2623

SECOND WORLD CONGRESS ON ADULT GUARDIANSHIP

MELBOURNE, AUSTRALIA
15 OCTOBER 2012

ADULT GUARDIANSHIP: LAW, AUTONOMY AND SEXUALITY

The Honourable Michael Kirby AC CMG

SECOND WORLD CONGRESS ON ADULT GUARDIANSHIP

MELBOURNE, AUSTRALIA

15 OCTOBER 2012

ADULT GUARDIANSHIP: LAW, AUTONOMY AND SEXUALITY [*]

THE HONOURABLE MICHAEL KIRBY AC CMG[***]

LIFE, TEARS, WRONGS

Let me begin with the words of the 16th Century poet, Thomas Kyd:

> *Oh eyes, no eyes, but fountains fraught with tears;*
> *Oh life, no life, but lively form of death;*
> *Oh world, no world, but mass of public wrongs.*

Life, tears, death and a world of many wrongs have been companions to the law of guardianship over the centuries. Every society must have laws to protect the vulnerable. Even the earliest human societies recognised the need for this, when inborn or later-acquired disabilities impacted on the individual's capacity and competence to make decisions for themselves. When this happens, the law must step in, with an answer.

---

[*] Address at the opening of the Second World Congress on Adult Guardianship, Melbourne, Australia, 15 October 2012.

[**] Justice of the High Court of Australia (1996-2009); President of the Court of Appeal of New South Wales (1984-96); Chairman of the Australian Law Reform Commission (1975-84). One time President of the International Commission of Jurists (1995-8) The author expresses appreciation for the assistance of Clare Humphreys, Deakin University and The Victoria Law Foundation and the Office of the Public Advocate (Victoria) in the provision of materials for the preparation of this address. Responsibility for its content is that of the author alone.

But what should that answer be? This is the challenge that has brought to this world congress experts from across Australia and across the world. I believe that I speak for the legal community of this nation in bidding the participants welcome. And in paying respects to them for the important work that they do on behalf of the vulnerable and disadvantaged.

I encourage all of us to consider the never-ending need for law reform that lies at the heart of consideration of the law of guardianship.

These remarks will be divided, like Cesar's Gaul, into three parts:

- A reflection in the history and some of the current controversies about the law of guardianship;
- A reminder of the new paradigm that is presented to this field by the adoption of the *United Nations Disabilities Convention*[1] which (as in so many other fields of endeavour) constitutes an assertion by humanity of the basic principles to be observed by all nation states and their peoples in responding to the individual, social and global issues of disability; and
- In case these categories might appear too bland and benign for the inquisitive minds of the congress participants, some thoughts will be offered on issue of growing importance, the sexual needs of people with disabilities. And how these needs are to be met by guardians and others, with proper respect for individual autonomy but in a real world where such issues often produce high levels of discomfort amongst families, carers and other citizens.

In my journey through these ideas, I will offer a glimpse into the world of eyes filled with tears, lives of living death and wrongs that our society only partly addresses with rights. At my conclusion, I will suggest, that, sadly, in this discipline, there are unanswerable problems; ambivalent answers; conflicting principles; uncertain policies; new pressures; deep anxieties; enormous needs; and many unfulfilled promises.

---

[1] *Convention on the Rights of Persons with Disabilities*, opened for signature, 30 March 2007; 999 UNTS 3 (entered into force 3 May 2008).

From the daily dilemmas of professional work and the law, we can look to the horizon and wonder about the variety and difficulties of the challenges presented by this discipline. As a human being who has passed three score years and ten, I now have a greater interest in the subjects of this conference than I do in many others to which I am invited. If mortal man and woman survive, as increasing numbers do[2], the chances of their encountering a guardian increase. So the relevance of this discipline will increase with every passing year.

HISTORY AND THE ETERNAL CONFLICT

Australia, like Canada, India, Nigeria, Malaysia and the United States, is a federation. Substantially, in this country, the law on guardianship is provided by the sub-national legislatures of the States and the self-governing Territories of the Commonwealth and by the residual common law. Although this means that there are important differences in statutory law, from one jurisdiction to another, at an international congress such as this, it would be inappropriate to dwell upon purely parochial and local concerns. This should be done only as such concerns illustrate common themes and abiding challenges, likely to arise because of the very nature of the issues being addressed by the local laws.

