



Office of the Public Advocate

Principles and values in Victorian guardianship legislation

Position paper

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Contact: Dr John Chesterman
Manager, Policy and Education
The Office of the Public Advocate

Prepared by: Barbara Carter
Office of the Public Advocate



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This paper has been developed by the Office of the Public Advocate in preparation for the review by the Victoria Law Reform Commission of the Guardianship and Administration Act 1986.

Thank you to the OPA staff members who formed the working group that developed this position paper.



1. Summary of current and proposed principles

The chart below sets out the current principles and values articulated in the legislation and proposed changes.

Proposed	Current
<p>Purpose The Purpose of the Act is to fulfil the responsibility of the State to protect and promote the dignity and well-being of people with a disability.</p> <p>To this end the Act establishes the Public Advocate, mechanisms for the appointment of guardians and administrators where needed and regimes for medical decision-making.</p> <p>Preamble</p> <p>This Act is premised upon the following commitments and acknowledgements:</p> <ul style="list-style-type: none"> • All people have inherent dignity and the responsibility to respect and foster the dignity of others. • All people have rights that must be respected in accordance with national and state legislation and international instruments. • All people are entitled to the support and services they require to lead a life of basic human dignity • Victoria is committed to being an inclusive society where all people are valued. • Victoria is committed to being a safe society, where people live their lives free from abuse, neglect and exploitation. • Victoria is committed to 	<p>Purpose The Purpose of the Act is to enable persons with a disability to have a guardian or administrator appointed when they need a guardian or administrator.</p> <p>There is no Preamble in the current Act</p>



supporting people with disabilities that may hinder their participation in society or prevent them from reaching their potential.

Objects of the Act / values

It is the intention of Parliament that the provisions of this Act be interpreted and that every function, power, authority, discretion, jurisdiction and duty conferred or imposed by this Act is to be exercised or performed so that:

- a) the human dignity and rights of the person with a disability are protected and promoted;
- b) the personal and social well-being of the person with a disability is promoted;
- c) the person with a disability is able to live in safety and security;
- d) any limitations on the rights and freedom of a person are reasonable, proportionate and justified.

Guardianship principles

- 1) A guardian must act in a way that promotes the personal and social well-being of the represented person.
- 2) Without limiting subsection (1), a guardian promotes the personal and social well-being of a represented person if the guardian acts as far as possible:
 - (a) as an advocate for the represented person;
 - (b) to foster the represented person's dignity;
 - (c) to make the judgments and decisions that the person would have made after due consideration if able to do so, to the extent that this would not cause him or her undue harm;
 - (d) in consultation with the represented person, taking into account as far as possible

Objects of the Act / values

(2) It is the intention of Parliament that the provisions of this Act be interpreted and that every function, power, authority, discretion, jurisdiction and duty conferred or imposed by this Act is to be exercised or performed so that-

- (a) the means which is the least restrictive of a person's freedom of decision and action as is possible in the circumstances is adopted; and
- (b) the best interests of a person with a disability are promoted; and
- (c) the wishes of a person with a disability are wherever possible given effect to.

Guardianship principles

- 28. Exercise of authority by guardian
- (1) A guardian must act in the best interests of the represented person.
- (2) Without limiting subsection (1), a guardian acts in the best interests of a represented person if the guardian acts as far as possible-
 - (a) as an advocate for the represented person; and
 - (b) in such a way as to encourage the represented person to participate as much as possible in the life of the community; and
 - (c) in such a way as to encourage and assist the represented person to become capable of caring for herself or himself and of making reasonable judgments in respect of matters relating to her or his person; and
 - (d) in such a way as to protect the



<p>his or her wishes;</p> <p>(e) In consultation with important people in the life of the represented person;</p> <p>(f) in a way that fosters the person's positive relationships, friendships and connections with others;</p> <p>(g) to preserve and foster the person's capacity for self-determination;</p> <p>(h) so that the person lives in safety and security and is protected from abuse, exploitation and neglect;</p> <p>(i) so that the person is able to participate in and contribute to the community to the extent that s/he is able and wishes to do so;</p> <p>(j) with respect for the person's cultural and/or ethnic values and circumstances.</p>	<p>represented person from neglect, abuse or exploitation; and</p> <p>(e) in consultation with the represented person, taking into account, as far as possible, the wishes of the represented person.</p>
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2. Introduction

