***The end result is not the achievement of human rights and social justice,
but an increase in individual human suffering and social exclusion.***