



Submission to the VLRC Guardianship Consultation Paper

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INTRODUCTION

Carers Victoria is the state-wide peak organisation representing people who provide unpaid care. We represent more than 700,000 family carers across Victoria – people caring for ageing parents, children with disabilities, and spouses with mental illness or chronic health issues. Last financial year, Carers Victoria provided over 20,000 direct services to family carers.

Carers Victoria is a member of the national network of Carer Associations, as well as the Victorian Carer Services Network. It is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership based organisation. Our members primarily consist of family carers. They play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

The focus of this submission

In this submission we continue to advocate with and on behalf of caring families where a member has a significant lifelong decision making disability. We make particular reference to the needs of ageing parent carers and their adult off-spring.

Recent improvements in medicine and better overall care have resulted in the first generation of adults with significant decision making disabilities outliving their parents. There is currently an estimated 3024 ageing parent carers in Victoria. This number is anticipated to increase to 4008 by 2012 and to 9144 by 2023.¹ There is a severe and chronic lack of supported accommodation for adults with decision making disabilities. Those who are living with family are frequently not recorded in waiting list statistics. As adults with decision making disabilities and their parents age so does the broader Victorian community. There will be a shortage of both informal and formal carers over the coming decades.

We believe that many siblings want to contribute to the ongoing support of their adult brother or sister. The current Guardianship and Administration Act must be reformed to ensure appropriate representation can be undertaken by families of adults with significant decision making disabilities and to support and facilitate succession planning by ageing parent carers. A new Act must provide a system that facilitates and supports the ongoing involvement of siblings, extended family and friends in the representation and care of adults both prior to and after their parents choose to relinquish the role, are no longer capable of providing care and support, or die.

The central proposals in this submission are the need to differentiate arrangements for people with different disabilities, and the need for formal representation mechanisms for families of people with life long decision making disabilities. There is a need for the legislation of Family Meetings by OPA case worker/mediators as outlined in 'About Section 4'.

People with significant lifelong decision making disabilities and their ageing families are a priority issue for Carers Victoria. We have advocated for them across all levels of government and in a variety of social and public policy forums. We will continue to advocate for them following the release of the Commission's final report.

Carers Victoria has addressed many but not all of the questions in the Consultation Paper as outlined below.

In addition we have addressed issues around the interface of guardianship laws and mental health laws, as a consequence of its inclusion in the Consultation Paper.

Contact with family carers which informs this submission

2009

- 29 July. Carers Victoria held a consultation with ageing parent carers in Crib Point to explore their experience and understanding of the *Guardianship Act 1986*.
- 18 August. We met with a private provider of administration.
- 8 September – 20 October. We delivered 4 X 6 hour *Planning for the Future* sessions to ageing parent carers at Alkira Adult Day Training Service in Box Hill.
- 25 September. Carers Victoria submitted to the Victorian Parliamentary Inquiry into Powers of Attorney. We proposed that many adults with lifelong intellectual disabilities should be able to be supported to make Enduring Powers of Attorney and that the Inquiry could introduce procedural reforms to make this possible and safe.
- 17 December. Carers Victoria and Marianne Dalton (an ageing parent) appeared before the Victorian Parliamentary Inquiry to provide verbal evidence.
- 25 September. Carers Victoria submitted to VLRC review of Guardianship
- 5 October. Carers Victoria submitted to The Role of VCAT in a Changing World. We highlighted the difficulties caring families have with VCAT processes, and the attitudes expressed by many Tribunal Members. We called for better training of Members and procedural changes to allow people without capacity to appear.
- 21 October. We attended Gippsland Carers AGM and Forum on Guardianship.
- 19 November. We attended the VLRC Disability reference committee meeting at the VLRC.

2010

- March - the VLRC released a Guardianship Information Paper.
- 10 February – 1 April. We delivered 4 X 6 hour *Planning for the Future* sessions to ageing parent carers at Nadrasca Adult Day Training Service in Nunawading.
- 8 April. Carers Victoria and VLRC co hosted consultations with ageing parent carers in Hastings.
- 6 May. Carers Victoria and VLRC co hosted consultations with ageing parent carers in Melbourne.
- 20 May. Carers Victoria attended the VLRC Disability reference committee meeting at the VLRC.

- 25 May. We attended the Gippsland Carers Forum on Reform of the Guardianship and Administration Act 1986.
- 27 May. Carers Victoria submitted to the VLRC
- 29 June. Carers Victoria submitted to the Senate Community Affairs Committee, Planning Services for People Ageing with a Disability and their Caring Families.
- 8 July– 8 October. We delivered 4 X 6 hour *Planning for the Future* to participants in the Respite for Older Carers at Respite Connections in Footscray.
- 13 September –25 October. We delivered 4X 6 hour sessions on *Transition to Adulthood* to parents of teenagers with intellectual disabilities at Western Interchange.
- 9 November. A 2 hour session on Enduring Powers of Attorney was delivered to carers in Naree Warren.
- 13 September –25 October. We delivered 4X 6 hour sessions on the *Transition to Adulthood* to parents of teenagers with intellectual disabilities attending Marnebek in Cranbourne.
- 7 October. We delivered 1 X 3 hour session on Succession Planning to siblings and extended family members of adults with lifelong decision making disabilities.
- 29 November, Carers Victoria made a verbal submission to the Senate Community Affairs Committee, Planning Services for People Ageing with a Disability and their Caring Families.

2011

- 18 March. VLRC released the Guardianship Consultation Paper.
- 24 March. Carers Victoria and VLRC co hosted consultations with ageing parent carers in Melbourne.
- 29 March. Carers Victoria and VLRC co hosted consultations with ageing parent carers in Hastings.
- 12 April. We attended Guardianship and Administration Act Review Consultative Committee Meeting.
- 15 April, Carers Victoria and VLRC roundtable consultation.

PARADOXES IN THE CURRENT GUARDIANSHIP AND ADMINISTRATION SYSTEM

- The legal guardianship of parents of people with lifelong severe decision making disabilities ends once their son or daughter reaches eighteen years of age. Under the current Guardianship and Administration Act and there is no clear pathway for individuals or families to ensure the interests of the person with a decision making disability are supported, represented or protected.

- Adults with significant lifelong decision making disabilities have no automatic right to a supporter or advocate when financial and lifestyle decisions are being made on their behalf.
- There is no accepted way to test a person’s capacity to make or be supported to make a particular decision in Victoria.
- Families are discouraged from applying to VCAT for Guardianship. The current law assumes that unless there are issues of abuse and neglect they have the informal power as parents to make decisions with and on behalf on their adult sons and daughters. However changes in Victoria since 1986 such Privacy Regulations and the increasing focus on risk minimisation by service providers, corporate organisations and government means that families have increasing difficulties in representing their son or daughter to third parties. There is an increasing need for the formalisation of previously informal supported and substitute decision making arrangements.
- The existing Person Responsible mechanism appears to work well in primary health care settings, however admission to acute care can trigger the need for lifestyle decisions (residential care) in which the wishes of the family and their son or daughter can be ignored. Hospitals can make applications to VCAT for a Guardianship order to ensure early discharge of the person with a disability.
- Families who apply for guardianship are routinely given only administration which is burdensome, costly and many families report, ‘dehumanising’.
- Families who are appointed administrators undertake an onerous amount of reporting for very small sums of money. Most adults with lifelong severe decision making disabilities have few if any assets and are likely to live on income support payments. The current fortnightly rate for a single adult over 21 and living at home is:

○ Disability Support Pension	\$670.90
○ Mobility allowance, standard rate	\$ 83.00
○ Pharmaceutical allowance	\$ 6.00
Total weekly income	\$379.95 ²
- When private administrators are appointed, financial *best interests* can over-ride life-style decisions. Administration is often a defacto form of guardianship and yet there is no pathway out of administration. This directly contradicts the principle of *least restrictive alternative* in the current Act.
- Administration refers to guardianship of a person’s estate³. Our consultations alerted us to numerous case examples where public administrators, operating under the principle of *best interests* have overridden the wishes of appointed Guardians and caring families. Our discussions with public administrators and family carers also revealed that administrators may have very little contact with the represented person.
- Current Guardianship law appoints guardians for a time limited or decision specific term, often during a transition in living arrangements. Once the decision has been made by the guardian and the represented person has moved guardianship lapses. In effect, the lifestyle decisions of the previously represented person are now made by the residential service provider, who becomes the de facto guardian. This is not a significant improvement on the situation to that existed in Victoria prior to the

introduction of the *Guardianship Act 1986*, when the chief psychiatrist of the institution in which an adult resided had authority to all aspects of their life.