Like each of the federations mentioned, and like many other nations (indeed, virtually all English speaking jurisdictions), Australia's legal system is basically grounded in the common law and its concepts. This is the law, built up in the countries that derived their legal traditions from England. In such countries, the basic doctrines and principles are those expounded both recently and in centuries past, by well-trained, uncorrupted, senior public officials, called judges, operating in open court, under the stimulus of deciding actual cases, usually with the aid of talented and well-trained advocates. This history has meant that many of the underlying principles relating to respect for, and protection of, individual autonomy in persons (and the provision for decisions in their lives when their capacity to make such decisions is, or

---

[2] P. Le Gay Brereton, "Acting for the Incapable – A Delicate Balance", *Law Society Journal (NSW)*, December 2011, 57.

has become, impaired) are relatively well known. Commonly, they are derived from a broad *protective* principle.

Substantially, the guardianship laws of England first emerged between about 1255 and 1290AD[3]. These were the earliest times in which the unifying power of the King, given expressions by the King's judges, propounded a basic doctrines protective of the vulnerable. Where because of infancy, mental incapacity (such as "lunacy") or physical incompetence, persons were rendered vulnerable to abuse or oppression, the judges were there to uphold the role of the King as the default protector of those who could not adequately protect themselves, as other adults might do. The King was *parens patriae,* or the parent of the nation[4]. Under this legal doctrine, the King was responsible for protecting and controlling children and adults with impaired capacity to fend for themselves. In time, the actual exercise of this power came to be performed by the judges rather than by the King personally or by other royal officials. Into recent decades, in Australia and many other common law jurisdictions, the care exerted, with the sanction of binding and enforceable orders, was exercised by the judges. They were generally very defensive of their control over it.

As recently as 1991, in the High Court of Australia, a case arose concerning the proposed sterilisation of a mentally handicapped young woman. The court insisted that the *parens patriae* jurisdiction continued to operate and was very wide. The judges even described it as "unlimited" and "incapable of being defined", lest it be accidently reduced[5]. By the same token, the power was such as to be exercised only in accordance with principle. The principle was that declared by the judges, unless a legislature had earlier stepped in to occupy the field. As sometimes it did[6].

Although this doctrine was intended to be protective, because it was exercised by judges for the vulnerable, the fact is that most of the judges charged with this task

---

[3] Sarah Burningham, "Developments in Canadian Adult Guardianship and Co-decision-making Law (2009), 18 *Dalhousie Journal of Legal Studies,* 127.

[4] Barbara Carter, "The Case for Dignity as the Governing Principle of Adult Guardianship" (2010), 19(1) *Res Publica,* 1.

[5] *Secretary, Department of Health and Community Services (NT) v JWB and SMB* (*Marion's* case) (1991) 175 *Commonwealth Law Reports* 218 at 258, per Mason CJ, Dawson, Toohey and Gaudron JJ.

[6] The High Court of Australia has held that *parens patriae* is part of the inherent jurisdiction of courts which will survive unless excluded by legislation. See *Marion's* case Ibid.

were atypical, privileged and elderly males. The rules therefore tended to reflect their gender, class, education, means and life experience. They also reflected the law's changing theories about disability. Originally, they exhibited notions of "demonic possession" or "lunacy". Deep attitudes of shame were sometimes derived from Biblical understandings and social expectations about acceptable behaviour. Many societies, not just ours, have exhibited (and some still do) hostile attitudes towards disability, dementia, sexuality and any unorthodoxy. They may also be hostile towards unpopular conduct and opinions. This has sometimes resulted in the grave misuse of the law to impose intolerable conditions and expectations upon minorities, as, for example, for holding unorthodox beliefs or exhibiting unusual, but harmless or self-regarding behaviours. The concentration camps of the Nazis in Germany and the gulags of the Soviet Union bore witness to the oppressive overreach of such forms of intolerance of non-conformity. But sometimes, there were also elements of overreach on the part of the English law which provides the foundation for the legal systems of a third of humanity, including Australia.