In considering the principles and values of the Act, the Public Advocate suggests that:

- The Act should be set in its societal context with the community values upon which it is built articulated in the legislation.
- The values and principles underpinning the current s4(2) should be reframed to be complementary to each other rather than in tension or competition.
- The principles should be oriented towards goals (eg well-being) rather than processes (eg act in the best interests).

Legislation in the area of guardianship should be grounded in a theory of justice that attempts to address four fundamental philosophical questions:

- What is the essence of our common humanity?



- How can we live together in peace and harmony?
- What does society owe to people with disabilities?
- To what extent and in what circumstances is it justifiable to override the will of a person?

The way that we approach these questions should shape the legislation and in turn will determine the way in which our efforts are judged.

3. Purpose and preamble

The prominent human rights organisation, Mental Disability Advocacy Centre, in Hungary has developed 29 indicators of a human rights compliant guardianship system.¹ Indicator 1 is:

The legislative purpose or preamble to the law encompasses respect for the human rights, dignity and fundamental freedom of people with mental disabilities.

Currently the Guardianship and Administration Act 1986 does not articulate a theory of justice that meets this indicator or addresses these philosophical questions. Moreover, the Purpose and Objects of the Act concern only the person with a disability and are effectively silent on the responsibilities of the society of which they are a part.

The most effective way to place legislation in its societal context is through a preamble and/or statement of purpose. The Act does not have a preamble and the statement of purpose simply states:

The Purpose of the Act is to enable persons with a disability to have a guardian or administrator appointed when they need a guardian or administrator.²

The Public Advocate considers that the Statement of Purpose should begin with a wider vision of legislative purpose followed by a more specific statement about how the Act contributes to the realisation of the vision. The following statement is an example for consideration:

- The Purpose of the Act is to fulfil the responsibility of the State to protect and promote the dignity and well-being of people with a disability.

¹ *Guardianship and Human Rights in Bulgaria*. Mental Disability Advocacy Center report, Budapest. 2007: 118.

² *Guardianship and Administration Act 1986* Section 1.



- To this end the Act establishes the Public Advocate, mechanisms for the appointment of guardians and administrators where needed and regimes for medical decision-making.

The Public Advocate proposes that the Act should also contain a Preamble that sets out the commitment of Parliament to building a just society and the values that will underpin that commitment. The values and commitment statements below are intentionally broad and applicable to all citizens. Only the final statement refers specifically to people with disabilities to highlight that people with disabilities, along with all other people, are essential and valued members of a just society.

The following value statements should be considered:

This Act is premised upon the following commitments and acknowledgements:

- All people have inherent dignity and the responsibility to respect and foster the dignity of others.
- All people have rights that must be respected in accordance with national and state legislation and international instruments.
- All people are entitled to the support and services they require to lead a life of basic human dignity.
- Victoria is committed to being an inclusive society where all people are valued.
- Victoria is committed to being a safe society, where people live their lives free from abuse, neglect and exploitation.
- Victoria is committed to supporting people with disabilities that may hinder their participation in society or prevent them from reaching their potential.

4. Proposed Objects of the Act

The Public Advocate proposes re-working of the Objects of the Act to provide a more integrated approach. The proposed Objects below are complementary, in contrast to the current Objects that hold competing values in tension.

It is the intention of Parliament that the provisions of this Act be interpreted and that every function, power, authority, discretion, jurisdiction and duty conferred or imposed by this Act is to be exercised or performed so that:

- a) the human dignity and rights of the person with a disability are protected and promoted;



- b) the personal and social well-being of the person with a disability is promoted;
- c) the person with a disability is able to live in safety and security;
- d) any limitations on the rights and freedom of a person are reasonable, proportionate and justified.

