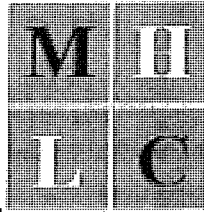


Submission No. 78

RECEIVED  
30 JUN 2011



**Victorian Law Reform Commission –  
Guardianship Review  
Submission in response to the  
Consultation Paper**

**June 2011**

**Mental Health Legal Centre Inc**

Mental Health Legal Centre Inc  
9<sup>th</sup> Floor 10-16 Queen Street  
Melbourne Victoria 3000  
Ph: 03 9629 4422

**Enquiries to:**

**Catherine Leslie  
Lawyer / Policy officer**

## **Background**

The Mental Health Legal Centre Inc (MHLC) is a Victorian state-wide specialist community legal centre which, for nearly 25 years has assisted people in Victoria where their legal issue relates to their diagnosed mental illness. The MHLC receives the majority of its funding from the Victorian Department of Health and Victoria Legal Aid. In addition project funding has been secured from philanthropic and other funding sources for a range of projects.

The MHLC provides telephone legal advice and referral, direct legal advocacy and community education about mental health and the law for people in Victoria with, or labelled as having, a mental illness. The MHLC also undertakes research, law reform and policy work, the aim of which is to further the rights of people with mental illness in Victoria.

Legal services provided by the MHLC in the areas of Guardianship and Administration generally involve assisting clients who are subject to, or are going to be made subject to Administration Orders. From time to time we also provide legal advice on a person's advance directive.

Recent law reform and policy projects by the MHLC around advance directives are of particular relevance to this review including

- A multi-staged research project on advance directives for mental health involving consultation with consumers/users of mental health services and clinicians and other stakeholders to gauge their views on advance directives. The findings from the research are currently being written up with a view to making recommendations for reform in law and practice to ensure appropriate recognition and respect for advance directives for mental health.
- Development of a draft online pro-forma advance directive document consistent with the above project's aim of engaging in, and developing resources for, community education around advance directives, available at: [www.communitylaw.org.au/mentalhealth](http://www.communitylaw.org.au/mentalhealth)

Other recent submissions of the MHLC of relevance to this review are:

- Victorian Department of Human Services (DHS)- Submission to the consultation paper, Review of the Mental Health Act, February 2009

- Victorian Parliamentary Law Reform Committee (VPLRC) – Review of Powers of Attorney, September 2009
- Victorian Department of Health (formerly DHS) – Submission to the Exposure Draft Mental Health Bill, Review of the Mental Health Act, February 2011

With this background, we welcome the opportunity to make a submission in response to the Victorian Law Reform Commission's (VLRC) Consultation Paper in its review of guardianship and administration laws.

**Executive summary:**

- We agree with the general principles of new guardianship laws, proposed by the Commission, in particular specific reference to the dignity of risk, principles of capacity, substituted judgment and the importance of wishes and preferences and a person's participation in decisions regardless of their capacity.
- We do not support an additional general principle about the role of "carers" or "families" and, to a lesser extent "other supportive relationships". We believe that the general principles proposed – in particular supported decision-making - adequately recognise supportive relationships and roles to the extent that the person with the disability recognises and acknowledges such roles themselves.
- We support the term guardian being replaced by "personal decision maker" and Administrator, by the term "financial decision maker".
- Education about guardianship laws is important both for people with mental illness, but also to service providers who often have significant power over their clients' access to information about their rights and support to exercise them. Adequate training and resourcing for service providers and Tribunal staff and resourcing community organisations including the Office of the Public Advocate, Community Legal Centres, Victoria Legal Aid and other community advocacy groups is essential.
- MHLC would like to see consumers themselves involved in the development, design and implementation of resources, education and training.
- The MHLC supports VCAT collecting more extensive data which is then easily accessible and can determine the effect of policy initiatives and identify systemic issues regarding access to justice.
- We agree with the Commissions proposals to introduce mechanisms for personally-appointed supported decision-making arrangements which can enhance a

person's ability to access relevant information, understanding of their options, as well as their decision-making capacity overall. A person should be able to nominate more than one supporter, with prescribed roles as they see fit and appointed through an integrated advance directive document if the person so chooses.

- The test for making a supported decision-making arrangement should not be too onerous. There should also options for revoking or varying an arrangement, including where the supporter no longer wishes or is able to continue in that role. Organisations such as the MHLC and others should be adequately resourced to ensure people have clear accessible and timely information, both as supporters and executors of the arrangement.

- Given the critical and trusting role that a supporter will play and the importance of ongoing training and a consistent attitude and approach to the role, we do not believe it is desirable that any coordinated program of supporters engage volunteers. We would much rather such a program be staffed by paid employees with adequate funding and training to support people with psychiatric disability who choose to avail themselves of such support.

- We do not support VCAT-made supported decision-making orders as they are not necessarily a rights-promoting measure. We would prefer to see VCAT having the express power to order that particular instructions in a person's advance directive be implemented or carried out

- We do not support the introduction of co-decision-making agreements. It is hard to see how co-decision-making could operate free of the apparent risk of abuse and exploitation through even subtle coercion by the threat of more restrictive substitute decision-making orders in the event an agreement is not reached.

- OPA has an important role to continue to play in implementing supported decision-making, including community education materials and advice. We do not believe OPA to be best placed to conduct specialist training for supporters for people with mental illness.

- We do not support OPA having a broader investigatory or monitoring role.

- Enduring powers should only be activated once a person is determined – by VCAT – to lack capacity for that particular decision.

- We support an online registration system for enduring powers, which could also hold advance directives and supported decision-making arrangements. It is important however, that people also have the option of lodging their documents in hard copy, either by post or in person.

- On balance, the MHLC takes the view that registration of enduring powers of attorney should be compulsory provided it is free and accessible in a range of formats. In our view, failure to register should not be fatal to the effectiveness of a document per se. Registration at a later stage should be permitted and proof of its validity may be required.
- Privacy and security of the wide range of very sensitive material that may be in a person's advance directive, is of great concern to mental health consumers. The privacy of individuals making a power of attorney or advance directive must not be diminished, nor safeguards put aside for the sake of facilitating easy access by third parties to the register. A two-tiered system warrants consideration such as in the UK & Wales where there is very stringent standards to be met to determine the relevance and level of detail appropriate to disclose. We support the use of a PIN for the person themselves and any appointees to only relevant documents.
- We strongly support advance directives (instructional directives) which are outlined in legislation, but which preserve common law rights. It should be possible to include medical and non-medical lifestyle decisions in an advance directive.
- Advance directives should be enforceable, but displaceable in certain circumstances. VCAT should be empowered to determine any applications for override of an advance directive. This process must apply to treatment refusals. A simpler process may be more appropriate for other directives. There should be robust sanctions which are enforceable, for unlawful overrides.
- Ideally, advance directives legislation must not distinguish between psychiatric and non-psychiatric treatment decisions. Advance directives must also have equal legislative recognition and consistent enforceability and implementation whether under guardianship or mental health laws.
- The obligations on personally-appointed substitute decision-makers and service providers who would otherwise implement instructional directives, should be the same, as should the process for seeking to override advance directives.
- Disability should not longer be a separate criterion for the appointment of a substitute decision-maker.
- We support the introduction of capacity principles and a definition of incapacity.
- MHLC is firmly of the view that parents and carers of people with mental illness should not be given additional standing or specific powers, as of right, to participate in guardianship or administration proceedings at VCAT by filing a document stating their wishes.

- An administrator's role should be limited. It should not be able to use its power to exercise moral or social control over a person and their lifestyle.
- We support substituted judgment being the paramount consideration for substitute decision-makers, not 'best interests'. This will assist the law to promote a person's dignity of risk.
- The law should specifically require substitute decision-makers to act honestly, respond appropriately to conflicts of interest and to treat the represented person with courtesy and respect at all times.
- We 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.
- We support there being more general accountability mechanisms for substitute decisions-makers however any such responsibilities must be balanced against subjecting private guardians to what may be onerous, intrusive reporting requirements.
- We believe that the individual decisions of not only the Public Advocate and State Trustees but also private guardians and attorneys should be subject to merits review. The person affected as well as anyone who could establish a special interest may be able to seek such a review. A reviewable decision should be defined as 'any decision in connection with the exercise of the substitute decision-maker's functions under the Act'.
- We are concerned that any anonymity for people providing information to OPA does not interfere with the represented person's fundamental right to access information in a timely way to enable them to respond to any allegations or assertions made about them in a hearing or any other process under the law.
- We do not believe OPA is best placed to take responsibility for civil penalty proceedings for breach of guardianship laws. We would prefer to see this made the responsibility of the proposed investigations unit at VCAT. This would ensure a greater transparency and independence.
- We do not believe that the Public Advocate should be given the role of formally monitoring personally-appointed decision-makers. We do however see a continuing role for OPA in supporting decision-makers by providing information and education and support.
- The critical stakeholders in designing a register of personal appointments are people with the lived experience of mental illness and their legal representatives and

advocates. We also see a role for the Public Advocate alongside legal and advocacy organisations such as the MHLC.

- We do not believe that the Public Advocate should be given the role of formally monitoring personally-appointed decision-makers. We do however see a continuing role for OPA in supporting decision-makers by providing information and education and support.
- The MHLC strongly supports a designated unit at VCAT being empowered and sufficiently resourced to enable people to more actively participate in hearings including providing proposed represented person with information and referrals around advocacy services prior to hearing. There should also be the creation of a statutory power for VCAT to order person be represented where necessary.
- We believe it is critical that VCAT seriously consider less restrictive alternatives such as supported decision-making before any order appointing a substitute decision-maker is made. This includes VCAT having the power to order compulsion or implementation of particular parts of a person's advance directive, as appropriate.
- We do not support VCAT having the power to make orders of unlimited duration. They should be limited to 12 months maximum. On the expiration of an order no further order should be made without conducting a de novo hearing.
- We support VCAT files being closed to the public with only the parties having a right of access. If information is provided confidentially to VCAT, the presumption should be that the affected person can see the material, but that other parties may not. It is the responsibility of the person providing the information to justify any desire or need to keep it confidential – particularly from the affected person – and VCAT must advise them of the risk that the information will be disclosed at least to the affected person, and potentially other parties.
- We support a person having the right to at least one reassessment hearing during the period of the order, however we strongly recommend a lower, more accessible threshold apply to the granting of such an application, including if they can demonstrate a change in circumstances from the time the order was made.
- We are strongly of the view that, if VCAT establishes multi-member panels, the Chairperson of any multi-member panel must be a qualified lawyer.
- We reiterate the importance of broad accessible information and resources about VCAT, its role, the hearing process, right to legal representation and how to access it, and guardianship laws more generally in the community. These resources must be also be accessible in a range of community languages.

- In our view the VCAT registry – or possibly the proposed new investigative unit – should take a more active role to ensure the affected person is aware of the hearing, understands the role of VCAT and encourage them to attend, and any time limits if they do not attend.
- In relation to the interaction between mental health and guardianship laws, the MHLC’s view is that the fusion model would appear the most human rights promoting of the 3 options. Overall, however, we found it very difficult to respond to this question in such a way as to contribute to an informed debate. The interaction of mental health and guardianship laws is an incredibly complex issue and we were disappointed that the community did not have a real opportunity to discuss and respond to a fusion model.
- The Commission’s preferred option C – to provide for the “limited use of guardianship laws” to enable personally-appointed proxy decision-makers to consent to or refuse psychiatric treatment, left many questions unanswered.
- Advance directives – particularly ones which go beyond strictly psychiatric treatment - are likely to straddle both laws, which makes for extreme uncertainty in the recognition, validity and enforceability of advance directives for a person with a mental illness. Advance directives are perhaps the most stark example of why consistency between guardianship laws and mental health laws is so important.



