

3rd International Conference on Therapeutic Jurisprudence

7-9 June 2006, Perth, Western Australia

Session 8E

**TAKING CARE IN GUARDIANSHIP WORK: BUILDING ON DISABILITY
EXPERIENCE**

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Taking care in guardianship work: Building on disability experience.

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Paper, given at the 3^d International Conference on Therapeutic Jurisprudence, Perth, Western Australia, 7-9th June 2006

Guardianship-and-administration tribunals are bound to hold as paramount the best interests of people who commonly are among the most vulnerable and dependent among us. These are people that are not able to make reasonable decisions for themselves by reason of a disability. Guardianship tribunals often appoint as guardians and administrators citizens who freely give of themselves in roles of decision-makers and advocates. These citizens frequently do so for extended periods of time, often involving a close, positive relationship with the person they represent. The transforming power of such protective and enabling relationships upon the disabling effects of impairment is well documented. Using Joan Tronto's concept of 'care' I will reflect upon the nature and value of this potential in organisational functioning and structure of guardianship tribunals.

I like the quote on the Center for Therapeutic Justice's website, attributed to lawyer and philosopher Sir Francis Bacon. It states:

If we are to achieve results never before accomplished, we must employ methods never before attempted.

I like it because generally I believe that we are at another juncture in human history where we need different results, and a different methodology to achieve them. I think also, that by nature, the guardianship jurisdiction *is* such a new methodology, be it one that is subject to deflection from its purposes.

Bacon was of course one of the important architects of the Enlightenment, heralding a new way of thinking about the world, compared to the previous medieval age. Its ideas are dominant today, including our belief in material progress, reason, individualism and materialism.

But whereas the Enlightenment brought a boon to mankind in many ways it has also brought losses and burdens. In particular it brought a *change* in thinking about people who were poor, and about people who had intellectual or physical impairments or a mental illness.

For example, the Enlightenment heralded an end to hospices, up till then attached to Christian churches and monasteries. These hospices gave voluntary, unpaid hospitality and service to the poor, the dying, travellers and

those with impairments. Their service was given, not primarily because this was supposed to be “good” for these poor unfortunates, but because doing so was rendering direct service to the body of Jesus Christ (Wolfensberger, 1979). Serving people in need was a good thing, spiritually speaking, for the giver of the service. This was not for everyone. It is not easy to truly serve all kinds of needy people who are strangers. Of course, I do not want to pass over a mixed history into antiquity of cultures that killed their impaired infants, such as Roman, Greek and Spartan societies, as well as societies, that served and valued their impaired members. The medieval Christian hospices were an example of the latter.

Nowadays of course we only think about such services as being good for the receiver, the poor disabled unfortunate or what have you. This is a significant change in attitude, which came with the advent of organised, paid human services. From then on it was a job, one that did no longer require a personal calling.

Historical exclusion of people with disabilities

In other ways the values of the Enlightenment also brought about a further devalued position of people who have some kind of impairment. Their history of segregation and institutionalisation, of eugenics, and discrimination, is founded upon common human fears such as of imperfection, unpredictability, loss of reason, dependency, vulnerability and death. These fears are seen as embodied in people who have impairments of various sorts and it is our innate fear of contamination somehow with these afflictions that has resulted in the generally lowly status of people with disabilities in contemporary society. The culmination of that treatment was of course the elimination of some 240,000 people with disabilities in Nazi-Germany, which was prompted by publication of a book by a lawyer and a medical doctor, Binding and Hoche in 1920. The book was called “Life unworthy of life”. It is worth remembering that reason and state ideology can make truly horrific bedfellows.

Today, despite, and at times because of, a large disability service industry, the vulnerability of most people with disabilities remains high (see for instance Reinders, 2000; Sobsey, 1994; Wolfensberger, 1984; 1984a; 1987, 1990, 1992). This is because the dominant values of our age exclude them from full acceptance in society (Reinders, 2000). If you are not healthy, wealthy, and intelligent you cannot be a consumer and you may become an undesirable human by-product. It is why the state funds advocacy, complaint services and anti-discrimination commissions regularly conducts inquiries about atrocities in institutions, nursing homes, about questions of abuse and so forth.

