

## **Ideas that shape adult guardianship**

*Barbara Carter*

*OPA 25-year symposium*

*29 July 2011.*

### **Introduction**

I am honoured to be invited to speak to you and I hope that you will forgive me for starting with a Biblical text if what follows does not sound like a sermon. As we are celebrating OPA's 25-year anniversary today, I have used the King James translation out of respect for its 400-year anniversary!

*Where there is no vision, the people perish but happy is he who keeps the law.*

*Proverbs 29:18.*

This passage provides an apt framework for reflecting on guardianship. We need to draw upon the breadth of human thinking to develop not just the vision for guardianship but also the law. Without the vision, we become narrow instrumentalists, without the law we have chaos.

The understandings and philosophical ideas that shape modern guardianship go deep into human history and experience. We can clearly see the origins of guardianship thinking in most religions and in Greek and Stoic philosophy. The ideas of the European Enlightenment still form the basis of most of our legal, political and social systems, including guardianship. Today, we see the importance given to ideas of personhood, human rights and justice when we struggle for a vision of guardianship that will shape the next 25 years.

The ideas of each era or generation are rarely new. They generally build on what has gone before and offer a different angle or insight. But we cannot take a concept out of the historical context in which it was developed and simply transplant it into our own situation. That is fundamentalism

with all its associated dangers. Instead, concepts must be reconsidered and re-evaluated for their relevance to the world we are living in.

One final word before we get started: we all like to have clarity and coherence. Therefore, it is very tempting to talk in terms of paradigm shifts and seek to replace one coherent way of looking at an issue with another. I'm not sure that is possible or even desirable in guardianship and we really need to learn to live with ambiguity.

### **Humans are interdependent social beings**

The first idea I would like to look at is the understanding that humans are interdependent social beings and what this means for guardianship.

There are many animals that live in groups or families but humans are particularly social in that we use systems of communication for self-expression and the exchange of ideas. Most of you know that the OPA Red Diamond is a nautical communication flag:

“I am disabled: communicate with me”

We are also dependent on others from the time we enter the world. As the Dalai Lama has said:

*We humans are social beings. We come into the world as the result of others' actions. We survive here in dependence on others. Whether we like it or not, there is hardly a moment of our lives when we do not benefit from others' activities.*

Our political and legal systems are based upon this. They recognise the responsibilities we bear towards each other. For a very long time, the State has accepted an extra level of responsibility for adults who are unable to care for themselves.

Guardianship is one important way in which the State meets these responsibilities. Over the years, the principles guiding how the State does this have changed, from a purely protective approach towards people with disabilities to one that is based more on the idea of all people being full citizens with all the associated privileges and responsibilities.<sup>1</sup>

## **Reciprocity**

If humans are interdependent and accept responsibilities towards each other, the principles and ethics that guide this relationship are obviously important. The ethic of reciprocity, often referred to as the Golden Rule is present in the principles of nearly every religion and in the philosophies of most ancient civilisations.

It is a universal maxim that:

*One should behave towards and treat others as one would like others to treat oneself*

The key element is that a person living by this rule will treat all people, not just members of their own family or group, not just those they like or those they know, with respect and consideration.

Adult guardianship provides a framework for both family members and the State, where necessary, to exercise responsibility for a person with a disability and to promote their interests. The principles, ethics and responsibilities remain the same whether the guardian is a family member or a delegate of the Public Advocate.

---

<sup>1</sup> Australia is rather unusual in giving full citizenship rights, including the right to vote, to people with disabilities. It is an issue in the USA where courts in some States routinely remove the right to vote of a person with a disability through guardianship orders. In Europe, the Venice Commission (a think tank of senior jurists) has proposed that a judge should be able to remove the right to vote of a person with a disability if that person “lacks proper judgment”. This is being strongly opposed by MDAC and other disability groups at present. By contrast, the right to vote for people with disabilities is uncontroversial in Australia.

As an example of this, I recall an investigation we did into an application for guardianship for a man who was a partial quadriplegic and had brain damage as the result of a car accident. He wanted to go to China for controversial stem cell therapy that was opposed by doctors in Australia. He was supported by his family who proposed to take him and also contribute most of the cost. At the end of the hearing, the Tribunal member appointed his brother as his guardian. The Member explained to the brother sensitively but firmly that he was being appointed to make decisions for his brother, not only as a family member but on behalf of the whole community and that society is concerned about and responsible for the well-being of his brother. A review hearing was set down for six months later when the anticipated treatment would be concluded.

### **Flourishing and gardening**

This leads us on to the question of why we think all should be treated in accordance with the Golden rule. This is where the concept of human flourishing is important. The idea of human flourishing can be traced to Greek philosophy, and to the thinking of Aristotle who described it as “*living well and doing well*”. Essential elements for flourishing are having one’s material needs met, having good relationships, being fulfilled and contributing to the society.