By the 19th Century, in England and in its colonies and other settlements and possessions, legislation was enacted to replace or modify, in particular respects, the broad inherent jurisdiction of the courts, under the common law or the invocation of the royal prerogative, to act as protector for the needs of disabled or incompetent persons. So began a legislative tussle between two great principles that have frequently coincided or clashed in the successive statutes enacted ever since. This conflict is resolved differently by different statutes and at different times. Yet all modern legislation constitutes a compromise of sorts between the two basic principles which are at work here:

- First, the principle of *due process* and strict control over the deployment of public power to take control of the person, property and decisions of an individual, said to be suffering incompetence or a disability. This is the crucial notion given effect in the 19th Century *Lunacy Acts*. Although these statutes came to have a bad name, they were initially enacted as a protective mechanism. They were seeking to make sure that the people who were alleged to be mentally incompetent or disabled were indeed so and were not being abused. And that those who claimed control over them and over their decisions, were rendered accountable to the law, ultimately to judges and courts[7] with full power to reverse, vary or control their interventions; and

- ∗ Secondly, came legislation enacted after the mid 20th Century which was designed to introduce a more benign, medical, *social security* or *protective* model. This represented an adjunct to mental health reforms. It enlarged the powers of the non-legal paramedical professions. It substituted new, sometimes highly interventionist mechanisms, designed to respond flexibly and quickly to issues of incompetence and disability.

I say that these are never ending tussles because, while helping professions criticise the delays, costs, uncertainties and intimidation of the *due process* model, lawyers and those of like mind often criticise the forms of oppression that can exist when well meaning, but effectively unaccountable, officials take benign charge of people's lives and substitute their views of what is best for them for those of the people themselves, their families and closest friends.

This is the tussle that still lies at the heart of the contemporary doctrinal, legal and other controversies that arise in respect of guardianship. The controversies are ultimately unanswerable because both the *due process* model and the *help and care* model are right and justifiable in particular contexts. The need is to ensure appropriate elements of each and to provide that due process as well as help and care are maintained in harmony at every point in the journey.

The statutory regimes that have been adopted in Australia are not dissimilar to those adopted in the legislation of other like countries. The actual requirements vary between the jurisdictions. But a number of themes are common in the majority of such laws[8]. Ordinarily, when making a decision, a guardian, as substitute decision maker, is enjoined to:

- ∗ Take into the account the wishes of the subject person;
- ∗ Adopt the least restrictive approach available in the circumstances; and

---

[7] An example is *Lunacy Act* 1898 (NSW) providing that people could only be placed under restraint for "unsound mind", pursuant to a judicial order. And also forbidding cruel treatment. See e.g. ss4 and 5.

[8] Discussed Queensland Law Reform Commission, *Shaping Queensland's Guardianship Legislation: Practice and Capacity* (QLRC, discussion paper, WP 64, 2008, [4.10]-[4.39].

- ∗ Consider the best interests and welfare of the person involved.[9]

Although in every Australian jurisdiction providing for forms of guardianships, the law makes reference to taking into account the person's wishes, only the laws of the Australian Capital Territory and of the State of South Australia expressly assign the person's wishes to be given priority over other considerations[10].

All of the Australian statutes create a tribunal of some kind, with supervisory jurisdiction in such matters. In the Northern Territory of Australia, the Local Court performs these functions. In the Capital Territory and in each of the States, either a specific Guardianship Tribunal or Board has been established (NSW, SA and Tas) or general administrative tribunals have been given jurisdiction (ACT, Qld, Vic, and WA). In each jurisdiction a guardianship official has been created, variously known as the Public Advocate or Public Guardian. In most jurisdictions advanced directives are provided for. In some instances of health care, specific appointments are made. In all but one State (NSW) enduring guardians or enduring attorneys are created. Default decision-makers are provided. In each jurisdiction medical, dental and other health professionals are designated with specified powers to make decisions for defined persons, as provided in the law[11].

The consequence of this substantial statutory network of rights and duties is that the higher courts, and particularly the federal Supreme Court known as the High Court of Australia (upon which I served), rarely become involved. However, when I was President of the New South Wales Court of Appeal in the 1980s and '90s, I participated in many decisions relevant to the bodies established in New South Wales, to give effect to the then prevailing compromise between due process and health and care.

At the time, the governing law was the *Protected Estates Act* 1983 (NSW). One decision that I wrote in those years has been much applied in later cases: *Holt v*

---

[9] Ben White, Lilly Willmott and Shih-Ning et al, "Adults Who Lack Capacity: Substituted Decision-Making", ch.6 in Ben White, Fiona McDonald and Lindy Willmott, (eds) *Health Law in Australia,* Law Book, 2010, Sydney,149 at 162 (with references to relevant legislation).