**Introduction:**

As a long-term campaigner for advance directives, the MHLC is encouraged by the way the Victorian Law Reform Commission (Commission) has explored law reform options for supported decision-making, in particular through advance directives and supported decision-making arrangements. As we stated in our previous submission to the Commission's Information Paper, the goals and spirit of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and in particular Article 12 (autonomy, capacity & equal recognition before the law) can only be realised with recognition and force of such measures in domestic law. What is unclear however, is the extent to which any recommendations by the Commission about reform of guardianship laws, will apply to people with mental illness, particularly given the Commission's limited reference in relation to the Mental Health Act and the separate and ongoing review of that Act by the Department of Health.

We reiterate our grave concerns – expressed in our various submissions to both these reviews – that people with mental illness will not be afforded consistency nor equality, nor certainty in the promotion and protection of their rights in the absence of a true comprehensive 'root and branch' review and reform of these various capacity-based laws which affect them. While similar issues – substitute decision-making and assessment of capacity, supported decision-making, participation in decision-making, compatibility with the Victorian Charter and human rights more broadly – have been considered in these separate reviews, the reform options proposed in the Commission's Consultation Paper and the Exposure Draft Mental Health Bill to resolve these fundamental questions are starkly different.

We strongly urge the Commission therefore to carefully consider ways in which reforms will apply consistently to all people with mental illness, whether they appear to fall within the ambit of the Mental Health Act or guardianship laws. In our view, the areas of supported decision-making, advance directives and personally-appointed proxy decision-makers need special attention in this regard.

In preparing this submission to the Commission, the MHLC convened a forum and consulted informally with mental health consumers– some of whom identify as being "mental health consumers", others as "psychiatric survivors". We wanted to discuss key reform proposals and find out consumers' views. The report from our consumer consultation is appended to our submission at Appendix 1. We have also appended documents which illustrate our submissions in relation to advance directives,

specifically, the advance directive prepared by long-time consumer activist Merinda Epstein (appropriately de-identified) at Appendix 2.

## **Part 2: The Direction of New Laws**

### **Chapter 4**

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

We generally agree with the matters identified as influencing the need for change in guardianship laws. In relation to ‘integration’ however [at para 4.14 – 4.16], whilst the Commission espouses “a fully integrated range of supported and substitute decision-making mechanisms... [that] should be designed to form part of one system” [at para 4.16) it is clear that people with mental illness will be excluded in many ways. The continued existence of mental health laws is a real barrier to a fully-integrated model as we discuss further at question 157.

### **Chapter 5**

**Question 2 – Do you agree with the Commission’s draft statement of purpose for new guardianship laws?**

The MHLC agrees with the Commission’s draft statement of purpose. We are pleased to see a move towards the more empowering language or promotion of rights and dignity of people and support for people to realise their rights, consistent with the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

**Question 3 – Do you agree with the Commission’s draft general principles for new guardianship laws?**

**And**

**Question 4 – Are there principles you think should be added or removed from these general principles?**

We agree with the general principles proposed by the Commission, in particular specific reference to the dignity of risk, principles of capacity, substituted judgment and the importance of wishes and preferences and a person's participation in decisions regardless of their capacity. In relation to limitations on restrictions of a person's rights, whilst we support the inclusion of the principle that limitations must be "justified, reasonable and proportionate" we believe it is nevertheless important to retain a separate principle to ensure any limitations are the "least restrictive" in the circumstances. In our view, whilst related, these principles are distinct. For example, there may be a number of treatment options for a person which may all be justified, reasonable and proportionate restrictions on their right to be free from medical treatment without consent (s10(c) Victorian Charter), of which one is clearly the least restrictive in the circumstances.

To the principle of communication, we support adding an explicit reference to the right to access information and have the information explained to them in a manner and language they can understand.

We do not support an additional general principle about the role of "carers" or "families" and, to a lesser extent "other supportive relationships". We believe that the general principles proposed – in particular supported decision-making - adequately recognise supportive relationships and roles to the extent that the person with the disability recognises and acknowledges such roles themselves. We note that in some cases a "carer" role may be self-identified, whereas the person with the mental illness will identify someone else as their support person/s. Therefore we do not support additional rights ascribed to family members or "carers" beyond what the person has identified. People identify their supports differently and we believe strongly that the starting principles should always be the autonomy of person whose rights are most affected by guardianship laws – namely the person with the disability. To the extent the Commission proposes a greater range of mechanisms for the person themselves to identify supports and formalise these, we believe this effectively covers the issue.

## **Chapter 6**

### **Question 5 – Do you agree with the Commission's proposal that Victoria's various substitutes decision-making laws be consolidated into one single Act?**

Yes, we agree that substitute decision-making laws should be consolidated into the one single Act, however, as we note at question 157 the Commission should also give serious

consideration to consolidating mental health laws also, at least to the extent that they also provide a model for substitute decision-making in health. We also reiterate the views of the Federation of Community Legal Centres (FCLC) that extensive community education must also accompany such consolidation (see also our responses to Qs 10 – 12 below).

**Question 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?**

MHLC agrees with the Commission’s proposal to replace the terminology of the “person responsible” to one which describes more effectively the person’s role being that of a “medical” or “health” decision maker.

**Question 7 – Do you agree with the Commission’s proposal that the term ‘guardian’ should be replaced with ‘adult guardian’?**

**and**

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

In the spirit of promoting personal autonomy (as reinforced by the UN Convention on the Rights of Persons with Disabilities (CRPD)), we are of the view that the term ‘guardian’ is not the most appropriate term for substitute decision-makers for adults. We therefore prefer the terms outlined in Option D – “personal decision maker” and “financial decision maker”. The term ‘decision maker’ also makes clear the role and function of the person appointed, as distinct from others who may be appointed in support roles without decision-making power.

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

We support better integration of the terminology used for decision-makers appointed by the person themselves and those appointed by VCAT in each of the two distinct areas. It is important however, that the terms used also reflect whether the decision-maker is personally appointed or not. For example, the use of terms such as ‘enduring’ or ‘agent’ could be considered.

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

- **People with disabilities**

Education about guardianship laws is important both for people who may be subject to such laws themselves, but also to service providers who often have significant power over a person with a mental illness, influencing their access to information about their rights and support to exercise them. Case managers at community mental health services for example have a role in providing information to a person about their rights, facilitating access to a lawyer and referring the person for support for their psychosocial needs, eg. housing or financial counselling. However, case managers do frequently also apply to VCAT for the appointment of an administrator or guardian for a person.

Training and resourcing for service providers and Tribunal staff and adequate resourcing of community organisations including the Office of the Public Advocate, Community Legal Centres, Victoria Legal Aid and other community advocacy groups is essential to ensuring consumers have access to information about guardianship laws and access to independent legal advice about their rights and options and support to exercise them. It is important this education, support and legal advice/representation be made available to a person at key points in the process. For example:

- planning in advance of a crisis when the person retains their decision-making capacity;
- when a person is taken from their home or out of the community, forcibly or otherwise, for example being incarcerated in prison, detained in a psychiatric inpatient unit, moved to supported accommodation in a Community Care Unit;
- when an application is made to VCAT to appoint a guardian or administrator;
- when a hearing at VCAT is scheduled for a person;
- when VCAT makes an order appointing a guardian or administrator;
- when a person is subject to guardianship or administration orders made by VCAT and wants to challenge these orders

We strongly recommend the availability and promotion of community education resources which are accessible in a range of formats, including online and in print. For example, MHLC often refers clients to the 'Take Control' booklet produced by OPA for personally-appointed proxy decision-makers.

MHLC would like to see consumers themselves involved in the development, design and implementation of resources, education and training. For example, in promoting the use of advance directives for mental health, MHLC has run community education sessions at community organisations, community mental health services, psychiatric disability rehabilitation and support services (PDRSSs) and hospitals. Both a lawyer and consumer project worker developed and presented these sessions and were involved in promoting the MHLC's additional online resources widely through the community, to consumers, mental health services and other community support and advocacy organisations.

### **Case Study - development of the MHLC's online pro forma advance directive for mental health**

MHLC has developed an online pro forma advance directive document has been available on the MHLC's website since August 2008.<sup>1</sup> Although advance directives currently have no legal enforceability in Victorian law, the MHLC was strongly committed to encouraging people with mental illness to consider the option of drafting such a document in advance of a mental health crisis. It can be both a tool of empowerment for the person themselves in their own planning, and is a way of making known to services and others involved in decisions about care and treatment, what the person wants. The pro forma advance directive and accompanying information make clear that the MHLC form is just one suggested way to document these wishes. The document can be filled in online, then the relevant pages printed out, or it can be completed by hand in hard copy.

The online proforma was developed by a project worker at MHLC, who was, importantly, herself a mental health consumer, with significant experience over 20 years working in the consumer movement both in Australia and the United States. With funding from Freehills Lawyers and after researching different model documents in other jurisdictions and consulting with consumers in Australia and overseas, the project worker developed a pro forma form and accompanying information. The project worker's own personal experience of the service system, and her communication skills and style honed having worked extensively with consumers, ensured the document is accessible and readable and user-friendly for as many different types of people as possible. The accompanying information in particular is written in a conversational,

---

<sup>1</sup> Available via the link at [http://www.communitylaw.org.au/mhlc/cb\\_pages/advance\\_directives.php](http://www.communitylaw.org.au/mhlc/cb_pages/advance_directives.php) (accessed 1 June 2011)

non-confrontational style and is specifically targeted to a consumer audience to prompt them to consider what they want to say in an advance directive should they choose to make one. We have so far had very positive feedback from consumers, advocates, carers and other service providers about the form, its accessibility and style. Though we are unaware how many people may have chosen to use our particular pro forma document, we understand from consumer networks it has been recommended for use on the ground in various parts of Australia, New Zealand and the UK.

Development of the form and materials by a person with the lived experience of mental illness in our view, has been the key to its success & widespread circulation.

We also strongly advocate for increased measures, resources and training to enable VCAT members and staff to ensure people understand the process and their rights and have been provided with every opportunity to attend a hearing and participate in the process. Specific recommendations are addressed below at Questions 135, 137, 142, 146-8, 151-2.

**Question 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?**

**and**

**Question 12 – Would an education and awareness campaign assist the community to better understand and make use of guardianship laws?**

We believe an education and awareness campaign is essential to ensuring people with mental illness are better able to understand and make use of guardianship laws. Particularly important will be informing the community of the Commission's final recommendations about the relationship between guardianship and mental health laws. This distinction is not always well understood by consumers and others in the community.

We urge the Commission to recommend adequate funding be provided not only to OPA to continue to produce comprehensive and accessible materials such as the 'Take Control' booklet, but also to existing community organisations already conducting effective community legal education, such as CLCs and local community organisations. The MHLIC for example, produced a guide for advocates before the Guardianship List at

VCAT. We also engaged in community awareness-building and promotion of advance directives for mental health, through presentations to consumer, carer and service provider groups, as well as the dissemination of the online pro forma advance directives document on the MHLC website<sup>2</sup> as an resource for people to use if they choose.

As stated above, we believe that employing people with the lived experience of mental illness – consumers – themselves is central to the design, development and implementation of any awareness raising campaign among people with mental illness, carer organisations and mental health service providers. In this respect, we are encouraged that the Commission's sees "significant potential for an expanded role for peer education"<sup>3</sup> which we reiterate must be adequately funded.