We do not tend to talk much about flourishing when we reflect on guardianship but we do talk about well-being, which is very close in meaning. I like the term flourishing because the horticultural allusion enables us to think of a guardian as being like a gardener.

Guardianship is about working in the way that will best enable the represented person to grow and flourish. In order to grow and flourish, the environment must be stable and healthy. We must be in a situation that suits us, respects our particular

characteristics and meets our needs. Much of a guardian's work is about trying to clear away the impediments to a person's growth and flourishing and help them reach a stage where they do not need the intensive support of a guardian any longer.

Very often, guardianship is about protecting a powerless person from violence, sexual abuse or exploitation, which are very significant impediments to flourishing. Sometimes, it is about ensuring that a person living with a family member has the opportunity to go out and be part of the community or maintain their relationships with other members of their family as well as the one with whom they are living. Guardians often comment that the greatest challenges of their work arise, not from their client, but from others in their clients' lives.

### **Rationality and autonomy**

I would now like to turn to some of the thinking that emerged during the Enlightenment period of the 18<sup>th</sup> Century in Europe and, in particular, to the ideas of rationality and personal autonomy that are key elements of Enlightenment thinking.

The basic idea of rationality and reason is that humans develop and become "mature" through the use of their reason. People should seek knowledge and use their own reason rather than being told how to think by others. Traditionally, before the 18<sup>th</sup> century, kings, emperors and the church maintained strict control over the populace, to the extent of controlling not only what people did but also what they thought and believed. Philosophers such as Immanuel Kant argued that humanity must abandon a life of unreason, of relying on superstition, faith, and blind obedience. Instead, we must order our lives according to reason because reason is the key to a "good life".

The link between rationality and autonomy is freedom. Given the freedom to do so, you are able to think rationally for yourself and thereby achieve autonomy or self-determination. This concept of human autonomy changes the relationship

between individuals and the state and raises the question of how much power the State should have over individuals' lives. Today, it is at the heart of many of the debates about disability and guardianship, including the much-discussed Article 12 of the United Nations Convention on the Rights of Persons with Disabilities.

Modern adult guardianship is firmly grounded in these ideas of rationality and autonomy. Guardianship laws are, traditionally, framed around the deficits of reason in the person and seek to remedy those deficits through the appointment of a substitute who will make decisions that need to be made so the person can fit into society. The majority of substitute decision-making regimes and even supported decision-making assume and even favour a purely rational approach to the task. We can see this most clearly in the accepted medical consent principles with which we are all familiar.

A most unfortunate consequence of placing reason at the apex of what it is to be human, is a tendency to place people with cognitive disabilities at a lower level simply because they have an impairment in their reasoning capacity. We are only just beginning to catch on to the fact that people make decisions and set the direction of their lives based as much on their identity, values and emotions as on reason. This is a newly emerging area of thinking and research being developed by philosophers and psychologists and presents a challenge to guardianship, as well as to law, medicine and bioethics.

## **Universality**

Another aspect of Enlightenment thinking relevant to guardianship is universality. The idea is that humans are equal by nature and are part of a "universal community". This perspective suggests that guardianship should be directed towards ensuring that people with disabilities are accepted as a part of that "universal community". In practice, this means that guardianship needs to go well beyond compensating for the

deficits of the person and must make a positive contribution to the person's social and personal well-being and their role in society so that they can take their place as members of the universal community.

## **Personhood**

It may be because of the ways some have tried to apply the Enlightenment Model (as it is now sometimes referred to) to the 21<sup>st</sup> century that greater attention is now being paid to ideas about *Personhood*. Ideas about personhood broaden the idea of what it is to be human. I do not want to enter the complex debates that surround this concept and can take us into the realms of whether animals, foetuses or people in a persistent vegetative state are persons. Instead, I want to concentrate on what is generally agreed. It is generally agreed:

- that once humans are born they are persons,
- that being a person generally involves some consciousness of self and awareness of oneself as an individual,
- that persons are sustained and shaped through relationship with others,
- that persons seek meaning in their lives, and
- that a person is an embodied creature, not just a mind enclosed in a mobile delivery mechanism.

Ideas of personhood are beginning to influence the thinking about guardianship internationally. The Convention on the Rights of Persons with Disabilities states that people with disability are equal persons before the law and have the right to recognition everywhere as persons before the law.

Ideas of personhood are also beginning to enter the legal debates around capacity that some are beginning to find somewhat arid and circular.

I remember vividly a situation where Mary, an intellectually disabled woman, was found to be the only match amongst her

large family for her sister who had leukaemia and needed a bone marrow donor. She had travelled from Ireland to be the donor for her sister but because this was a special procedure, the consent of VCAT was required. Mary understood the basics of the procedure and was very proud and happy to be the one who could help her sister. Her personhood was sustained and shaped by her relationships with her family and she knew that this was a very important thing she, and only she, could do for her sister. She also had no doubt that this was the right thing to do. Notions of legal capacity based on rational understanding seemed almost foreign in that hospital meeting room where Mary's personhood shone clear and bright and certain.

