

3/12/2013

Inquiry into Accommodation and Intensive Family Support for People with Disabilities

Dear Ms Dickinson,

My submission relates mainly to accommodation needs, in particular in the autism community. I am the now single parent of a 24 year old son with Autism Spectrum Disorder (ASD). My son was in the first cohort of boys in Perth formally diagnosed with Asperger Syndrome by Dr. Peter Chauvel, who was the former paediatric neurologist at PMH.

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, staff was willing but inexperienced, and in others they were unwilling to have him in the class at all.

Patrick had problems with learning in a classroom situation, social interaction with peers and being bullied. He is dyspraxic and dysgraphic. He had been to three different schools when I made the decision to home school him at age 10, after he said to me, "I hate my life, I wish I was dead."

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 Certificate 1 in Retail Operations through the Disability Services section at Leederville TAFE. He has also completed a Certificate 3 in Children's Services at TAFE, and is currently unemployed. Many people with ASD are chronically unemployed or underemployed. I worked very hard on an academic and social skills program I devised myself and he has made improvements over the years.

This all 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. He has since disowned him and has no contact with either him or me. Ironically, he works for the Sisters of Mercy. My understanding is he earns a six-figure salary, but as Patrick is over 18, he cannot

be compelled by law to take any responsibility for him. I have been Patrick's sole carer since he was 12.

Because of the trauma relating to his school experiences, our family breakup, and a life-threatening incident the police called "failure to assist," Patrick now has severe anxiety and Post-Traumatic Stress Disorder (PTSD) and sees the consultant psychiatrist at the Autism Association. The perpetrators of the failure to assist in a life-threatening incident were his father, grandmother and uncle. For legal reasons, they were never charged. With the exception of a motor vehicle accident, WA has no duty to rescue legislation. I was also a victim in the same incident and have PTSD.

As you may know, OCD, Tourette's Syndrome, depression, anxiety and ADHD are common co-morbid medical conditions and have a strong familial link. The elder of my two daughters, who is married and functions as normal, has Asperger's Syndrome and OCD, and my younger daughter, who is single, has depression. Neither has any contact with either me or their brother. My elder brother functions very successfully as normal but also has very pronounced ASD traits, which probably benefit him in his job as a scientist. The younger of my two brothers had depression and committed suicide when Patrick was a baby. After my family breakdown, I suffered depression and severe anxiety, for which I was hospitalised following a suicide attempt in 2005. Probably due to stress, I have acquired three auto-immune diseases and gastric reflux disease and even if I were relieved of my caring responsibilities, I wouldn't be able to work fulltime. I work part time and have worked as a research librarian, an ESL teacher and a standards monitor for the Disability Services Commission. I have applied for a similar position with the Mental Health Commission.

I didn't have any funding for Patrick until he was 21. Because he "only" had Asperger Syndrome, Patrick wasn't eligible to join the Autism Association, but joined when he was 16. He was made eligible to join DSC in 2010.

Patrick now receives Family Living Initiative (FLI) funding from DSC. I used it for wages and costs of Patrick having a support worker to accompany him to TAFE and for respite for Patrick to go on short breaks with a support worker. This means he can go on holiday with young guy (usually a uni student), and access the community like other guys his age. However, he cannot move out of home. The only options available to him are Community Living Plan (CLP) and CAP funding. We recently applied for CAP but were knocked back. This is an extremely competitive process. Families are vying against each other for a limited amount of funding. ***The stress of writing these applications is enormous.***

Parents try to write about the worst day in the child's life and their most negative behaviour traits so that they can present a worst case scenario in the hope of getting CAP funding. This is contrary to everything we have tried to do as Carers and parents. We have tried to concentrate on the positives, to help them with their education, to prepare them with life skills and make them as independent as we can. ***We try to see the person, not the problem.*** The CAP process is damaging, distressing and humiliating.

My son can be charming, funny and kind. He can be rude, distant and unkind. He is very intelligent but has an uneven profile of abilities. He loves to socialise but on his terms only. One hour of social interaction means two hours in the man cave. He needs someone to be available to problem solve for him 24/7. He loves British steam trains, Thomas the Tank Engine, Monty Python, manga films, Disney

films, political satire and Doctor Who. If we lived in Cardiff, they would employ him on the set. He knows the entire history of Doctor Who from 1963 to the present day. He has featured in the West Australian for Autism Awareness month and on Today Tonight, as a result of the newspaper article.

When we get knocked back it often takes weeks to recover and resubmit another application. Many families are so traumatised by multiple knockbacks they refuse to do any more CAP applications, leading to the entire responsibility of care and accommodation being shouldered by the parents, often only the mother. Suitable accommodation for people with disabilities, and in particular, people with ASD is an enormous unmet need. The default Carer becomes the family, which in my case is me.

Patrick's support needs are too great to be able to choose CLP. CAP is our only option. He is "too high-functioning" for a group home, but not high-functioning enough for CLP. CAP funding for him to live in the community and house share with a support worker is the only option open to him.

The number of people in WA currently being diagnosed with ASD is around 1 in 120. Girls are notoriously under or undiagnosed. The government of WA needs to become involved with individuals, Carers and organisations in the autism community to plan for the tsunami of individuals with ASD who will be requiring supported accommodation now and in the future. The human cost of failure to plan now cannot be measured.

I am indebted for the academic references to Dr. Jasmine McDonald, Graduate Research Fellow, UWA.

Melissa Kelly