

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600

3 July 2008

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am submitting to the Inquiry because I am a carer of two young boys with special needs. My eldest, is 7 and has a moderate degree of Autism with an Intellectual Disability, Auditory Processing Disorder and Dyspraxia. He attends a Special School. My youngest, is 4 and has recently been assessed as having Aspergers Syndrome. He is high functioning, but suffers from high levels of anxiety, has difficulty controlling his emotions and fitting in socially with his peers.

Whilst I would not swap my boys for any other children in the world, this is not what I would choose. Family life is not what I anticipated when I was a newlywed, longing to have a baby. I have watched my children struggle with basic everyday tasks that other people take for granted. At three years of age, my eldest had a handful of words (which were used very sparingly), had uncontrollable tantrums, refused to sit at the table with other children, had unusual repetitive behaviours and intense interests. Playgroup was impossible to attend and I left there each week in tears not knowing why my little boy was behaving this way. Help seemed to be nowhere to be found and it took some 18 months before he was finally diagnosed with Autism at three and a half, after a merry go round of Doctors visits.

Since then, it feels like I have had to struggle for every little bit of help we have received, almost stumbling over services rather than being informed of what we were entitled to. My eldest attended Early Intervention for 12 months in 2005 for 3 hours per week. This was supplemented by Private Speech and Occupational Therapy and Psychology, at a significant cost to the family budget. After school activities consisted mainly of therapy visits rather than the usual activities of swimming or sport.

I am grateful that my elder son is able to attend a Special School; however I am very afraid of what lies ahead for my younger son, who does not have an Intellectual Disability. The papers seem to be full lately of stories about the terrible treatment of kids with Aspergers in mainstream schools. Mainstream school is the only option for my youngest, and I know that most kids with Aspergers don't get any extra support, even though they would benefit greatly from it. I am exhausted now, and he hasn't even started school yet. I have been through all this with my elder son, and it doesn't get any easier second time around. All of the grief I felt with the first diagnosis is being brought back to the surface again and it is so hard watching other typically developing children the same age and thinking about what could have been.

The impact on family life (and the relationship with my husband) is huge. As a family, it is extremely difficult to go anywhere with the boys due to their low attention span and the need for constant supervision. My elder boy has no concept of danger and would speak to anyone, go with anyone and wanders off. He becomes overwhelmed in noisy environments and both are easily overstimulated in shopping centres and other hot noisy environments. Outings are major, planned events; often ending with exhausted parents who wonder why simple things have to be so hard.

I understand that many of our struggles are similar to those that other families without a special needs child may have. The difference is that the behaviour and level of supervision required is constant; there is never a break.

I worry about the future, wondering what it will hold for my boys. Even though they are young, I am fearful of them having to live in this world without family to help them. Will other people be as caring, compassionate and understanding as their family has been? Will they have jobs, live independently, have relationships? My husband and I are working hard to give them the best possible chance in life, because I know I cannot rely on anyone else to give them that chance.

Things that would really help my family are:

- Respite – currently I am unable to access weekend and overnight respite in the area due to waiting lists (some services have closed their waiting list)
- School Holiday Care – most service providers offer care until children reach High School age (12 or 13). What do I do with my sons when they reach that age? Do I have to stop working because I won't have any care options available during school holidays? Also, my elder son is in Mainstream Holiday Care and whilst this is OK at the moment, his odd behaviours make him an easy target for bullying. There is no School Holiday Program in the area for children with mild – moderate needs which means they have to attend programs for mainstream children. Why can't special schools operate School Holiday Programs?
- Assistance for children with Aspergers Syndrome – Aspergers seems to be considered a "mild" disability. Aspergers effects a person's behaviour, social response and communication FOR LIFE. Assistance in the school years could have a huge impact on the quality of life in later years.

These things would help at the moment. I am sure that there are many other things my boys will need as they get older.

I hope that my story is heard and makes a difference.

Yours sincerely

Sue