SUBMISSION
INQUIRY INTO DISABILITY CARE AND SUPPORT

As the mother of a 33 year-old woman with autism and a concomitant intellectual disability and who needs full-time assistance in all aspects of her daily life, I feel that an inquiry into the establishment of a long-term disability care and support scheme is long overdue. I believe it to be imperative that such a scheme is introduced without further delay. Do not allow inquiries, reports or politics to prevent this essential step for our country.

My husband and I are in our sixties and our daughter currently lives at home but is in transition into supported living. She attends a full-time day options program and, in the fifteen years since she left the education system has lost many of the skills she had acquired through long and tortuous years of training. While we are grateful that our daughter attends a full-time day options program, it does not offer quality but rather fills in the time due to funding and staffing constraints.

All adult services for people with profound disabilities are “closed”, that is, you don’t graduate and come out the other end and enter a career. Generally, you are there until you reach aged care. Governments, both state and federal, must plan for growth and the coming wave of people with a disability who will require services. Younger parents of disabled children are not prepared to wait many years for services. In today’s society, with both parents generally working, there seems to be an expectation that services will be available when needed.

Some form of national disability insurance, perhaps modelled on or as an extension of the medicare levy, would provide a financial base where these services could be planned, put in place and be ready without parents struggling against the ‘system’ for many years. One would not have to beg, it would be a right. To gain support, the general population needs to be educated that ‘disability’ can happen in a split second. For instance, your son or daughter has a car crash, you do not have a claim for compensation and suddenly you become a fulltime care; you have a child and are told he or she has a profound disability at birth and you are facing a lifetime of care. A national disability insurance scheme would at least assist with the financial burden.

The current network of non-government organisations already in place would appear to be ideally situated to provide an improved and expanded set of services. I am concerned at the rapid growth of profit-making organisations that have sprung up recently as there is little enough money in the disability sector without having much of it siphoned off as ‘profit’. As much of the disability dollar as possible should go to the people needing services. I do not believe governments should be in the business of providing ‘on the ground’ services – governments should be the funding bodies, set the standards and ensure they are met and adhered to. Constant and rigid auditing of service providers as happens in the aged care sector would go a long way to ensuring improved quality of care.

I believe block funding can and does have a rightful place in the mix, contrary to a lot of people who believe that individualised funding is the answer. Not everyone wants or is able to administer individual funding. Certainly, as you get old you feel the need to let go of the reins. Anecdotally, my information is that individualised funding almost always falls short of providing the level of service parents are looking for. Parents can be seduced by what appears to be a large amount of money only to find it doesn’t go very far at the market rates charged by professionals and organisations providing services. It appears to me that when governments hand out small sums in individualised funding as opposed to funding organisations for defined contract periods, it doesn’t improve either the quality or quantity of services available, it only saves governments money.

I do not believe that people born with a disability should be disadvantaged in comparison to someone who has a car accident, ends up with the same form of disability, yet can sue and receive a great deal of money. Surely, in a civilised society we should be able to care appropriately for all those who cannot care for themselves and provide them with a quality of life.

I am afraid that, having read the questions posed in the Productivity Commission Circular DCS 1 of 14 April 2010, I must leave it to brains brighter than mine to resolve the details and intricacies of how such a scheme would be run. However, I feel it is imperative that any monies raised be kept absolutely separate from health and used for disability services only.

In addition there are a number of extra points I would like to make:

- Aged care and disability care must be separated. They are not synonymous. Just because you are old does not mean you are disabled and just because you are disabled doesn’t mean you’re old. You cannot apply the same rules across the board.

- The requirement in the Northern Territory (I assume this applies in other jurisdictions also) that people with a disability who live in supported accommodation must contribute 80% of their pension towards their care (as is the case in aged care) is inequitable. If we are looking to provide a quality of life to people with a disability, expecting them to live on 20% of the disability support pension is unfair. In the supported living model I am familiar with, out of this 20% remaining from the pension, the person is expected to pay for their own furniture and linen; they must clothe themselves, buy their toiletries, pay for their outings and yet find money left over to save for treats for themselves, gifts for friends and family, and go on holidays.

  While I hesitate to draw comparisons between aged and disabled, when you are in aged care you are at the end of your life; if you are a young disabled person, you have your whole life ahead of you. You should be able to do the fun things other young people do – go out to dinner, to the movies, to concerts, go up in a hot air balloon, buy a guitar and learn how to play, go for a ride on a Harley. You cannot do this without money. The current system doesn’t allow for this.

- Currently, if you are receiving services in one state and have to move interstate for any reason, you automatically go to the back of the queue. When you have waited for many years to gain access to services, you are basically trapped, especially if your son/daughter is part of a block-funded service. If, as a parent, you have the misfortune to fall ill and need to move or simply wish to retire interstate, you are in the invidious position of losing everything you have achieved over many years. The states must be able to reach some agreement over portability. We are one nation after all.

- From the time you discover your child has a disability, you are involved in the ‘system’. First you have early intervention provided in the Northern Territory through the health system, then you move to the education system through pre-school, primary and lastly secondary school. The government invests a great deal of money in educating our children. Your child is painstakingly taught life skills, routines, hygiene and the myriad things that school offers. You have qualified teachers formulating stimulating programs that provide structure and learning. Then at approximately 18 years of age, you’re on your own again and suddenly you find you have moved back into the health system. Like many parents I know, I would have loved my daughter to stay at school for the rest of her life. She is not ill; she has a disability and needs constant training and assistance.

Post school you discover the real challenge of having a child with a disability. Whereas at school you had a right for your child to receive an education, now you will have to fight for the limited spaces provided in post-school day programs. Even if you manage to gain a place for your child, you will find these programs staffed by people who may have a Certificate in Disability Care if you're lucky. The jobs are poorly paid (mainly due to the lack of government funding provided) and undervalued by our society. In the Northern Territory, in many cases staff are no sooner trained than they are lost to the hospital system where jobs as Personal Care Assistants provide a government job, higher wages and better benefits.

Most post-school day programs are run by non-government organisations and they urgently need government funding to reflect the real cost of providing these services on behalf of government (which has the moral and legal obligation to provide them) – they need to be able to pay salaries that will attract trained and qualified staff and they need money to allow for growth in their client base.

The quality of most day programs would be greatly enhanced if there was enough funding to allow qualified special education teachers to be employed to inspire, mentor and lead a team of support workers. Instead of the limited, and in many instances, time-wasting activities usually involving a lot of travelling and waiting, we could continue to see the same stimulating learning programs that were offered in the education system.

Creating extended learning centres, perhaps attached to TAFE centres, where people with a disability could continue their education and training over the next five to ten years after leaving secondary education would be an excellent model to adopt, would lessen the pressure on NGOs, and would allow disabled people to retain and extend their skills base.

- Finally, when you feel it is time for your child to leave home and move into supported living, you then discover there is an enormous waiting list and you face another uphill battle to gain a place for your son or daughter.

  Most parents already experience guilt over the thought of placing their child in a supported living house. We need to know that our children will be able to maintain the same quality of life we have given them in the past and that they will be treated with dignity and respect. There is a huge element of trust involved which has not always been honoured. We are scared at the thought of dying and leaving our children without anyone to fight for them.

  We want homes, not institutions. We want a quality of life, not an existence. We need to be confident that as we age, our children will continue to receive quality care.

Thank you for taking the time to read my thoughts. I have great hopes that a better and fairer system will come out of this inquiry. I just hope that my family and the very many other families around Australia are not let down yet again.

Meredith Dewar
Darwin, Northern Territory

12 August 2010