- People with significant lifelong decision making disabilities are extremely vulnerable. Recent examples of abuse within Department of Human Services Community Residential Units⁴ demonstrate how difficult it is for them to have their abuse recognised or to seek legal redress. The maintenance of strong ongoing family relationships following transition from the family home can provide adults with an important source of practical protection of their rights and well being. It is important that the new Act provides a mechanism for families to be recognised in their supportive, co- or substitute decision making roles.
- Many adults with significant lifelong decision making disabilities who were deinstitutionalised in the 1970s and 1980s are now living in boarding houses and Supported Residential Services. Some of these people do not have supportive family relationships and are unlikely to have a supporter/advocate. Reports of poor living conditions and poor support by proprietors in these largely unregulated sectors are well documented⁵. The current pattern of decision specific and time limited guardianship appointments does not serve this population well. The new Act needs to provide a mechanism for a co-decision maker /supporter/advocate to be appointed in an ongoing capacity – for as long as the person finds it useful. This should be subject to periodic reviews.
- A feature of our consultations has been that parents report that disability services may be very antagonistic towards families advocating on behalf of their adult sons and daughters. We have had many reports of Guardians being ignored and an instance of Plenary Guardians seeking to ensure a service recognise their son's rights and entitlements' under the *Disability Act 2006*, the *Victorian Charter of Human Rights and Responsibilities 2008* and the *Guardianship and Administration Act 1986* were faced with the service concerned applying to VCAT to have their guardianship revoked⁶.
- Where no guardian is appointed, decisions can be made in the best interests of services rather than in the best interests of the person.
- Adults with impaired capacity are discouraged from attending VCAT hearings held on their behalf, and few do so. It is therefore unclear on what basis VCAT Members have been making judgements concerning their capacity, wishes and best interests.

One couple expressed it this way:

Nobody takes any notice of parents caring for their disabled child whilst still a child. Someone gives you some forms to complete, a doctor makes a certification and Centrelink eventually recognise the situation and then you are on your own. Doctors write referrals, do tests and deliver bad news. Help in any form is largely hidden from view and discovered by accident. Over the years there have been improvements but the situation remains extremely difficult. Parents cope and keep on doing so long after the child becomes an adult.

Nothing changes. The parents have from long experience learned what is best. Numerous doctors have made that very observation: "You know her best, you know what's best".

Like all parents, we will take all the advice we can get but we will continue to do as we have always done: provide the best care possible for our daughter and we will

resist with all our might any attempt to interfere with or diminish or dispute or deprive us of that right.

In places the VLRC Consultation Paper acknowledges the rights of parents but then diminishes them or ignores them completely. “We ask whether new principles should include a statement about the role of family and other support networks in a person’s life” (Chapter 7 Supported Decision Making Mechanisms).⁷

Does the Consultation Paper propose reforms that address these paradoxes?

Carers Victoria congratulates the Commission on its broad and deep investigation of the *Guardianship and Administration Act 1986*. The Commission has documented many of the paradoxes cited above. Carers Victoria believes that these issues may be most successfully addressed by empowering individuals and families, and by enshrining appropriate and proportionate checks and balances in the new Act.

The VLRCs Consultation Paper has not made clear whether or not it wants families to continue to act informally or *under the radar* until it is time to consider succession planning. While much of the Consultation Paper addresses the need to ensure that there are appropriate enablers for Enduring Attorneys to deal with third parties on behalf of the person with a disability, no provision is made to facilitate family representation of the person with a disability to those same third parties. It is unclear whether VLRC considers that families would benefit from formalising their status as supporters or advocates by seeking a VCAT hearing. The latter would have significant resource implications and could only be operationalised if families’ experience of the system in general and VCAT in particular improves significantly.

A fundamental requirement of good law making in this context is the clear *differentiation* in the new Act between the needs of and responses to adults with significant lifelong decision making disabilities and the needs of people who have had capacity as adults but develop or acquire a disability, They require different arrangements for representation while both will be largely reliant on family members.

This submission will illustrate this argument as well as address a selection of the 159 questions posed by the Commission in the Guardianship Consultation Paper 2011.

ABOUT PART 2: THE DIRECTION OF NEW LAWS

Chapter 4 Structure of New Laws

1. Do you have any general comments about the matters identified by the Commission as influencing the need for change? Are there other important matters that should affect the content of future guardianship laws?

We congratulate the Commission on its broad and far reaching investigation of need for change. We are concerned however that the Consultation Paper appears to have privileged the needs of securing the private assets of older Victorians who lose capacity

over the needs of Victorians with lifelong severe decision making disabilities who rely on others, usually family, to plan and coordinate their lives.

We would like the Commission to reconsider this conflation of needs. The new Act might contain a section that deals specifically with the needs of adults with severe lifelong decision making disabilities and their families.

Victorians with capacity have a considerable body of Trust law at their disposal to protect their assets. Adults with lifelong decision making disabilities generally have few if any assets and only statutory income. Their relationship with service providers and state apparatus' often begins at the time of diagnosis of their disability and lasts a lifetime. The formulation of a new Guardianship Act that clearly and unequivocally acknowledges families of this group as supporters/advocates/guardians has the potential to significantly improve the quality of their life across their lifespan.

Currently, disability policy and programs demonstrate a dedifferentiated approach to the needs of people with very different disabilities, and on how their needs impact on their families, friends and services providers. This is likely to be a consequence of the move from an *Intellectually Disabled Persons Services Act 1986* to the current *Disability Act 2006* which encompasses a broader range of disability types. Generalisation of policy and practices across the needs of a greater diversity of people, together with an increased focus on human and disability rights frameworks have in our view, led to a dedifferentiation of policy and practices in the sector. We believe that it is important that the new Act avoids reproducing this dedifferentiated approach.

For example, it is not clear what a rights approach means in practice for adults whose disability is such that they are unable to comprehend their rights, are not self determining, and cannot make major life decisions. It is not clear what a rights approach means to caring families of people with significant lifelong decision making disabilities, where substitute and supported decision making strategies within the family are the norm.

Policy assumptions about independent adult rights for all people with a disability, together with idealised views of how the lives of all people with a disability can parallel the challenges and opportunities of people without a disability are not helpful. They are not helpful to people with significant lifelong decision making disabilities or to their families. Assumptions about autonomy, self determination, choice and participation for all people with a disability make little sense when applied to adults with significant lifelong decision making disabilities. The assumptions contained within the disability rights discourse do not match with lived experiences of their caring families, who are the primary supporters and advocates of their adult sons and daughters affairs.

We would like to see the new Act establish a dual approach in order to satisfy the needs of both older adults who have lost capacity, as well as a smaller group of adults who have never had capacity, who experience lifelong decision making disabilities and usually experience constant family support and guidance in their lives.

It is a mistake to lump those losing their faculties and those who have been disabled from birth or an early age under the one piece of legislation. Whilst it may not have been the case in 1986 it is clear now that the main focus is firmly on the protection of the elderly as they succumb in distressing and increasing numbers to dementia and other debilitating illnesses. For those who have built a life for themselves it is obvious that systems need to be available which allow decisions to be made in accordance with their previously stated wishes or which reflect the person's preferences, interests and beliefs when they were capable of decision-making. This emphasis is not a good fit for those who have never been capable of many decisions.

Accepted modern thought reinforces the belief that all those suffering mental disability can be treated under the same principles. The United Nations Charter and government policy emphasise the rights of all individuals. Amongst its principles the Commission proposes that

“All adults are presumed to have the ability to make decisions that affect their lives unless this is shown not to be the case” (Consultation Paper – Summary, Page 15) Almost all other principles and therefore most of the recommendations are based on the first part of this whilst ignoring “unless this is shown not to be the case.” The mechanisms proposed to protect the no – longer capable are not applicable to those who have never had such capacity.⁸

The Commission must take a more nuanced approach that reflects the reality that for adults with lifelong severe or profound decision making disabilities, adulthood is ambiguous. Most rely on their families to help them enact their choices.

Carers Victoria canvassed the proposal that the VLRC recommend that the new Act contain a separate section for adults with severe lifelong decision making disabilities on 15 April 2011. This proposal has been overwhelmingly endorsed by the families we have consulted with. While Carers Victoria strongly endorses retaining the protective functions of VCAT for adults whose family may not act in their best interests, the majority of families do. We trust that the VLRC can lead the way in ensuring mechanisms are available for current and future representation for people with lifelong significant decision making disabilities.

Differentiation of policy and practice regarding this group needs to be enabling. The new Act should:

- Recognise the interdependence of people with lifelong decision making disabilities and their families
- Adopt a default position which recognises that most caring families and friends act in the interests of adults with lifelong severe decision making disabilities.
- Empower and enable informal caring relationships by ensuring a mechanism for families to represent the person with lifelong decision making disabilities to third parties as necessary.
- Support caring families to undertake the non-normative tasks associated with caring for an adult with lifelong decision making disabilities
- Empower families and friends with information about rights, their limitations, strategies for supported decision making and for promoting as much choice and participation as feasible.
- Ensure that families and adults with severe lifelong decision making disabilities can put in place arrangements for their future representation and ongoing family support, including anticipatory arrangements.
- Maximise sibling and other extended family involvement in the ongoing care of adults with lifelong decision making disabilities by providing a clear mechanism for them to take up representation roles.

