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28 MAR 2011

Submission No. 69



M Dalton

To: law.reform@lawreform.vic.gov.au

28/03/2011 10:09

Subject: guardianship - particularly for parents of disabled children

Dear Panel,

**Re: Guardianship consultation Paper 2011**

The paper has some interesting things in it, and if guardianship can be obtained without a crisis, but, rather because of a need due to impaired capacity, then life will be less fraught for many carers. However, it is with dismay that I find that there is no recommendation for a special tribunal, with experience and training in all aspects of the complexities around impaired capacity, and around caring for someone with impaired capacity. The explanation given by Neil was that " governments don't like paying for extra things ". Saying that to a group of parents with intellectually disabled children indicated he has not grasped the nub of our lives. We have lived witness to that statement everyday of our lives, as we fight and fight, to have our children's basic human rights recognized. In my opinion Government not wanting to do it is not a good reason for not lobbying for adequate services.

This group of parents face all the work of looking after someone with impaired capacity, try to provide quality of life experiences and holidays, as well as worry about future services for their child when they can no longer manage. Little help is available and when this loved child reaches 18 years an added burden of huge significance is that parents no longer have legal status. Nothing is proposed to give parents legal status automatically. I imagine a system where it is given as a right to that group of parents ( remembering their child has already satisfied the medical criteria in becoming " a disabled pensioner " ) and that right only being removed on a substantiated challenge to their performance as carers. **This is a very special group of people**

The other disappointment with the paper is there is not a mechanism suggested for the group of parents of children with intellectually disabled children who attempted to get legal status by applying for guardianship but instead were given administration orders, which they never wanted, required or asked for, to opt out of the system without their child's financial affairs going to the State Trustees. The scenario of needing legal status, but, getting accounting, demonstrates perfectly how badly this group of parents has been served by the current system, and how inadequately trained the VCAT representatives who have dealt with guardianship are. If the judgement responsibilities pass onto the Office of The Public Advocate ( OPA ) as suggested, I think there is real danger of a conflict of interest, as we see demonstrated with Department of Human Services where they are responsible for setting standards, funding, and service delivery. The OPA would then be responsible for advocating, educating and judging. The judging body should be independent. Please consider how to improve our situation, because in your paper there is little for us.

Marianne Dalton

31 MAR 2011

M Dalton

31/03/2011 23:34

Dear Emma,

The case of parents of intellectually disabled adult children does not seem to be understood by your panel. Hundreds of these parents "fly under the radar" is the common expression, which means they quietly go about their business without ever applying for anything in terms of guardianship. They hear about the onerous accounting, and the negative attitude towards parent carers from VCAT representatives, and that VCAT do not believe in giving guardianship anyway. If you went to large providers of day programs for intellectually disabled people, you would discover that most clients do not have an administrator appointed. This means that most parents do not have to answer to anyone.

Many of us who tried to get legal status in order to protect our child from unscrupulous agents, acting with an agenda other than the best interests of our child, are now in the situation of not having guardianship, but, administration, which we do not need as our children are more than happy to have mum and dad look after the bills etc., and in lots of cases supplement the pension to provide a decent quality of life. In our particular case we have lived in the same area all our married lives and the local bank teller (of similar age to our daughter) actually grew up three houses away and has a full understanding of our situation. We do not need any further piece of paper to have standing at the bank as our daughter's representative. We want to be free of the cost and hassle of administration and we certainly do not want State Trustees involved.

We were prepared to put up with the administration requirements in order to have guardianship. We wanted to have the right to act on our daughter's behalf. The suggestion that we need checking up on in case we are ripping our child off is unbelievably insulting. We have devoted over twenty years to caring for her full time. Do you understand that is over twenty years of films we did not see, over twenty years of friends we couldn't visit, over twenty years of very brief moments of time to ourselves and over twenty years of broken sleep every night. All resulting in complete exhaustion and in long term health effects,..... and VCAT need to see if we are doing the right things with the disability pension. You have no idea what that feels like. How could you? However, you are going to have to try to have a much deeper understanding of the situation of parents caring for adult children with intellectual disability if you are going to get these recommendations adequately address our

issues and help people in our situation. Our difficulty is that when our children turn eighteen we have no legal status to act on their behalf, but their need to have us act on their behalf has not changed. They unfortunately, have not at age eighteen, recovered.

Regards,  
Marianne Dalton