[10] Ibid, 162 [6.90]. See *Guardianship and Management of Property Act* 1991 (ACT), s4(2)(a) [b]; *Guardianship and Administration Act* 1993 (SA), s5 (a)-(b).

[11] A helpful schedule appears in White, McDonald, Willmott et al., above n.9, at 164-165.

Protective Commissioner[12]*.* Re-reading it for this congress, I noted a number of the criteria that I suggested – which I believe are still relevant, in Australia and beyond:

1. When the law governing this area is expressed in legislation, it is the legislation that must be interpreted and applied. The legislation should not be shackled with ideas inherited from earlier times or other disciplines or sources. Thus, protective office holders in this field bear some analogies to trustees and corporate guardians. However, the needs here are so peculiar, intimate and personal that care needs to be exercised against importing alien or immaterial analogies, rules and procedures to burden the discretions given by express law, which are necessarily usually very broad;
2. The abiding rule in the exercise of the powers and discretions under the legislation is the achievement of the "best interests of the person," the subject to those powers. This is a rule of long standing. Indeed, it stretches back to the essential idea that lay at the heart of the principle of *parens patriae*;
3. In some family and other situations, inter-related property interests may sometimes present a potential conflict of interest and duty, rendering the subject of concern especially vulnerable. This is where the interposition of an independent, dispassionate, neutral and professional public office holder can sometimes be specially useful and even necessary;
4. None the less, within the particular disability or incompetence of the subject, he or she may be able, and should be encouraged, so far as possible, to interact with a manager to express preferences that will be able to influence "the broad direction of the management" of his or for her affairs; and
5. In many cases, particularly where the aggregate property or interests are modest, the "ingredient of love and affection... to the protected person which an appropriate family member can add to the task of management" will make interaction between that person and the subject person the most appropriate way to ensure an appropriate "quality of life". A lifetime's knowledge of the person and a true and personal devotion to his or her interests may contribute to that quality. "It may more readily be secured by the appointment as manager of a family member with the requisite knowledge and motivation."

---

[12] (1993) 31 NSWLR 227.

The intervening 20 years does not cause me to modify these opinions. But of course, they are expressed in very general terms. And, as I said at the time, the legislation is what ultimately governs public officials, such as appointed guardians, on addition to the peculiar and unique circumstances of each case.

As in the past, so today. The last word is never written about legislation on guardianship. It goes on evolving and ever changing. Each decade or generation feels a need to return, and to adjust and test the present law and practice, so as to take into account developments and happenings elsewhere; changes in the relevant clientele, new management concerns and techniques; and debates over issues of underlying policy.

An instance of the tension in the law that I have identified can be found in the several public enquiries that have been conducted in recent years in several States of Australia. Thus, in the 1980s, the Cocks Committee in Victoria[13] proposed "guardianship orders" and a newly created board that would cover only those specific decisions that an individual was deemed unable to make. A "public advocate" was proposed, with responsibility for speak to individuals with disabilities; to assist the board; to investigate abuses; to provide education to the public; and, as a "last resort"[14], to act as the "guardian" of the subject person.

A decade later, in April 2012, a new wide-ranging report on the Victorian system has been delivered by the Victorian Law Reform Commission[15]. It looked at what it saw as a significantly changed legal and social environment. It raised three concerns. First, the increasing need for attention to risk management by service providers. Secondly, the relevance in the increase in the ageing population in Australia for age-related disabilities, in particular dementia, which is of rising incidence and which has resulted in increased applications for guardianship and administrative appointments outside the more traditional scope of intellectual disabilities. And thirdly, the advent of the *United Nations Convention on the Rights of Persons with Disabilities*. This

---

[13] Parliament of Victoria, Report of the *Minister's Committee on Rights and Protective Legislation for Intellectually Handicapped Persons* (1982).
[14] Ibid, 24-25.
[15] Victorian Law Reform Commission, *Guardianship: Final Report* (VLRC 24, 2012).

has served as a catalyst for re-considering notions concerning capacity, rights and autonomy.

Within the specialised professions and groups that have so much day to day engagement with these fields, many voices are now raised about the way in which the cognitive ability of an individual adapts to understanding and appreciating the context of the precise decision that he or she is making[16]. Other voices are properly raised to question the social context that may explain the particular values and choices on disability that different societies and cultures reflect at different times. As Dr Amita Dhanda of Hyderabad, India, has pointed out, a kind of "cultural imperialism" can sometimes influence how the dominant group perceives vulnerable minorities in its midst[17].