- Retain mechanisms for identifying and dealing with those situations where families are not acting in the best interests of the person with the disability.
- Clearly differentiate between people who have never had capacity and people who have lost capacity.
- Be consistent with the Victorian Recognising and Supporting Care Relationships policy framework (DHS 2006)

A Proposal for Formalising Informal Representation

Carers Victoria proposes that caring families of people with lifelong decision making disabilities should have access to a mechanism to formalise their roles in representing the decisions of and advocating for the person with a disability. This may occur at transition to adulthood or a later time when representation and succession planning become issues of concern. Families need the right to apply to the Guardianship List for formal appointment as co decision makers, supported decision makers or substitute decision makers, in particular to enable them to make representation to third parties on behalf of the person with a disability and to plan succession arrangements.

Decision making about the application should maximise the participation and involvement of adults with lifelong decision making disabilities. A suitable mechanism for this could be that applicants to the Guardianship list have the option of first applying for a Family Meeting with OPA. This could occur in an environment that is familiar to the proposed represented person and be a first step in a VCAT hearing process. VCAT may find that preliminary work done to identify existing 'Circles of Support' arrangements will provide a useful methodology to identify and engage key stakeholders in formal representation. The application could include a brief summary of the proposed persons diagnosis, and prognosis where relevant.

Family Meetings facilitated by OPA case workers/mediators would:

- Gather and maintain a record of the adults 'Circle of Support' and invite them to attend the Family Meeting,
- Explain the meeting purpose and processes to invitees.

The meeting would address and document:

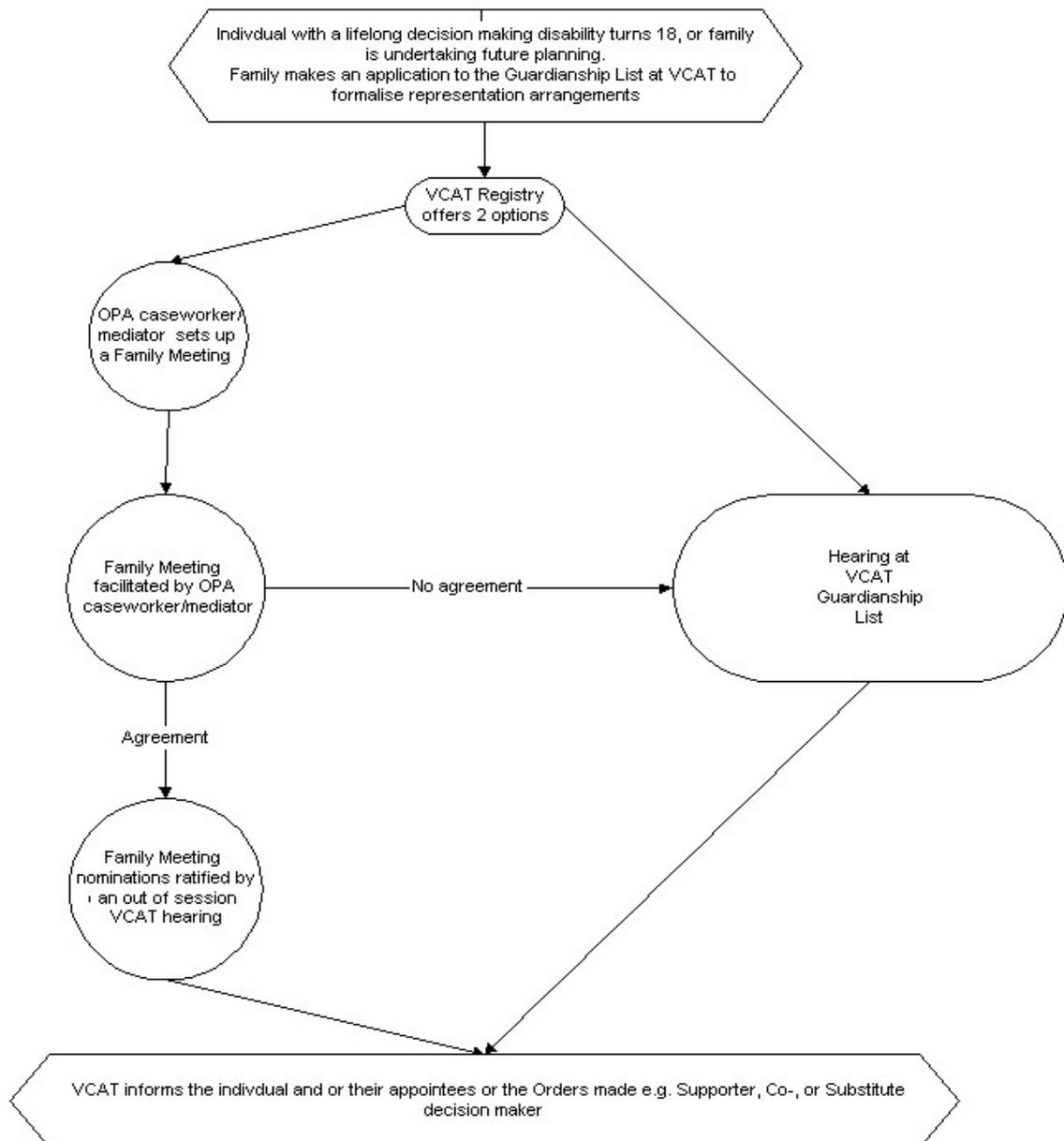
- Who is important to the person?
- What is important to the person?
- The person's most effective mode of communication.
- The education and employment history of the person.
- The representation needs or adults with significant lifelong decision making disabilities such as whether they need a substitute decision maker in some areas, a supporter in other areas, and so on. ie the sorts of decisions that they have capacity to make, those with which they need help and those issues they are unable to comprehend.
- Who is best placed to undertake the representation tasks identified?
- Who might be appropriate to carry out the role as an alternative, if that person needs a break?
- Evidence of a positive relationship between the represented person and the proposed supported or substitute decision makers.
- That the proposed supporters agree to undertake the role.

- Strategies that the person with a disability can use if they are unhappy with these arrangements or experience maltreatment.
- Succession planning arrangements. Who might take over decision making or support roles in financial, health and lifestyle matters in the long-term?
- How to activate a Succession Order.
- The support available from OPA and or other community agencies to help the people undertake their representation tasks.
- Providing nominees with details of how to re-engage OPA in the event that they are no longer able to fulfil the role/s.
- Nominate support, co- or substitute decision makers, complete a checklist for each area (lifestyle, health and medical) of the powers and limitations of each support or substitute decision maker.
- Agree on reporting and monitoring requirements.
- Make recommendations to VCAT for ratification.
- Provide information on community organisations where participants can seek further support and guidance.

Following the meeting:

- The OPA case worker/ mediator would forward details about nominated representatives to the Guardianship List at VCAT for ratification (VCAT sends Orders to both Supported or Substitute decision makers and OPA).
- Log VCAT Orders on an electronic register as well as recording the adult's 'Circle of Support' and their contact details. Only the names of decision makers, the powers conferred upon them and limitations of their powers would be accessible to third parties by logging onto an internet site, filling in the represented person's name and PIN. Corporate organisations such as banks could establish accounts with the site and be charged a fee each time they make an inquiry.
- Provide support to decision makers regarding in their anticipated role and responsibility.
- Audit reports of decision making practices.
- Initiate reviews of representation arrangements.

Diagram of the proposed formalisation mechanism



This proposal demonstrates person centred and family focused practice. It dovetails with the Commission's consideration of a pre-hearing investigation. We stress the importance of OPA undertaking the investigations as OPA employees should have expertise in relation to disability supported and co decision making. VCAT employees appear to have broader, less specific knowledge and skills.

Chapter 5: Principles of New Laws

2. Do you agree with the Commission's draft statement of purpose for new guardianship laws?

Yes, we congratulate the Commission on the proposed Statement of Purpose.

3 & 4. Do you agree with the Commission's draft general principles for new guardianship laws? Are there principles you think should be added or removed from these general principles?

The new Act needs to be directed to support family care provided in the community.

Currently:

97.5% people < 65 with severe and profound limitations live in the community,

2.5% in 'cared' accommodation,

10% live alone,

84% live with family,

3.2% live with others, probably friends.⁹

In Victoria 4 large residential institutions remain (Colanda, Sandhurst, Oakleigh and Plenty Residential Services) accommodate a total of 355 people with decision making disabilities, and there is a strong lobby to have them closed.¹⁰ The new Act therefore needs a fundamentally new focus. Care in the home will be the lived experience of the majority of users of the new Act. Their best interests and those of their families will be served by an Act that responds to and reflects this reality.

We believe that the importance of family relationships and a person's culture should appear directly under the new Act's Statement of Purpose. The lived reality of most caring families is of informal supported or substitute decision making in an environment of interconnected needs and close relationships.

The Commission will be aware that many of the problems currently encountered by family carers arise from the lack of recognition of informal caring relationships by third parties. The assumption made by the Cocks Committee in the drafting of the current Act that families could continue to *fly under the radar* no longer stands. The new Act must provide mechanisms which facilitate and formalise family roles in representing their family member to third parties (financial institutions, government agencies, corporate services) and negotiating on their behalf.