4.1 The human dignity and rights of the person with a disability are protected and promoted

OPA considers that respect for human dignity provides the most satisfactory available answer to the question “What is the essence of our common humanity?” It is, therefore, the key value upon which the legislation should be based. The concept of dignity has gained acceptance over history, although views about the source and basis of dignity vary. Philosophers have variously grounded dignity in nature (Stoic philosophy), in humans being made in the image of God (Judeo-Christian theology), in reason and autonomy (the Enlightenment), or in humanism and social connection. There are prominent references to human dignity in United Nations Conventions, charters of human rights and national constitutions.³

There are two aspects to human dignity that need to be incorporated into a proper understanding of the concept. The first is the idea of inherent dignity; that whatever its basis, people have dignity by virtue of being born into the human community and their dignity must be respected by others. The second, related, aspect is that dignity is interdependent and dialogical. It is accorded to others and can only be exercised in relationship with others, expressed by the philosopher Martin Buber as the I/Thou relationship. In the words of Buber, “all actual life is encounter”.⁴

Julie is a young woman with a mild intellectual disability who lives in a small town. She lacks confidence and dearly wishes to have a boyfriend and be accepted into the community. She develops a relationship with a man without a disability and begins her first sexual relationship. Over time, he isolates her from her family and other friends and prostitutes her to other men in group sex. She says that this is what she wants as having him as a boyfriend is very important to her. Her parents and some in the community are horrified that she is being exploited in this way. Others say that she is capable of making this decision and is simply doing what other young women without disability frequently do. Is dignity a key value in Julie’s situation and, if so, what action should follow from this?

The case study of Julie demonstrates the interdependent and dialogical nature of human dignity. Not only has Julie’s dignity been insulted: so too has the dignity of the men who have group sex with her. The community has an interest not only in protecting Julie in this situation but also in working with the men involved to change their patterns of behaviour.

Human rights theorists consider dignity to be intrinsic to human rights and may argue that if human rights are the basis of guardianship, respect for dignity is thereby included as a human right

³ See, for example, the Constitution of the United States and the United Nations Declaration on Human Rights. The Victorian Charter of Human Rights identifies dignity as one of the four key principles around which protected rights are grouped.

⁴ Buber, Martin: *I and Thou*. Walter Arnold Kaufman (3rd edition) 1970: 62



and does not need to be separately considered. The alternative view is that human dignity is a concept that precedes human rights; that human rights are derived from the more general concept of human dignity. The discourse of human dignity in a human rights framework is largely individual, based upon the Kantian understanding of dignity grounded in reason and individual autonomy. It does not, in the view of the Public Advocate, give adequate attention to the dialogical, relationship-based aspect of dignity or to the idea that dignity can be grounded in values other than reason. This is especially significant when looking at issues around cognitive disability and diminished capacity.

Language inevitably creates meaning and the language of human rights is frequently combative: rights are asserted, claimed, stood by or breached. There is little sense in language or discourse that rights are possessed and exercised collectively as well as individually, even though this is certainly part of a more sophisticated understanding of human rights.⁵

The Public Advocate considers that the fostering of human dignity should be the primary value in the legislation. Human rights should be included as deriving from, and as an expression of, human dignity.

4.2 The personal and social well-being of the person with a disability is promoted

The Public Advocate prefers this principle to the principle of best interests. It is argued below that the term “best interests” has taken on negative connotations and is frequently used pejoratively.

If it is agreed that the fundamental purpose of social legislation such as the Act is to make people’s lives better, there are advantages in identifying this as a principle in the legislation.⁶ The goal of well-being does this and is found frequently in health policy and legislation. In this Act, it is important to articulate that well-being has social as well as personal and medical dimensions and that true well-being cannot be achieved in isolation from others.

Well-being can be seen as a parallel concept to the concept of best interests but the idea of personal and social well-being provides a clearer goal to which actions and decisions should be directed. It places the emphasis on the person rather than on the guardian, on the outcome to be sought rather than the process.

