

Submission

The 'Better Support for Carers' Committee

When: Wednesday 6th August

Where: Parliament House

Macquarie Street

Sydney

Time: 9:00 am – 4:45 pm

Public Hearing Program

Room 814-815 (Level 8)

I would love to be able to attend parliament in person to hear the speakers debate this topic, but I give up a lot of time to disability issues, and this week I need to catch up with my work.

I am the mother and full time carer to a 25 year old son who has Cornelia de Lange Syndrome. He has severe intellectual impairment, autistic behaviours, physical anomalies and a lot of recurring and chronic medical issues. He is incontinent and needs full care in every aspect of his life, including personal care. His expressive language is at the level of an 18 month old baby. He attends a Community Participation program Monday to Friday from 9.30am to 2.30pm. He goes to a privately run (Dadhc funded) respite home for 8 or 9 x 4 night stays a year. The rest of every one of his days and nights is spent with me. My husband steps in to take over, with the help of the respite home, so I can have a short holiday once every two years or so.

I fit my casual work as a Biology Technician into the hours my son is in his day program. I am lucky in that I am also able to put my son's needs before my work. I can therefore be available to care for him when he is sick or needs hospitalisation. The downside of this, of course, is that I have not been able to build a career, nor build up a superannuation nest egg. I am far more dependent upon my husband's income than a woman of my age and work experience should be. But then again, I'm lucky that I still have a husband, and he is able to work full-time. He has also had to make career sacrifices because of our son's needs, and frankly many husbands don't last the distance when a child with a disability enters the marriage picture.

I am now 53 years old. I look around me at the many, many women I know who have been caring for their loved ones for twice as long as I, and longer, and marvel at how they keep going. They keep going because they have no choice. It is negligent of our society that the burden of care with no financial reward, and in fact, severe financial penalty, is thrust upon so many women. The fact that there is no end to their caring role is what terrifies all carers. They know they are going to die at some point, and that when they do they will leave behind a frightened, bewildered adult son or daughter who does not comprehend that they no longer have the love and care of their parent, or even the home in which they felt secure.

Presently supported accommodation is only provided in crisis situations, if at all. Because of this, people with disabilities are forced to live with strangers they have never met before and may or may not get along with. They are invariably placed in a group home out of their neighbourhood, and even out of their city or town, isolated from everything they used to know. They no longer know even the people at the local shops, and have to travel for hours each day to get to their work or day program.

Carers want to be able to help their loved one settle into a new environment long before there is a crisis situation. They want to be able to support their child over a long period of time during this transition, and also enjoy a little time to themselves. Every other Australian expects to have a retirement and we carers should have that expectation as well.

My husband and I have had one weekend – yes, that is 2 nights – holiday alone together in the 25 years since our son was born. The only way we can enjoy any interest or hobby is to go alone. The other parent needs to be providing the 24 hour care for our son. One day I hope to have a holiday with my husband.

For the future care of my son I am lobbying for a cluster of group homes wherein 20 people with intellectual disability share 24 hour care and have the opportunity of continuing friendships, society and support from each other. This is also the most economical housing choice. This is what he needs.

In the mean time Dadhc has to increase the availability of respite care, and stop blocking respite beds with all the people in those crisis situations. All this achieves is many more families in crisis due to the lack of available respite care.

Presently the greatest need of people in my caring position is supported accommodation. And 90% of carers, including myself, want to be able to choose the model of accommodation which best suits the needs of their son or daughter. I suspect the other 10% are the ones who have their child in supported accommodation already, and are afraid they will lose their places if the available money is to be shared with the rest of us. I find it objectionable that there are many so-called “advocacy groups” – funded by government – that do not advocate for needs of the majority of carers. The single group home with 3-5 residents is not the only model that people want, but this is the only model that advocacy groups will recommend.

Yours Sincerely,

Jenny

Secretary, CdLS Association Inc

Vice President RASAIID Inc

Mother of David