Over history, particular social attitudes have existed, for example, in respect of women, as of persons with disabilities and other excluded groups, including sexual minorities. Dr Dhanda is surely right to point out that notions of "legal capacity" may tend to favour individuals who reason and express themselves more articulately (in words and conduct) and in a way that the relevant decision-makers can understand and approve of. To mediate on behalf of less favoured groups, it would often be important to have "supported decision-making". This concept reflects the idea towards which I was reaching in my *Holt* decision in 1993. As Barbara Carter has pointed out:[18]

> "Most people in the community seek the support of others in making significant decisions about their lives. In modern society there is a high level of dependence on the expertise and knowledge of those with special qualifications, skills and talents, depending on the sorts of decisions that a person is faced with. In addition, people talk about their choices with others and few decisions, especially about important matters, are made in isolation."

---

[16] Nick O'Neill and Carmelle Peisah, chapter 1, "Capacity" in Nick O'Neill and Carmelle Peisah (Eds), *Capacity and the Law*, 2011, Sydney University Press, Law Book Co., 29.

[17] Amanda Amita Dhanda, "Legal Capacity in the Disability Rights Convention: Strangle Hold of the Past or Lodestar for the Future?" 34 *Syracuse Journal of International Law and Commerce*, 438 (2007).

[18] Barbara Carter, *Supported Decision-making: Background and Discussion Paper*, Office of the Public Advocate, Victoria, 4.

These are reasons for the engagement of family members, close friends and potential service providers, supporting and advocating on behalf of a subject person, so that he or she can make relevant decisions as far as possible. This constitutes a desirable and natural way to go about reaching such decisions. It contrasts markedly with the more traditional concept of *substituted* decision-making by which one person is appointed with legal power simply to take over and substitute that official's decisions for those (however approximate) that the subject person does or would make, in the language of the Beatles, "with a little help from [their] friends."

In Queensland, the State Law Reform Commission has also been conducting an enquiry into the operation of the legislation in force in that State. It has been doing so in the hope of ensuring that Queensland law and practice will reflect more closely the universal principles now set out in the *Disabilities Convention*. In particular, the Commission has proposed that the general principles contained in the present State legislation, should give greater weight to personal autonomy.   And that the law should define capacity in terms more harmonious with the Convention.

The Queensland Commission has suggested that greater significance needs to be attached to considering the wishes of the individual concerned. It proposes that the language used in the present general principles of the State statute, regarding the need to "protect" individuals, should be re-worded to place emphasis on protecting "the rights, interests and opportunities" of the individual[19].

This approach would seem to deploy less paternalistic language. It tends to shift the focus of the law away from *protecting* the individual – with its assumption that the person, by definition, needs protection. It would re-focus concern upon the actual *requirements* that the person affected needs, order to live, in so far as possible, a fulfilling life. The Queensland Commission suggests that informal decision makers should be equally *bound* to follow expressed principles rather than merely *encouraged* to abide them[20].

---

[19] Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws*, Report number 67 (2010), 95.

[20] [2005] Eur Court HR 405 (61 603/00)

These two State enquiries in Australia show the ways in which, stimulated by an international convention to which this country has subscribed, legislation can be reviewed, and changed in ways that would shift the emphasis along the spectrum. It would move the law away from the imposition of a [well meaning but substantively unreviewable] *help and care* official decision more closely towards a *due process* approach, which emphasises and facilitates, so far as possible, the ascertainment and effectuation, of the wishes and interests of the individual concerned.

THE INTERNATIONAL DIMENSION AND HUMAN RIGHTS

Basically, the foregoing developments have been encouraged by the *Disabilities Convention*. This is simply one of the most recent of the panoply of international human rights instruments, adopted by the United Nations heralded by the *Charter* of 1945, and the *Universal Declaration of Human Rights* of 1948.