It is important to acknowledge that the idea of well-being is not purely individual or morally neutral but sits within a generally accepted agreement within society of the “good”. Thus, the concept of personal and social well-being is not just a Utilitarian concept in which the maximisation of personal or collective benefit is the goal. Classic Utilitarianism does not concern itself with the wider questions of personal integrity, agency, friendship and family or the sources of meaning in life, all of which are highly relevant to guardianship and the Act. Personal and social well-being is, instead, about having the capabilities (to use Martha Nussbaum’s framework) for a flourishing life.⁷ In this sense the role of a guardian in promoting personal and social well-

⁵ There is also the issue of how one can claim a right based in relationship.

⁶ It is closely associated with the older philosophical idea of human flourishing.

⁷ Nussbaum, M: *Frontiers of Justice: Disability, Nationality, Species Membership*. Harvard University Press. 2007: 75.



being is like that of a gardener where the environment needed for the person to have a full life is provided and the impediments to growth and flourishing are removed as far as possible.⁸

Sarah is a young woman who has an intellectual disability and has also been diagnosed with a depressive illness. She lives with her mother who has cared for her all her life. The relationship between them is generally warm and loving. Sarah's mother does not allow her to go to Day Centre activities and her social interaction outside the home is minimal. She has a medical condition that severely limits her mobility but her mother refuses to consider medical treatment that would alleviate it. Her mother also refuses to consider treatment for depression, saying that she is opposed to drugs. The principle of promoting Sarah's personal and social well-being appears particularly pertinent to Sarah's situation.

The Public Advocate considers that the principle of promoting Sarah's personal and social well-being provides a clearer focus for any intervention under the Act than that of acting in her best interests.

4.3 The person with a disability is able to live in safety and security

Any theory of justice must address the question of protection and the question is central to guardianship legislation. A civil society protects its members from harm. Few would regard a society characterised by danger and insecurity as a "good" society and citizens accept limitations on their absolute liberty in order to live in safety and security. This is the fundamental and generally accepted basis of much of our law. It provides part of the answer to the question posed above "How can we live together in peace and harmony?"

In disability discourse, however, the question of protection can generate strong negative views and is regarded by some people with disabilities as unwarranted discrimination. This is partly because it is associated with the paternalism of institutionalisation whereby protection is seen as limiting the full participation of people with disabilities in society by shielding them from the normal risks of life. It is partly because it is only people with a disability who are protected under legislation from abuse, neglect and exploitation, arguably because they are less able to protect themselves. Finally, the legislation also protects people against their own decisions and actions if they lack the capacity to make reasonable decisions for themselves. It can therefore be seen as impinging on some of their rights.⁹

In a just and inclusive civil society, there would be no need for a protective jurisdiction specifically for people with disabilities. The general protections of law would be adequate. However, within our society people with disabilities are more often subject to abuse, neglect and exploitation than others and may also be less able to make self-protective decisions. An important part of what society owes to people with disabilities is a life of reasonable safety and security.

⁸ Carter, B: "Just what do we think we are doing?" *International IGN Conference on guardianship*, Conferencebook 2008: 69.

⁹ These arguments were strongly made in the UN Convention on the Rights of Persons with Disabilities by organisations such as Inclusion International. www.inclusion-international.org



Eva has lived in the same house in the Dandenong Ranges outside Melbourne for sixty years. It is set on the side of the hill 3km from the nearest town and has no hot water or heating. Eva has no family but has several animals that are very important in her life. She adamantly rejects all services except for one meal on weekdays that a café provides by arrangement with the local Council. Eva's health and personal hygiene are deteriorating rapidly. She is finding it difficult to walk into town and she has had several falls on the steep path up to her house. She has now been threatened and assaulted in her home and money has been stolen from her but she is deeply suspicious of Police and other authorities and will not seek assistance. She refuses to be assessed by the Aged Care Assessment Service so it is not known whether she has a disability. What protection does society owe to Eva and should this protection depend on whether or not she has a cognitive disability?

The Public Advocate considers that safety and security are key values that should be included in the Objects of the Act.