Chapter 6: Clear and Accessible Laws

5. Do you agree with the Commission's proposal that Victoria's various substitute decision-making laws be consolidated into one single Act?

Yes.

6. Do you agree with the Commission's proposal that the term 'medical decision maker' or 'health decision maker' should replace 'person responsible' in legislation? If so, which one do you prefer?

Yes, we concur with the Commission and we prefer the term 'Health decision maker'.

7. Do you agree with the Commission's proposal that the term 'guardian' should be replaced with 'adult guardian'?

Yes.

8. Do you agree with the Commission’s proposal that the term ‘administrator’ should be replaced with ‘financial guardian’?

Yes.

9. Should the terminology used for powers of attorney be better integrated with the terminology for guardianship and administration? What terms should be used?

Yes, perhaps VCAT appointments could use:

- Health decision maker,
- Lifestyle decision maker,
- Financial decision maker.

And personal appointments could use:

- Enduring Health decision maker,
- Enduring Lifestyle decision maker,
- Enduring Financial decision maker.

10. Do you have any specific ideas about how to better target education about guardianship laws towards:

- people with disabilities
- family, friends and carers of people with disabilities
- CALD groups
- Indigenous communities
- older people
- young people
- health and community sector professionals
- lawyers? And

11. Should the Public Advocate play a greater role in producing community education materials and educating the community about substitute decision making? What other bodies could play a role?

Generic community education material needs to be produced by OPA to providers of community education such as Consumer Affairs Victoria, neighbourhood houses and local councils.

Many of the particular constituencies listed above have community radio, community newspapers and peak representation bodies, some of whom are funded to deliver community education. The Office of the Public Advocate must collaborate with peak bodies to develop radio announcements, newspaper ads, education kits and session plans in formats and languages that are accessible to the constituencies being targeted. These materials must promote the options for families and individuals with decision making disabilities as well as the opportunities for adults with capacity to nominate their enduring decision makers should that they lose decision making capacity in the future. Community education campaigns will need adequate and ongoing funding to achieve the desired outcome of greater self determination for adults with decision making disabilities.

The new Act could be introduced to students of various health and allied health professions during their professional training. In-service training must be offered to professionals who work with the constituencies’ listed above through their regular providers of professional development.

We strongly recommend the targeting of schools and adult day centres attended by people with intellectual disability to improve the understanding of the new Act by teachers, trainers, and families of adults with lifelong decision making disabilities. In particular we would like to see the development and roll out of education programs targeting individuals and families at key life transition points; becoming an adult, leaving home, and succession

care planning. Carers Victoria is currently developing and delivering transition to adulthood and succession planning education programs.

12. Would an educational and awareness campaign assist the community to better understand and make use of guardianship laws?

Yes.

13. What type of data do you think needs to be collected and made available and from what bodies?

As a peak body engaged in systemic advocacy, the development and delivery of education for caring families and the provider of a state wide Advisory Line to family carers, access to good data is essential. In order to educate families and service providers about reforms to guardianship law, to monitor their effectiveness, to help us assess whether complaints of systemic abuse by families represent a particular or generalised problem, it would be useful to have access to de-identified data, aggregated for those with a lifelong decision making disability, or an acquired decision making disability on the:

- percentage of cases the affected person attends the hearing,
- aids required for their meaningful participation,
- percentage of cases where an interpreter is used at a hearing,
- percentage of hearings in which the person is legally represented, or has family and friends in attendance,
- percentage of cases that are triggered by concerns about family conflict, abuse and/or neglect,
- percentage of cases that are triggered by a need to formalise informal decision making arrangements,
- percentage of cases concerned with succession planning,
- percentage of cases that have had a pre hearing investigation,
- percentage of cases where the recommendations of the Family Meeting are ratified,
- number and types of orders made and their duration– with the publication of representative judgements,
- where hearings are held,
- basis on which the person’s degree of capacity was determined,
- material detailing the relevant expertise of Guardianship List Members.

ABOUT PART 3: SUPPORTED DECISION MAKING

Chapter 7: Supported Decision Making

14, 15 & 16. Do you agree with the Commission’s proposal to introduce new supported decision-making arrangements? Do you agree with any or all of the proposed roles of supporters and co-decision makers? What steps would need to be taken in order to ensure that these appointments operated fairly and efficiently?

Yes, we believe that this proposal supports our shared agenda of advancing the dignity and rights of people with decision making disabilities and their families. We are pleased that the Commission understands the interdependent nature of most people’s lives.¹¹ We believe that legislating new supported and co decision making arrangements will require the development of resources that make explicit the values and processes underpinning these reforms to guide caring families and others. Reform should be followed by evaluative studies, discourse amongst academic, legal and disability practitioners, the

development of expertise and publications promoting best practice approaches and outcomes.

Carers Victoria and the Commission co-hosted two round table consultations with ageing parent carers of adults with significant lifelong decision making disabilities to discuss these and other recommendations. We remain unclear as to who the Commission proposes would be able to utilise these proposed arrangements. The mother of a woman who has Down syndrome, a mild intellectual disability and good verbal communication felt that co decision making would benefit her daughter. Other parents whose adult children have poor verbal communication skills but who are able to make their wishes known using assisted communication were left unclear as to whether or not reformed representation arrangements would be available to assist their situations.

17. Do you agree that the Public Advocate should not be a ‘supporter’ or a ‘co-decision maker’?

Yes, to appoint the Public Advocate a supporter or co-decision maker would diminish the intent and veracity of these reforms. Both supporter and co-decision maker roles require a strong, close and long term relationship with the person. Neither the Public Advocate nor her advocate guardians are able to fulfil these criteria.

18. Do you think that the Public Advocate should play a role in training supporters and co decision makers and monitoring supported decision-making arrangements?

Where family members are caring for an adult with significant lifelong decision making disabilities we think that the Public Advocate should, in consultation with peak advocacy bodies, write training materials. It may also be useful for the Public Advocate to offer training for trainers, but that the actual training should be delivered by recognised and trusted community educators.

We do however strongly support the OPA telephone advisory service and its promotion to all parties in this system.

19. Should the Public Advocate establish and coordinate a volunteer support program to assist people who do not have family or friends willing and able to take on these roles?

Yes, there are many adults with decision making disabilities who have no family or friends suitable to undertake these roles. Community volunteers are preferable to guardianship under OPA and/or Administration by the State Trustees or similar. Many do an excellent job.

We would also like to see the Commission address the issue of intergenerational caring. The Consultation Paper does not clearly define the role of a ‘second generation carers’. Sibling and other family carers will need a clear pathway for ongoing involvement scaffolded by support and an accessible system. Siblings may not have the tenacity of their parents and without a more family friendly system in place; parents will be reluctant to ask their other children to take up representation roles. We believe it is important that the new Act facilitates ongoing family and sibling involvement in the lives of people with significant lifelong decision making disabilities. The Commission heard at a number of Roundtable Consultations that the current system is so unwieldy that parents are unwilling to ask their other adult children to take over the role supporter/advocate despite knowing that they are both willing and best placed to do it well.

20. Should ‘supporter’ or ‘co-decision-maker’ arrangements apply to financial matters, or be limited to personal decision making?

The application of the current Act is hampered by the different way guardianship and administration is conferred. This issue was explained and illustrated with case examples in our first submission to the commission in May 2010. To disallow supporter or co decision-maker arrangements to apply to financial decisions would reproduce this anomaly in the new Act.

21. Do you agree with the suggested training and monitoring roles for the Public Advocate? Are there any other functions the Public Advocate should perform in relation to supporters?

The existing role of the Public Advocate should be expanded judiciously. The Commission is looking to expand the role of the Public Advocate to be the designer, educator and monitor of new supported and co decision making arrangements, while retaining its function of alternative guardian. At roundtable consultations with family carers problems with the Office of the Public Advocate have been reported.

Resource constraints on the Public Advocate who works with many of Victoria’s most vulnerable and disenfranchised citizens means that at times sourcing accommodation at a time of a crisis will rely on good professional relationships between hospital social workers, OPA guardian/advocates, Department of Human Services and residential aged care services. Decisions may be made expediently rather than with careful collaborative planning involving the person with a disability and their family.

The appointment of independent monitors could be considered.

22. What safeguards do you think are necessary to protect supported people from abuse?

Abuse is most likely to occur in situations of poverty, disenfranchisement, exclusion, and isolation. The Commission may profitably consider how best to ensure that individuals with a significant lifelong decision making disability and their families may be supported, encouraged and included in the Victorian community.

We observe that families who have a member with a significant lifelong decision making disability are likely to encounter more observation and scrutiny by health, allied health and disability services than almost any other single family cohort, except Indigenous Australians and Torres Strait Islander peoples.

We believe that the ongoing involvement of a range of significant others; parents, siblings, other relatives and friends will provides adults with significant lifelong decision making disabilities with substantial protection from abuse.