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

The MHLC supports VCAT collecting more extensive data, such as that collected by the Mental Health Review Board. It is important that data is collected and analysed by VCAT and is easily accessible so as to determine the effect of policy initiatives and identify systemic issues regarding access to justice. This allows not only VCAT but also the community more broadly to target resources and community education, support and representation to meet the needs of people who come in contact with or are made subject to guardianship laws. Accordingly (and taking into account the Commission's new law reform proposals) we support the collection of the additional data below:

- Rate of initial hearings which are adjourned and the reasons why they are adjourned;
- Where an initial hearing is adjourned to allow the person to attend the hearing, general data about how VCAT has encouraged the person to attend and the subsequent rate of attendance at the hearing by the affected person;
- Details of the number of applications made for review of individual decisions by guardians or administrators or other substitute decision-makers, including who is making the application and the types of orders made;
- rate of legal representation at different types of guardianship list hearings;
- details of any applications for override of a person's advance directive, including who is making the application and the types of orders made;

---

<sup>2</sup> Available at: [http://www.communitylaw.org.au/mhlc/cb\\_pages/advance\\_directives.php](http://www.communitylaw.org.au/mhlc/cb_pages/advance_directives.php) (accessed 1 June 2011)

<sup>3</sup> Consultation Paper at [6.95]



- Details of any applications and orders made in relation to supported decision-making arrangements (to the extent VCAT has a role in this process);

### ***Part 3 – Supported decision making.***

#### ***Chapter 7; Supported Decision Making***

#### **Question 14 – Do you agree with the Commission’s proposal to introduce new supported decision-making arrangements?**

We agree with the Commissions proposals to introduce mechanisms for personally-appointed or executed supported decision-making arrangements. Support can enhance the person’s ability to access relevant information, and understanding of their options, as well as their decision-making capacity overall. In the same way as consumers were supportive of the general principle of appoint key supporter/s under a ‘nominated person scheme’ under the Exposure Draft Mental Health Bill,<sup>4</sup> in particular through an advance directive, consumers have roundly supported this proposal by the Commission.

Consumers to whom we spoke were reluctant however to support VCAT-appointed supporters or, if they did, were of the view that they should be given far narrower powers than if they were personally appointed. As one consumer we spoke to remarked, with a VCAT-made order:

it’s almost like taking it out of the person’s control, even though making an order like this would need their consent. Almost like a contradiction.<sup>5</sup>

MHLC takes the view that, while it may seem desirable that all people have the opportunity to appoint a supporter, not everyone will wish to do so. Whilst we understand the Commission proposes a person must consent to any VCAT-made order, we are concerned at the possibility that consumers may be pressured or unduly influenced by others to consent to such orders upon the threat of more restrictive orders like the appointment of a guardian or administrator if they do not agree. We therefore do not consider this option as necessarily a rights-promoting measure. Whilst we understand the desire for VCAT to have a range of less restrictive alternative measures to put in place, we would prefer to see VCAT for example, having the express power to order that particular instructions in a person’s advance directive be implemented or carried out. See our answer to questions 41-43

---

<sup>4</sup> See MHLC submission to the Exposure Draft Mental Health Bill 2010.

<sup>5</sup> See Consumer Consultation report p 8

**Question 15 – Do you agree with any or all of the proposed roles of supporters and co-decision makers?**

We strongly agree with the proposed role of supporters, provided they are personally-appointed as indicated above.

Although MHLC indicated its preliminary support for co-decision-making, upon further consideration and after consulting with consumers, we have concerns about how co-decision-making would work in practice. Consumers were reluctant to support legalising a role such as this, as it is very unclear where the line would be drawn between decision-making which is truly supportive with both parties on equal footing with equal power, and decision-making which involves coercion by the other party to ensure a desired outcome. This is particularly concerning given the need for agreement between the parties for a decision to be binding.

It is hard to see how co-decision-making could operate free of the apparent risk of abuse and exploitation through even subtle coercion by the threat of more restrictive substitute decision-making orders in the event an agreement is not reached. The risk of coercion was largely the reason why consumers were reluctant to support this measure, although it was conceded this would depend on the relationship the person had with their “supporter”.

One consumer explained that, rather than a support mechanism, co-decision-making sounded as if it were a step closer to taking away her autonomy and decision-making ability. She said:

I would find it threatening that the co-decision-maker could sway my decision – threatening my choice, my autonomy. It would feel like it would be stressful & anxiety-provoking.<sup>6</sup>

Although we have made enquiries of consumer and legal advocacy organisations in Alberta, upon whose legislative provisions the Commission has based its proposals, we are unable to advise the Commission as to how these provisions are working in practice – the extent of their use and by whom and whether mental health consumers are actually aware of and using these opportunities.

---

<sup>6</sup> Appendix 1, p 8-9.

As we described above, MHLC is not comfortable supporting VCAT-made appointments as these may not necessarily empower the person themselves. If VCAT were to have such power it is likely to result in applications by third parties to become a supporter themselves and legitimise what may not necessarily be a supportive relationship from the consumer's perspective. We are concerned that, given the already low rate of legal representation of and attendance at hearings by the affected person, the person's own views about whether a supporter should be appointed, may not be heard as strongly as that of the third party applicant. If VCAT were ultimately to have the power to make such an order, it is imperative that VCAT insist it hears from the person themselves before any such order can be made.

Consumers we spoke to identified a difference between choosing to appoint someone and making no such appointment because there is no-one they trust sufficiently. If an application by a third party were to succeed in such a case, it would be akin to 'forced' supported decision-making which is contrary to the spirit of empowerment which underpins supported decision-making.

**Question 16 - What steps would need to be taken in order to ensure that these appointments operated fairly and efficiently?**

We believe that people should be able to nominate more than one supporter if they wish, for particular types of decisions. A person should therefore be able to ascribe limits as they see fit, both in terms of scope and time, to the powers of their supporter. It is therefore crucial that there be widely accessible information making a supported decision-making arrangement and its effect, including the right to limit such an arrangement in any way the person sees fit.

In our submission to the Exposure Draft Mental Health Bill in relation to the proposed nominated person scheme, we expressed concern that the scheme was structured on the assumption that a mental health consumer would want to nominate only one person to this role.<sup>7</sup> We noted in our submission that:

Consumers at the MHLC's forum on the Draft Bill saw this as a distinct disadvantage of the scheme and were in favour of having the power to appoint alternative nominated persons in the event the first could not fulfil the role, and

---

<sup>7</sup> That scheme under the Draft Bill mandated that information be provided to the nominated person and that they must be consulted on a whole range of matters to do with a person's treatment or admission to hospital. We note that no such mandatory provisions are proposed by the Commission.

multiple support people, for example in various roles. A person may for example prefer to nominate one person to be advised of their admission to hospital at the outset, who may then be able to make the necessary arrangements for the person's personal affairs, but choose not to have this person consulted about ongoing decisions related to treatment.

One consumer described:

I actually think that limiting it to just one person... is really limiting. In my own life I think that doesn't quite work and I'd like the capacity to nominate a few people. Like have my 3 people who are my support network... kept in the loop...<sup>8</sup>

In our view these considerations apply equally to supported decision-making arrangements. We note that Alberta has a prescribed form for supported decision-making authorisations. In our view, further careful consultation should be undertaken with the community especially people with mental illness about the desirability of prescribing a particular form for executing such an arrangement. We are concerned that a prescribed form may impact people's decision to make an advance directive, the very point of which may well be to appoint supporter/s for various matters and provide accompanying instructions about how best to perform that role, and which is part of a comprehensive advance directive document.

#### **Case study – Example of an advance directive appointing “supporters”**

Merinda Epstein is a mental health consumer who is regarded as a pioneer in the mental health consumer movement in Australia. She has made an advance directive in the event she becomes unwell (see Appendix 2). Merinda's advance directive has a number of parts comprising:

1. Key principles;
2. Advance Directive for treating clinicians and services;
3. Advance Directive for friends and family;

---

<sup>8</sup> See MHLC submission at p 33 (footnotes omitted), available at [http://www.communitylaw.org.au/mhlc/cb\\_pages/mental\\_health\\_act\\_reform.php](http://www.communitylaw.org.au/mhlc/cb_pages/mental_health_act_reform.php)

4. Advance Directive for work; and

5. Reminders to herself.

Although split into different parts, the advance directive is designed to be a much integrated document. For example, the key principles (section 1) apply to everyone who may use the document – clinicians as well as supporters. Also, in section 3 - the advance directive for friends and family - whilst Merinda nominates numerous supporters some of whom have particular roles, Merinda asks they also understand her background and how best to support her (in both sections 1 and 3), which may be by prompting her with her own reminders (section 5).

Merinda's advance directive illustrates the value of having the opportunity to appoint supporters in an integrated document such as an advance directive.

Consideration could be given to enabling any supporters nominated in an advance directive with the appropriate power to access information on the person's behalf – such as those in Merinda's advance directive – to be recognised as valid supporters. At the very least the making of a supported decision-making arrangement should be flexible enough to be incorporated into or executed as part of a person's advance directive.

Merinda's advance directive for example, clearly authorises supporters to have access to information (through the explicit confidentiality waiver) but she asks this authority to be exercised in accordance with the general principles – in particular instructions about when she envisages the advance directive to be implemented

We believe people should also be the option of making a self-revoking arrangement, or providing the arrangement for a defined period of time or which is valid in certain circumstances. For example a person may wish to authorise their sister to communicate with their employer and access necessary information while the person is receiving psychiatric treatment in hospital, but when they are discharged, want such authorisation to cease.

A supporter should have the option to cease acting in that supporter role, or apply to VCAT for revocation of the document. Similarly, the person themselves should have the option of revoking or varying the arrangement, or otherwise (for example if they did not

meet the requisite “capacity” test) applying to VCAT to revoke, rescind or vary an arrangement.

In terms of threshold criteria for executing a supported decision-making arrangement, the MHLC is concerned that too high a “capacity” threshold or standard may dissuade people who could otherwise understand the nature and effect of the document they were signing. Whilst we support people making such arrangements on the basis of informed consent, we do so provided that they are not subject to any unnecessarily strict regulatory burden. It defeats the purpose of ‘support’ if the community and mental health consumers don’t know about or are unable to understand or access mechanisms to appoint someone or some people in this way.

We therefore strongly support the provision of clear accessible and timely information for both the person and their supporter/s about their roles, rights, responsibilities and options including how the appointment differs from, for example, a power of attorney.. Further, that adequate resourcing of organisations such as the MHLC, VLA and other CLCs is critical to ensure people have independent legal advice about and representation for seeking redress.

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

We agree with the Commission that the Public Advocate should not be a supporter. In our view, this would risk confusing the various roles which OPA could play, particularly the difference between the Public Advocate’s appointment as substitute decision-maker of last resort, and that of a supporter, with no decision-making power. In any event, we think it unlikely that people with psychiatric disability would voluntarily choose the Public Advocate as their supporter.

As previously stated, we do not support the introduction of co-decision makers.

**Question 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?**

While the OPA has an important role in the implementation of supported decision-making more broadly and is well-placed to continue and expand if necessary its production of accessible information and materials for people, including for supporters, in our experience OPA is not necessarily best-suited to conducting specialist training for

supporters of people with psychiatric disability. We stress the need for community organisations with the skills and expertise in working with people with mental illness specifically to play a central role in training supporters about their key roles and responsibilities. Again we highlight the importance of consumer/peer support workers developing and conducting such training. Key aspects the information and training should include how to support a person by enhancing rather than diminishing their autonomy, how to avoid unduly influencing the person and special attention to key underlying principles proposed by the Commission, including respect for inherent dignity.