The guardianship jurisdiction

It is in that context of devaluation and vulnerability of people with disabilities that guardianship legislation for so-called incompetent adults came about. Of course the purpose of guardianship jurisdictions for adults who do not have the ability to make reasonable decisions about their life or their estate, is to offer protection, and a degree of personal advancement.

Interestingly, guardianship jurisdiction is one of those initiatives that emerged during a brief period from the late 1980's to early 90's when there was a burst of social enlightenment about the needs of people with a disability. This period also saw implementation of disability rights and anti-discrimination legislation, a flowering of community-based approaches to disability services, and the emergence of the disability movement. The social position of people remains weak, additionally through developments in bioethics, re-institutionalisation in hostels, boarding houses and group homes. But some safeguards are now in danger of being weakened through their absorption into current bureaucratic and managerialist approaches to human service. And weak safeguards can indeed become a part of the problem, if even through a "dog-in-the-manger" phenomenon.

This weakening can occur in several ways, including through absorption by large one-stop-shop tribunals that combine a wide range of jurisdictions and functions. The more legalistic, adversarial and formal practices and language

will inevitably impact on the guardianship jurisdiction and eventually weaken or even drive out its opposite approach. The question of in whose interests such changes are made is relevant. Having said that I am not aware that in the Australian creation of such super tribunals it has ever been claimed these innovations *were* implemented in the best interests of the highly vulnerable people that guardianship tribunals serve.

Guardianship jurisdiction is not based on values that are socially dominant, which is another reason why the little guardianship boat itself is vulnerable in a sea of qualitatively different values. Guardianship for instance seeks to build on freely-given service to a cognitively impaired person, from their family or friends, when it appoints a guardian to decide about a suitable place of accommodation, access to services, perhaps to limit undesirable contact, or any other need. Or when it appoints aunt Mary or brother Jack to manage their financial affairs, in the best interests of the most vulnerable party *only*.

The Western Australian guardianship legislation *requires* advocacy by the guardian on behalf of what it calls the represented person. And the tribunal must have regard to the desirability of preserving existing relationships that the represented person has. A close personal relationship is a requirement even in making appointments. It balances these communal values with regard for the autonomy of the represented person as far as possible.

A close personal relationship is an important safeguard but others are important too because people do have all kinds of conflicts of interest, that may not necessarily be apparent at time of appointment. I'll expand on this below.

So, guardianship legislation builds on that ancient, freely given, sense of wanting to be of service to another, despite any personal costs of doing so. This contrasts with the modern values of individualistic materialism. Guardianship legislation and practice emphasises being in relationship with others as a good rather than looking out for number one. It regards the

individual in relationship. These are post-Baconian, post-Enlightenment values with a new methodology, for different results.

Commonly tribunal members will hear from appointed guardians and administrators that what they are doing is “not a big deal”. It’s what that person would equally have done for them, or there is a sense of obligation to the vulnerable family member or friend, which goes beyond conditional assistance.

Good guardianship law brings out the best of what is in all of us. What am I referring to exactly? Well, for example, when my daughter was four years old she observed me getting a handtowel off the towel rack in the bathroom, wheel over to the sink with towel on my lap, dry my hands, wheel back to the towel rack and put the towel back. “Daddy”, she said, “why cannot I do this for you?” “Well, if I can do a simple thing like that for myself I like to do that by myself”, I said. “But, I *want* to do that”, she said. As many of you here will know, the powers of a four-year old daughter are much greater than that of her dad could ever hope to be, so I gave in, gracefully. Good for her! Because this is the attitude that will be a lifeline to her in a world where too often people bounce off each other as unrelated atoms in a chaotic universe.

It is this communal sense of wellbeing through voluntary assistance to others, that guardianship taps into and which it can use to safeguard its own quality of practice. Guardianship not just because it is good for *them*, but also because its proper practice is good for *us*!

Guardianship jurisdiction is a mix between being a human service, a facilitator to bring about personal support and of doing advocacy for another in need. And it is a tribunal where decisions are made to resolve a gap in someone’s needs, upon someone’s application. It is entirely coherent therefore to expect a wide range of active expertise and experience on a guardianship tribunal, one well briefed in the social position of people with impairments, and able to communicate with represented persons, their families and others in informal or in more formal ways where required.

I have been a member of the local guardianship jurisdiction for almost 14 years. When I sit behind that big table at the Tribunal, physically separated from the proposed represented person and their family and friends I don't just sit there as merely a technical practitioner of the law. No-one does of course. Everyone brings themselves along.