Where abuse by families or others is suspected we recommend the retention of current protective mechanisms where interested parties can make an application to VCAT. In order for these issues to be resolved all parties to a hearing need to experience an inquisitorial rather than adversarial approach This would be best supported by the establishment of a protocol whereby OPA conducts a pre hearing investigation prior to a hearing date being set. (See Formalising Informal Representation above)

ABOUT PART 4: PERSONAL APPOINTMENTS

Chapter 8: Personal Appointments

23. Should all enduring powers be activated at the same time? If so, when should this occur?

No, the skills and abilities required to evaluate information in relation to medical treatment decisions, financial decisions and lifestyle decisions are different. We are aware that many ageing parent carers would like to be able to activate enduring powers prior to their loss of capacity in order to ensure that they are able to teach their attorney(s) how and why they do things and to encourage their attorneys to make decisions in relation to both the parent and the person with a disability.

24 & 25. Should parents and carers of children with disabilities be able to file a document with VCAT that states their wishes about future guardianship or administration arrangements? And 25. Should these wishes be a factor VCAT is required to consider when it appoints a substitute decision maker or supporter?

The urgent requirement for a workable, accessible and affordable succession planning mechanism was the subject of a great deal of discussion in our first submission to the Commission. The importance of this issue for caring families was reflected in joint roundtable consultations with ageing parent carers. We are pleased that the Commission has given this issue consideration. The proposal that parents lodge a statement with VCAT outlining who they would like to take up a supported, co-, or substitute decision making role and VCAT considering this document when the parent dies or loses capacity is merely a formalisation of the current situation. Currently it is suggested to parents that they include a paragraph in their will outlining who they would like to take over the caring role to guide VCAT in its appointment of a guardian or an administrator.

In keeping with the Commission's own commitment to preserving the dignity and promoting the participation of people with significant lifelong decision making disabilities in the appointment of supporter, co or substitute decision makers we again recommend the need for formal mechanisms for legitimising family representation and the use of family roundtable meetings to collaborate on representation arrangements.

Procedures for families wanting to launch a Succession Order could be developed by VCAT. Applications could be the subject of a pre hearing investigation by OPA who convenes a Family Meeting involving family, friends and others with an ongoing interest in the person's life. (See above) How and in what circumstances the Succession Orders will be activated could also be determined.

The OPA representative could then recommend that VCAT ratify a Succession Order with notification sent to all participants. When the Succession Order is activated the names and powers of support and substitute decision makers would be become active on an electronic register and accessible online. A represented person's name and PIN could be provided to third parties on request in order to verify the authority of the individual with whom they are dealing.

26. Should the number of enduring appointments be reduced from three to two by removing the option of appointing an agent under the *Medical Treatment Act 1988* (Vic) and by requiring people to use an enduring guardianship appointment for medical treatment matters?

No

27. Should there only be one type of appointment with a range of possible powers?
Yes with potentially different appointees for different powers.

28. Should an online registration system be created for enduring powers?
Yes.

29. Which organisation should hold the register?

-

30. Should registration be voluntary or compulsory?

-

31. If registration is compulsory, what effect should this have on the validity of unregistered appointments?

And if registration is compulsory, what impact will it have on increasing the difficulties for informal family decision making?

32. When is the best time for registration to occur?

-

33. Who should have access to the register? What safeguards could be put in place to protect an individual's privacy while allowing appropriate people to access it?

-

34. Should it be necessary to notify a public authority and/or various other people when a power of attorney is activated?

-

35. Should a donor be able to specify that certain people should be notified when a power of attorney is activated? Who should be notified and why?

Yes. It can be particularly important that all family members and friends are notified of changes in the person's circumstances and how decision making will be managed.

36. How might notification work in a situation where a person's capacity is fluctuating?

-

37. Should a donor also be able to specify that people/bodies should not be notified when a power of attorney is activated?

Yes.

38. Do you think that the law concerning instructional medical directives should be set out in legislation?

Yes.

39. Do you think it should be possible to make statutory instructional directives about things other than medical treatment?

Yes.

40. What types of things should it be possible to include in an instructional directive?

Recording lifestyle matters, even if they are unachievable will broadly indicate the donor's preferences. Advice about framing achievable instructional directives can be made available.

41. Should the wishes expressed in a document making a personal appointment be binding, or should they merely be matters that the personally appointed decision maker must consider?

The rapidity of systems change suggests the 'must consider' option is likely to be best.

42. If the wishes are merely one of the matters that the personally appointed decision maker must consider, should that person be required to provide written reasons for departing from them?

No

43. If the wishes are binding upon the personally appointed decision maker, should it be possible to override them in some circumstances? Do you think VCAT should perform this role and (if so) in what circumstances?

No.

44. Should the same rules apply to both enduring guardians and enduring attorneys (financial)? If not, in what circumstances should they differ?

Yes.

45. Should there be sanctions for overriding an instructional directive in a way that does not comply with the law? What should these sanctions be?

Yes.

46. Should there be an electronic registration system for advance directives?

Yes.

47. Should registration extend to medical and lifestyle instructional directives?

Yes, especially medical directives.

48. Should registration be voluntary or compulsory?

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49. Are there issues that arise in relation to the registration of advance directives that differ from those that are relevant when considering the registration of personal appointments?

-

ABOUT PART 5: VCAT APPOINTMENTS

Chapter 10: VCAT Appointments and Who Are They For?

50. Do you agree with the Commission's proposal that disability should no longer be a separate criterion for the appointment of a substitute decision maker, but that it should be necessary for VCAT to find that a person is incapable of making their own decisions (*or being supported to make their own decisions*) because of a disability before it can appoint a guardian or an administrator?

Yes. We encourage the Commission to differentiate between different types of disabilities in the new Act, particularly between physical and sensory disabilities and decision making disabilities. We suggest that the new act require VCAT to find that an adult has a significant decision making disability before it can appoint a guardian or an administrator. The criteria should include reference to including the use of supported decision making in determining capacity.

51. Do you agree with the Commission's suggestions for capacity principles (Option A) and a legislative definition of incapacity (Option B) in order to provide legislative guidance on how to determine when a person is unable to make their own decisions? Are there additional or other ways to provide this guidance?

Yes. We agree with the Commission's suggestions to use options A & B to provide legislative guidance. The regular publication of findings and the development of case law in relation to the operation of these principles would provide further guidance to all those with an interest in this area of law.

52. Do you agree with the Commission's proposal (Option B) that new guardianship laws should allow VCAT to appoint a guardian or an administrator for a person when it is satisfied that the person is unable to make (or be supported to make) their own decisions because of a disability—and is unlikely to regain or achieve that capacity—and might have some future need for a guardian or an administrator?

This proposal appears designed to address the concerns of parents of adults with significant lifelong decision making disabilities. We are unclear about how it fits in with the appointment of supported and co decision makers. If adults with significant lifelong decision making disabilities are deemed at a VCAT pre hearing family meeting to lack the capacity to utilise co and support decision making arrangements then the outcome of the pre hearing investigation should be the appointment of substitute Health, Financial and Lifestyle Decision Maker(s) whose authority is ratified by VCAT. Unless otherwise indicated, ongoing family or friend appointments should be made. Such appointments should be registered.

Chapter 11: Age

53. Do you agree with the Commission's proposal (Option C) to lower the age limit of the *Guardianship and Administration Act 1986* (Vic) to 16 and to raise the age limit of the *Children, Youth and Families Act 2005* (Vic) to 18?

Yes.

54. Is there a risk that young people may not have access to the same services that are currently available if the Commission's proposal is adopted? What could be done to manage this risk?

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Chapter 12: The Distinction between Guardianship and Administration

We are concerned by aspects of confusion in the practice of public administrators and detailed them with case study illustrations in our first submission to the Commission. We anticipate the current lack of practical distinction between the roles of Guardians and Administrators will continue as the disability sector undergoes major reforms. In particular the adoption of self directed or self managed care may heighten the number of issues which arise from the lack of representation rights of parents as Administrators or Guardians in dealing with third parties. The Productivity Commission's Draft Report into Disability Care and Support (2011) sets out a model of self directed and self managed funding and incorrectly assumes that parents are both guardians and administrators of adult children with decision making disabilities.

55. Should the current distinction between guardianship and administration be retained? If so, do you agree with any of the options (A (i)–(v)) described by the Commission?

We think not. Option B which allows the appointment of single or several decision makers with specified powers may be more enabling for caring families.

56. Do you agree with any of the suggested ways to manage the overlap between the powers of guardians and administrators? Are there any other ways to manage this overlap?

The specification of powers of administrators or guardians to allow VCAT to make clear and specific orders is desirable. Where there are several decision makers, the development of clear protocols and procedures between them and increased training may assist.

57. Should new guardianship laws guide VCAT about how to choose between family members and the Public Advocate when appointing a guardian or between family members and State Trustees (or some other professional administrator) when appointing an administrator? If not, how could this issue of recognising existing family relationships be addressed?

Yes, family meetings and joint 'problem solving' in family meetings may achieve family agreement about family members who are willing and capable of undertaking the role of guardian and or administrator. They would also be a means of identifying potential risk in family appointments. For people with significant decision making disabilities who have positive, supportive relationships with their families, family appointment should be the default position.