4.4 Any limitations on the rights and freedoms of the person with a disability are reasonable, proportionate and justified

This principle is drawn from the Victorian Charter of Human Rights.¹⁰

(2) A human right may be subject under law only to such reasonable limits as can be demonstrably justified in a free and democratic society based on human dignity, equality and freedom, and taking into account all relevant factors including-

- (a) the nature of the right; and
- (b) the importance of the purpose of the limitation; and
- (c) the nature and extent of the limitation; and
- (d) the relationship between the limitation and its purpose; and
- (e) any less restrictive means reasonably available to achieve the purpose that the limitation seeks to achieve.

It also reflects the United Nations Convention on the Rights of Persons with Disabilities 2006:¹¹

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

Currently the Objects of the Act include the provision that *the means least restrictive of a person's freedom of action and decision as is possible in the circumstances should be adopted.*¹² This

¹⁰ Victorian Charter of Human Rights and Responsibilities Act 2006. Section 7(2).

¹¹ United Nations Convention on the Rights of Persons with Disabilities. Article 12(4).



wording though in some ways similar to that proposed, gives primacy to the civil freedoms of decision and action and reflects the thinking of the time about interference by the State. There is a strong implication in this wording that freedom from State interference is always to be valued above the positive benefits a person may receive under the Act.

It is the experience of the Public Advocate over the past ten to fifteen years that much of the focus of advocacy and guardianship has shifted away from such civil freedoms towards helping people to access the services, health care and other assistance that will enable them to live safer, happier and healthier lives. In relation to mental health, the Public Advocate notes that a leading Australian academic has also identified “a possible shift in focus at the international level away from the civil/political right to refuse treatment under an autonomy model to a focus on the social/economic right to treatment”.¹³

The *Guardianship and Administration Act* 1986 provides a basis and rationale for intervention in the life of a person with disability through the appointment of a guardian or an administrator. By its nature, it involves the balancing of rights and freedoms and limitations on some rights and freedoms in order to promote other important social values. A requirement that limitations are reasonable, proportionate and justified provides a suitably stringent test of any restrictive action taken under the Act and will adequately protect the rights of people with a disability.

The Public Advocate considers that the proposed provision better reflects the essence of guardianship legislation than the current provision.

5. Current Objects of the Act

In the current Act, the Objects are set down in s4(2):

- (2) It is the intention of Parliament that the provisions of this Act be interpreted and that every function, power, authority, discretion, jurisdiction and duty conferred or imposed by this Act is to be exercised or performed so that-
- (a) the means which is the least restrictive of a person's freedom of decision and action as is possible in the circumstances is adopted; and
 - (b) the best interests of a person with a disability are promoted; and
 - (c) the wishes of a person with a disability are wherever possible given effect to.

These Objects express contrary or competing values that are held in tension and require those working under the Act to balance the values in each situation. It is rare that a situation arises in which action to promote one of these values does not cut across the others.

Each of the current Objects of the Act will now be discussed.

¹² *Guardianship and Administration Act* 1986. Section 4(2)(a).

¹³ McSherry, B: “Mental health and human rights: the role of the law in developing a right to enjoy the highest attainable standard of mental health in Australia”. (2008) 15 *Journal of Law and Medicine* 776.



5.1 The means which is the least restrictive of a person's freedom of decision and action as is possible in the circumstances is adopted

S4(2)(a) articulates the value of individual freedom in decision-making and action as a key value in the legislation. Further, in s22(2)(a) the Tribunal, in determining whether a person is in need of a guardian must consider:

- (a) whether the needs of the person in respect of whom the application is made could be met by other means less restrictive of the person's freedom of decision and action.

Because it removes a person's right to make his or her own decisions, guardianship is identified in the Act as being the authority most restrictive of a person's freedom of decision and action. This has the foreseeable but unfortunate consequence of reinforcing the shame and stigma sometimes associated with having a guardian or administrator. By specifically valuing freedom of decision and action, the Act can effectively devalue other freedoms and rights.