We also note the growing use by consumer organisations such as Our Consumer Place, of 'Intentional Peer Support' - a way of working which empowers consumers to work most effectively in a 'peer support' role and to avoid coercive or paternalistic attitudes and methods of working.

We agree with the submission of VLA that OPA is not the appropriate nor desirable body to undertake monitoring of supported decision-making. Rather, we endorse the suggestion that the proposed investigations unit attached to VCAT have responsibility and the resources to monitor the use of such arrangements. As for what constitutes "monitoring", in our view this would likely be limited to more quantifiable data, such as the number and type of orders made by VCAT in relation to supporters and supported decision-making arrangements, the number and type of applications for revocation of the document and resolution of disputes by VCAT.

**Question 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?**

Again, we reiterate that appointing a supporter should only be done freely and voluntarily and never be forced on a person, even if it would appear to others to be "less restrictive" than substitute decision-making. Given the critical and trusting role that a supporter will play and the importance of ongoing training and a consistent attitude and approach to the role, we do not believe it is desirable that any coordinated program engage volunteers. We would much rather such a program be staffed by paid employees with adequate funding and training to support people with psychiatric disability who choose to avail themselves of such support. We strongly encourage the Commission to explore the use and training of consumer peer support workers in various jurisdictions,

including the work that organisations such as Our Consumer Place in Melbourne are doing around training in Intentional Peer Support. Any organisation/s providing such training must be properly resourced to do so.

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

To the extent that MHLC supports the introduction of a legally recognised ‘supporter’ role appointed by the person themselves, we believe this should be available for financial matters also.

**Question 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?**

**and**

**Question 22 – What safeguards do you think are necessary to protect supported people from abuse?**

See our answers to questions 17-19.

**Part 4 – Personal appointments**

**Chapter 8 – Personal appointments.**

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

MHLC is of the view that enduring powers should only be activated – that is, only take effect - once a person is determined to lack capacity for that particular decision. This is consistent with the promotion of the rights to respect for dignity and autonomy, and to ensure that substitute decision-making only operates as a measure of last resort, where such infringement of rights is demonstrably justified.<sup>9</sup>

Mental health consumers we spoke to support being able to indicate in an advance directive itself, when their decision-making capacity might be impaired such that decisions defer to their advance directive. Similarly, consumers were keen to indicate the circumstances in which they would regain capacity, and the decision rests with

---

<sup>9</sup> See s 7(2) Victorian Charter of Human Rights and Responsibilities.



them, rather than deferring to the advance directive document.<sup>10</sup> The same applies to activation of powers of attorney. Broadly speaking, this is in response to a need to ensure that proxy decision-makers do not exercise their decision-making power prematurely and deny the person their own autonomy, but at the same time facilitating to the greatest extent possible, any supports which may assist the person to exercise their capacity. Consumers want to be able to identify, in their advance directive for example, when it is that they require support to make their own decision, and when it is that their proxy should step in to actually make a decision. In our view, such directives are important to signal to others at what point the person may be on the 'continuum' of decision-making in particular circumstances. In the MHLIC's view, these circumstances, instructions or directives must be taken into account in considering a person's capacity and in any assessment to determine whether they lack capacity to make the particular decision.

We note OPA's view that making financial POAs operative immediately upon signing – when the person retained capacity – is desirable as it would address the needs of people who may require additional support or whose capacity may fluctuate on a daily basis.<sup>11</sup> MHLIC however, believes that these issues can be better addressed by the Commission's proposed new supported decision-making arrangements, or through the use of a general power of attorney.

We note OPA's concerns that, due to the fact that capacity is decision-specific, it would be undesirable for capacity assessments to be made each time a decision is proposed to be made.

In this respect, we refer the Commission to the legislative provisions in Alberta, Canada. It would appear – from the legislation at least - that a person may appoint an 'agent' to make personal decisions<sup>12</sup> under the *Personal Directives Act 2000* (with or without explanatory instructions or 'directives' about how decisions are to be made) and that directive only comes into effect once a doctor or psychologist assesses the person's relevant capacity and completes a form which declares the person lacks capacity to make the particular decision.<sup>13</sup> To clarify when a person, for whom a personal directive

---

<sup>10</sup> See Appendix 2, p 6

<sup>11</sup> Consultation Paper [8.99]

<sup>12</sup> The definition of 'personal matter' excludes financial decisions and certain specific medical procedures such as psychosurgery and termination of pregnancy. It does not appear to preclude psychiatric treatment generally.

<sup>13</sup> See Form Schedule 2 – 'Declaration of Incapacity'. Alternatively, a service provider may complete a similar form after consulting with a doctor or psychologist.

is in effect, has regained the relevant capacity, further forms must be completed when a “significant change” has been noticed in the person’s capacity, whether by an agent (as agreed by the service provider)<sup>14</sup>, or the service provider itself<sup>15</sup>.

Under the *Personal Directives Act 2000* service providers – including healthcare providers and housing providers - also have a continuing duty to consider a person’s decision-making capacity.<sup>16</sup> Given that the nature of mental illness is such that a person’s capacity may fluctuate, we are of the view that such a duty represents good practice, provided that services have adequate training and support, or have access to expert referrals as appropriate.

Although we are unaware of how these provisions relating to capacity assessments and activation have operated in practice in Alberta, we believe they deserve further consideration.

**Question 24 – 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**

**Question 25 – Should these wishes be a factor VCAT is required to consider when it appoints a substitute decision maker or supporter?**

MHLC is firmly of the view that parents and carers of people with mental illness should not be given additional standing or specific powers, as of right, to participate in guardianship or administration proceedings at VCAT by filing a document stating their wishes. Many clients who are subject to Administration Orders appointing State Trustees frequently complain that their family members or carers are consulted more readily than they themselves are. As a consequence, many clients feel they are not kept ‘in the loop’ and in some cases are not informed of decisions being made, or why they are made. In this context, VCAT hearings represent an important independent process to allow a person to convey their own views & wishes. That is not to say that family members, parents or support people can not have a crucial role in the VCAT process where they are personally-appointed supporters or otherwise acting consistently with the person’s own wishes that they participate. We are concerned that if, regardless of

---

<sup>14</sup> See Schedule 4 – ‘Determination of regained capacity’

<sup>15</sup> See ‘Schedule 5 – Determination of regained capacity’

<sup>16</sup> section 21

the person's views, family members, parents and carers were able to file statements of their wishes which VCAT would then be required to consider, this could further disempower the person whose rights are most acutely affected by guardianship laws. These matters could be dealt with by VCAT on a case-by-case basis, having regard to the new guardianship laws principles.

**Question 26 – Should the number of enduring appointment 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?**

and

**Question 27 – Should there only be one type of appointment with a range of possible powers?**

We do not support reducing appointments to one type with a range of possible powers. In our view the key issue is to ensure that a person understands the nature and scope of the powers they are bestowing on their substitute decision-makers and likewise, that substitute decision-makers are clear about their nature and scope of their role and responsibilities that flow from that. We note the Commission's preferred option – to reduce from three to two the numbers of enduring appointments, by effectively merging the existing powers of an agent under the *Medical Treatment Act 1988* (MTA) and those of an enduring guardian. If this were to be the case, it is our strong view that a person should be able to articulate and limit the powers of an enduring guardian given the extensive powers a person may have in making for example both medical and accommodation decisions for the person. Whilst we understand the desire to simplify appointments, particularly where there is confusion and overlap in the medical/healthcare context, we strongly support people having the right to, for example in an advance directive, delineate the powers of proxy decision-makers. In light of the Commission's options for reform where psychiatric treatment is concerned (question 157), if the option of limited use of guardianship were to be pursued (Option C as preferred by the Commission), it is even more important that a person have the right to appoint, if they so chose, different people to make decisions about for example, accommodation, psychiatric and non-psychiatric treatment decisions.

We believe it is important to strike an appropriate balance between reducing complexity and promoting the autonomy of the person to the greatest extent, including the right to nominate decision-makers to particular, delineated roles.

**Question 28 – Should an online registration system be created for enduring powers?**

We support an online registration system for enduring powers, which could also hold advance directives and supported decision-making arrangements. It is important however, that people also have the option of lodging their documents in hard copy, either by post or in person.

**Question 29 – Which organisation should hold the register?**

We are strongly of the view that the organisation which holds the register must be independent and accountable. We do not have any particular experience with the Registry of Births, Deaths and Marriages, however we support this Registry as a holder of the register subject to our other submissions around privacy and safeguards.

**Question 30 – Should registration be voluntary or compulsory?**

Consumers to whom we spoke were somewhat divided on this issue, at least insofar as it relates to advance directives, in which a person may choose to appoint someone as a proxy decision-maker. Some were strongly in favour of registration as it would add credibility to the document and resolve any questions about lack of implementation due to the document not being accessible. Others however were far more reluctant to support registration due to privacy concerns and the feeling that registration should be by choice, whether to do so, and if so, when to do so.<sup>17</sup>

On balance, the MHLC takes the view that registration of enduring powers of attorney should be compulsory provided it is free and accessible in a range of formats. We note that most of our clients are receiving the pension as their sole source of income and a significant proportion of our client group is not necessarily computer literate. We therefore recommend registration be possible directly online or via lodging a paper form, which could then be scanned and stored electronically. Likewise revocations need to be equally straightforward and accessible.

---

<sup>17</sup> See Appendix 1, p7-8.

**Question 31 – If registration is compulsory, what effect should this have on unregistered appointments?**

**and**

**Question 32 – When is the best time for registration to occur?**

We support people being encouraged to register an enduring power or an advance directive once it is signed, and the person has been given information about the effect of the document if not registered and the person then subsequently loses decision-making capacity. In our view, failure to register should not be fatal to the effectiveness of a document per se. Registration at a later stage should be permitted and proof of its validity may be required. Consumers are particularly concerned about the fact that advance directives are drafted when the person is well and it may be a long time before the person becomes unwell or loses their capacity such that the document “kicks in” so to speak. For advance directives, given the nature and potential breadth of such a document, there are many reasons why people may not wish to register the document immediately upon signing.

Some consumers we spoke to were very concerned about third party accessing the register and then being privy to very detailed sensitive information. Particularly in advance of a crisis, people may only wish those people specifically named as supporters or proxy decision-makers to see those parts of the document that is relevant to them. In our view, the key to the success of the registration system will be ensuring consumers are confident their privacy is protected. (See below at q 33) Furthermore, that people have access to independent legal advice to explain their options and assist in drafting such documents if necessary.

For example, if a third party such as a hospital or health service has checked the register and makes all reasonable efforts to satisfy itself of the existence of a valid power (such as checking the person’s clinical record or contacting any known ‘supporters’) it may be reasonable for them to take appropriate action in good faith on the basis their being no valid document in place. The person should also be provided with information about when activation would take place – in our view, upon proven lack of capacity. It may be appropriate that this is determined by a doctor’s certification, or alternatively parties, including an interested person should be able to apply to VCAT for a determination of a person’s capacity, or lack thereof in particular decision-making area/s.