Chapter 13: Powers of Guardians and Administrators

58. Do you agree with the Commission's proposal (Option A (iii)) that new guardianship laws should contain comprehensive lists of the decision-making powers that can and cannot be given to a guardian and an administrator?

Yes, this option would provide clarity to all involved and could be used to protect the rights of adults with significant decision making disabilities where necessary.

59. If yes to Q 58, what decisions should a guardian be able and unable to make?

We support the use of a tick box checklist which is worked through at a VCAT pre hearing family meeting. Families could suggest any other powers that might reasonably be needed and VCAT could ratify the list in its Order.

60. If yes to Q 58, what decisions should an administrator be able and unable to make?

We agree that administrators should be unable to make the decisions set out in paragraph 13.113.

61. Do you believe that any of the other options are a better way of dealing with the decision making powers that a guardian or an administrator could or could not be given?

No.

62. Should it be possible for VCAT to order that a guardian or an administrator have the power to make decisions about any of the following matters:

- whether a represented person should continue to hold a driver licence
- a will by the represented person
- organ donation by the represented person?

Vic Roads Medical Review assists Victorians by assessing their fitness to drive under the Road Safety Act 1996. It has a role in license cancellation.

There is a need for a mechanism which supports people with decision making disabilities and their families in the preparation of a will for the represented person. Current Intestacy

rules, based on 'blood relationships' risk assets being distributed to relatives who have never had a close and positive relationship with the person with a disability.

The Person Responsible (usually family) should be able to consent to organ donation.

63. Should new guardianship legislation extend or clarify the provisions in section 50A of the Guardianship and Administration Act 1986 (Vic) which permit an administrator to make small gifts on behalf of a represented person in limited circumstances?

Yes, exchanging gifts is an important part of family and community life.

64. Should new guardianship legislation alter or clarify the anti-ademption provisions in section 53 of the Guardianship and Administration Act 1986 (Vic)?

-

65. Should new guardianship legislation enable State Trustees to be given the same powers as those of other administrators?

-

66. Who should conduct litigation on behalf of a represented person?

Litigation should be on the list of powers provided to guardians and administrators. Where there is litigation to be pursued VCAT should decide who is better placed to undertake the task and likely to achieve a good outcome for the represented person. Good outcome in this context should be holistic and requiring equal consideration of *quality of life* and *financial best interests*.

67. Should it be possible for a court or tribunal to order that an administrator or guardian who conducts litigation on behalf of a represented person is personally liable for some or all of the costs of that litigation?

Yes, if VCAT feels that the litigation may not succeed.

68. Should new guardianship laws permit VCAT to authorise a guardian, or other person, to use some force to ensure that a represented person complies with the guardian's decisions?

Yes.

69. If yes to Q 68, do you agree with the additional safeguards proposed by the Commission?

Yes.

ABOUT PART 6: STATUTORY APPOINTMENTS

Chapter 14: Automatic Appointments—the Person Responsible

70. Do you agree with the Commission's proposal (Option B) that the hierarchy for automatic appointees, as currently set out in section 37 of the *Guardianship and Administration Act 1986* (Vic), should be retained?

Yes.

71. What alterations (if any) should be made to the list?

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72. Do you think new guardianship legislation should require an automatic appointee to take a substituted judgment approach to decision making?

Yes, but supported and co decision making also have a place.

73. Do you think that new guardianship legislation should contain additional measures for scrutinising the decisions made by automatic appointees? If so, what should those measures be?

No. We believe there are adequate protections in place if the person's best interests are not well served.

Chapter 15: Informal Assistance — Admission into Care

74. Do you think there should be specific laws about people being admitted to and remaining in residential care facilities in situations where they do not have capacity to consent to those living arrangements but are not objecting to them?

Yes. We think that relying on informal arrangements through family relationships and Enduring Powers works well generally. It would work better if families of people with a lifelong disability had access to a mechanism for formal representation.

In the current situation where parents have no formal representation or advocate status, the need for safeguards for the person with a disability is demonstrated when admission to care is driven by the need for early discharge from an acute setting and a time limited VCAT Guardianship arrangement. People with a disability and their families can be disempowered as a consequence of 'system pressures.'

It is also important to safe guard against residential service providers becoming the de facto guardians once admissions are made and where people have not been able to appoint an enduring lifestyle or financial decision maker. The development of a means of formal family advocacy and representation will resolve this problem and encourage ongoing partnerships with families in the interests of the person with a disability.

75. If yes, do you agree with the Commission's Option E that new guardianship legislation should extend the automatic appointments scheme to permit the 'person responsible' to authorise living arrangements in a residential care facility in these circumstances if there are additional safeguards?

Yes. Particular safeguards are needed for the notification and review of decisions where entry into residential care is levered from an acute setting without family agreement.

76. If the automatic appointment scheme is expanded to cover these circumstances, do you agree with any or all of the possible safeguards suggested by the Commission? Are there any other safeguards that should be introduced?

As above.

77. If the automatic appointment scheme is expanded to cover these circumstances, should the hierarchy of automatic appointees be changed?

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78. If the automatic appointment scheme is expanded to cover these circumstances, what residential facilities should fall within the scheme?

We would like to see our recommendations adopted to cover shared supported accommodation, supported residential services, respite houses when the accommodation need is not temporary, low and high care aged care facilities.

Chapter 16: Medical treatment

79. Do you think that the definition of medical treatment should be broadened?

Yes.

80. Should a broader definition include the prescription and administration of pharmaceutical drugs?

Yes.

81. Should it include paramedical procedures, such as physiotherapy? Should it include complementary health procedures, such as naturopathy and Chinese medicines? What else should it include?

Yes.

82. Do you think a distinction should be made between minor and other medical procedures when a person is unable to consent? If yes, how should the distinction be made between minor and other procedures?

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83. Do you agree that minor medical procedures should not require substituted consent if certain safeguards are met? Do you agree with the safeguards suggested?

Yes.

84. Do you believe the law should retain the requirement that a medical or dental practitioner must notify the Public Advocate where a person responsible does not consent or cannot be identified or contacted and the practitioner still wishes to carry out the procedure? If not, are there any other safeguards that might be more appropriate in these circumstances?

Perhaps a more practical approach would be a note in the patients file and the requirement that a medical and or dental practitioner seek a second opinion that the treatment is warranted and in the best interest of the patient.

85. Do you believe the process for obtaining substituted consent to participation in medical research procedures should be the same as the process for obtaining substituted consent for medical treatment?

Yes.

86. If the process is the same, what factors should the person responsible be required to consider before giving substituted consent to participation in a medical research procedure?

The person responsible should be required to take a substituted judgement approach to consent.

ABOUT PART 7: RESPONSIBILITY AND ACCOUNTABILITY UNDER THE LAW

Chapter 17: Responsibilities

87. Does the law need to provide more guidance about the relationship between the wishes a person expresses at the time a decision is made, and any past wishes, views, beliefs and values the person has expressed?

No. Close family representatives are likely to be aware of these matters.

88. Does the law currently strike the right balance between following the wishes of the person, including those that involve risk or danger, and other important considerations such as the right of a person to be protected from harm?

Yes

89. Do you think there should be a general set of decision-making principles that should apply to all types of substituted and supported decisions?

Yes.

90. Do you agree with the Commission's proposal (Option C) that substituted judgment should be the paramount consideration for decision makers? Or, do you think that substituted judgment should be just one guiding principle to consider?

We agree with the former component.

91. Is substituted judgment relevant to supported decision making?

Yes.

92. Do you agree that new guardianship laws should specifically require substitute decision makers to act honestly and respond appropriately to avoid conflicts of interest?

Yes.

93. Do you agree that new guardianship laws should specifically require guardians and administrators to treat the represented person and important people in their life with courtesy and respect at all times?

Yes.

94. Should new guardianship laws contain the same decision-making principles for financial decisions and personal decisions?

Yes.

95. If no, how could financial decision makers be guided to balance the need for sound financial management with the principle of substituted judgment where these considerations might conflict?

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96. Should there be separate and distinct principles for medical decision making? If so, what should these principles be?

Yes.

Chapter 18: Confidentiality

97. Do you agree with the Commission’s proposal that new guardianship legislation should authorise all substitute decision makers, including automatic appointees, to have access to confidential and private information about the represented person on a ‘need to know’ basis?

Yes.

98. Do you believe that new guardianship legislation should contain a provision similar to section 101 of the *Guardianship Act 1988* (NSW) for dealing with misuse of confidential or private information?

Yes.

Chapter 19: Accountability and Review of Substitute Decision Making

99. Do you think that private guardians and attorneys should be required to lodge periodic reports about their activities with a public official?

Yes, although the level of reporting in relation to private administration should reflect the amounts of money being accounted for. Family carers of adults with significant lifelong decision making disabilities are currently required to undertake a costly and disproportionate accounting and auditing for very small sums of discretionary income. For most adults in this situation, income is a combination of the Disability Support Pension and the Mobility Allowance. We believe that families should agree on a reporting regime with an OPA caseworker at the Family Meeting where their appointment is discussed and VCAT should ratify it. In this way the majority of families who are doing the right thing would experience a very ‘light touch’ while in situations where there was a perceived need for greater help or oversight arrangements could be agreed upon and written into the Order.

