

Submission to the Victorian Law Reform Commission, Guardianship & Administration Act Consultation, 9 March 2010, by Tony & Heather Tregale, Parents, Plenary Guardians & Administrators

Submission No. 11

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Background:

Our son, now 34, was born with autism, limited intellectual capacity, limited speech (now gone), and later developed mood swings.

We undertook an extensive program of behaviour management through information from the USA and Europe (before the internet) to do as much as we could to bring our son into our world. Our success was limited at that time because of the lack of technology, services and our being accepted by the few services available, as the state's medical review professional refused to diagnose our son as autistic. Yet he was later, by the Child and Adolescent Psychiatry Unit of the Austin Hospital – After he had missed-out on important services!

After many years of intensive behaviour management, and 24/7 care, we reluctantly decided we were getting no younger and may depart this world at any time. So we very reluctantly sought a group home for our son, who was 20 when he was offered a Department of Human Services (DHS/the department) supported accommodation group home in Preston.

Having been Community Visitors under the Guardianship & Administration Act for 6 years prior to X going into a group home, we were well aware of the questionable service level and quality being provided to residents by the DHS. But we considered we still had sufficient ability and capacity to question the service level and quality on behalf of our son.

In practice, we found the department extremely difficult when we demonstrated their service delivery failed to match that depicted in their well documented care policies, standards and values. The department was also reluctant to provide us with records being kept on our son, so we could more effectively evaluate the level and quality of care he was receiving. They claimed that as our son was an adult, we were not privileged to view his personal information without a guardianship order.

Given our son had/has no meaningful communications, and was unable by reason of his disability to make reasonable judgements in respect of all or any matters concerning his personal circumstances and/or estate, we saw Plenary (whole of life) Guardianship (continuing to be legal parents) as a very obvious necessity, given our son's ability was little more than that of a regular 2 year old child.

Well, the Administrative Appeals Tribunal refused to accept our views of our son's needs, and repeatedly rejected our application under Section 22(c) of the Guardianship & Administration Act.

Finally, after extensive legal support and a prolonged hearing at VCAT, we achieved a Plenary Guardianship Order and an Administration Order in 1997. Despite great difficulty at many VCAT renewal hearings, we have remained Plenary Guardians and Administrators to this date.

Our Concerns:

1. We are concerned that more emphasis is placed by VCAT on the person's need for a guardian, than on the suitability of the guardian/s. There is on-going scrutiny by VCAT of the person's need for a guardian, yet little on-going scrutiny of the guardian/s by VCAT.
2. The rights and role of the plenary guardian of an adult is frequently unclear, and their role is not fully accepted by the community and authorities. Yet parents of a child are not unclear of their role, and their role is accepted by all.
3. One of the major concerns of caring parents with an adult family member in a group home, is their family member's quality of life care. This is especially so where the family member has very limited intellectual capacity, as there is generally no one in their family members life more interested than they. The caring parents therefore need access to as many lifestyle monitoring parameters as possible.
4. Access to lifestyle monitoring parameters of their family member living in a group home is becoming more and more difficult, as more privacy powers are enacted. The latest restriction is the CAAS (CAPS) program.
5. Caring parents need easier access to Plenary Guardianship in order to better support, and to better monitor their family member's quality of life care. Getting Plenary Guardianship was a four year nightmare for us, even with legal support.
6. Service providers have little reason to be accountable for service level and quality, if only their staff read that of what their staff write about their residents. Without a guardian, advocate, caring parent, family, friends or an independent third person having the right to monitor service provision, there is little accountability.
7. It should be noted that Community Visitors, under Division 7 of the Disability Act 2006, are not obligated to speak with the residents of the group home they are inspecting.

In a group home where all or any of the residents have no meaningful communications, and are unable by reason of their disability to make reasonable judgements in respect of all or any matters concerning their personal circumstances and/or estate, Community Visitors cannot ascertain from them a meaningful interpretation of how they find the level and quality of the service they are receiving.

Therefore, without contacting the parents, families, friends or an independent third person following their visit to the group home, they get just the views of the service provider staff.

8. The "Person Responsible" legislation is quite confusing. The OPA and VCAT frequently use this to negate requests for guardianship, other than health. Whereas, the person responsible legislation relates only to health.

9. Forcing caring parents to have short term Limited Guardianship for special and specific purposes, just adds to the burden and stress caring parents already endure in having to fight bureaucratic and hand-out service provision for even basic services.
10. Those having the responsibility for the finances of a person deemed as "disabled", under the Disability Act 2006, and deemed as unable to manage their own finances, shouldn't be an "Official Administrator" under the Guardian & Administration Act. There is no protection of the finances of a person with a disability where they have an informal administrator.

Specific Questions from Terms of Reference:

6. We assume the question is focused on the degree of "Capacity" between "Normal IQ" and the IQ defining the person as disabled. Certainly there is a guardianship need to cover those in this slot who are a risk to themselves and others, and where a guardian would be advantageous.
7. Use of a Psychologist.
8. Yes!
9. It is difficult to legislate/define the need to take risks and make bad decisions. It must be left to the judgement of the guardian, as to what is in the persons "best interests v calculated risks".
10. To a reasonable extent only.
11. Yes!
12. The main two must be separated, as Administration is the most common. A range of power could make the situation even more complex that it is now.
13. Apart from Plenary Guardianship, orders need to have their decisions clearly defined.
14. No Comment.
15. No Comment.
16. No Comment.
17. Lots
18. The attitude of the OPA should be less despotic, dogmatic and bureaucratic. They need to have a much more customer service approach with far less cohesion with the DHS,
19. VCAT needs to ensure more consistency between its Deputy Presidents.
20. No Comment
21. Yes! People with limited capacity need transparency not privacy to expand their quality of life. There is far too much emphasis on Privacy for people who have little to be private about. They need to be "public" to expand their quality of life.
22. No! They are very self-explanatory.
23. No Comment.
- 24 -32. No Comment

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