

## **Submission to The Long Term Care and Disability Support Scheme**

I was diagnosed with cerebral palsy (spastic diplegia) at 12 months of age and I use a wheelchair for mobility. As I have moved into adulthood, the biggest issue I've faced is the lack of services like occupational therapy, through the community health service. In particular, the waiting list for an occupational therapist assessment for a new wheelchair is up to 12 months. Although I can access occupational therapist visits through an Enhanced Primary Care Program under Medicare, it is limited to 5 visits, which can be inadequate particularly as I may have to try several wheelchairs until I find one that is appropriate for my needs. Waiting lists to access services like occupational therapy through community health need to be reduced, there needs to be more support and resource funding for this area. People who are dependent upon wheelchairs and other adapted equipment need to have appropriate support so that the equipment chosen is appropriate for their needs.

### **Participation in the community**

I have been extremely fortunate that the transition to new stages of life, like commencing university studies and living away from home has been fairly smooth. However, more needs to be done to assist people with disabilities to move into further education or employment. There are many support services available, yet often they are not well-known amongst the disability community. The profile of education and employment services needs to be raised so that people with disabilities are connected to the right type of support and can maximise their abilities both in the workforce or further education.

### **Support from the family**

During the university year, I live independently in on-campus accommodation. The proposed disability support scheme must have provisions which will ensure that adequate financial support is available if people with a disability need to move away from home in order to complete their university studies.

## **High cost of living with a disability**

As a wheelchair user, I would like to see a disability support scheme which would see greater funding being made available to cover the cost of mobility devices. For people who use wheelchairs on an everyday basis, the waiting list for Program of Appliances for Disabled People (PADP) support is simply too long (I have been told up to two years), leaving many such as myself having to cover the entire cost of a wheelchair to get it within an appropriate period of time.

## **Choice and Control**

Having lived with cerebral palsy to 22 years I believe that in no one understands my disability and its impacts than me. As, such there should be greater consultation between health-care services and people with disabilities to ensure that the support which is provided are appropriate for a person's particular needs.

On the point of the health profession, an area of focus of the disability support scheme should be greater investment in transition medicine, to more adequately support people who have had a disability since childhood. Presently, there is a significant gap in clinical and support services once people with a life- long disability has outgrown the paediatric system.

## **Areas that should be included under the scheme**

Home and vehicle modifications should definitely be included under the proposed scheme. Learning how to drive is a significant milestone in any young person's life, however it can be difficult for someone with a lifelong disability to achieve this goal. An occupational therapist assessment to determine the type of vehicle modifications I needed was \$400, this was an out-of-pocket expense. As people who need to drive with hand controls have to be taught by a qualified instructor, there is the added cost of driving lessons, which can become exorbitant depended upon how many lessons that person may need before they become comfortable using the hand controls.

The financial cost of learning how to drive can be a deterrent for many with a physical disability. I believe it is essential that all costs (both vehicle modifications and necessary driving lessons) should be included under the scheme. Not having to be dependent on others such as family or friends or public transport not only

increases independence but may increase employment opportunities as you are able to get yourself from your job with ease.

Similarly, when I finish university and eventually look at purchasing a house, the cost of modifications e.g. ramps, support railings, lowering benches and cupboards will be expensive. If this was covered by the scheme, I would face significantly less financial pressure.

There needs to be greater employment support. One of my biggest concerns is that I will finish University qualified in my chosen area yet find it difficult to gain employment as workplaces may be ill-equipped or unaware of how they can support a person with a disability.

It is my hope that the introduction of a National Disability Support Scheme will improve both the quality and delivery of services and provide adequate financial support to better assist people with a disability.

Kind regards,

Kathryn Millar