100. Should people exercising substitute decision making powers be required to provide periodic declarations of compliance with their responsibilities?

Yes.

101. Who should receive and monitor the declarations?

For families caring for an adult with a significant lifelong decision making disability the form and content of these declarations could be agreed upon in a Family Meeting with an OPA caseworker. It would then become the caseworker’s responsibility to monitor them.

102. Do you think that substitute decision makers should declare an oath or sign a statement agreeing to comply with their responsibilities before they undertake their roles?

Yes, and this should be done in the context of a Family Meeting and would serve to give the meeting an appropriate sense of gravity.

103. Should there be random audits of the way substitute decision makers perform their responsibilities?

No. existing protections are adequate.

104. Who should carry out these random audits?

-

105. Should VCAT be able to order administrators and financial attorneys to repay funds that have been misused?

Yes.

106. Is there a need for more specific penalties for substitute decision makers who misuse or abuse their powers?

Yes, perhaps they could be registered on VCATs data base to ensure that they are not appointed to perform these duties on behalf of anyone else.

107. If yes, what types of conduct should warrant a specific penalty?

Deliberate neglect of their duties and responsibilities, misrepresentation of their conduct in reports to authorities, actions where they have privileged their interests over the interests of the person they are representing.

108. Should penalties for substitute decision makers who misuse or abuse their powers be increased?

Yes.

109. Should penalties be the same, regardless of whether the substitute decision makers have been personally appointed or appointed by VCAT?

Yes.

110. Should civil penalties be introduced for substitute decision makers who misuse or abuse their powers?

Yes.

111. Do you agree with the Commission's proposal (Option B) that new guardianship laws should permit merits review of decisions made by the Public Advocate as a guardian and by State Trustees as an administrator?

Yes.

112. Who should be entitled to apply for merits review of a guardian's or administrator's decision?

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113. What should constitute a 'reviewable decision'?

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114. Are there any additional steps that need to be taken to limit trivial, vexatious or repeated applications for merits review of a guardian's or administrator's decision?

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115. Should merits review of decisions by administrators be treated differently to merits review of decisions by guardians?

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116. Who should conduct merits review of decisions of public guardians and administrators?

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117. Should VCAT have the discretionary power to appoint a guardian or administrator on the condition that they complete any training requirements specified in the order?

Yes.

ABOUT PART 8: IMPLEMENTING AND REGULATING NEW LAWS

Chapter 20: The Public Advocate

Recommendations' contained within the Consultation Paper could together result in OPA being given responsibility for setting standards around supported, co-, and substitute decision making, undertaking the education of decision makers, monitoring their performance; and to be the alternative guardian. We believe a separation of powers is required. We have already canvassed our preference for the education of decision makers to be the responsibility of peak advocacy bodies. We would also like to see the focus shift from 'monitoring' to 'supporting' families where a member has a significant lifelong decision making disability. We provide some suggestions as to how this could be achieved below. Greater interference in the lives of caring families may be a perverse outcome of the new Act. Whilst it may encourage caring families to formalise their decision making role in order to overcome problems they encounter with third parties such as banks, service providers, medical and allied health professionals etc., they are likely to find themselves subject to greater and unwelcome scrutiny, more paperwork and invasive random audits.

Our recommendation of the use of family meetings and a caseworker role for OPA employees will have resource implications. We suggest individuals who have private assets and who have lost capacity without availing themselves of the opportunity to appoint enduring decision makers incur a fee for involving OPA and to make these appointments and for VCAT to ratify them. These fees could be used to subsidise OPA's work with adults and families where a member has a significant lifelong decision making disability.

118. Do you believe the Public Advocate's investigation function should extend beyond cases concerning guardianship and administration?

Yes.

119. Do you think the Public Advocate's investigatory powers should be clarified so that she can require people and organisations to provide her with documents and attend her offices to answer questions?

Yes.

120. Do you think the Public Advocate should have the power to enter private premises with a warrant issued by a judicial officer when there are reasonable grounds for suspecting that a person with a disability has been neglected, exploited or abused is on those premises?

Yes.

121. Do you think it is necessary to protect the anonymity of people who provide the Public Advocate with information about the possible abuse, neglect or exploitation of people with a disability?

No. People providing information should be accountable for it.

122. Should the Public Advocate be able to take civil penalty proceedings against people who have allegedly breached guardianship legislation?

Yes.

123. Do you support clarifying the Public Advocate’s individual and systemic advocacy functions in guardianship legislation?

Yes.

124. Do you think that the legislation should include principles to guide the Public Advocate when undertaking her advocacy functions?

No.

125. Do you think that the Public Advocate’s functions in relation to community advocacy are necessary?

Yes.

126. Do you agree that the Public Advocate should continue to be both the guardian of last resort and an advocate?

Yes.

127. Should the Public Advocate be responsible for training and supporting private guardians?

We support the Public Advocate producing training materials in collaboration with peak bodies and providing training to trainers, but not their training of private guardians, administrators, co or supporter decision makers. We strongly support the continuation of the Public Advocates Advisory Line.

128. Should the Public Advocate be responsible for monitoring the activities of all or some private guardians?

Yes.

However, we have consistently argued for the introduction of Family Meetings involving a representative of the Public Advocate. A logical part of the discussion would be the ability of the representative to come to an agreement with the family how their performance is to be supported and if required monitored. For this to happen OPA would have to be given a range of monitoring powers, but we would anticipate their judicious use.

129. If so, how should any monitoring activities be performed?

The OPA employee organises and facilitates a Family Meeting, sends recommendations to VCAT for ratification and makes an agreement with those present as to how their performance can be supported and monitored if required. This person should become the point of contact for the family with OPA, in a caseworker role. They should be responsible for uploading details of who has what powers on the electronic register and keeping these details up to date. There should also be an area in this register that can’t be viewed by the public where the person with a significant lifelong decision making disability’s circle of support and their contact details are kept to ensure continuity from meeting to meeting.

130. Do you think the Public Advocate should play a role in designing a register of personal appointments?

Yes, if they are to be primarily responsible to uploading details and maintain the data.

131. Do you think the Public Advocate should be given responsibility for monitoring the activities of personally appointed substitute decision makers?

Yes.

132. If so, what functions and powers should be given to the Public Advocate to undertake this responsibility?

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133. Do you think the Public Advocate should be given any responsibilities to deal with possible misuses of power by a person who is automatically appointed by legislation to make decisions for another person?

The Public Advocate should be able to make an application to VCAT for a hearing where there are concerns about the performance of supporter, co-, or substitute decision makers.

134. Do you think the Public Advocate should be required to report annually to Parliament?

Yes.

Chapter 21: VCAT

135. Should the Guardianship List be supported by a body such as the New South Wales Guardianship Tribunal's Coordination and Investigation Unit so that it can take a more active role in preparing cases for hearing?

No. OPA could take the role of pre hearing investigations.

136. Should the Public Advocate be funded to undertake this role?

Yes, historically OPA was established to advocate on behalf of people with disabilities, its employees have expertise in the area and it has a community focus.

137. Do you agree with any of the options proposed by the Commission to improve legal assistance and advocacy support for people in Guardianship List matters at VCAT?

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138. Should VCAT be required to consider making supported and co-decision-making orders before appointing a substitute decision maker?

Yes.

139. Do you think that new guardianship legislation should specify a maximum period for all guardianship and administration orders?

No. arrangements need to be individualised.

140. If so, what should that maximum period be?

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141. Following the expiry of an order, should it be possible for VCAT to reassess or make a new guardianship or administration order in the absence of the parties, with their consent?

No.

142. Should VCAT advise a person who provides them with confidential information that the information may be made available to the proposed represented person and other parties?

Yes.

143. Should a person who provides VCAT with confidential information be responsible for requesting and justifying the need to keep the information confidential?

Yes.

144. Should VCAT Guardianship List files remain open to the public, with some restrictions about who can gain access, or should the files be closed to the public, with only the parties having a right of access?

Given the private nature of material which comprises a person's file with the Guardianship list at VCAT we strongly support the closure of these files to the public with only the approved parties having a right to access.

145. Should the period in which an application for a rehearing can be made be extended beyond the current 28-day limit?

Yes.

146. Should VCAT be required to inform parties of the right to seek a rehearing?

Yes, absolutely.

147. Should a represented person be requested to opt out of, rather than opt in to, a reassessment hearing?

No.

148. Should a represented person be entitled to at least one unscheduled reassessment of the order during the period of the order?

Yes.

149. Should the legislation allow guardians and administrators to seek a VCAT order to enforce decisions they make which a third party refuses to accept?

Yes.

150. Should multi-member panels, with members drawn from a range of backgrounds, be the standard practice for initial guardianship and administration applications?

Yes. We strongly endorse this reform proposal.