The particular utility of the *Disabilities Convention,* in an Australian context, is that, almost uniquely, this is a nation whose legal system has to operate without a national (or for the most part even a sub-national) human rights charter: constitutional, statutory, or otherwise. The reason for this peculiar omission was a decision made by the founders, during framing of the *Australian Constitution* in the 1890s. They rejected the American approach of a Bill of Rights. They preferred, instead, to put their faith in specific legislation enacted, as needed from time to time, by elected parliaments. The ensuing decades have shown the utility that can sometimes be provided by broad statements of universal rights. Yet although Australia regularly ratifies (and generally conforms to) international human rights treaties, its elected politicians have proved remarkably resistant to the adoption of a generic, national rights charter or statue. There are two Australian exceptions, namely the Australian Capital Territory and the State of Victoria where general rights legislation has been enacted and reaffirmed. Elsewhere in this country, the lack of such provisions has made the adoption and observance of international human rights principles all the more important.

The handbook published by the Office of the High Commissioner for Human Rights in Geneva, addressed to the *Disabilities Convention,* has been described as being at odds with the practice of substituted guardianship that runs through the current State and Territory legislation in Australia[21]. The handbook has been seen as critical of the paradigm of "*substituted* decision making" and favourable, instead, to the paradigm of "*supported* decision-making", involving family, close friends and those observe close to the subject person, generally along the lines that I urged 20 years ago in the *Holt* case[22].

Encouraged by this view of the international treaty, some disability groups have even called for the abolition of guardianship law and substituted decision-making practice altogether. This call has elicited a response defensive of guardianship, as the least offensive and practically the most protective "social justice approach to deliver the best outcome-based rights for vulnerable persons"[23]

I hope that the perceptive observer will discern in these debates the same tussle or tension that I have previously described between those who favour the predominance of a *due process* model (protective of the individual) and those who favour a *help and care* model (engaging trained officials dedicated to their vision of that objective).

This debate about the scope for capacity and autonomy on the part of disabled persons is reflected, in turn, in the Council of Europe's *Convention for the Protection of Human Rights and Fundamental Freedoms* of 1950[24] and in decisions in the European Court of Human Rights, generally favouring maximising autonomy, including in the context of mental disability[25]. Recent developments in the law in

---

[21] United Nations, Office of the High Commissioner for Human Rights, *From Exclusion to Equality: Realising the Rights of Persons with Disabilities* (Geneva, 2007).

[22] Barbara Carter, "Adult Guardianship: Human Rights or Social Justice?" (2010) 18 *Journal of Law and Medicine* 145; Tina Minkowitz, "Advocacy by Users and Survivors of Psychiatry", Mental Health Commission, Wellington (2006), 11-20.

[23] John Chesterman, "The Review of Victoria's Guardianship Legislation: State Policy Development in an Age of Human Rights" (2010) 69(1) *Australian Journal of Public Administration*, 61. See also Barbara Carter, above n.22, 149.

[24] Council of Europe, *European Convention for the Protection of Human Rights and Fundamental Freedoms*, open for signature 4 November 1950; ets 5 Art 5 (entered into force 3 September 1953).

[25] *Stork v Germany* [2005] Eur Court HR 406 (61603/00).

Canada[26] and in the United Kingdom[27] appear also to be reflecting this same trend. The emphasis of recent legislation has been to move away from well-meaning officials making decisions for others designated as in need and instead to place emphasis on individuals making (so far as they can) their own decisions and receiving support for that purpose from their friends, families and the social network around them.

The objective of each model is basically the same: namely achieving the best interest of the person concerned. But the way of achieving that end is relevantly different. It shifts the focus along the spectrum that I have described, for the purpose of laying greater emphasis in the law upon extracting as much autonomy from the circumstances as the individual can possibly manifest.

The end result of this logic is, or may be, the need for us in Australia to go back to the drawing board and to reconsider the guardianship model that is the centrepiece of the current legislation of every jurisdiction of this country. Perhaps we need to continue moving towards a more modern and nuanced model: one that stands apart from the competence classification and which emphasises the fullest possible exploration of the person's circle of family, close friends and networks, provided they are not contaminated by any relevant conflict of interest and duty.

SEXUAL SELF-DETERMINATION AND EXPRESSION

I reach the last topic. I refer to the capacity of individuals with cognitive and physical impairment to engage in sexual relationships or activities. There is no doubt that this can be a particular source of conflict for family members and service providers. They may share a concern about considerations such as exploitation, pregnancy, infection, remarrying, will-alteration and the financial implications bound up in such questions. In particular, sexual activities, relationships and expression have been found in Australia to create particular anxiety and resistance amongst families, co-

---

[26] See e.g. *Adult Protection and Decision-making Act* 2003 (Yukon; SY203c21 p11; *Representation Agreement Act* 1996 (BC). RSRC 1996 c 405; *Adult Guardianship and Co-decision-making Act* 2000 (SASK); ss2000cA-5.3.

