

Dear Commissioners Owens and McKenzie,

Thankyou for forwarding me the Draft Report of the Productivity Commission Review of the Disability Discrimination Act 1992.

My submission (Kiefel Family, # 168) dealt with the funding and provision of disability services to preschool children with autism.

I welcome many of the findings and recommendations of the report, particularly draft recommendation 9.1 which says that behaviour that is the symptom of a disability should be included in the DDA.

However, I do not concur with draft finding 14.3 that provision or funding of disability services is best left to government. I have a particular concern about the provision of early intervention services which prevent young children from developing profound and lifelong disabilities.

Since making my submission in May 2003, the Victorian Government has unilaterally decided to further slash the hours of service to children attending Irabina from 5.5 hours per week to just 2 hours per week. No other services will be offered to the children to compensate for the loss of treatment at Irabina. The children just have to cop the cuts.

The cuts guarantee profound lifelong disability for a high proportion of autistic children, in particular those whose autism is severe. Putting the human cost aside, these cuts to childhood services will result in enormous long-term expense for the community. Autism is currently estimated to affect up to 4 per thousand children, mainly boys.

The Victorian government brushes off parents' shocked and desperate pleas for mercy by writing to parents saying "there will always be issues of demand" In other words they will always refuse to meet the early intervention needs of Victoria's autistic children.

My letter of protest to Premier Bracks was answered with a promise that in accordance with the Public Records Act 1973, my letter would be filed away for future reference. I find it outrageous that there is a law to protect a piece of paper while there is no law that protects a disabled child.

Saying that decisions about the funding of disability services belong to government is referring this issue back to a process where there are no rules and disabled people have few rights. There is not even an obligation on government to be truthful. The Irabina parents have found that when senior politicians are questioned in the media about the cuts to early intervention services, they emphatically deny that it is happening.

The modern democratic process is complex with many powerbrokers and gatekeepers, one of the key players is the media. We are told by the lawyers we have consulted that the laws offer our children little protection and that we need to "go to the media".

Going to the media requires extraordinary effort, energy and persistence. We have to keep thinking of fresh angles and innovative strategies, working on the right approaches, the right phrases and the right timing without looking like we are recycling our issues. Corporations employ communications experts to engage with the media in their own language. This is what exhausted demoralised parents compete with when they try to "go to the media".

Luck is a big factor in successfully "going to the media". For example Saddam Hussien was captured the week that Irabina mothers held a singing protest in the Burke Street Mall. Although on the morning of our protest, several media outlets said they intended to cover our story, not one reporter showed up. Parents just have to keep trying to be heard, but when you are responsible for the care and rehabilitation of an autistic toddler you don't have time or energy to spend protesting on the off-chance that the media will be interested on that day.

Disabled children need an avenue where they can be guaranteed a hearing and those in power are compelled to answer questions truthfully. This is the advantage that the legal system has over the democratic system.

I urge the Commissioners to consider the capacity and limitations of the Australian democratic process to deliver fair outcomes to small children with autism. It is not in the long-term interest of the community to deny children access to early intervention services that will stop them from developing profound and lifelong disability. I believe that it is in the long-term interest of the community to offer children in this circumstance some protection under the Disability Discrimination Act.

I would also urge the Commissioners to examine the inequities between provision of early intervention services for children with autism and children with other disabilities. I regret that it is beyond my capacity to provide quality information to the Commission on this topic. I am informed that there is significantly more early intervention support for children with sensory disabilities, Down's syndrome and cerebral palsy than there is for children with autism.

Thankyou for the opportunity to express my views,