

Dalton family presentation
2nd World Congress on Adult Guardianship
15–16 October 2012

Thank you Madam Chairman,

It has been most interesting to listen to the theory presented by the previous speakers, and the examples of the conduct of guardianship in those three countries. Unfortunately our experience of guardianship here is a very different matter, and we have a very long way to go.

Marianne and I are parents of a young lady with multiple disabilities. We have no legal right to act on our daughter's behalf because, according to the administrators of our guardianship regulations, she is over eighteen and therefore must be 'independent'. But our daughter cannot speak on her own behalf because she has an intellectual disability. And because she has an intellectual disability she cannot appoint someone to act or speak for her as her Power of Attorney.

I can see that some of you, particularly our overseas delegates, are struggling with this. I'll say it again:

Our daughter has a permanent intellectual disability due to brain damage and she cannot make decisions for herself.

She is unable by law to appoint someone as her Power of Attorney because she has an intellectual disability.

The administrators of the Guardianship List refuse to appoint anyone as her legal guardian because they have a belief that people over the age of eighteen need to be independent.

Now wouldn't you think that in the past twelve years since this absurd catch-22 situation was imposed on us that someone associated with the administration of guardianship in this state would have had the brains to state the obvious? 'This

situation that we impose on the most vulnerable *robs* them of any legal standing in our society’.

It ought to be obvious, even to these administrators, that under this regime our daughter is in a legal limbo. She does not have the legal supports that the rest of us take for granted. She depends on the goodness of other people to look out for her best interests, and if people choose not to respect her interests she is open to abuse, and she has no one who can legally speak on her behalf.

Our daughter is now 33. At age four she developed epilepsy, which was initially well controlled, but which became progressively worse and worse. By her early teenage years she was having between up to 30 tonic-clonic seizures every day: full crash-to-the-ground seizures with self-inflicted facial wounds, many bruises and injuries. She slept in a hammock because seizures threw her out of bed. Windows in the house were replaced by acrylic sheeting because she crashed through glass. The large number of seizures and the associated battering of her head damaged her brain, and her previously normal IQ collapsed over a few years, leaving her with a permanent intellectual disability, along with the daily seizures, and not surprisingly some associated psychiatric concerns.

For most of her life our daughter has required 24 hours a day attention. Our family (we also have a now thirty-year-old son) was inevitably entirely oriented around our daughter’s disabilities. We all undertook *this* guardianship of her without question. We assisted her in organising her life and in dealing with her disabilities. We ensured that she had the best of opportunities and experiences within the limitations she had to live with. Never once under the present administrators of our guardianship regulations has anyone taken the remotest interest in our capacities as parents.

Our daughter had started at high school, and she had high aspirations for herself before her brain injury destroyed those. In spite of her considerable challenges, though, she remained keen to be as involved in the world as she could. She looked forward to leaving home, and to finding some independence.

With that in mind, when she was in her late teens we asked for, and were given, legal guardianship of her, which allowed us to legally speak for her and act on her behalf in situations which were beyond her understanding. We presumed that we would be

acting on her behalf for the rest of her life, and that guardianship would allow us to assist her in negotiating the world beyond the family home.

Our experience of this initial Guardianship Hearing, conducted by the old Guardianship Board, was extremely affirming and supportive. We sat around a table – our daughter, the guardianship officer and us. We discussed our situation. Our daughter was asked whether she would prefer to have some help in making decisions. She said she did. We were asked did we feel able, in the extremely difficult circumstances in which we found ourselves just looking after our daughter, to act as her guardians. We thought we could. So, it was agreed between all of us that the best course of action was the obvious one: that we take on the legal guardianship of our daughter. We left that meeting considerably reassured, and pleased that our society acknowledged the worth of our support of our daughter and that that support had a legal sanction into the future.

However, the next hearing to consider our guardianship orders three years later was an awful shock. The Victorian Civil and Administrative Tribunal whose expertise is in building regulations and backyard fences had replaced the old Guardianship Board as administrators of the Guardianship List. Some bureaucrat within the Tribunal had decided that everyone over the age of eighteen should be independent.

Consequently, we were sternly told that we were no longer legally entitled to act on our daughter's behalf, and that she was to speak for herself. This decision was made by an officer who never spoke to our daughter, who never listened to her, who never discussed her abilities with us. We questioned then, and we question still, the professionalism and the ethical integrity of that behaviour.

