

How do we decide the fate of another?

by John Chesterman

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MARY is an elderly woman with Alzheimer's disease and some other minor health problems. She lives alone and gets by with the help of the local council's "meals on wheels" and her neighbours. Her cognitive abilities are declining, and some mild delusional thoughts have led her to make occasional threatening outbursts. After an admission to hospital, Mary's doctor decides to make a guardianship application, taking the view that Mary is no longer able to look after herself or make significant decisions. With no close friends or relatives, the Public Advocate is appointed as Mary's guardian, removing Mary's right to decide where, and with whom, she lives.

Mary's guardian has to balance up several considerations in working out where Mary should live. Foremost among these are her wishes and wellbeing, two factors that ordinarily run together but, where cognitive decline is concerned, sometimes don't. Mary wants to stay in her own home with her dog, but her health is clearly deteriorating.

This scenario is an increasingly common one throughout Australia. If Mary is moved into an aged care facility, her guardian has overridden her wishes. If she is left at home, her guardian stands accused of neglecting her. Among the questions being considered by her guardian are some relatively new ones: is Mary having her human rights breached if she is placed in an aged care home against her wishes? Or, indeed, is she having her human rights breached if she is left at home and suffers as a result? Victoria's guardianship legislation, which is undergoing its first "root-and-branch" review, was enacted in 1986 and led the way in balancing the protection of people with disabilities with recognition of their rights. But some significant societal changes have overtaken it.

We now have an international Convention on the Rights of Persons with Disabilities, and Australia has just announced that it will sign the optional protocol, which will allow individuals to take their cases to Geneva. Together with Victoria's human rights charter and our equal opportunity legislation, this new legal terrain should be celebrated, as it provides improved protections for people with disabilities, and ensures that any steps encroaching on their freedoms are the least restrictive possible. The convention goes so far as to assert that people with disabilities have "legal capacity on an equal basis with others", and there is even some debate about whether guardianship itself can be reconciled with this provision (Australia argues that it can be).

In addition to these legal changes there have been two other significant developments since 1986 - one demographic and the other sociological - that shape the terrain in which guardianship decisions are made. When the guardianship legislation was enacted the most significant guardianship cases involved intellectually disabled Victorians who lived in institutions. Since then the process of deinstitutionalisation has disbanded most institutions, though the recent National Disability Strategy report shows that many people with disabilities are still shut out of mainstream society.

At the same time, there has been a sharp rise in the number of Victorians with dementia and acquired brain injuries. People in these two groups, who now constitute more than half of the Public Advocate's new guardianship clients, present different guardianship dilemmas to those presented by people with intellectual disabilities. People with dementia will often have fluctuating levels of cognitive capacity, making hard-and-fast determinations difficult.

Moreover, such people, such as those with acquired brain injuries, routinely had sound cognitive functioning before the onset of their illness. This presents new challenges in determining the preferences of such people, as much can be learned from the way they have lived their lives in the past and the choices they have made. Among the many questions for guardians is how consistent guardianship decisions should be with a person's earlier life and choices.

The other development is sociological. We are now more aware of risk, and are more risk averse, than at any time in our history. We may pride ourselves on our freedom, and we rhetorically accept that the freedom to choose how we live means putting up with the consequences of those choices.

That is fine when the person making the choice is the one who has to live with its consequences. It is much more problematic for someone under a guardianship order, when the decision is being made for them. But how should the risk associated with leaving Mary in her own home be weighed up against her wish to remain there? What level of risk to Mary is our society prepared to accommodate in respecting her wishes?

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