

11/05/2010  
Victorian Law Reform Commission  
P. O. Box 4637  
MELBOURNE 3001

Dear Sir/Madam

I am writing to address what I see as the need for law reform in the area of Intellectual Disability (as distinct from other types of disability).

I would like to preface my concerns by stating the following:-

I have been involved in the disability sector for nearly 40 years – as a mother, volunteer, clinical educator, served on endless committees, acted as a consultant and held many other roles.

The Disability Services Act of 1986 has instigated major reforms in service delivery to people with a disability.

The Act has initiated improvements in the following areas (to name just few):-

- Deinstitutionalisation
- Qualified staff
- Higher expectations, standards, and outcomes of service delivery
- Competitiveness in service delivery
- Accountability through audits, reports, and funding criteria
- Improved community services
- Community awareness and increased tolerance/understanding of people with a disability.

As we worked through the process of deinstitutionalisation in the '80s, I said "We have one more step to take! To see people with a disability not merely accepted but valued". Last week, I attended a 2 day conference in Bendigo – "*My Future, My Way*" and am pleased to say I witnessed more than a glimmer, of people with a disability being valued and in fact highly regarded!! This is the Act in action!!.

However, as we move forward and plan for the future it is difficult to find the balance between "*protecting the vulnerable and allowing choices & decision making*". particularly in the area of "intellectual" Disability, and it is this balance I wish to address.

**INTELLECTUAL DISABILITY:**

I believe the Laws fail to address the specific needs of persons with an intellectual disability and overlooks the role of parents who have faithfully cared for their son/daughter with an intellectual disability for many years (in my instance 40 years).

### **1. GAPS IN THE LAW**

There is no “Entitlement” to Care in our laws.

(I understand in England there is the “*Fair Access to Care*” Act, which entitles a person with a disability to care.) People with a disability are dependant on welfare.

### **2. ANOMALIES IN THE LAW**

Under the *Guardianship Act* a person needs to have the “*capacity*” in order to give Power of Attorney, while the *Disability Act* states that a person with a disability has the right to make his/her own choices and decisions with no mention of “*capacity*”.

I believe the disability Act should state that the rights to make decisions and choices should be at the level of their “*capacity*” to do so, as is written under “Power of Attorney”.

### **3. PARENTS:**

Parents who remain the primary carers for their over 18 year old child with an intellectual disability, should have the same roles, responsibilities and rights as clearly defined under the Family Law Act for children up to the age of 18 years.

Parents should *not* have to apply for Guardianship of their own child after the age of 18 years. Like many parents, I object, in fact I find it insulting - to think that after 40 years of caring for my son, I need to apply for Guardianship in order to have any “legal” say in his life!

I have consulted with a Barrister, QC, & Papal Knight - who has advised that:-

- The law can't have it both ways i.e. the need for capacity under one Act, while allowing rights, decisions and choices under another act
- To Push the boundaries and let some one else decide!
- If “age” was challenged in a court of law i.e. chronological versus neurological age (providing there is “expert” assessments) the law would be over ruled.

### **SO FAR:**

My son (who is nearly 40 years old) is in the process of being professionally assessed by a Professor of Neurology who has verbally stated that “Damien has the skills of a pre school aged child!” (about 5 or 6 years old).

I have obtained papers for “Power of Attorney” which can be witnessed by police.

I have approached the local police to ask if they would witness “Power of Attorney”

They have said “Yes that is not a problem”. I explained that it may well be a problem since my son does not have the *capacity* to do so, and asked where their responsibility started and finished. After consulting, (I presume with a higher level) they (the police) stated that they only have to witness the signature and do not have to determine the *capacity* of a person. I spoke to the public advocates office and explained the situation – they said “The police cannot do that”! (witness Damien's signature on a Power of Attorney Document). Interesting?? Who, then has the responsibility to determine “capacity” as stated under the Guardianship Act?

Like many parents, I have experienced difficulties with service providers, in the application/interpretation of the Disability Act at grass root level.

**I would like to tell a story to demonstrate this.**

**Damien loves to have coins in his wallet, which he uses in vending machines to purchase coke.**

**Knowing he is having far too much Coke I asked the staff to reduce the coke to 1 can per week.**

**The response was “*We can’t stop him, he has the right to decisions and choices*”**

**I stated that I thought his choice was uninformed – as he has no idea of the consequences of his actions – i.e the affect on his health, his epilepsy, congenital heart, brain damage, weight etc and that I think 1 can of coke a week is sufficient.**

**The response was “*Don’t worry, we stop him after the 2<sup>nd</sup> can (per day).*”**

**The only difference between what the staff said and what I said is 9 cans of coke a week!! This is the Disability Act in practice at grass root level.**

**A far more worrying problem is the future plans for long term residential care. The Department do not want to fund 7/24 supervision.**

**They want to fund units with one person living in each unit and a Carer who will supervise them.**

**My response – if you placed a 6 year old to live alone in a unit with occasional supervision – it would be considered child neglect which falls under the umbrella of child abuse.**

**I can cite many other (what I consider ludicrous examples) of the act in action at grass root levels.**

**Unless we write “*capacity*” into the Disability Act and acknowledge the role of parents as their carer, (without having to apply for Guardianship), this situation will continue.**

**Finally, I believe we are all faced with a question that was put to me some time ago by someone who I see has a clear, unbiased, uncluttered perception of the ultimate issue we all face.**

***“Nanny, is Damien an adult or a child?”***

**(yes, that’s right - my 6 year old grand daughter). Out of the mouths of babes .....**

**She knows at the age of 6 years, she is more advanced than Damien at 38 years.**

**I am prepared to speak openly about the issues occurring at grass root levels and hope we can work together to find the balance between protecting and empowering people with an intellectual disability.**

**Yours faithfully**

**Katherine Haggarty**