Kiefel Family Submission to the Inquiry into the *Disability Discrimination Act 1992*

This submission is made by parents of a child with Autism. Our situation is typical for families with a young child recently diagnosed with autism. Many people incorrectly hold the view that children with autism cannot and should not be helped. This has grim consequences for people with autism and their families.

Autism is a highly treatable condition if treatment is commenced at an early age. The earlier treatment commences the better the long-term prognosis. In the USA, the majority of children with untreated autism will require institutional care by the time they are teenagers. The most effective treatment is autism specific behavioural intervention supervised and delivered by professionals with up to date training and experience. When intervention is delivered at a young age with sufficient frequency and intensity, the prognosis improves significantly to the point where many sufferers are able to live fully or partially independent lives. Parents have an important role to play although very few parents possess the skills and experience required to treat their child's autism at the time of diagnosis. Parents require substantial training and support to rehabilitate a child with autism. Sadly when parents turn to the state for help, they usually find that the expertise and treatment their child desperately needs does not exist, is not available within a meaningful time-frame or is only available through the private sector at prohibitive expense.

Autism is a spectrum disorder that can be mild or severe. Our son is at the more severe end of the spectrum. At age 2 years and 8 months, his language and social skills were assessed as being typical of a 6 to 12 month old infant. Our son was incapable of speech and functional social interaction. The paediatrician who diagnosed our son advised us to accept the possibility that our son may never speak. He told us that intensive intervention was a waste of money. It was clear to us that this doctor held very low expectations for our son because of his autism.

We are very glad that we ignored the advice of this expert. After 12 months of intensive behavioural intervention our three year ten month old son can speak in meaningful sentences of up to 4 words, can verbally express some of his wants, dislikes and feelings, can follow simple instructions and participate successfully in some social situations. Many of his violent and aggressive behaviours have been replaced by functional social skills. People often comment to us that our son has been transformed. Although he still has serious behavioural problems, our son's progress to date gives us confidence that he is not a hopeless case. Our son has shown us over and over again that he can learn, that he enjoys learning and that he wants to participate in life.

Obtaining the treatment that our son needs is expensive and difficult. The total out of pocket expense for our family of treating our son this year will be approximately $30,000. Our family receives Commonwealth support of approximately $2,200 pa and support in the form of 3 hours per week of early intervention from the philanthropically funded "Irabina - I Can't Wait Program". We receive no other government support although this support has been requested from the Victorian Department of Human Services at the time our son was diagnosed, some 16 months ago.

Although we receive only three hours per week at Irabina, this time is invaluable. We are angry that the services Irabina can offer to each child have been whittled back to a minimum because of systematic underfunding by government. Ten years ago Irabina offered children with autism five full days of service per week. This has been progressively reduced to up to six hours of service per week for children in the state government funded program and three hours per week for children in the charity funded program. Families in both the state government and charity-funded programs are currently required to pay fees of $1300 pa to help fund their child's treatment.

Contrast this situation with the services that are freely available to normally developing children in the state health and education systems.

The impact of reduced service must not be underestimated. Because of the enormous workload on staff, the limited access our family has to the centre and lengthy breaks to accommodate school holidays, it took five months for the staff at Irabina to complete a service plan for our son. This forces many families into the private sector. Other families simply have to wait. We know that there is a small window of opportunity to rehabilitate our son. Unless his difficult behaviour improves, it will be used as a reason to suspend him from school when he is older.

We know that we need to make financial arrangements not only for our own retirement but also for our son's retirement. Paying for our son's essential therapy severely restricts our ability to do this. It is important to us that our son is able to live his entire life with the same dignity that is afforded to "normal" members of the community. We are scared of what will happen to him if he is forced to depend entirely on the compassion and common sense of government. It is important to us that our son is rehabilitated to the point where he can receive an education, participate in the workforce and make a contribution to the community. It is important to us that our son knows the security of home ownership.

In our community it is generally taken for granted that a child with a severe medical condition requiring urgent treatment receives the support of the community. People in the community that we speak with consider it inappropriate that children with autism are allowed to develop profound and lifelong disability for lack of treatment. They question whether this can or should be legal.

Like many parents before us, we have written to our local MP and state government ministers complaining about the paucity of services for children with autism. The responses are not satisfactory. The government's position is that nothing can be done because there is not enough money. No other justifications are offered, the thinking behind the paradigm is never articulated. The "no money" argument conveniently overlooks the fact that money is allocated at the discretion of government. As a discretionary process, the allocation of funding is inherently discriminatory.

We do not understand how funding the early treatment of autism can consistently receive such low priority when there is a Disability Discrimination Act. We believe that it is unjust that the DDA offers more protection to government than it does to young children with autism. Without effective anti-discrimination laws it is very difficult, if not impossible, to bring government decision-makers to account. Most families with an autistic member lack the financial resources, energy and time to bring decision makers to account either through the democratic process or through the legal system.

Better outcomes for children with autism are possible in countries where the laws specify their right to effective treatment. In a recent Canadian case, the BC Court of Appeal ordered the province to allocate sufficient funds for the early treatment of autism because failure to do so has unacceptably grave consequences (refer attached article from the Canadian Globe and Mail, http://www.globeandmail.com/servlet/story/RTGAM.20030515.wauti0515/BNStory/National/)

We firmly believe that it is necessary that the DDA be strengthened to confer rights on disabled people