An alternative perspective is that the appointment of a guardian or an administrator may free a person from undue influence or coercion, from the exploitation of others and create a legal space in which the individual can flourish within their family and wider community. Section 28 (Exercise of authority by a guardian) clearly suggests that this is the intention of guardianship, however s22(2)(a) and s22(5) (Appointment of a Guardian) contribute to the more negative perspective on guardianship.

Freddie is 80 and lives in an aged care facility. He has mild dementia and his wife died three years ago. He has four children who live nearby and are in conflict with each other. They disagree about what is best for Freddie and each believes that the others are trying to exploit him financially and will persuade him to change his Will. His Will leaves his estate equally to his four children. One of his children wants her father to come and live with her and says she is able to care for him but the others are suspicious of her motives. Freddie is happy where he is living and does not want to be dependent on his daughter. He loves his children and grandchildren but hates the fights. Attempts by the aged care facility to broker agreement between the children have not been successful. Would a guardianship order for access to persons be a restrictive option in situations like this?

Adoption of the least restrictive means principle is common to social legislation of the past 30 years. It draws on the concept of negative liberty where liberty is seen as freedom from imposed interference rather than positive liberty where freedom is the freedom for a person to achieve all that is possible for them.¹⁴ It is a legislative expression of the view that the State should keep out of the lives of its citizens, except as a last resort. Unfortunately, it can become a justification for "the lazy State", where government neglects its positive responsibility towards its citizens.¹⁵

¹⁴ Berlin, I., 'Two concepts of liberty' in I. Berlin, *Four Essays on Liberty*. Oxford University Press 1969.

¹⁵ Nussbaum, M: "Women's bodies: Violence, security, capability". *Journal of Human Development* Vol. 6, No.2, July 2005: 176.



For these reasons, the Public Advocate prefers the alternative principle that any limitations on the rights and freedoms of the person with a disability should be reasonable, proportionate and justified.

5.2 The best interests of a person with a disability are promoted

The term “best interests” is not defined in the Act apart from the guidance provided to guardians by s28, where certain actions taken by a guardian are regarded as being in the best interests of the represented person. The term does not add meaning beyond the inclusions in s28(2) and invites the question “Yes, but what should acting in a person’s best interests achieve for the represented person?”

As justification for the concept, it can be argued that competent people make decisions in their own best interests so therefore those acting for them should do the same on their behalf. Debates then arise about whether the definition of best interests should be wide enough to include altruism and those critical interests of care, concern and commitment to the people and ideas that give meaning to a person’s life. If the narrow interpretation is accepted, it is probably better termed self-interest. If the broader interpretation is accepted, it very close to the concept of substituted judgment.

Jess is a woman of 36 who has two children, aged six and eight. She has an acquired brain injury from a car accident. She lives in a country town in Victoria. Her marriage broke up following the accident and her children live with their father in the same town. Jess is unable to drive and life has been limited since the accident but she still sees her children after school and at the weekend and has many friends in the town. Jess’ doctors have suggested that if she moved to Melbourne there would be better rehabilitation available to her. Jess’ parents live in Melbourne and would be happy for her to live with them. This would mean, however, that she would have much less involvement in the lives of her children and would be more dependent on her parents in a number of ways. Would the principle of personal and social well-being provide clearer guidance for any intervention under the Act than that of best interests?

Concepts can take on different meanings over time and common usage interpretation may differ from the original intent of the legislation. The Public Advocate suggests that this has happened in the Act. In common usage, best interests has come to be associated negatively with paternalism which itself is perceived negatively as being antithetical to individual rights. Whilst this may be a misinterpretation of the Act, it creates a problem in community understanding and acceptance of the legislation.

The Public Advocate proposes that this principle be replaced by the principle of personal and social well-being.