[27] *Mental Capacity Act* 2005 (Eng), ss15, 16, 17 and *Mental Capacity Act* 2008 (Eng).

residents and carers, where the sexual expression concerned reflects a minority same-sex orientation or a different sexual identity from the norm. What is then to be done?

Investigations of this subject have shown that sexual desires, and their manifestations, are amongst the last human feelings that close down as an individual declines in their mental and physical capacities.[28] Acquaintance with Holocaust literature demonstrates that, even in the direst circumstances of degradation, terror and starvation, the sexual flame continued to burn. This reality of human existence was brought home to me recently when reading a new biography of the great English novelist, E.M. Forster.[29] The book quotes extremely vivid descriptions, written by Forster in his diary in his 90s, candidly describing pleasurable sexual experiences. To the end, Forster, an Oxford Don, retained his sexual feelings and capacity to take pleasure from them. He observed publicly the discretion expected of him by his family, friends, acquaintances and society. But what of a gay or lesbian person of declining capacities, rejected by their blood family? Who is the real "family" of such a person? It may be quite different and consist of other members of their minority community, a same-sex partner or heterodox supporters. What of elderly family members who have rejected a gay or lesbian child, who might suddenly find themselves needing care and assistance by the very family member they have disowned? What if the onset of dementia means a reduction in the ability of the patient to conceal, or to self-censor, behaviour embarrassing to others? Including to other residents in an aged care facility?[30]

What is to happen where some members of the family refuse to acknowledge an elderly individual's gay or lesbian partner? Is that partner to be denied the chance to grieve the loss of, or to provide support and comfort to, the individual in decline?[31] What is the proper conduct to be expected of professional and other staff in nursing homes and care facilities, dealing with these situations?

---

[28] Melissa White, 'The Eternal Flame: Capacity to Consent to Sexual Behaviour Among Nursing Staff Residents with Dementia' (2011) 18 *Elder Law Journal* 139-141.

[29] Wendy Moffatt, *E.M. Forster: A New Life* at (Bloomsbury, London, 2010), 314 ("The worm that never dies")

[30] Heather Birch, *It's Not Just About Sex! Dementia, Lesbians and Gay Men* (2009) Alzheimer's Australia conference presentation 3.

[31] Ibid, 11.

And if such situations appear difficult and challenging, the problems become even more acute where, whether heterosexual or homosexual, a resident in care, because of dementia, begins to display overt sexual conduct? This may range from little more than unwanted sexual advances to non-harmful behaviour such as semi-private masturbation, flirting and other disinhibited sexual conduct, engaging the attention of co-residents, visitors and staff.[32]

Until now, in many nursing facilities in Australia, as elsewhere, staff will often concur with adult children in totally rejecting any such sexual expression. They may do so even to the point of ignoring the resident's rights to privacy, to sexual expression and to sexual pleasure. The authors of one recently published article observed:[33]

> "Allowing persons with dementia to make autonomous decisions about sexuality may indeed expose them to some element of risk such as emotional distress if a relationship ends; however, these are risks that any sexually active person faces throughout his or her life, and we should not confuse a bad or unwise decision with incompetence. Seeking to 'protect' individuals with dementia by not allowing them to express their sexual needs, thereby stifling their autonomy or personhood, is a far greater failure of the duty of care."

I do not underestimate the difficulty of the decisions that need be taken in such matters. I acknowledge that they will often fall to be made in institutions or situations that contain other residents who may reflect values and attitudes on such matters, inherited from an earlier time. The complexity of the decisions involved will range from respecting the rights of living spouses or partners to continue a sex life as a source of affection, support, reassurance and comfort where one spouse is suffering from dementia[34] to finding private spaces for sexual autonomy which would be taken

---

[32] Russell Shuttleworth et al, "Sexuality in Residential Aged Care: A Survey of Perceptions and Policies in Australian Nursing Homes" (2010), 28 *Sexuality and Disability*, 190.

[33] Laura Tarzia, Deidre Featherstonhaugh and Michael Bauer, "Dementia, Sexuality and Consent in Residential Aged Care Facilities" (2012) *Journal of Medical Ethics* 3.