In my case I very obviously *also* sit there as someone with direct experience of significant physical impairment and of disabling practices. This is important to recognise. I am connected with the represented person and their family sitting across the table through shared experience of public attitudes towards disability. I also feel that connection through our shared experience of the disability- and other service systems and our shared experience of professionals' attitudes. I feel this when I sit at that table facing a director of nursing of a specialist nursing home that annually sends me invitations to use that facility for respite care. The same facility where I once stayed for six weeks and was distressed by the dignity that was taken away from its residents in many ways, leading me to decide to stay out of such places at all costs.

In some ways I share the experience of humiliation in many people that come before me. When professionals treat them as a case in a care factory rather than as a human being. Like the leading spinal surgeon's foot that once pointed at my body, when lying on the floor in the rehabilitation hospital's spinal gym, and said facing his gaggle of students that accompanied him: "and this is a C5/6", referring to the location of my spinal injury, without acknowledging a person lying there.

I share their feelings of frustration when their advocacy, and that of their friends, for humane treatment, is dismissed as that of, or for, a difficult patient, or is regarded as no more than a part of their pathology.

Whereas commonly there is an *a priori* social belief in the goodness of human services, I know, with them, that this is not necessarily so. Of course I also

draw on other knowledge. On my academic knowledge of the human service system, of disability advocacy, and on that of the law, but I also share *their* experience—representing another kind of knowledge. Now, I am not telling you this to wear my disability on my sleeve or to say that *only* people with experience of disability can be decent tribunal members. Of course that's not so. No, I tell you this to illustrate my belief that any guardianship jurisdiction should be more than a tribunal, a facilitator or just another human service.

I think it *can* be more, and keep on track, by taking the disability experience of interdependence as a practical guide. Using this may safeguard tribunals from some of the inevitable forces that afflict, over time, all human service organisations. I stress the universality of these influences and do not imply that guardianship tribunals are a special case.

These, often unconsciously experienced forces, include bureaucratisation in response to increasing complexity; distantiating from the people they aim to serve; deflection from their original mission; and loss of awareness of the nature of needs to be served (for example, see Wolfensberger, 1989).

Part of the mixed world in which tribunals also are located involves their exposure to managerialism, ubiquitously present in Australian public services, according to Michael Pusey's research (Pusey, 1989). Managerialism is about the belief that managing a disability services is essentially no different to managing a fisheries department, or any other enterprise. Managerialism places priority on countable outcomes over process. It fits with the belief of human service as a business model, and of constant managed change. There are no reasons to think that this situation has changed for the better since Pusey's study.

There are other, associated forces that impact upon guardianship work. These include the losses of social cohesion and trust in public institutions in general. Specific to guardianship we might also say that an overly legalistic approach is another of these forces.

Managing and minimising these forces to keep on track will well serve the primary clientele of guardianship jurisdictions. I propose an approach by which to do that, which is really no more or less than to use the essence of guardianship; committed relationship.

Relationship, interdependence and care

I coined the term disability experience of interdependence after researching the attitudes of people with disabilities, mainly quadriplegia, towards euthanasia. But I am by no means the first to identify the acknowledgment of our interdependence as a source of wellbeing. There is a sizeable and growing body of literature that shows that, contrary to popular belief, the experience of disability can involve a sense of life satisfaction that is equal to, or even greater than that of the average Josephine (see for example Dijkers, 1999, Bach & McDaniel, 1993; Crewe, 1996; Keaney & Glueckauf, 1993 and many other citations in Leipoldt, 2006). (1994. This was found to be true even in circumstances of ventilator-assisted people with quadriplegia (Bach & Tilton, 1994) and also applies to family carers of people with significant intellectual disability. This is not to deny that life with a disability is not often very difficult, full of frustrations and negative attitudes towards one. There can be however a good life satisfaction, a sense of a rewarding experience nevertheless and of meaning, under circumstances of positive, mutually rewarding relationships.

The disability experience of interdependence is one where one *may* learn to live well with dependency, vulnerability, limitation and unpredictability. As participants in my study told me in different ways, they did not feel dependent when even intimate tasks were done for them by people with whom they had a good, positive relationship.