5.3 The wishes of a person with a disability are wherever possible given effect to



This principle is one of the three foundational principles of the current Act. It expresses the perspective that the current wishes of the person are of particular importance and should prevail wherever possible. In practice, it generally operates to counterbalance the principle of “best interests”. Thus, the wishes of a person would not be given effect to if they were not considered to be in the person’s “best interests”. It is interesting to note that in Section 28(1), Exercise of authority by a guardian, priority is given to the best interests principle. In section 28(2)(e) a guardian is to act in the best interests of the represented person by, *inter alia*, acting “in consultation with the represented person, **taking into account, as far as possible, the wishes of the represented person**”. This is a distinct change of emphasis from the principle in the Objects of the Act of **giving effect to the wishes of the person with a disability wherever possible**.

The Public Advocate considers that her proposed framework of complementary Objects of the Act removes the need for this principle to be articulated in the Objects. Instead, the Public Advocate suggests that it be retained as a subsidiary principle to personal and social well-being, with the same wording of the current Act.

6. Omitted alternative principle of autonomy

In this section, brief consideration is given to the principle of autonomy. After careful consideration, this principle has not been included in the Public Advocate’s proposed Objects.

The concept of autonomy has its basis in the Enlightenment, most particularly in the philosophy of Kant, where it emerged as a challenge to the excessive power of Church and State structures in the lives of ordinary citizens. It is now more often referred to in the context of the rights of the individual to make his or her own decisions over and against others in their family or community. In Kant’s philosophy, autonomy is based on the human capacity for reason. Not everyone has the level of capacity necessary to be able to act autonomously in all areas of their life but unfortunately, the level of capacity needed is rarely considered in the literature. Nor are the implications considered for those not having the capacity to act autonomously.

A simple definition of autonomy as “the right to make your own decisions” is frequently used within the disability community.¹⁶ A further right claimed on the basis of autonomy is “the right to make bad decisions”. Whilst the complaint of some in the disability community that it is only people without disabilities who are “allowed” to make bad decisions is deeply felt and has merit, to base these rights claims upon the idea of autonomy appears to be an over-simplification and too great a distortion of the classic principle. For similar reasons it is misleading to describe the revocation of a guardianship or administration order as restoring a person’s autonomy.

The right to autonomy is better understood as the right of a self-reflective person, free from undue influence or coercion, to determine the overall direction of his or her life, in keeping with her own reasonably consistent set of values. Even this definition avoids the question debated by philosophers of whether the idea of autonomy is a morally neutral concept or whether it is

¹⁶ See, for example, www.inclusion-international.org/site_uploads/.../Families%20Workshop.doc



premised on the assumption that a person's value system should be consistent with generally accepted moral principles.

Paul is a young man who has been brought up as a member of a closed Christian sect and is the fourth of seven children. He has a mild intellectual disability but he is able to make most decisions for himself. Paul also has significant health problems. His father and two of his siblings have left the sect and he has no contact with them because this is forbidden by his faith. His father says that he is worried about whether Paul is receiving adequate health care because the sect relies on faith healing. He also says that Paul wants to see his family members who have left the sect. However, Paul also wishes to remain living with his other family members and to attend his church. Can Paul be autonomous in these circumstances? Is autonomy an appropriate principle to consider in this situation?

7. Principles for guardianship

The Public Advocate suggests that the framework of the current s28 should be retained but the over-arching principle and inclusions should be amended as follows:

Exercise of authority by a guardian

- 1) A guardian must act in a way that promotes the personal and social well-being of the represented person.
- 2) Without limiting subsection (1), a guardian promotes the personal and social well-being of a represented person if the guardian acts as far as possible:
 - a) as an advocate for the represented person;
 - b) to foster the represented person's dignity;
 - c) to make the judgments and decisions that the person would have made after due consideration if able to do so, to the extent that this would not cause him or her undue harm;
 - d) in consultation with the represented person, taking into account as far as possible his or her wishes
 - e) in consultation with important people in the life of the represented person
 - f) in a way that fosters the person's positive relationships, friendships and connections with others;
 - g) to preserve and foster the person's capacity for self-determination;
 - h) so that the person lives in safety and security and is protected from abuse, exploitation and neglect;
 - i) so that the person is able to participate in and contribute to the community to the extent that s/he is able and wishes to do so;
 - j) with respect for the person's cultural and/or ethnic values and circumstances.

