

Submission
No 38

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

Name: Ms Jennifer Rollo OAM

Date received: 5/08/2010

The Director
Standing Committee on Social Issues
Parliament House
SYDNEY 2000

INQUIRY INTO THE SERVICES DELIVERED BY ADHC

SUBMISSION

Jennifer Rollo OAM

5th August 2010

In NSW, the disability support system clearly does not have enough money to adequately meet the needs of people with disability (PWD) resulting in a system of crisis intervention only. It is impossible to plan for the future of our children when there is no choice. It also appears to those parents who are crying out for support that there is a lot of misuse of funding. For example increasing the number of bureaucrats and management staff, but not increasing supported accommodation places. Holding conferences to discuss unmet need, or worse, self-congratulations about how well the services are doing, using money that could have increased the number of respite or supported accommodation beds.

Accountability

Parents are afraid to complain about inadequate service provision for fear of retribution. When they are afraid their children will lose the inadequate service they are getting, you know that the alternative is no service at all.

When my son was a young child I assumed there would be services in place to meet his changing needs as he grew. What I have discovered is that existing good services have been starved of money causing closure, or so much negative change that the services are no longer useful. We are forced to fit our children into services that do not work. What we need are services that meet the needs of individuals. Obviously this would be fixed by individual funding packages. NGOs would then need to change the programs they offer to stay in business.

I have also been forced to become a lobbyist and a fundraiser for disability and disability health services, writing endless submissions to government inquiries, attending meetings with service providers and other parent groups, and attending round tables to advise governments about policy, leaving less time for my family and making my role as carer to my son more strained. I have no doubt that this has contributed significantly to my marriage of nearly 3 decades ending – like so many other marriages when there is a child with a disability.

ADHC's Vacancy Management Policy has had a devastating effect on families. Service providers lose the support of their local community in fundraising and personal involvement when they are no longer seen as providing services to the children and adults of their neighbours and friends. PWD are

no longer finding supported accommodation in their local area – IF AT ALL – because the department deems someone from out of the area most needy at that time. The person who DOES get that vacancy has been taken away from everything and everyone THEY know. People are shuttled around every morning and afternoon in taxis and vans to their workplaces or day programs, or perhaps worse, are so far away they are no longer able to access their programs and friends. We are made to accept these situations and to feel grateful for any accommodation crumbs that come our way.

This policy makes it impossible to plan any future for our sons and daughters. It means that parents can no longer invest their time and efforts into a local service provider who should one day provide accommodation services for their own child.

I have been involved for the past seven years with a group of parents in my local area trying to secure supported accommodation for our 20 sons and daughters with intellectual disability. See our web site: www.rasaid.org.au . We have discovered that there are three basic needs for our dream of a cluster of 5 houses to be built. The first is land in the local area - and there are a number of government-owned blocks that could be suitable – but we mothers are expected to identify & obtain this land. The second is capital works money for building the project. The availability of this funding seems to come and go periodically, but we have been unable to secure a promise for our project at the times it was available. The third is recurrent funding for the care of the residents. This ADHC funding must be found for our sons and daughters eventually. We have bipartisan support in principle from all three levels of government, and many times have felt close to achieving all three of these elements. The one fly in the ointment is always the department's vacancy management policy, which means that not all – or, indeed perhaps none – of our PWD might be housed in this project should it go ahead. The invocation of this policy inevitably results in the removal of potential offers of support.

More than once we have been told by the department that we are queue-jumping . This is a terrible thing to accuse parents of when we are just trying to help our children have a future. We parents are supremely conscious of our fellow carers. We frequently acknowledge the needs of other carers being higher than our own even when that is blatantly not the case in the eyes of other observers. The department uses this fact to prevent any of us from questioning their vacancy management policy.

Respite.

I started using respite services when my son turned 18 years. Throughout his childhood I had the support of my parents who would take him for one weekend every school holidays to give me a chance to spend quality time with my other children. As my parents aged and my son became more difficult to handle, they reluctantly could no longer manage this.

Luckily at this time I discovered a local respite service which is funded by the department, but supported and run by a religious community. They have been invaluable to my son and my family. This is the Estia Foundation at Gladesville.

They have embraced our family and saved my sanity. David has been able to learn to let others care for him which is very important should he ever achieve supported accommodation, and will certainly

be needed if/when I should suddenly die and he is left without my care. More importantly he is given the opportunity of being with his peers. He loves staying at the respite house.

From my point of view I have a chance to break away from the 9am to 3pm routine that dominates my existence, for a few days every month to 6 weeks.


This private respite service has NEVER cancelled my son's respite stay, despite occasionally having a blocked bed. (The most recent blocked bed was blocked for two years by a young man who was eventually placed many miles away, never to be seen again. Dreadful!) I know people who use ADHC respite whose places are regularly cancelled at the last minute. When I apply for respite I just specify my preferences, which are usually met. I do not have to justify why I need a break like they have to in ADHC respite houses. Estia knows the lives and situations of all its clients so we are not made to feel we are in competition with our friends. This is much healthier for relationships and our own mental health. Why cannot ADHC respite services do the same?

Day service

My son's day placement is for 5 days a week, but a few years ago, when ATLAS funding was reviewed, many of the clients lost one or two, or even more, days' service. His were cut by one day which was devastating for him and for me. At that time I was working casually (as I had been for over 25 years), trying to juggle caring for my son, bringing in a pittance by way of wages, and trying to keep my brain engaged. As my son's medical and daily needs changed, this juggling act became more difficult. Occasionally I was unable to keep the balls in the air, but losing a day of service meant I was going to have to stop juggling at all. My son was reassessed and was able to keep his 5 day placement. I was able to continue working for a few more years.

I hope my submission will help make positive changes to disability service provision in NSW.

Sincerely,

A handwritten signature in black ink, appearing to read 'Jenny Rollo', with a large loop at the end.

Jenny Rollo OAM

Mother to David, aged 27 years, who has Cornelia de Lange Syndrome