“Loss of dignity” is a label that pops up in most people’s minds when they consider that some people, perhaps even themselves one day, need help with the private tasks of toileting, dressing, assistance with eating and so on. But for the people that I interviewed this was no longer an issue. They had

transcended that fear. It had little or nothing to do with being accorded disability rights of some sort, be it rights to complain or for protection of discrimination. And indeed even with dying people research has shown that so-called “dying with dignity” is something that depends on social support, competent attention to their illness-related concerns and the ways one looks at ones own situation. These dimensions of dignity are relevant also to the disability experience of interdependence.

Achieving such dignity or transcendence of fears about the human condition, as these are magnified in the disability experience, takes hard work. Good, mutually supportive relationships are not a given. They require a raft of virtues: such as reaching out to others; generosity; assertiveness; graciousness; planning ahead; a sense of humour; social, rather than individualistic autonomy; letting go of those things we cannot control; and a focus on “what life is all about”, which is, circularly enough, good relationships. This is the picture of what constitutes a good life experience under challenging circumstances of an ongoing nature. *And* it is one that is applicable to anyone, disabled or not.

It should also be said that conversely, a low life satisfaction and high vulnerability go hand in hand with an absence of good supportive relationships.

If this is all part of a core disability experience than guardianship jurisdictions are doing much good where they value, facilitate and support a focus on the individuals needs within rewarding relationships. One could say that this is supporting the primary relationship between represented person and guardian or administrator. I suggest going beyond that primary relationship in applying what works well at that level to the structure, management and daily practice of guardianship tribunals.

After all, a well-functioning organisation has a good level of coherence with the needs of its focal people, its organisational primary relationship. Any successful business, models itself according to a focus on its customers

needs because meeting the customers' needs is a recipe for economic success. Not necessarily so in the human service area, including guardianship jurisdictions, where the latter often exist within larger bureaucracies that adopt a business model but where even the crude breadline rationale for meeting the needs of usually poor, devalued people does not exist. Consequently, for example, where its building is located may perhaps be driven less so by the needs of the "proposed represented persons' than by imperatives of being located in close proximity to courts where some of the tribunal 's appointees may have regular business, or by being co-located with many other tribunals of widely divergent natures.

A framework of care

I suggest that Joan Tronto's (1995) framework of "care" is applied to guardianship jurisdictions, in order to at least soften the effects of such, and other influences upon the quality of its work. The *practice* of care is known to anyone and a healthy development of personal autonomy depends on having been cared for properly in one's life. In Tronto's words, "it includes everything that we do to maintain and repair our world so that we can live in it as well as possible."

She emphasises the imperative for organisational coherence with the needs of its clients in putting it that judgments about [the process of] care arise out of the real lived experiences of people..." and that "from this standpoint we must reformulate our account of human nature, of what activities count as centrally human, and our values, *rethinking what we expect from our institutions*" (emphasis is mine, EL). Her framework of care recognises the person in community, like the disability experience of interdependence does. It is in effect a non-paternalistic policy framework of care that enables dignity and life satisfaction even under gravely adverse circumstances.

In Joan Tronto 's (1995) framework of care, firstly proper attention has to be paid to needs, secondly, responsibility must be taken for meeting them, thirdly the approach must be competent, and fourth there should be responsiveness

to those receiving the service. Commonsense? Yes. But how often is care really conducted in this way?

She identifies the caring processes as “caring about”; “taking care of”; “care giving”; and “care receiving”. In other words true care requires consciousness of what it is that needs to be done, who for and why—involving a consciousness of personal and social values. It is of course difficult to conceive how this might work well without taking account of the central role of mutual human relationships. Consciousness of values and due care then are keys to flourishing personal lives as they are to the proper organisation of a guardianship tribunal or to a truly civil and sustainable world.

Here I can only touch on what application of such a framework to guardianship might practically mean. As Tronto (1995) proposes, the framework of care is more about creating a *climate for good political judgment* rather than being prescriptive. Its specific applications depend on the setting to which it is applied, including regard for cultural differences. The framework of care applied to therapeutic justice and guardianship work really deserves in-depth exploration. I merely propose some examples here.