**Question 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?**

In our view, due to the very sensitive information people are likely to put in a document such as power of attorney or advance directive, this issue needs careful consideration to ensure that the privacy of individuals making a power of attorney or advance directive is not diminished, nor safeguards put aside for the sake of facilitating easy access by third parties. The label of mental illness itself can be incredibly stigmatising and the mere fact that a person has an advance directive which covers psychiatric treatment decisions could be highly prejudicial to a person were a bank for example able to find out this information when the person is applying for a financial product and there is no evidence to show or suspect that the person has impaired decision-making capacity. Likewise, a determination of incapacity for financial decisions for example, is not determinative of a lack of capacity for other types of decision-making. A finding of incapacity in one ‘area’ is one such piece information that should be disclosed in only limited circumstances where the person seeking the information can demonstrate a special interest in the matter and disclosure wouldn’t frustrate the spirit of the directive.

For people with mental illness who have had an experience of treatment in the public mental health system in particular, protection of the privacy of their personal and health information is of the utmost importance. Clients often complain that information they provide to mental health services for example is mis-interpreted or in some cases used against them. The use and disclosure of information on a person’s clinical file, even to the person themselves, is controlled by health service in the exercise of their obligations under Freedom of Information and Health Records legislation.

Advance directives can play an important role in providing a mechanism for the person to identify not only what information they believe is important for others to know, but to dictate what information is disclosed, to whom and how. In addressing this, we are encouraged by the two-tier search system that appears to operate on the Registry in England and Wales. We note that only very limited information is given to a person conducting an initial search. We are concerned however, to ensure that for any subsequent search by 3<sup>rd</sup> parties there is a very stringent standard to meet to determine the relevance and level of detail sought about documents which are or may be registered. In the case of the bank example above, it would not be sufficient for the bank to merely assert the person was a client and expect to receive full and detailed

information about a person's entire advance directive, which might include information unrelated to the person's finances. Similarly, the person may remain well and retain their decision-making capacity in which case it is entirely unnecessary – and arguably prejudicial – for the bank to know of the existence of an advance directive drawn up in anticipation of a future mental health crisis.

For the person to have access to the registry themselves, we support the use of a PIN for the person to have access to their documents and for any appointees to have access to only those documents which are relevant to them. We accept this may pose some problems for an advance directive where a person wishes to make one comprehensive document of various parts, but only grant access to the relevant parts to different people.

In this respect, we note that in Alberta, Canada, the registry holds only summary information about the existence of the document, and the further details of the document are accessible by contacting a named person or agent or organisation. However, in other respects the system in Alberta, which it would seem relies on the discretion of individuals relating to disclosure, may not necessarily result in greater protection of a person's privacy.

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

We do not believe it is necessary nor desirable that public authorities are notified upon activation of a power of attorney. We do however support notification in accordance with the person's instructions, as described at questions 35 & 37.

**Question 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?**

**and**

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

A person should have the power to specify particular people to be informed when a power of attorney is activated and similarly specify who should not be notified. This should be a completely voluntary option and a matter of choice for the person.

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

We note the provisions in Alberta, Canada's laws, providing for medical assessment that a person has impaired or lacks decision-making capacity (see question 23). We are uncertain how these provisions might work in practice to ensure a transparent and accountable process. Therefore we endorse the submission of VLA on this matter, and suggest that before any notification is made to any nominated persons, VCAT must make a determination that the person lacks capacity for that particular decision, thereby signalling the activation of the power of attorney, or advance directive - whatever the case may be – as enforceable documents.

**Chapter – 9 Documentary Wishes About Your Future**

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

MHLC has consistently advocated for broad legislative recognition of advance directives, and in particular those in relation to mental health in which a person with a mental illness outlines what they want to happen both in terms of their psychiatric treatment preferences and also non-medical or life management arrangements (see discussion below at questions 39-40). Although it is clear that a limited form of advance directives – advance statements – have received support in the Exposure Draft Mental Health Bill, we maintain our long-held position that comprehensive advance directive legislation ideally be introduced which does not separate psychiatric from non-psychiatric medical treatment directives.

In our view however, it is critical that such legislative recognition in no way abrogate, but rather preserve common law rights in relation to advance directives.

Importantly for our clients and people with mental illness more generally however, is the fact that advance directives have equal legislative recognition and consistent enforceability and implementation whether under guardianship or mental health laws.

**Case study – advance directive to compel medication preferences to be implemented sooner**



Our client, Vladimir, was subject to compulsory psychiatric treatment by way of a community treatment order (CTO) under the *Mental Health Act 1986 (Vic)*. His treatment included three-weekly injections of an antipsychotic medication. If he had to continue with involuntary treatment Vladimir said he preferred oral medication since, in his view, the side effects were better than the injection. Our client's private psychiatrist also supported a move to oral medication however, despite this, the treating team at the mental health service (responsible for the CTO) asserted that a trial of oral medication was "not yet feasible". We made submissions on our client's behalf at his Mental Health Review Board hearing that, even if the Board were to confirm the CTO, it should order a revision of our client's treatment plan to enable his preferred medication – oral medication - to be properly taken into account. The Board did order a revision of the treatment plan and noted in its statement of reasons that, "the treatment plan read like a prompt for the treating team rather than as a document written for [Vladimir's] information and after proper consultation with him".

According to Vladimir's subsequent, updated treatment plan, the dose of his injection has been reduced and the frequency of his depot injection has been reduced from every 3 to every 4 weeks. The treating team plan to gradually reintroduce oral medication whilst weaning him off the injection.

In our view, if advance directives had legal force and a commensurate robust obligation on service providers to implement them, this is one case in which our client could have used it to ensure the substitute decision-maker (in this case the authorised psychiatrist of the mental health service) provided treatment in a less restrictive manner, consistent with our client's wishes. Indeed an advance directive may have achieved this outcome in a more timely way.

Our consultation with consumers also confirmed a strong feeling among consumers that the enforceability of an advance directive should not be dependent upon there being a person appointed by way of a 'hybrid' directive.<sup>18</sup> That is, the relative weight of an advance directive should be equal whether or not an 'enduring guardian' is appointed alongside the making of instructions/directives. One person stressed this highlighted

---

<sup>18</sup> See Appendix 1, p 6

the difference between advocacy and actual substitute decision-making by an ‘enduring guardian’:

If the appointment of an enduring guardian is to ensure an advance directive is followed or honoured – this is an advocacy issue, NOT a guardianship issue<sup>19</sup>

The obligations on personally-appointed substitute decision-makers and service providers who would otherwise implement instructional directives, should be the same, as should the process for seeking to override advance directives. In this respect, we note that Alberta’s Personal Directives legislation applies broadly to services providers generally.<sup>20</sup>

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

**and**

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

The MHLC maintains a strong view that consumers should have the flexibility to be able to include in their advance directive whatever is most important to them, whether that be medical or psychiatric treatment or other lifestyle directives. It is important that law reform around advance directives preserve the key difference between an advance directive as a consumer-driven document, and a treatment plan or other type of discharge or care planning initiated by a health service. That is advance directives should not be clinically prescriptive as this risks focussing on the service’s or others needs, not what the person determines their own needs and supports to be. The MHLC does not advocate a prescribed form to be used for advance directives, however we refer the Commission to a draft pro forma document we have developed, available online which we invite people to use as a starting point to making their own advance

---

<sup>19</sup> *ibid*, p 4.

<sup>20</sup> At Part IV.

directive for mental health, if they wish to.<sup>21</sup> The mental health consumer and project worker who developed the pro forma found, after consulting with consumers and networks both formally and informally in Australia and other parts of the world, that consumers did not want documents which were too prescriptive – they didn't want to be told what they could say and what they could not. As the project worker explained, when it comes to advance care planning – a clinically driven process, “everyone asks a million questions, but none of them are the rights ones”.

For that reason, the MHLC's form prompts people to think broadly beyond mental health care and treatment about “rest of life” issues including other (non-psychiatric) health issues such as physical issues/allergies as well as accommodation, keys, care of children, pets, garden, relationships, social ties and work.

We also prompt people to think about including other things that they want the people caring for them to know, such as interests, daily routines, life history etc. In our view it is important that these matters are not prohibited from being included in an advance directive. One of the particular benefits of an advance directive for people with mental illness, is that it contains the wealth of information the person wants to convey in the one document.

Our discussions with consumers including those who have made advance directives themselves, has highlighted the blurred lines between when an advance directive might come with the ambit of guardianship laws and also mental health laws, particularly in relation to lifestyle issues such as living arrangements, employment, care of children etc. This further highlights the need for consistency in the way supported decision-making is prioritised by Tribunal and service system obligations and powers, to ensure that substitute decision-making is only ever used as a last resort.

Consumers we spoke to were also keen to have control over determining when an advance directive would be ‘activated’, namely, when the document itself should take precedence over what the person themselves was saying. To this end, some participants proposed the person making the directive should have the option of stating in the document itself when the advance directive might be set aside and their own views take priority. This was understood to mean indicating in what circumstances one's own

---

<sup>21</sup> MHLC pro forma advance directive document available at [http://www.communitylaw.org.au/mhlc/cb\\_pages/advance\\_directives.php](http://www.communitylaw.org.au/mhlc/cb_pages/advance_directives.php)

“capacity” would be diminished (and the directive relied upon) and when “capacity” or autonomy was regained.<sup>22</sup>

**Question 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?**

and

**Question 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?**

MHLC is strongly of the view that prior capacitous wishes expressed in advance directive should have far greater weight than being “merely one of the factors” to be considered by substitute decision-makers. It is imperative that the starting point be that wishes in an advance directive are binding upon both decision-makers and service providers in these circumstances. This is consistent with the promotion of the person’s rights consistent with the CRPD, in particular Article 12 and consequently, our submission about substituted judgment at questions 90-91. Anything less, and the document risks being effectively ignored and the views of the person much maligned in the decision-making process.

**Case study – enforceable rather than discretionary directives**

The MHLC represented Lionel before the Mental Health Review Board. Lionel had been treated involuntarily on a community treatment order (CTO) for some time. He had also been seeing a private psychiatrist for some time who was prepared to continue to treat him, despite his being on a CTO. At the hearing we argued that Lionel should be discharged because he could be treated less restrictively as a voluntary patient through his private psychiatrist. Alternatively, we argued the Board should exercise its discretion to order a revision of Lionel’s treatment plan or vary the treatment plan to ensure the private psychiatrist was named on it. In that case, the Board ultimately confirmed the CTO yet decided not to exercise what was in the Mental Health Act only a

---

<sup>22</sup> See Appendix at p 6.

mere discretion to order a revision of the treatment. This case highlights the difference a discretionary power and an enforceable obligation can have on people's lives.

Had our client had the opportunity to make an advance directive that was from the outset enforceable, both the treating team and the Board would have been compelled to better scrutinise our client's treatment which would have likely resulted in our client receiving voluntary treatment through his private psychiatrist, in a least restrictive manner, avoiding the need for coercive treatment.

**Question 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 this perform this role and (if so) in what circumstances?**

We recognise that wishes in an advance directive may be displaceable in certain circumstances, but in our view a decision to override an advance directive should only be taken following a carefully prescribed process which ensures that any restriction on the person's rights – in particular the right to exercise their capacity by making decisions in advance – is demonstrably justified, proportionate and indeed necessary.<sup>23</sup> The right to autonomy and bodily integrity is a fundamental tenet of both human rights law and the common law and, accordingly, we believe that this right should not be abrogated by overriding an advance directive without prior authorisation by VCAT. Consumers at the forum were resoundingly in favour of this option, where participants expressed overwhelmingly the need to implement advance directives as a powerful human rights tool which should not be easily dismissed. As one consumer emphatically explained:

Mental health treatment is unique – violations occur simply by virtue of a person being drugged against their will. Advance directives are in response to this violation and so they need prior judicial authorisation to override a directive..<sup>24</sup>

It is our strong view that an advance directive can never be overridden simply because others perceive or may perceive the decision to be not in the person's "best interests". The principle of autonomy provides that all people have the right to make to make decisions that others may disagree with, or think are risky or unwise, even irrational,

---

<sup>23</sup> Consistent with s 7 of the Victorian Charter of Human Rights & Responsibilities.