I suggest that we see respect for personhood in our current legislation when we recognise guardianship as a relationship between two people, when we act in accordance with the represented person's wishes wherever possible, where we foster their positive relationships with others, act as their advocate and promote their full participation in the life of the community. I would suggest that we fall short of this when we see a guardian as purely concerned with making rational substitute decisions for another person and forget about everyone's driving need to find meaning in life.

## **Human dignity and human rights**

Concepts of human dignity and human rights are central to guardianship.

There are two important elements to the concept of **human dignity**. The first is the idea of inherent dignity: that people have dignity by virtue of being human. The second is that dignity is interdependent and dialogical. It is something you impart to others and they impart to you. Human dignity accommodates the idea of protection and safety that is traditionally the basis of guardianship. Few would consider a society characterised by danger and insecurity as a "good"

society. We all accept limitations on our liberty in order to live a safe and dignified life.

One of the ways of expressing the concept of human dignity is through the construct of **human rights**. Guardianship is increasingly being seen as a human rights issue. The outstanding work of the Mental Disability Advocacy Council, based in Budapest, has highlighted the abuse of the human rights of many people with disabilities through the guardianship and is making progress in fundamental guardianship reforms in Eastern Europe.

The idea of human rights is closely associated with the idea of personal freedom in Western society and we see this very clearly in our guardianship systems. We see guardianship as a last resort, put into place when “there is no alternative less restrictive of the person’s freedom of action and decision”. The emphasis in guardianship law is still on civil and political rights and it is extremely difficult to get social, economic and cultural rights onto the agenda. Therefore, legal guardianship tends to be characterised as a limitation of human rights (and by some as antithetical to human rights) whereas the right to safety and protection is also a fundamental right. In human rights terms, guardianship should be seen as rights protecting and rights affirming.

My worry is that attempting to recast guardianship in a human rights framework and win the debate about the equal importance of all human rights is not going to succeed in our lifetimes and will leave us all exhausted. In addition, human rights can be such a dominating way of thinking and is framed in such powerful language that it tends to sweep aside more subtle ways of looking at guardianship. It can set us on the rather lonely path of individual entitlement where we pay insufficient attention to the crucial issues of care, co-operation and social inclusion. These are essential to a good guardianship system and

good guardianship practice but they are not generally recognised as human rights.

## **Individuality and Individualism**

It is now time to explore the associated ideas of individuality and individualism. The importance of each person as an individual is basic to our history of political, social and economic thinking and liberal democratic principles that emphasise individuality are at the heart of our political and legal systems.

Respect for each person as an individual has also been an underpinning idea for deinstitutionalisation and modern guardianship in Australia. As an example, those of us working in this area over the years have been privileged and delighted to see the blossoming of many people who move out of institutions into homes where their individuality is respected and they have greater opportunity to decide how they want to spend their time and live their lives.

Individualism is the dark side of individuality. It is associated with the emergence of neo-liberalism in the late 20<sup>th</sup> century as a dominant force in public policy. Individualism seeks freedom from restrictions on individual autonomy, and emphasises the importance of personal choice and the pursuit of affluence and independence. Such philosophies tend to confer greatest benefit on those able to cope with and exploit rapid change in society. This is not usually people with cognitive disabilities.

I would also suggest that we need to guard against “responsibilisation” where people are expected to take individual responsibility for matters over which they have no real control, absolving government and powerful instrumentalities of liability and responsibility. Thus, the solution to a social problem may be sought by the appointment of a guardian for the individual rather than addressing a

widespread societal problem. This attitude is reflected in Margaret Thatcher's memorable quote: "There is no such thing as society: there are individual men and women and there are families".

The challenge for guardianship is to create frameworks and practices that foster autonomy and individual respect for people with disabilities whilst avoiding pushing people onto the rocks of alienation and isolation that is also a feature of our society. The painting on the front of OPA's short history of a sailing ship on a stormy sea is a reminder to us that we are all in this together.

## **Justice**

The last idea I wish to talk about is the idea of justice. One of the things most people agree on is that we want to live in a fair and just society. It gets a little sticky when we try to unpack this by working out what a just society would look like and what is a fair distribution of society's resources and supports.

In modern times, John Rawls, in his key work, *Theory of Justice*, argued that decisions about the justice and morality of an issue should be made from behind an imagined Veil of Ignorance. Rawls asks you to imagine that societal roles are going to be completely re-fashioned and the resources of society redistributed, and that from behind the *veil of ignorance*, you do not know what role you will be given in society. Only then can you truly consider the morality and fairness of an issue.

