Inquiry into Disability Care & Support - Productivity Commission

July 30, 2010

Dear Sir/Madam,

I've thought long and hard about writing a submission, as I don't feel confident enough to be able to write fluently and truly express the issues we face as a family. I believe most of the questions you pose, have been addressed.

I am the primary carer of our six children, two of whom have been diagnosed with Autism.

Our 8 year old son was diagnosed in April 2009 with High Functioning ASD after seeking answers to his often odd, unexplained and frequent challenging behaviours. Although verbal, he often has difficulties expressing his needs and making himself understood by others. Many times he has put himself in danger as a result of a very strong "flight" response, and has gotten himself lost on many occasions, once ending in hospital concussed and with a broken arm. He has exhibited these behaviours from a very young age and spent 3 years in preschool to give us the opportunity to try and understand his needs and seek a diagnosis.

During 2009, in her first year at primary school, our now 6 year old daughter begun displaying extreme emotional, social and behavioural difficulties and welfare staff, school nurse and teacher, suggested we seek advice and an assessment for her. In mid 2010 she also received a diagnosis of HF ASD as well as a severe behavioural disorder. Her ASD prior to starting school , was somewhat masked by our already ASD "friendly" home.

Her diagnosis and seeking out support and further assistance, was delayed due to our eight year old's need for hospitalization in January and February of this year. He has since been diagnosed with Cynovial Cell Sarcoma (soft tissue cancer).

The stress, isolation and financial difficulties experienced by our family is severe and has strained our almost 24 year marriage, to the point where it on the verge of collapse. Our 14 year old is, and has experienced bouts of depression and self esteem issues to the point where we have seeked counseling for him.

In January of this year, I gave up my part time job to cater for our two children's additional needs. Centerlink guidelines disqualify me for getting the Carer payment as my husband's income is considered to be too high. Only three of our five children still at home, are used in these calculations.

The costs of private therapists- speech therapists, occupational therapists, psychologists and ABA therapists are exuberant and while the Carer Allowance, and Medicare plans are helpful, they only marginally cover some of our expenses. To make matters worse, I believe the current government is considering removing Occupational Therapists from the Mental Health Care Scheme.

In addition to this, we have been making applications for funding under the Students with Disabilities Program through the Education Department. This has been a very long and arduous process and after 18 months we are still not receiving any support. To make matters worse, the criteria for funding eligibility changed last year, right in the middle of applications, making many children who would have been eligible under the old criteria, now ineligible. At the time, our son had been provisionally enrolled (pending formal funding approval) at an autism specific school setting, as his needs were considered to be severe enough. The Education Department did not agree.

Our daughter doesn't even come close to qualifying for additional support at school under ASD, as her IQ and language scores are deemed as too high. However the danger her behaviour poses not only to herself, but to other students and staff is not considered. She exhibits 5+ severe behavioural outburst per week (hundreds smaller behavioural outbursts), where she throws furniture, has attacked staff, has had to be physically removed from the classroom, or the other students removed from near her. She has even threatened to jump out of windows and absconds from class regularly. The cost to her education, self esteem, and further development cannot be calculated.

We are tired and exhausted.

I spend many, many hours trying to support our children's education and trying to come up with novel, visual ways to reiterated what is being taught at school. I have attended many courses and workshops to learn how to assist their education. **Schools need this training too, if they are to have a chance of educating and not merely babysitting our children. Schools need additional, trained Aides and programs that work. Our children need funding and access to additional classroom support and autism specific, individualized programs. Our school has come up with such a program with the financial support from philanthropic agencies. This is facing closure due to lack of funding and financial support.**

I have read the hundreds of submissions and feel terrible for the many families who are so much worse off than we are. The families whose children's medical needs mean they cannot sleep at night. The disabled adults, who without supported housing, have to rely on their ageing parents for their basic needs. However, ASD poses its own challenges and these are very real. I remember the heartbreak, hopelessness and embarrassment my family felt, when on a recent outing to the zoo, my son who is terrified of anything different , screamed for the first 3 – 4 hours! He kicked, punched, and begged "Please take me home mummy". I felt humiliated and hurt at the stares and the whispers and having to explain that my child had autism. I felt terribly hurt for his 14 year old brother who walked meters ahead, embarrassed by his brother's outburst. I felt hurt for my 8 year old's inability to see this as a positive experience and his inability to connect with the world. Is his inability to connect any easier to bear? A physical disability or impairment is easy for the world to see. Autism is not, and has to be explained again and again.

I know, and thank God that we are so much better off than many other families. I am plagued by guilt that I sometimes feel our lot is way too hard. Yet I am also a pragmatist. **Without support at school, many of the HF/ Aspergers kids have no hope of a real education and one day being able to fit into mainstream society as productive, independent adults. The criteria for eligibility for assistance under Students with Disability Porgram need to be more flexible.** Many of our children miss out on early intervention as their HF ASD/ Aspergers isn't picked up until they have begun school and are too old to qualify.

Whether the incidence of Autism is on the rise, or whether the medical profession is just getting better at diagnosis, the number of children and families needing support is on the increase. With Autism specific and ongoing intervention, many of our children have a real chance of overcoming or learning to cope with the many challenges they face.