

## SUBMISSION TO BETTER SUPPORT FOR CARERS INQUIRY

### Personal Information:

Name: Mrs. Nicole  
Address:  
Mobile:  
Employment: Audit Graduate, DECS

Submission No. 1181

(Inq into better support for carers)

Rec 4/8/08

### Family Information:

Husband: Owen  
Employed: Full time, Fitter & Turner, Holdens

Children: Andrew  
Jordan  
Daniel

Pets: Sandy, Little dog  
Numerous budgies.

### About the person we care for:

Our son/brother, Andrew, is a fifteen year old intellectually disabled child. Andrew currently attends Elizabeth Special School but next year will transfer to Gepps Cross Senior School (also a special school).

Andrew doesn't have a recognised physical disability, but suffers from low muscle tone and displays a distinct lack of balance. This can mean an outing is quite 'hands-on' to ensure there are no falls, especially where there is uneven ground, stairs etc.

Andrew also displays frequent challenging behaviours. The most frequent and profuse being his language and communication evidenced by constant swearing. Andrew's emotional language was assessed in 2007 - with the use of an evaluative tool that required a psychiatrist's input - as being 18 months to 2 years. This immense difficulty with communication and coping with difficult, stressful situations means that Andrew frequently reverts to using bad language.

Andrew is also extremely volatile, aggressive and violent. He frequently hits out when he doesn't get his way and often hits out where no trigger situations have occurred.

Andrew's health is generally very good. He has 50% vision in his left eye but his right eye is almost perfect. He has been able to actively participate in many sports including basketball, bowling, swimming, tennis and soccer. In April 2008, Andrew won a gold and bronze medal at the Special Olympics Junior National Games in Canberra.

## Role and Contribution of Carers in society and how this should be recognised.

The role of caring for Andrew goes beyond that of 'parents/siblings'. The extreme behaviours and situations we face with Andrew can be very isolating socially.

We attended a Police Expo and Andrew didn't want to leave when it was time to go, so behaved aggressively and swore, "Fucking dickheads, I'm gonna bash you" etc. It took both parents and two police officers to 'carry' him out and to the car. During this time both siblings were extremely upset and embarrassed.

If as parents/family we do not continue to care for Andrew, the cost to the government to care for this child will be very high. We know this because throughout his schooling there have been school staff who have refused to work with him. Our role as Carers goes beyond that of parents/siblings. We are educators, inventors and security.

Carers need to be recognised with increased and individualised support. This support needs to be more readily available and more easily accessed. To get 19 hours a month one on one support through CSI, I had to mentally and physically breakdown in front of the disability support workers. I had to repeat this behaviour a number of times, before a submission would even be written. We, as Carers, shouldn't have to fall to such low levels in order to receive basic assistance. It is humiliating and degrading, but unfortunately necessary to get basic level of support.

The CSI support pays for a carer once a week to take Andrew out bowling, and do social activities. During this time Andrew is exposed to different settings and experiences. Certain behaviour is expected of him (even if he doesn't meet it). One thing we have asked his support worker to be mindful of is Andrew's behaviour around women to teach him respectful, appropriate behaviour.

## Barriers to social and economic participation.

The biggest barrier to social and economic participation has been Andrew's behaviour. Even though he attends a 'special' school, he has been suspended many times. Despite the obvious fact that his behaviour stems from his disability. Respite services have sent him home, and even refused to continue to provide an accessible service. I know a number of families with challenging, disabled children who also experience this problem. It appears that the more challenging your child is, the less help you can access.

I have only been in work since April 2008. Prior to this, I have been studying Commerce/Law at Adelaide University. Studying has been especially difficult, when I need to leave lectures and tutorials to go collect Andrew from school/respice. However, my husband and I knew that I would not be able to work until we could have a number of care options in place.

These care options may now be in place, but we have had to fight very hard to get them there. My husband has had to change his work hours to be home at 3 pm for Andrew.

Our greatest concern is Andrew's future. What happens if he gets suspended from school, or in years to come day options/supported work placement. Andrew's behaviours aren't going to go away. This has been recognised through Disability SA, who talk of managing his behaviours at an acceptable level. It is a very real possibility that either my husband or I will have to give up work in the future. Many parents of disabled children face this problem.

To find/retain employment, Carers need affordable, reliable care for the person they care for. That support needs to cater for the more challenging behaviours. Care levels need to increase as the level of disability/challenging behaviours increases. It is a frequent comment amongst other parents of disabled children that service providers seem to think we are there to make their jobs/lives easier. It should be them who are providing a service to us and making our lives easier.

#### Practical measures to support Carers.

Aside from the obvious, increased financial support and respite, there needs to be an overhaul of the support worker/respite system. Better training and increased accreditation for support workers/respite providers. To get the right people in the job, increased pay rates for the sector.

Carers need to be able to have greater flexibility with their respite options/financial support. A 'bucket of funds', for the carer and carer to utilise how it best suits them would be a step forward (although managed by Disability SA/similar to prevent the funds going to the pokies in some cases).

#### Strategies for the future.

Carers have hopes and plans for the future, but uncertainty about the person they care for. Carers need some certainty to answer the oft asked question, "What will happen to X if I die?"

Australia needs to plan ahead for the future of all carers to ease the emotional burden on their carers. So many carers are existing at a low socio economic level but want to move up in the world. We need better support to do that. We need better access to care, that is flexible and affordable, so that we can work/study/improve skills.

Society needs to gain a better understanding of carer roles, especially that of the young carer. Although, it must be stated that great strides have been taken in the last few years. South Australia has Carer's legislation now, which whilst provides great recognition doesn't have much bite where employers do not meet support levels for carers.

Thankyou for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for Carers in Australia.

Yours truly,

Nicole