It is worthwhile mentioning how Guardianship Hearings were conducted under this new regime. We were ordered to attend a court house close to where our daughter lived. The presiding officer seated herself in the magistrate's chair. We were summoned and directed to sit within the bowels of the court. There was perhaps eight metres between us and the Tribunal officer. There was no discussion. We were told that our guardianship was to be revoked. The explanation given was simply that 'people over the age of eighteen must be independent'. We objected, saying that it was very important to us to have the piece of paper that said that we were legally able to act on our daughter's behalf. We explained that because our daughter did not live with us we had already experienced situations in which people acted without consulting our daughter and without consulting us. We were told that a bit of paper

would not make any difference, and that it had been decided that people over eighteen needed to be able to act independently of their parents.

Now wouldn't you think that any decent human being, or even any lawyer with just a modicum of professional integrity, would hesitate at this point? Wouldn't you hope that a twinge of self doubt might actually lead them to say: 'I do not know anything of this family because I haven't spoken with them. I do not know anything of this person's ability to act or speak on her own behalf because I have not spoken with her. I do not feel qualified to make a judgment about her capacity to act and speak independently because I have limited experience of disabilities. I also feel uncertain about taking this action because this person's parents have previously been granted legal guardianship of her by a legally constituted body appointed to make such decisions, and the decision was taken by someone not dissimilar to myself.'

And wouldn't you also hope that a decent human being, or at least a lawyer with just the faintest breath of professional integrity might have felt some passing awkwardness in bringing down a determination that imposed 'independence' on an disabled individual without even allowing that individual to exercising the supposed independence so conferred, by actually asking the person whether they felt they might ever need help in making decisions.

But there was at least a proviso. If we ever felt that our daughter's welfare was at risk, we were told that we could easily apply for a single-issue guardianship of limited duration to deal with specific situations. Different situations would require different temporary guardianship orders. This is utter madness isn't it? If you had three significant problems at once, and believe me we have experienced just that, you are required to make three separate applications for limited tenure guardianship.

On one occasion we were stupid enough to expect some support from the Tribunal. It had been decided, unbeknown to our daughter, and without advising us that she was to be moved to an Aged Care Facility. We discovered this inadvertently and we learned that this was to happen on a Saturday morning. On the Thursday we rang the Tribunal, explained the situation in some detail, explained that a certain Tribunal officer, whom we named, had advised us that we could obtain a temporary guardianship within twenty-four hours for any situation which might concern us. The Tribunal officer took our information but said that they were very busy at the moment and that someone would get back to us as soon as possible. We waited, and waited.

Finally we gave up and phoned the relevant government minister, who thankfully appreciated the gravity of the situation and had the action of the hospital in question stopped.

Yes, it was a hospital that chose to behave in this way towards our daughter. And do you know why they did? Because they could; our daughter has no legal ability to defend herself. And that is due to the appalling neglect of this Tribunal.

Such is the brainless stupidity and hypocrisy of this commitment to 'independence' for the disabled that it was also determined *at that same hearing* that because our daughter suffers a permanent intellectual disability she was unable to administer her financial affairs and we were therefore ordered to account for all of her expenditure, and to submit an annual return to be audited by the Tribunal, at a cost to us (this year) of \$112.80. The 80 cents is obviously important to them.

Does this make sense to anyone here? Is there anything resembling an integrity of thought in place here?

And do you know that the only time anyone from this Tribunal has ever expressed any interest in us is when a member of the Tribunal wrote to us pointing out that if our daughter kept spending her pension at her current rate she would be bankrupt in two years? (This is apparently our \$112.80 at work.) We were required to submit a written explanation as to how we proposed to deal with this situation.

With guardianship removed our daughter was now to negotiate with, for example, the Department of Human Services in relation to her housing, with Centrelink in relation to her pension, with hospitals in relation to her treatments, or with doctors in relation to her symptoms and her medications, and with staff in houses run by the Department of Human Services. Those tasks were clearly beyond her, and of course, we continued to offer her all the support we had provided throughout her life.

However, importantly, we now had no *legal* right to be involved. And our daughter had no one to legally speak for her. And we discovered that this made a significant and unfortunate difference.

VCAT's implementation of the guardianship regulations had actually made our daughter legally invisible. The thoughtless decision to make 'independence' a

primary concern when considering guardianship orders actually entrenches the old paternalism and condescension. I'm sure you can all see that exact same paternalism and condescension so patently at work in what I have explained of the Tribunal's behaviour. People in our daughter's situation suffer a civic death at their hands – they are able to be ignored when decisions are made about them. Whatever its intention (and God only knows *what* its intention is) the present set-up, including the very conduct of guardianship administrators themselves, re-emphasises the view that people with an intellectual disability are of no more consequence than the Tribunal's backyard fences. They are simply items about which decisions must be made.