[34] Joan Heron and Sandra Taylor, "Nurse, Manager, Perceptions Regarding Sexual Intimacy, Rights of Aged Care Residents: An Exploratory Queensland Study" (2009) 4(1), *Practice Reflexions,* 21; Sally Parker, "What Barriers to Sexual Expression are Experienced by Older People in 24-Hour Care Facilities?" (2006), 16 *Review of Clinical Gerontology,* 277.

for granted in an individual's home but which may be much less available or afforded in shared accommodation and missing completely in most general hospital wards.

Gay and lesbian residents are much more likely to be adversely affected than the norm by negative and homophobic reactions in the part of staff and other residents[35]. The fact that many residential aged and health care facilities in Australia are operated by religious organisations will sometimes make the management of these issues especially difficult and painful for all concerned.

There will be some (perhaps some participants at this congress) who would prefer not to speak, or think, of such matters. They might opt to cloak them in the privacy of silence, shame and denial. However, the autonomy and dignity of the human individual, including in their sexual expression, survives even into care sentential facilities and even into dementia. Professional skill, kindness, the health and happiness of the person and their wellbeing will include respect for some measure of desired sexual expression. Nursing staff in residential aged care have reported that residents who have intimate sexual partners often take greater pride in their hygiene and physical appearance and display more positive self images than those without.[36]

Human rights matter most, in practice, when they are hard to accord to others. Yet it is then that they may be most important to those others whose wellbeing and identity are at risk. Of course one person's human rights extend only to the point that their protection commences to infringe on the human rights of others. Living as we do in a more honest world of truthful sexual expression means that increasing numbers of individuals in the future, certainly in most western communities, will present with this issue. They will do so even in circumstances of severe physical and mental decline. It might be attractive to some people's religious and aesthetic inclinations to wish that these challenges would go away. But this is unlikely to happen. As the baby boomers grow older, they will carry with them into nursing homes the post World War II attitudes to sexual freedom and expression with which they grew up and lived outside.

---

[35] Mark Hughes, "Privacy, Sexual Identity and Aged Care" (2004) 39(4) *Australian Journal of Social Issues,* 17.

[36] See Melissa White, above n.28, 144.

CONCLUSIONS

My journey of tears, vulnerable lives and public wrongs has concluded. So what have I suggested?

The law responds to people's physical and mental disability and diminished competence. It has done so since ancient times. The history of this chapter of the law reflects an indelible tension between a *due process* model and the *caring and helping* one. Each model has its strengths and weaknesses. At any point, the law will find itself in an uneasy compromise between these competing and sometimes conflicting demands. Under the stimulus of the global statements of universal human rights and the language of the new United Nations *Disabilities Convention*, it seems likely that Australia and other countries will see growing questioning of the substituted decision-maker approach. They will face enhanced favouring of assisted decision-making that engages the natural circle of friends of the person affected, their family and the closest acquaintances, to the fullest extent feasible.

To the extent that this happens in Australia, it is likely to demand a significant reconsideration of the guardianship model presently in place in the law of every State and Territory jurisdiction of Australia. But the help and care supporters will doubtless be as resilient in defence of their model as the lawyers and autonomy advocates have always been of theirs.

If these problems are not enough, other and newer challenges are looming on the horizon of adult disability if not already with us. They are more practical, down to earth, complex and pressing. Amongst the most acute of these, is the issue of sexuality and disabled persons. And their right to enjoy full dignity and autonomy and the pleasurable, meaningful, well-being, relationships and self expression that sexual expression can bring. In all human lives, but perhaps in a life of disability and disempowerment especially, considerations of pleasure and fulfilment are not to be decried or ignored. Nor are they needlessly to be denied just because relatives get embarrassed; heirs get nervous; religious get wrathful; and care-givers get offended and subjected to new and difficult demands.

I end as I began. With an expression of thanks and praise for those who help others with disabilities, including those who do it beyond legal duty, for reasons of love, kindness. Such feelings towards the vulnerable are a distinctive mark of civilized human beings and civilized societies. Whatever the legal model in place, we must preserve and protect this essentially moral dimension. How it plays out in particular situations is a challenge that offers us difficult and perplexing dilemmas, as it has always done. And the solution to these dilemmas lies somewhere on the ever shifting spectrum between the legal machinery for *due process and protection* and that for *care and help* to those who have a special need for help in times of acute dependency.