In this proposal, the over-arching principle of personal and social well-being replaces best interests for the reasons presented above. Subsection 2(a) is retained to emphasise that advocacy is integral to guardianship and that guardians have a responsibility greater than that of a disinterested decision-maker. Subsection 2(b) repeats the key legislative value of fostering human dignity. Subsections 2(c) to 2(g) guide how a guardian should respond to the represented person and those



close to them when carrying out the responsibilities of the role. Subsections 2(h) to 2(j) guide the guardian on the questions of the person in relation to their community.

It is not suggested that all the proposed guardianship principles will be relevant to every guardianship case. They should not be unreasonably arduous or be treated as a checklist: a guardian should not be required to acquit herself/himself against each of them in justifying a decision. Instead they provide guidance to a guardian of what may be included in promoting the personal and social well-being of the represented person whilst acknowledging that in particular circumstances quite different considerations may be applied (“*without limiting subsection (1)*”).

The proposed guardianship principles aim, like the proposed objects of the Act, to be integrated and complementary.

Kyle is 21 years of age and has an intellectual disability and Prader-Willi syndrome. One feature of this condition is the inability to control eating. Unless others control the person’s eating, people with Prader Willi usually die at an early age.

Kyle is seriously overweight. His condition is life threatening and the medical advice is that he may die even if a strictly controlled eating program is now put in place. Kyle is very lonely and can no longer move about easily. His relationship with his parents is very strained. He says that food is the only pleasure in his life even though he can never experience the feeling of having eaten to fullness. He understands that he will almost certainly die from his condition but says that he accepts this and does not want to make any changes.

He has been assessed as not being clinically depressed. A guardian has been appointed to make decisions for him and must decide whether it is in Kyle’s interests to impose severe restrictions on him in the hope that his life can be saved.

The guardian knows Kyle’s expressed wishes and has talked extensively with him. If she is to act in a way that will promote Kyle’s personal and social well-being she must act in consultation with the people who are important to him, in such a way that he can participate in the community, so that he is protected from abuse, neglect and exploitation and with consideration of the judgment he would make if he were able to make reasonable judgments for himself. The guardian must also consider what is practical and realistic in making decisions for Kyle.

After serious consideration and consultation with Kyle and with others involved, the guardian decides to move Kyle into a community residential unit run by the Department of Human Services where his eating will be controlled and he will attend a day program with meaningful activity that he enjoys. He is under strict medical supervision by specialists in this area. In this way, she hopes to improve both his personal and his social well-being. In making this decision, the guardian has had to carefully consider the balance of factors contributing to Kyle’s personal and social well-being.

A year later, Kyle is still alive and has lost half his body weight. His relationship with his parents has improved greatly. The restrictions on his eating will always be necessary and unwelcome to him but he enjoys the company of those with whom he lives, the many activities that he can now be involved in and he says he is glad he is still alive. It can be



concluded that the guardian in this case promoted the personal and social well-being of Kyle.

8. Conclusion

The fundamental questions posed in the Introduction to this document have guided the development of these principles and values. With the inevitable risk of oversimplification, the Public Advocate suggests that the beginnings of answers to the four questions can be summarised as follows:

The essence of our common humanity is that, by being born into the human community, we have equal inherent dignity and human rights that are maintained and enhanced through our social interactions and relationships with others.

We are more likely to live together in peace and harmony if our social, political and legal systems are based on a shared ethical understanding of what is good and right, by providing adequate attention to the protection of all people and by maintaining on-going civil discourse and education on these and other questions around justice and community.

Society owes people with disabilities acceptance as people of equal worth and dignity together with the support, resources and encouragement to have the capabilities to lead a life of dignity and human flourishing.

It is justifiable to override the will of a person where the person has diminished capacity and there is a serious risk to his or her health and welfare.

The Public Advocate hopes that this document contributes to an understanding of the overall purpose of guardianship legislation: fostering a just and civil society that values, respects, protects and promotes the dignity and well-being of people with a disability.