

Clarke, Pamela

Subject: FW: re an addition to the submission of Dr. Jasmine McDonald
Attachments: CRC education and health standing committee.docx

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From: Melissa Kelly [mailto:emmykelly@bigpond.com]
Sent: Monday, 25 June 2012 12:14 PM
To: Gordon, Brian
Subject: re an addition to the submission of Dr. Jasmine McDonald



Dear Dr. Gordon,

Please find attached another family testimony about the education system and children with autism. Jasmine gave me your email address and advised me to send it to you with the hope it can be added to her Appendix of family experiences. It is only two pages, and I disclose information which is very personal, but both my son and I discussed it and decided not to use pseudonyms, as we want people to understand the level of crisis which families experience, and we don't believe education and change is best served by secrecy. I am indebted to Dr. McDonald for the use of her research in my citations.

Yours faithfully,

Melissa Kelly and Patrick Barter.

My son Patrick, now aged 23, was diagnosed with Asperger's Syndrome at age 7yrs 10 months by Dr. Chauvel, who was the Head of Paediatric Neurology at PMH. His diagnosis was confirmed by a Speech Pathologist and a Clinical Psychologist. Patrick had been experiencing difficulties since he began preschool, but because Asperger's Syndrome only went into DSM-IV in 1994, very little was known about it in the wider community.

Indeed, I was very lucky I knew about Asperger's Syndrome, as I was working as the Information Officer for the Cerebral Palsy Association of WA and read Uta Frith's book on the topic as part of my work. Patrick was then seven, but I knew he had displayed a markedly different quality of behaviour and social interaction since the age of three. As Dr. Chauvel was the visiting neurologist for the Association, I knew him professionally, and after discussion with Patrick's Occupational Therapist, I made an appointment for Patrick to see Dr. Chauvel.

In the following years, I struggled to find an educational fit for Patrick. When distressed, had extremely disruptive and antisocial behaviours such as self-injurious, tantrum, obsessional and compulsive, which often made normal family life and schooling very difficult (Gray and Holden, 1992).

Research into the education of children with an ASD indicates that parents have ongoing, serious difficulties finding an educational fit for their children (Crosby, 1998; Forlin, 1995; Forlin et. al., 1998; O'Donoghue, 2000; Shaddock, 2007). School staff believes that the type of the child's disability is related to how difficult they will be to teach. Students with emotional/behavioural, language and literacy problems, general learning difficulties, ASD and intellectual disability are often regarded as the most challenging, and therefore least desirable to teach. Patrick proved to be no exception. In some cases, teachers were willing but inexperienced, and in others they were unwilling to have him in the class at all.

Throughout his struggle to find an educational fit, I was treated patronisingly, condescendingly and ignorantly by many "professionals." I went to meetings where I was referred to as "mum," instead of Mrs. Barter, where I was told that because he was my third child I wasn't as strict with him as I had been with my daughters, and where I sat alone on one side of a table facing four or five teachers and Ed. Dept. staff on the other. When I look back, I am surprised the Monty Python boys didn't leap out and cry "No-one expects the Spanish Inquisition!" My black humour is one of my coping strategies.

Patrick had problems with learning in an open plan classroom situation, social interaction with peers and being bullied. He was also dyspraxic, and it later transpired, dysgraphic (cannot write.) At age 10, I was getting him ready for his third school when he looked at me and said, "I hate my life, I wish I was dead." As my brother had committed suicide when Patrick was twelve weeks old, I made the instant and unplanned decision to withdraw him from school and teach him myself.

I began a program for him myself, and in Year 8 he was enrolled at *SIDE – the School of Isolated and Distance Education*. I was Patrick's home tutor for the years he was enrolled. Patrick completed Year 10 at SIDE and then completed a Certi.1 in Retail Operations at Leederville TAFE. After working for two and a half years in the retail sector, and being unemployed for some time, he became interested, through his voluntary work, in working with school-aged children, and returned to TAFE to do a Cert. 3 in Out of School Hours Care, which he is due to finish at the end of this year.

At no time when I was home schooling was I contacted by the Department, to see if I was managing or if Patrick was being taught appropriately. It was a case of “out of sight, out of mind,” and I believe the Department was only too glad to be rid of both me and my son.

Home schooling, a choice which was forced on me, exacted a heavy toll, and came at a great personal cost. Research on the social impact on families having a child with an ASD has shown that the child's behaviour can be a constant source of stress to caregivers, particularly mothers. Social isolation of the whole family often results and siblings are at risk of depression and anxiety (Gray & Holden, 1992; Powers, 1989). Unfortunately, many marriages fail under the pressure, and recent estimates put the marriage failure rate as high as 80%. Siblings clearly see that their brother is very different, and can be tolerant and compassionate, or antagonistic, embarrassed and intolerant (Attwood, 2007).

My whole family imploded and never recovered. My husband left home when Patrick was twelve and has refused any custodial responsibility since then, or any financial support since the age of 18. Patrick's father earns a six-figure salary, but as Patrick is over eighteen, his father cannot be compelled by law to take any responsibility for him. I have been Patrick's teacher since he was ten, his sole carer since he was twelve and the sole financial provider since he was eighteen. In a two year period, my husband and both my daughters left home, my father died, I lost my social status and my financial security. I had to pack up and sell my family home and find another home. Over the years, I lost my earning potential and the potential for any career path or meaningful superannuation.

Research has shown there is a strong familial link in autism and children who are diagnosed usually have a first degree relative who is also on the spectrum. My elder brother functions successfully as normal but also has very pronounced AS traits, which probably benefit him in his job as a scientist, and the younger of my two brothers had depression and committed suicide when Patrick was a baby. My elder daughter who has AS but functions as normal, lives overseas, and the younger lives in Perth. Neither has any contact with me or their brother.

After my family breakdown, I suffered depression and severe anxiety, and attempted suicide in 2005. After I came home from hospital I had no carer and no family support, and attempted suicide again. I was found by my former husband, who checked I was still breathing and left without calling an ambulance, leaving our son, then aged fifteen, alone in the house with me still in a coma. I remained comatose for another twenty-four hours before I began to wake up. The circumstances surrounding this failure to assist were so traumatic for Patrick and me that we didn't talk about it for four years.

With a variety of treatments and finding supportive friends and networks in the disability community, I began to recover and went back to study for another tertiary qualification. I am still Patrick's carer, I teach English as a second language and do voluntary advocacy work in the disability community for families trying to get services for their family member with a disability. If through my help, I can prevent what happened to me from happening to another family, then what we went through will not have been in vain.

I wholly support the recommendations of Dr. Jasmine McDonald, and submit this very personal story in the hope that these recommendations are implemented, and the number of children and families still not receiving adequate educational and therapy services will decrease, instead of growing.