<sup>24</sup> Appendix 1, at p 7

but the law must promote and protect the dignity of risk for all people, including people with psychiatric disability.

The MHLC recommends an advance directive should only be overridden in very limited circumstances and that a rigorous standard of proof be applied. For example, where it is impossible to implement because services are not and cannot be made available or when circumstances have changed so significantly since the making of the directive that to implement the directive would clearly frustrate the original intention of the person making the advance directive.

Consistent with our submission on reform of the mental health act, we are strongly of the view that at the very least, an advance directive to refuse treatment **MUST** go before a full hearing of VCAT and a determination made by Tribunal before it can be overridden. The person must also be provided with legal representation and consumers are also adamant on this point.<sup>25</sup> Nevertheless we recognise that, given the extremely broad and potentially varied nature of the wishes, preferences and decisions people will make in an advance directive, it is not necessarily desirable that all decisions to override any part of a directive go through a prior judicial authorisation process.

Any decision-maker or service provider or Board/Tribunal that intends to override an advance directive must first provide written reasons for wanting to do so and provide the person with an explanation before any relevant application is made to override the directive or part of it. If a hearing is conducted, VCAT must provide a written statement of reasons for its decision also. We are also of the view that a valid decision to override a particular directive/s or part of an advance directive should not have the effect of invalidating the remaining directive. It should not affect the enforceability or validity of the remaining directives or part/s of the directive.

As to other matters which should guide the Tribunal in deciding on such an application, we recommend the Commission consider codifying the manner in which the common law has developed around advance directives in other jurisdictions in Australia. In particular, the relationship between general emergency treatment principles and advance refusals of treatment, which was espoused, in our view compatibly with human rights, by McDougall J in *Hunter and New England Area Health Service v A* [2009] NSWSC

---

<sup>25</sup> See appendix p 6.

761\_6 August 2009. In that case, His Honour expressly limits the applicability of the principle of emergency medical treatment to circumstances in which, among other things ‘the person has not signified that he or she does not wish the treatment, or treatment of that kind, to be carried out’.<sup>26</sup> In other words, medical practitioners cannot rely on the ‘doctrine of necessity’ to override a valid advance directive.

Finally, we would be concerned if the focus on, and complexities associated with the enforceability of advance directives resulted in a limited prescriptive form as this is anathema to the very reason behind advance directives in the first instance. It is also the MHLC’s strong view that care should be taken when ascribing the enforceability of an advance directive, that its usefulness as a bridging document for support and best practice by service providers is not ignored. Although some consumers may choose to have their advance directive only acted upon around the time when they are in crisis, for others there would be no point in a document that is only consulted when they have lost capacity and a substitute decision-maker steps in to make a decision. This is especially true for an advance directive such as Merinda Epstein’s (at Appendix 2), which is an important document for identifying optimum supports in advance of a crisis, which may indeed avert the situation even getting to an acute crisis point. If advance directives are too crisis-oriented in terms of their enforceability, this may have the undesired effect of rendering some advance directives obsolete.

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

We do not see a reason to differentiate the general obligations to follow a person’s advance directive between enduring guardians and financial attorneys.

**Question 45 – Should there be sanctions for overriding an instructional directive in a way that does not comply with the law? What should they sanctions be?**

We strongly support sanctions for unlawfully overriding an advance directive. Such sanctions must also be enforceable through a robust body which reports directly to parliament. It would be appropriate for sanctions to be severe in cases of gross violations of the law. In our view it is also imperative that data is collected on the frequency and circumstances of overrides of advance directives and that the responsible body have the power and resources to investigate individual cases and systemic issues.

---

<sup>26</sup> At para [40]

We note that the Exposure Draft Mental Health Bill proposed notification of all overrides of an advance directive to the Mental Health Commission. We urge a coordinated approach to monitoring and data collection and analysis, given the fact that an advance directive for a person with a mental illness may fall within under the umbrella of either or both mental health and guardianship.

**Question 46 – Should there be an electronic registration system for advance directives?**

and

**Question 47 – Should registration extend to medical and lifestyle instructional directives?**

The MHLC supports the introduction of an electronic registration system for advance directives for medical and lifestyle arrangements. In the MHLC's view, there are difficulties in relying solely on a person's hospital record as the place to store the directive. What happens if a person attends a hospital out of their area? What happens if key documents like the advance directive, even if their existence is known, do not get sent from the mental health service where it's stored, to the treating hospital or mental health service, or is sent through too late? However, as noted above at question 33, the significant concerns that consumers have about protection of their privacy and confidentiality of what may be a very detailed document will need to be resolved to enable consumers to have trust in a system which is accessible and promotes the use of advance directives more broadly. Consumers at the MHLC's forum remarked that it may be a long time after the drafting of the directive that it would be activated. Some people were adamant that electronic registration with other legally enforceable documents such as powers of attorney gives the advance directive "credibility". Then again, as one person stressed,

Others should only need to see it when necessary [and] it should be my choice [when I register it].

**Question 48 – Should registration be voluntary or compulsory?**

As stated above at questions 30-31, consumers are somewhat divided on the issue. The MHLC supports, on balance, a compulsory registration system, provided it does not cost the consumer to register a directive, there are appropriate and enforceable and that



failure to register does not render the document invalid of itself. Rather, this opens the door for VCAT ratification of the directive. We understand the need for clinicians and others to know where to find the advance directive in a timely manner, or else the risk is it will not be acted upon. Nevertheless, we hear some consumers' concerns about the privacy of such a personal document, and their desire to retain control over its storage and access.<sup>27</sup> For this reason, we support advance directives being registered at any time before they are activated and, if it has not been registered and a decision needs to be made which the person cannot make, VCAT should be empowered and resourced to conduct urgent hearings if necessary to enable a directive to be ratified..

We note that the Exposure Draft Mental Health Act only required clinicians to check the person's medical record to identify if they had an advance directive. These provisions are obviously confusing and unworkable in the face of proposed electronic registration under guardianship laws, particularly given the one advance document may overlap with both sets of laws.

**Question 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?**

As noted above in our response to question 33, access to the information contained in an advance directive for mental health is of a highly sensitive nature and arguably contains more complex and fuller details about the person's personal circumstances. This raises increasing complexity when it comes to protecting the person's privacy and its storage and access.

For example, the MHLC's draft pro-forma advance directive document has deliberately broad headings or prompts which, although loosely divided into psychiatric treatment and other life matters, the content may nevertheless cross over what is relevant to guardianship law and mental health law – in particular information about accommodation. In these circumstances, we recognise that some people may feel more comfortable having only limited information about their advance directive accessible via a register. See for example a description of the Alberta model at question 33.

There are many remaining questions about how a broad advance directive might be stored in order to both adequately protect the person's privacy, and also allow appropriate and relevant information to be disclosed in a timely manner to third parties

---

<sup>27</sup> See Appendix 1, p 7-8.

who will likely be implement it. Regulation of the “need to know” basis for accessing material in an advance directive raises some difficult issues such as who determines what amount of information a third party “needs to know”? For example, in Merinda Epstein’s advance directive<sup>28</sup> whilst the document is in discrete parts, it is intended that some or all parts will given to each supporter as Merinda sees fit. In our view, consistent with the empowering consumer-driven nature of the document, a person should have the option to identify who or which organisations may have access to what information, and who or which organisation should be prevented from accessing certain parts or information. For example, a person may have details about care of their children in the event they are hospitalised as well as identifying particular “early warning signs” or what to look out for to know when these supports should “kick in”. The person may very well not want the Department of Human Services to have access to any or all such information whilst they are well and managing well in the community.

It is also critical that people have access to clear information and legal advice about access to the directive or its relevant parts, by people named in the document and other 3<sup>rd</sup> parties.

## **Part 5 – VCAT APPOINTMENTS**

### **Chapter 10 – VCAT appointments and who they are for**

**Question 50- Do you agree with the Commissions 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 because of a disability before it can appoint a guardian or an administrator?**

We agree with the Commission’s proposal that disability no longer be a separate criterion for the appointment of a substitute decision-maker. In our view the proposal does provide for the focus to be on the person’s capacity rather than their disability. In our view it is important this shift be reflected in any VCAT application forms

**Question 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**

---

<sup>28</sup> See Appendix 2.

**make their own decisions? Are there additional or other ways to provide this guidance?**

We strongly support the articulation of capacity principles as well as a definition of incapacity in the legislation, based on the UK's Mental Capacity Act 2005. We are also encouraged by the acknowledgement at paragraph [10.83] of the Commission's Paper that the primary focus is on establishing incapacity and the evidentiary responsibility should rest with the person seeking to assert as much.

**Question 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 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?**

We do not support the ability of VCAT to appoint a substitute decision-maker in anticipation of some future lack of capacity. In our view this is inconsistent with the principle that substitute decision-making should only operate as last resort and autonomy be deprived a person when they are deemed to lack capacity to make that decision. A provision such as this would appear incongruous with the principle that capacity is decision & time specific and we cannot see how such a decision about future incapacity can reliably be made in advance. This is distinct from a person making their own advance directive since, as we recommend at question 23, the power is only activated when the person is determined, by VCAT, to lose capacity.

Given the nature of mental illness which may result in fluctuating capacity, we are concerned that an anticipatory appointment by VCAT could lead to abuse of person's rights rather than promoting creative ways to engage and support person to regain their capacity & develop decision-making skills as required by Art 12(4) CRPD.

### **Chapter 13 – Powers of Guardians and Administrators**

**Question 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?**

We agree with the Commission's proposal outlined in Option A (iii)

**Question 59 – If yes to Q58, what decisions should be a guardian be able and unable to make?**

We do not believe a guardian should have the power to make decisions on the person's behalf about voting, or personal and sexual relationships. As a general rule, the MHLC aims to reduce the use of involuntary and coercive measures for people with mental illness. However, we note that the extent to which a guardian may ultimately be able to exercise coercive powers will, to an extent, depend upon the Commission's final recommendation about the interaction between guardianship and mental health laws – see further our response to question 157.

**Question 60 – If yes to Q58, what decisions should an administrator be able and unable to make?**

The MHLC assists many clients with State Trustees as their appointed administrators who have real and unreasonable difficulties accessing the remainder of their income once bills and amenities are paid. Many find it extremely difficult and frustrating trying to negotiate with State Trustees to spend this money on what they themselves wish. It is not uncommon to hear clients complain of being 'drip-fed' small amounts of spending money and complain that State Trustees refuse access to money to enable them to make purchases, despite there being sufficient funds in their account. In these circumstances State Trustees may be acting on "instructions" or advice from the person's family or case manager when the person themselves has not been adequately consulted.

In the MHLC's view the role of an administrator should be to make decisions about payment of the person's rent, amenities, adequate food and clothing and other essential services. More often than not, our clients receive the Disability Support Pension which leaves little left over once these payments are made. What little remains is important for the person to have control over. We are concerned to ensure that administrators cannot use their financial power inappropriately to effectively exercise moral or social control over the person and their lifestyle, for example to prevent the person consuming alcohol, cigarettes or even illicit drugs. In addition, administrators should have a duty to make decisions consistent with the persons wishes to the greatest degree possible, and in a manner which affords the person the dignity of risk.

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

See our response to question 58.