So here are some suggestions under Tronto’s four headings:

Attention has to be paid to needs

- The focus ought to be wholly on the needs of the vulnerable clientele of the guardianship jurisdiction. Whose needs are central is the first question to ask;
- This will have implications for decisions such as having a stand-alone guardianship tribunal or one which is embedded with other jurisdictions, the structure of the organisation and attention to any conflicts of interest;
- Client needs must be clearly identified and understood at all levels of the organisation, involving for example tribunal member and staff orientation, induction, education and training;

- Tribunal members must be drawn from a variety of backgrounds and cultures and include and encourage active participation of people with direct experience of heightened vulnerability. Parents and family members of people with disabilities and people with disabilities themselves are such people;
- Where the hearings are located is important, as is the disability access of the building, means of communication and so on. The greatest possible informality is important for ease of access to tribunal processes.

Responsibility must be taken for meeting these needs

- Tribunals should be explicit in public statements of the needs of their clientele and the responsibilities that therefore fall within the tribunal's jurisdiction for meeting them;
- Processes by which this responsibility is put into practice should be clear and publicly available;
- The potency and quality of advocacy conducted by appointed administrators and guardians is often crucial to meeting represented persons' needs. At the same time, many individuals lack advocacy skills and many advocacy agencies lack potency for various reasons. Public Guardian Offices fulfil an important role but cannot fully meet this need either. A tapestry woven from multiple, strong advocacy approaches ranging from one-to-one Citizen Advocacy to independent systemic advocacy would be in the interests of vulnerable people with disability. Therefore avenues for the development of advocacy should be actively encouraged and supported by guardianship tribunals but cannot be conducted by themselves for obvious reasons of conflicts of interest.

Approach must be competent

- Obviously induction, ongoing orientation to the needs and social position of the highly vulnerable parties served, about changing human service

contexts, and education and training in legal, administrative and procedural matters are highly relevant;

- In guardianship supportive relationships can be strengthened by a tribunal order. The tribunal can support them through carefully and clearly structured orders, and regular monitoring and review processes should meet their objectives of accountability to the represented person;

Responsiveness to those receiving the service

- Their needs ought to be explicitly acknowledged in deed and word. I reverse this common saying here because human service organisations are almost universally very good in *telling* others about their aims but are less adept in *actually* meeting them;
- Recruitment of tribunal members and staff could take into account a sense of personal calling and commitment to be engaged in guardianship work;
- Avenues for ongoing feedback about processes and outcomes should be available, without of course intruding on the legal avenues of review and appeal;
- There should be an open and positive attitude to dealing with complaints as inherently good for the quality of applied care;
- Independent reviews of the operation of the guardianship jurisdiction where the voices of the represented person and their guardians and administrators can be heard are essential and their results should be publicly available;
- The value of the freely-given nature of the supportive relationship entered into by guardians and administrators should be expressly acknowledged in practice and word.

Of course, at any of these four stages communication with the relevant parties should be clear and responsive, and as Tronto (1995) emphasises the four stages are interactive and not presented in a chronological sequence. So examples of actions under these four headings could in effect appear under more than one of them. I stress that the above are some examples only. Much

more could be done through using the framework of care. The first step is willingness to adopt a culture of care.

Since the greatest functionality of organisations occurs when their beliefs, values, and organisational structure are coherent with truly meeting the needs of their clients, internal processes should also reflect the framework of care. Organisational modelling of the values used in guardianship legislation goes some way towards reflecting this framework in daily practice. Obviously a super tribunal that combines guardianship with other jurisdictions that are of a more legalistic and adversarial nature involving dispute resolution and mediation between parties of roughly equal power and competence will find this more difficult to do. In fact it would be easy, almost natural, for these values to drive out those of guardianship work. It is probably a matter for consciously deciding which values will form the organisational culture in any super tribunal. It would take strong leadership to assert the values of care, relationship and interdependence in a wider culture that embraces conflicting values.

I conclude by returning to Bacon's words

If we are to achieve results never before accomplished, we must employ methods never before attempted.

It all depends on us *wanting* to achieve different results and knowing what these might be. The etymological roots of "therapeutic" include serving, caring and healing. That of justice include "equity" and a "vindication of that what is right or true". The marriage of the two in the term "therapeutic justice " could be happy and long-lived by reference to the practice of care, founded upon the human condition of interdependence. Its transformative powers may hold great promise for the wellbeing of vulnerable people, as of our own, and of exemplary service by guardianship jurisdictions. A civil society depends upon it.

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