151. Do you have any views about how VCAT Guardianship List hearings should be conducted?

We have recommended that a great deal of the new work that may be generated by these reforms could be undertaken by OPA and recommendations made by OPA for ratification by VCAT. Where OPA recommendations are uncontested, VCAT could ratify OPA recommendations as a procedural matter rather than in the context of a hearing.

152. Do you have any ideas about how to achieve better attendance of the represented person at VCAT hearings?

We think it unlikely that VCAT hearings will be able to meaningfully involve adults with significant lifelong decision making disabilities in hearings without radical procedural reforms. On the other hand we believe that our recommendations calling for the introduction of pre hearing investigations and Family Meetings facilitated by OPA may succeed in promoting the meaningful contribution of the proposed represented person.

153 & 154. Do you have any ideas about how to make the Guardianship List more accessible to Indigenous people? What can be done to make the Guardianship List more accessible to users who come from culturally and linguistically diverse backgrounds?

We believe that the move to family focused practice results in practices that are more culturally appropriate and in turn may make OPA and the Guardianship List more accessible. This would have particular benefits in regard to its work with people from culturally and linguistically diverse backgrounds as well as Indigenous Australians.

155. What can be done to make the Guardianship List more accessible to users in regional areas?

We believe that Family Meetings orchestrated and facilitated by OPA case workers would make the reforms and protections provided by the new Act more accessible to people in regional areas. We understand that Consumer Affairs Victoria (CAV) has a presence in regional offices and there may be synergies employing OPA caseworkers and co locating them in these offices. CAV is also a logical distributor of community education materials to community service agencies wishing to undertake targeted community education. VCAT would need to visit each of the towns with CAV offices and hold hearings on a regular or as needed basis.

ABOUT PART 9: INTERACTION WITH OTHER LAWS

Chapter 22: Disability Act 2006 (Vic)

156. Do you agree with the Commission’s previous recommendation that the compulsory treatment provisions in the *Disability Act 2006 (Vic)* be extended to people with a cognitive impairment other than intellectual disability?

No.

Chapter 23: Mental Health Act 1986 (Vic)

Question 157. Do you agree with the Commission’s proposal (Option C) that it should be possible, in some circumstances, for guardianship to be used as a mechanism for authorizing psychiatric treatment and place of residence decisions for a person who is unable to make their own decisions due to mental illness?

Carers Victoria would like to congratulate the Commission on introducing a much needed discussion about the interface between guardianship and mental health law in Victoria. The Consultation Paper provides a compelling argument for the fusion of the two laws, based on a rationale that a separate mental health act is discriminatory both in principle and in its practice.

Fusion of the two acts could potentially address some of the intractable problems at the heart of the current Mental Health Act (1986 Vic). One of these is that an Authorised Psychiatrist is responsible for providing treatment advice, assessing capacity to consent and, on occasion when capacity is deemed to be insufficient, acting as a substitute decision maker for a person with a mental illness. The lack of separation between these roles can produce conflicts of interest and confusion. As a result, in spite of much consultation and efforts during the recent review of the Mental Health Act, the Exposure Draft Bill contains Section 125 in which an incapacity to consent is equated with a refusal to consent to treatment. It is arguable that the potential inability to refuse psychiatric treatment is not only discriminatory, but that it also underpins the disempowering experience of the mental health system as reported by people with a mental illness. For a further discussion of this issue, please see Carers Victoria’s submission in response to the Draft Mental Health Bill¹².

There are many implications and challenges inherent in the fusion of mental health and guardianship laws. Some of these are legal, others pragmatic or to do with the mental health system’s culture and society’s attitudes towards people with a mental illness. The Commission has chosen to recommend a hybrid system (Option C) in response to some of the pragmatic obstacles to providing rapid decision making in emergency situations.

Carers Victoria considers that the Commission has been too hasty in abandoning the fusion model (Option B) and that the suggested hybrid model is just one of many unexamined possible alternatives.

It is acknowledged that Option C is necessarily preliminary and broad in nature. However, its lack of detail means that it presents many more questions than it can answer. For example:

- How would an “emergency” be defined?
- Who would determine when a situation was an emergency?
- What level of effort would be prescribed by legislation in relation to contacting an enduring guardian? What levers would be in place to encourage treating health professionals to do so?
- What would be the trigger for seeking a guardian? Would it be the result of a capacity test or based upon the need for treatment?
- In practice, how many people with a mental illness would appoint a guardian in advance? How many would appoint a family member, and to what extent would this responsibility be attractive or acceptable to those family members? How would families perceive the risk to the quality of their relationships if appointed guardians were family members?
- In the absence of an appointed guardian, how would VCAT appoint while avoiding a paternalistic “best interests” approach?
- If a supported decision making model was to mean that a person with a mental illness could actively choose their support person(s), is it likely that a supporting person would also be nominated as a possible substitute decision maker? What would be the implications of this in practice for maximizing supported decision making? If the two roles were to be separate, what would the interface between them look like?

There are many ways to test any proposed changes to the legislation. Some of these, consistent with the intentions behind the review of the Mental Health Act, are as follows:

- That new legislation, consistent with the Charter of Human Rights and Convention on the Rights of Persons with a Disability, is more supportive of the empowerment, dignity and autonomy of people with a mental illness.
- That change presumes capacity unless otherwise evidenced.
- That any changes are effective in creating a shift towards supported decision making. The extent of making and then adherence to, advance statements is one possible indicator here. Another measure, with some qualifications, might be the reduction of involuntary treatment orders. Substituted decision making should be a last resort and should be undertaken wherever possible by a person nominated by the person with a mental illness.
- That any changes support the increased appropriate involvement of family members in decisions and information sharing.

Next Steps

There will be a need for the intensive real world testing of any new model legislation and associated codes of conduct. This should be done through the involvement of the mental health community, especially consumers and carers, in addition to the community as a whole.

It is somewhat unfortunate that the Victorian Government has conducted its review of the Mental Health Act in parallel to its review of the Guardianship and Administration Act. This has meant that the level of awareness of the guardianship review within the mental health community has been very low and that reform fatigue may already have occurred.

Nevertheless, the potential benefits and profound implications of a fusion option are considerable and outweigh any preliminary reasons to reject it. There is a need for renewed engagement with consumers and carers and the introduction of what will be, to many, a new reform project. If further consultation does not occur, the debate will remain academic and risks becoming ideologically driven, missing the crucial process of collaborative problem solving. Additional resources to assist this process may be needed.

Carers Victoria is happy to collaborate with the Commission in this matter and assist in any way it can. It is noted that in other jurisdictions where similar reforms are occurring, developmental timelines are in the order of several years to achieve the structural and attitudinal changes necessary.

Chapter 24: Crimes (Mental Impairment and Unfitness to be Tried) Act 1997 (Vic)

158. Do you believe that an advocate should be made available to a person subject to the *Crimes (Mental Impairment and Unfitness to be Tried) Act 1997 (Vic)* at particular times?

Yes

159. Do you believe that the Public Advocate should be given a formal role as an advocate for people involved in proceedings or detained under the *Crimes (Mental Impairment and Unfitness to be Tried) Act 1997 (Vic)*?

Yes

REFERENCES

¹ These indicative estimates are projected from the Survey of Disability, Ageing and Carers (2003) national data on estimated numbers of ageing parent carers who are over 65 and living with their disabled offspring. They have assumed an even distribution of parent ageing from the 2003 cohort of parent carers between 45 and 64, and divided this by 24% - Victoria's share of the population.

² Centrelink Payment Rates, Available at:
http://www.centrelink.gov.au/internet/internet.nsf/payments/dsp_rates.htm

³ Logan, Bill (2001) *A Description of Adult Guardianship and Implications for Social Work*. Australian Social Work, Vol. 44, No.3 p 19.

⁴ Brouwer G E (March 2011) *Ombudsman Investigation Assault of a Disability Services Client by Department of Human Services Staff*, Available at:
http://www.ombudsman.vic.gov.au/resources/documents/Assault_of_a_Disability_Services_Client_by_Department_of_Human_Services_Staff.pdf

⁵ DHS (2009) 2008 Supported Residential Services Census, Summary Report, Residents.

⁶ Email from Peter and Ruth den Brinker to Penny Paul Coordinator: Carer Consultations on Monday, 10 May 2010 15:59 Re: Guardianship and Administration

⁷ Email from Anne & Peter Day to Penny Paul Coordinator: Carer Consultations on Thursday, 7 April 2011 10:37 PM following the Roundtable Consultation with ageing parent carers in Hastings on 29 March 2011.

⁸ Ibid.

⁹ Australian Institute of Health and Welfare, *Disability In Australia: trends in Prevalence, education, employment and Community Living*. AIHW Bulletin 61, 2008

¹⁰ Coalition for Disability Rights, *Call to the Parties 2010 State Election*. Victoria 2010 available at:
<http://www.carersvic.org.au/Assets/Files/cdr-call-to-the-parties-state-election-2010.pdf>

¹¹ Victorian Law Reform Commission (March 2011) *Guardianship Consultation Paper* p116.

¹² <http://www.carersvic.org.au/file-assets/policy-submission/response-to-mental-health-bill-exposure-draft/>