**Question 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 a represented person**
- **Organ donation by the represented person?**

We do not support an increase to the powers of guardians or administrators to make such decisions.

## **Part 7- Responsibilities and Accountability Under the Law**

### **Chapter 17 – Responsibilities**

#### **Question 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?**

If a person has made a valid advance directive, this should take precedence over the person's expressed wishes but only if VCAT has determined that the person does not have decision-making capacity for that particular decision. We do not think it desirable for the law to regulate the relationship between the weight of past wishes not expressed in an advance directive and present wishes. We note only that provided a person's capacity is not significantly impaired, they have the right to change their mind, consistent with the principles of dignity and autonomy in the CRPD.

#### **Question 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?**

As the MHLC's consumer consultation report found:

..., a common theme that emerged was people's keen concern that they not be treated differently simply because of the label of 'mental illness'. One consumer pointed out that people should be able to take risks without this necessarily affecting the validity of the advance directive:

[We] should be able to make 'bad' decisions - decisions that others may think are 'bad' - to take risks or [make] decisions we later think are 'bad'.<sup>29</sup>

We strongly oppose the current law's focus on 'best interests' as a criterion for both taking away a person's autonomous decision-making ability, and for guiding the substitute decision-maker. As we put forward strongly in our submission to the Commission's Information Paper, we support a move away from 'best interests' – a worrying paternalistic concept - to a human rights consistent focus, including prioritising the wishes of a person (particularly those expressed in an advance directives) and promoting the dignity of risk. We do not think the law currently strikes

---

<sup>29</sup> Appendix 1 p. 6

the right balance in this regard and reiterate that, in general, the principles in the UK's *Mental Capacity Act* should be implemented in Victorian reforms. Consistent with our submission to question 90 however, we support the principle of 'substituted judgment' over 'best interests'.

**Question 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?**

**and**

**Question 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 Commission's proposal that substituted judgment be the paramount consideration for decision-makers. In our view the important distinction between this principle and that of 'best interest' is the necessary obligation in the former to actually consult the person to find out what decision that would likely have made. In our view, where the person has made a clear, valid advance directive which applies to the decision at hand, this must be followed and decisions must be made consistently with the advance directive. In this circumstance, the advance directive must take precedence over the current wishes of the person. That is, after all, the point of an advance directive. If the person's current wishes conflict with their advance directive, the decision-maker should be obliged to consult the person and explain the decision as one which follows the person's advance directive. We would like to see explicit articulation of this principle in the legislation. It would still remain open to the decision-maker to apply to VCAT to override the advance directive if they felt it was necessary to do so.

**Case study – substituted judgment not 'best interests'**

Our client, Sanjula, has a mental illness and was given around \$70,000 by her parents. Her parents made it clear at the time that the money was a gift and they did not expect her to repay them. A private lawyer was subsequently appointed as both Sanjula's parents' Administrator. The Administrator then contacted our client demanding the money she had received be repaid, and stating it was only ever intended as a loan and that demanding repayment is in the parents' best interests. Our client maintains, as do her parents, that the money was only ever intended as a gift and was not to be repaid.

An obligation for administrators to act in accordance with substituted judgment would mean, in this case, the private administrator would arguably have to implement the clear wishes expressed at the time the gift was made – that it was just that – a gift, as opposed to a loan.

We reiterate that failure to have registered an advance directive should be no impediment to implementing these principles. In the case of a dispute, the substitute decision-maker, or the person themselves or another party, should have the power to apply to VCAT for a determination about the effect of an advance directive or for advice in the circumstances.

We also strongly support an added legislative duty on a substitute decision-maker to consult with the person generally, not just on the activation of their power, but on a continuing basis. This would go some way to ensuring the principle of substituted judgment is implemented in an empowering way for the person which preserves the person's right to participate in decision-making, consistent with their rights under Article 12 of the CRPD.

We note the Commission's proposed list of considerations (at [17.135]) for a person when they are unable to determine the actual decision the person would have made, or the decision would cause serious harm to the person, which enable the decision-maker to act to protect the person and social wellbeing of the person. We are encouraged that, in these circumstances the Commission nevertheless priorities the wishes of the person. We would however like to see the reference to consultation with "family and other important people in the life of the person where appropriate" include a specific duty to consult with any support people the person has nominated in an advance directive or as a separate supported decision-making arrangement. We reiterate that, for many of our clients, a person's family members are not always necessarily the person's chosen supporter, carer nor do they necessarily represent the person's optimum supports.

#### **Case study – Identifying supporters to consult in an advance directive**

Merinda Epstein's advance directive (attached at Appendix 2) Merinda nominates her brother, a doctor, as one of her supports. However, she expressly states that he "is



probably the least informed about my ‘illness’. I don’t want him to be used as the ‘default carer’ because he happens to be a medical doctor. I prefer him to just be my brother.”

Merinda nominates other supporters and family members whom she prefers to be consulted first.<sup>30</sup>

In our view, the principle of substituted judgment and consultation with the person alongside the other important principles outlined at question 3 should apply generally to all substitute decision-making to ensure that the rights to dignity and autonomy and respect of the affected person are promoted to the greatest extent possible.

**Question 91 – Is substituted judgment relevant to supported decision making?**

If supported decision-making operates as it is intended, that is, that the supporter has no decision-making power and does not attempt to use such power, then substituted judgment is irrelevant.

That is not to say that supporters should not also be provided with clear information and guidance around their role and its limits and how to perform their role. We also strongly support a continuing obligation on supporters to consult with the person themselves about the exercise of their power and, in particular, where the supporter has accessed information on the person’s behalf, to explain that information to the person in a manner in which they can understand it.

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

We agree with the Commission’s recommendation to specifically require substitute decision-makers to act honestly and respond appropriately to conflicts of interest and further, that there should be sanctions for failing to comply with such duties.

**Question 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?**

---

<sup>30</sup> See Appendix 2, p 5.

We agree wholeheartedly with the Commission's suggestion that the law should specifically require guardians and administrators to treat the person with courtesy and respect at all times.

Clients for whom State Trustees are appointed administrators frequently complain that they are not afforded the courtesy of a return phone call from their administrator, or have limits placed on the contact they can have with their administrator. Given it is the represented person whose rights, privacy, freedom of movement and property rights are being interfered with, we believe this obligation should only apply to the represented person. The reference to "important people in the person's life" is inherently subjective and in our view open to an interpretation which may disempower the person. The rights of the represented person to be treated with courtesy and respect should always come before any similar obligations to other family members or carers. For example, clients often express frustration at the fact that State Trustees will more readily consult with their family member or other carer before consulting with the represented person themselves. The following case study illustrates the risk of equating the rights of third parties with those of the person.

**Case study - Steven - client's estranged wife treated with more 'courtesy' & 'respect' than him**

In the course of negotiating with our client, Steven's administrator, State Trustees, for the sale of the family home to effect property settlement following divorce, we were advised by State Trustees to speak with our client's ex-wife. Steven was effectively estranged from his ex-wife, though they had some limited contact. State Trustees told us that we should speak with our client's ex-wife and effectively get instructions from her about the situation, rather than speaking with our client himself. In our view, this is disrespectful and a completely inappropriate way for State Trustees to behave towards our client. A requirement that State Trustees treat clients with due respect and courtesy would go some way to addressing such disrespectful behaviour, which is all too common. Were there a similar obligation to treat his ex-wife in such a way (whom State Trustees could argue fit the definition of 'an important person'), this would undermined the respect owed first and foremost to our client.

**Question 94 – Should new guardianship laws contain the same decision-making principles for financial decisions and person decisions?**

**and**

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

**and**

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

We agree with the Commission’s proposed legislative duties on all substitute decision-makers, including medical, as outlined at 17.150, and with the additional duties for financial decision-makers at 17.151.

We strongly oppose separate and distinct principles for medical decision-making as, in our view, this leaves open the possibility that a person’s wishes and decisions made in an advance directive could more easily be set aside for other competing interests of ‘best interests’ which would continue to engender a paternalistic approach to decision-making. A consistent approach to all decision-making with autonomy, respect and dignity at its core is the most human-rights promoting approach.

## **Chapter 18 – Confidentiality**

**Question 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?**

**And**

**Question 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?**

We agree with the Commission's preferred view about authority to access information (Option B) to the extent that it avoids questions of access to information being overlooked in individual cases (a limitation of option A). Nevertheless we support consumers having the ability to prescribe or limit, for example in an advance directive or the appointment document itself, the information which may be disclosed to that decision-maker. It is also important the legislation include commensurate responsibilities to maintain confidentiality and we agree broadly with the provisions in s101 of the NSW Guardianship Act 1988. However, we would add further, that any use or disclosure of such information must be done in accordance with the person's advance directive or other instructions. Failure to comply with these provisions should attract enforceable sanctions.

#### **Chapter 19 – Accountability and Review of Substitute Decision Making**

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

**and**

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

**and**

**Question 101 – Who should receive and monitor the declarations?**

**and**

**Question 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?**

We support there being more general accountability mechanisms for substitute decisions-makers however any such responsibilities must be balanced against subjecting private guardians to what may be onerous, intrusive reporting requirements. In some ways this may act as a disincentive for people to execute such arrangements or their willingness to agree to be nominated as decision-makers for others. Of the options proposed by the Commission, we support periodic declarations which would at least prompt the person to consider their role and responsibility, could be collected, analysed

and monitored by VCAT's investigation unit. It is appropriate that VCAT have the power to compel a report or periodic reports be lodged with the investigations unit by private guardians and attorneys however, in the absence of any evidence of unduly coercive, exploitative behaviour or abuse, or indeed the person not having exercised any of their powers, we find it hard to justify mandatory detailed periodic reporting.

**Question 103 – Should there be random audits on the way substitute decision makers perform their responsibilities?**

and

**Question 104 – Who should carry out these random audits?**

In light of our answers to questions 99-102 above, random audits may strike a more appropriate balance and could be conducted by the investigations unit at VCAT. In our view however, we suggest all these proposals for reform however require more considered consultation with consumers

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

We support VCAT having the power to order repayment of funds that have been misused. This must be enforceable. Currently only the Supreme Court has power to order recovery of assets which is an inaccessible option for many of our clients, due to the adverse cost implications.

**Question 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?**

We believe that the individual decisions of not only the Public Advocate and State Trustees but also private guardians and attorneys should be subject to merits review. This is an important means of ensuring that substitute decision-makers exercise their roles and responsibilities in a manner which best promotes the rights, dignity and respect of the represented person. We see this mechanism as critical to ensuring accountability for new principles of substituted judgment and the enforceability of advance directives.

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

The MHLC takes the view that the person affected would have automatic standing to bring an application for merits review. In addition a person with a special interest should also be able to seek a review. VCAT should be empowered to determine whether such an application is appropriate. For example, if the person is named as a supporter by the represented person in a valid advance directive or supported decision-making arrangement, or is named as someone who should be notified on the activation of the particular power, this may indeed satisfy the 'special interest' test.

**Question 113 – What should constitute a “reviewable decision”?**

We support the approach in New South Wales, that is, that a reviewable decision is any decision in connection with the exercise of the substitute decision-maker's functions under the Act. This must extend in our view to both an actual decision as well as a failure to make a decision, as the following case study illustrates.