And we also came to realise that we had become as inconsequential to any decisions made about our daughter as she was.

Some of the many, many problems we have experienced:

1. During a period of psychiatric difficulties for which our daughter was hospitalised while on holiday with us, she asked to leave the hospital. Even though the hospital knew that she had an intellectual disability, was having frequent daily seizures, was suffering a diagnosed psychosis, and was far from home, she was allowed to leave! We were not advised. That would not be done to someone with a legal guardian, or if it were there would be some legal recourse.
2. On two different occasions organisations have arranged to place our daughter in aged care facilities without asking either her or us. No one is required by law to consult with us. No one discussed the matter with our daughter because she was regarded as unable to evaluate the situation.
3. A new doctor altered our daughter's medication. She wasn't told. We were not advised. Our daughter ended up in hospital for ten days. The drug reaction was well known to us, to doctors familiar with her, and it was outlined in her medical history. We were not consulted because there is no legal requirement for that to be done.
4. Our daughter shattered her collarbone while having a seizure in the street. The ambulance people wound her arm around a few times and asked her if it hurt. She said it did, but not with the degree of urgency which they expected. They said she'd probably be right and sent her back to where she was living. The nurses at her

residence didn't check her and told her to just go to bed. Unable to undress herself she was taken, the next morning, to hospital and found to have multiple breaks. The doctor put her arm in a sling and sent her back to her residence in spite of the fact that he knew that she suffers multiple tonic-clonic seizures daily. She was told not to bump her shoulder at all or there could be permanent damage! No one spoke up for our daughter in this obviously dangerous situation and she was unable to explain the difficulties she would face. No one consulted us or advised us of the doctor's decision. Only after having belatedly heard of the accident from our daughter could we demand that she be treated appropriately. She was seven weeks in hospital.

The failure of those implementing the Guardianship Regulations to provide a legal endorsement of intellectually disabled people says very loudly that intellectually disabled people don't matter. And nor do their carers. Nothing that this Tribunal has done in their dealing with our family convinces me that they have any genuine, considered interest in people with intellectual disabilities. Their thoughtless, lazy, superficial, simplistic and unprofessional response to obviously complex guardianship issues holds out no hope for us that they would in any way be competent to deal with any of the many interesting proposals presented at this conference.

It remains for us a source of continued anger and bitterness that this Tribunal, which ought to have been for our family a source of support and encouragement, has actually been a hindrance to our daughter's welfare, and has simply been an added burden upon us.

Particularly after hearing at this conference about practices overseas, the conduct of this Tribunal here in our state is a source of embarrassment and shame.

Michael Dalton

Our experience in another setting

For the last eleven years of my father's life I acted as his Enduring Power of Attorney. He had developed an *age-related* intellectual disability, but in this case he and I both had a legal status. He had legally appointed me to act for him, and I had a legal document to say I could speak on his behalf if necessary. And what a difference that made compared to our experiences with our daughter.

No one *ever* acted behind my back in relation to decisions made about my father. No one sent him to aged care or anywhere else without first discussing it with me. He was afforded the legal respect of being able to nominate a person to act for him, and I was given the legal respect of being his official advocate.

Shouldn't I have the same legal right, and legal standing, in relation to my daughter? More importantly, shouldn't she have the same legal advantage as her grandfather had – a member of his family, who knew him well, who was able to speak on his behalf when necessary? The answer is yes. Absolutely yes!

What we need for our loved daughter is the same legal standing as was given to my father: that she is given the respect of being regarded as important enough to have someone who can legally speak and act on her behalf when necessary, and that the person she chooses, or who is appointed, has the legal authority to demand that they be involved in any decisions that seriously affect her.

The issue of guardianship for people with disabilities is a complex one, with a broad range of differing needs and situations to be accounted for. Our experience highlights the inadequacy of simplistic proposals, which are an insult to people with disabilities, and to their carers.

The proposed legislation authored by the Victorian Law Reform Commission, in recognising the complexity of the issue, presents proposals that we enthusiastically endorse. After listening to many parents the Law Reform Commission, in our view, got it right and we look forward to its full implementation.

Marianne Dalton