For Amartya Sen, a Nobel prize-winning economist, a just society is one in which people have the capability to choose and construct good lives. To do this, they must have a broad set of "capabilities" which he defines as "the power to do something". His writings examine how justice ties in with power, citizenship and democracy.

Another key intellectual, Martha Nussbaum, has paid particular attention to the question of justice and disability. She is a philosopher and lawyer who begins from the idea that human beings cooperate with each other from motives that include moral compassion and a love of justice. In her capabilities approach to justice, she identifies 10 minimum capabilities (or entitlements) that should be available to all people. The first three are:

1. Being able to live to the end of a human life of normal length.
2. Being able to have good health, be adequately nourished and have adequate shelter
3. Being able to move freely from place to place, to be secure against violent assault, have opportunities for sexual satisfaction and choice in matters of reproduction.

For people with disabilities, she suggests that guardianship can play an important part in helping people achieve these capabilities. Thus guardianship becomes a positive, enabling instrument rather than a restriction on liberty.

## **Conclusion**

What can we take from all of this? We have well-established understandings about how people should live together based on our human experience as interdependent social beings, the ethic of reciprocity and respect for each person's individuality. We are greatly influenced by Enlightenment thinking in the prominence we give to rationality and universality but we are starting to wonder whether rationality should really be the keystone of guardianship. More recently, ideas about human rights and ideas about the just society seem to jostle each other for pride of place in our vision for guardianship.

David Green, Victoria's second Public Advocate, once reflected:

*“We have scaled great heights in the pursuit of freedom and autonomy and can now realise freedom of choice to a level never before imagined. But at the same time as our differences are so readily accepted, tolerated and (in a post-modern sense) even extolled, we are confronted with decisions which in the legal and ethical sense require agreement about universal truths and values. This level of shared understanding often appears to be beyond us. The celebration of difference has been at the cost of the truths which bind us and give coherence and trust to our society”<sup>2</sup>.*

David has a way of going to the core or what is important in any issue and I suggest that it is time for us to pay more attention to the truths and understandings about guardianship that bind us together. For the things we pay attention to grow and flourish: those we neglect wither and die.

### **My vision for guardianship.**

So what might our vision for guardianship look like? John Chesterman has most unwisely encouraged me to indulge in a little blue sky thinking to finish but remember these are my personal ideas, so please don't blame OPA.

We have a long-standing commitment in Australia to people with disabilities being able to live their lives as full, involved members of the community. However, the legal, financial, government, community and support systems for people with disabilities are complex and fragmented. In the guardianship and advocacy area there is a strongly held commitment to least restrictive, last resort interventions into the lives of people with disabilities “Get in, fix it, get out”. In other words, we add to this fragmentation in the name of protecting people's rights. A great deal of energy goes into demarcation disputes: we spend a lot of time saying what we don't do as guardians or advocates and various services spend an equal amount of energy saying

---

<sup>2</sup> Green, David: “Ethical decision-making” Address given to Borderlands, Camberwell. 1998.

why a particular person does not meet the criteria for their service. (Having said that, I am sure everyone here could recount times when they have stepped over the bounds of their role to help someone out when there was nobody else available to do so).

I think we could set up support that cuts across all this, is available and accessible and assists people with disabilities to negotiate the world. We could call these people advocates or we could adopt the term Personal Ombudsman, depending on whether you like tradition or something a bit catchy. I envisage the role as having several levels and it would be managed by and accountable to the Public Advocate.

A person with a disability could ask for a personal ombudsman or advocate to assist in some area of their life or the appointment could be made at the request of another person as long as the person with a disability was agreeable. There would be elements of advocacy and case management involved and in some sense it may become an “enhanced case management” position. If there were issues where additional authority was needed, (what we now call guardianship) this would be decided upon after an application to VCAT. The position would remain that of advocate or Personal Ombudsman but with additional authority. There should also be a category of actions or decisions that VCAT must endorse, for example special procedures, a decision that a person lives in secure accommodation, the enforcement of decisions and so on.

I think that such a system for the representation of people with disabilities would go much further towards respecting the person’s humanity, promoting their human dignity and rights and allowing them to live their lives as full, involved members of the community. People would seek the appointment of an advocate and not be turned away as they frequently are now. There would be more advocates and fewer case managers and case management would be independent of service provision.

There would be much less likelihood of stigma associated with having an advocate just as there is no stigma in having a lawyer or an accountant to represent you in an area you are unfamiliar with. Such a system would place advocacy at the front and centre of the vision and the law.

To conclude: in this overview I have tried to identify some of the main strands of philosophical thinking that weave the fabric of guardianship, not just here but across the world and hope that my little frolic into looking at guardianship differently may stimulate your own ideas.

So, in the end, we return to where we began:

*Where there is no vision the people perish, but happy is he who keeps the law.*

---