**Case study – Review of a failure to make a decision**

Our client, Steven lived in rural Victoria and had dementia, which met the criteria of mental illness under the MHA. Whilst in hospital under an involuntary treatment order (ITO) Steven separated from his wife. She stayed in the family home and our client, upon discharge from hospital, moved to a nearby town. State Trustees was appointed as Steven's administrator and Steven and his wife divorced. Our client was eager to finalise the property settlement by selling the family home and using the proceeds to move on with his life. State Trustees however said it did not want to sell our client's house since, they argued, if they did so, our client would lose the support of his ex-wife whom State Trustees contended provided necessary support such as some cleaning and cooking. We attempted to negotiate with State Trustees to have the property sold and argued there were other supports that Steven could rely upon, rather than his ex-wife, from whom he was effectively estranged. We had good supporting medical evidence that sale of the house would be in Steven's best interests. Three months after first requesting State Trustees to act in selling the house, State Trustees eventually advised they were referring the matter to the Office of the Public Advocate for advice on our client's lifestyle issues. We eventually referred the matter to VCAT. The hearing is due to take place some six months after we first requested State Trustees act to sell the house.

Were there a clear provision in the law to apply for a review of an administrator's decision, including failure to make a decision – in this case refusal to sell the family home – property settlement could have been effected far sooner, allowing our client to move on with his life.

**Question 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?**

We see no need to expand VCAT's current discretion in relation to these matters. We agree with the submission of VLA however, that VCAT provide a statement of reasons in cases where matters are struck out or dismissed in such circumstances.

**Question 115 - Should merits review of decisions by administrators be treated differently to merits review of decisions by guardians?**

and

**Question 116 - Who should conduct merits review decisions of public guardians and administrators?**

In our view decisions by both administrators and guardians should be treated in the same way - by application to VCAT for merits review. VCAT is, in our view the most appropriate, independent body to undertake this role. As to which List is most appropriate, we do not put forward a specific view.

**Question 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?**

We support VCAT having the power to make an appointment conditional upon the person attending training. We reiterate however our strong views about consumer-led training if the represented person has a mental illness.

**Part 8 - Supplementary and Regulatory New Laws**

**Chapter 20 - The Public Advocate**

**Question 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?**

We do not object to a protection of anonymity in limited circumstances where it can be demonstrably justified such anonymity is necessary for example to prevent a serious risk of harm. We are concerned that anonymity does not interfere with the represented person's fundamental right to access information in a timely way to enable them to respond to any allegations or assertions made about them in a hearing or any other process under the law. Our clients are frequently frustrated by service providers listening to carers or family members when information is provided by them which may not be accurate or might otherwise be misleading and they have little or not opportunity to correct that information before decisions are made in response.

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

We do not believe OPA is best placed to take responsibility for civil penalty proceedings for breach of guardianship laws. We would prefer to see this made the responsibility of the proposed investigations unit at VCAT. This would ensure a greater transparency and independence.

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

In the MHLC's experience, OPA guardians do not always advocate strongly enough for the rights of people with mental illness. They have, for example, refused to take responsibility for accommodation decisions if a residence condition is attached to a person's Community Treatment Order (CTO), even where it may be least restrictive and involve better promotion of the person's rights and interests for OPA to be the decision-maker, than the authorised psychiatrist (under the CTO). The MHLC supports the Public Advocate's continuing its dual role – as a last resort - for people with mental illness provided OPA is sufficient resourced and committed to effective advocacy on behalf of people with a mental illness.



**Question 127 – Should the Public Advocate be responsible for training and supporting private guardians?**

We do see a role for OPA in training, provided OPA itself is properly resourced and its staff provided with the necessary training to enable them to work effectively with people with mental illness. In our view, ideally OPA would work collaboratively with other organisations to ensure that consumers themselves designed and implemented the training and support program and materials.

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

**and**

**Question 129 – If so, how should any monitoring activities be performed?**

We do not believe the Public Advocate should play a role in monitoring the activities of private guardians as this risks confusing OPA's role as a guardian of last resort and what should be an impartial monitoring body. For example, monitoring can and should lead to more detailed investigations as appropriate and, were OPA to engage in this, it would erode public confidence in OPA's impartiality, particularly if it made the recommendation that the Public Advocate be appointed instead, as a last resort if the private guardian arrangement is unsuccessful.

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

From the MHLC's perspective, the critical stakeholders in designing a register of personal appointments are people with the lived experience of mental illness and their legal representatives and advocates. We also see a role for the Public Advocate alongside legal and advocacy organisations such as the MHLC in designing a register, but this should not come at the expense of broad consumer consultation. Unless end users (including mental health consumers) are confident in the design of such a register, including the privacy protections, there is a risk that it won't be utilised, irrespective of mandatory registration requirements in law.

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

**and**

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

Consistent with our response to questions 128-9, we do not believe that the Public Advocate should be given the role of formally monitoring personally-appointed decision-makers. We do however see a continuing role for OPA in supporting decision-makers by providing information and education and support. We reiterate that it should not be OPA's role to investigate nor prosecute guardians who may be acting inappropriately in their role.

**Question 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?**

As stated previously, we do not think the Public Advocate should have a monitoring or investigatory role when it comes to substitute decision-making more generally.

**Question 134 – Do you think the Public Advocate should be required to report annually to Parliament?**

A requirement to report annually to parliament is an important step in making the OPA more accountable and enhance its independence. In this way, OPA can have a meaningful role in raising systemic issues and making recommendations for reform which have increased credibility and can generate greater public awareness about the interference of the rights of people with disabilities.

## **Chapter 21 – VCAT**

**Question 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?**

**and**

**Question 136 – Should the Public Advocate be funded to undertake this role?**

The MHLC strongly supports a designated unit at VCAT being empowered and sufficiently resourced to enable people to more actively participate in hearings.

Other than in providing general information and resources, the OPA should not have specific funding to undertake this role. In any event, it would be inappropriate for OPA to have prepared for a case when OPA is ultimately then appointed as a guardian. This would risk undermining confidence in the independence and impartiality of both VCAT and OPA.

See also our answers to questions 137-8 & 142-8.

**Question 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?**

We support Options A – providing proposed represented person with information and referrals around advocacy services prior to hearing; and C – creation of a statutory power for VCAT to order person be represented where necessary.

We strongly re-iterate our previous submission that VCAT should not make order in absence of person. We note that VCAT currently has very wide discretion in relation to the making of temporary orders under ss59 and 60 of the GAA. We consider that VCAT's discretion must be circumscribed. We would like to see the legislation set out grounds which must be satisfied before an 'interim' order can be made, and the need for urgency in its being made. VCAT could also take into account the following principles:

- a. every reasonable effort has been made to enable the person to attend or otherwise participate in the hearing (by video conferencing for example)
- b. whether an order must be made as a matter of urgency to prevent serious risk of serious harm to the person
- c. the making of the order is proportionate to the restriction on the person's human rights
- d. the order applies for a maximum period of 28 day

In such a case, VCAT should only have the power to make a limited order for a limited period of time.

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

We believe it is critical that VCAT seriously consider less restrictive alternatives such as supported decision-making before any order appointing a substitute decision-maker is made. In our view this could include the ratifying of a supporter nominated in a person's advance directive, appointing person as supporter, provided that was consistent with the person's wishes and with a limited order prescribing the power to access information. We are mindful of consumer's reluctance to support VCAT-appointments and therefore oppose any appointment which goes against the wishes of the person, particularly as expressed in an advance directive. We note that Alberta legislation requires that any Tribunal-appointed supporter have had personal contact with the person over the course of the past 12 months.

We consider that VCAT should instead have the power to order compulsion or implementation of particular parts of a person's advance directive, as appropriate.

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

**and**

**Question 140 – If so, what should that maximum period be?**

We do not support VCAT having the power to make orders of unlimited duration. Particularly given that for a person with a mental illness, their capacity may fluctuate, in our view, orders should be made for no more than 12 months, after which time they should expire and a new application and de novo hearing would need to be conducted.

**Question 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?**

We strongly oppose the ability for VCAT to reassess or make a new order *ex parte* on the papers. On the expiration of an order no further order should be made without conducting a de novo hearing.

**Question 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?**

**and**

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

**and**

**Question 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?**

The MHLC believes the two most important principles to promote are, first, the protection of the privacy of the affected person, by ensuring that the information on a person's file – likely to be highly sensitive, given the nature of guardianship list hearings, is not disclosed to anyone but the parties and their legal representatives. We therefore support files being closed to the public with only the parties having a right of access. It may be appropriate that, for example, support people have the opportunity to apply to VCAT for access, with strict criteria around disclosure of any information. Second, it is imperative that the affected person be afforded natural justice, including the right to access any material on which other parties seek to rely and to which the Member is privy, in order to have an opportunity to respond to any adverse material. Accordingly if information is provided confidentially to VCAT, the presumption should be that the affected person can see the material, but that other parties may not. It is the responsibility of the person providing the information to justify any desire or need to keep it confidential – particularly from the affected person – and VCAT must advise them of the risk that the information will be disclosed at least to the affected person, and potentially other parties.

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

The need to extend the 28-day rehearing limit is obviated if our concerns and suggestions at question 137 are properly adhered to.

**and**

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

As previously outlined in answer to question 137, we strongly support an obligation on VCAT to provide more and better information to a person about their rights, including the right to seek a rehearing. This should be done at the conclusion of all hearings, and could be followed up and monitored by the proposed investigations unit at VCAT.

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

and

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

We support a person having the right to at least one reassessment hearing during the period of the order, however we strongly recommend a lower, more accessible threshold apply to the granting of such an application. As we outlined to the Commission in our previous submission to the review, many people are 'knocked back' from reassessment hearings for lack of cogent medical evidence at the time. Accordingly it is imperative that a person also have the opportunity to have a reassessment hearing if they can demonstrate a change in circumstances from the time the order was made. Particularly given the Commission's proposed new focus on supported decision-making we strongly resist VCAT having the power to reject an application at this stage on the basis that the prima facie evidence would not support a change to the order.

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

We do not have a particular view about the benefit or otherwise of a multi-disciplinary multi-member panel, compared with the current system. We are nevertheless strongly of the view that the Chairperson of any multi-member panel must be a qualified lawyer, given the legal criteria which must be satisfied and questions of law which arise including in relation to the Charter.

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

We support a flexible approach to the hearing process which allows for the affected person to participate most fully in the hearing. As we recommended to the Transforming VCAT paper, it is important that VCAT members undergo specific training on mental illness and working with people affected by mental illness.

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

We reiterate the importance of broad accessible information and resources about VCAT, its role, the hearing process, right to legal representation and how to access it, and guardianship laws more generally in the community. These resources must be also be accessible in a range of community languages. Clients often complain they were unaware of their initial VCAT hearing, or, if told, they didn't understand what it meant or were told they needn't attend.

We draw the Commission's attention to the approach of the Mental Health Review Board to attendance at hearings. The Board and contact officers and other staff at the relevant mental health services where the Board sits, must at least ask the person if they will attend the hearing, rather than simply relying upon a written notice of hearing sent to the person. They may also actively encourage the person to attend the hearing and sometimes facilitate legal representation. The Board itself must be satisfied that, where a person does not attend, they have done so voluntarily and of their own accord.

In our view the VCAT registry – or possibly the proposed new investigative unit – should take a more active role to ensure the affected person is aware of the hearing, understands the role of VCAT and encourage them to attend, and any time limits if they do not attend. This is particularly important for people who are incarcerated in hospital as an involuntary patient under the MHA, or incarcerated in prison or on remand. People in such circumstances face additional barriers and therefore require more assertive support to access justice and their right to be heard in a fair hearing. We have assisted numerous clients who were unaware the hearing was taking place, or even that they were under an order until long after the order was made, by which time the 28 day times limit for a rehearing has long past. Access to video-conferencing facilities for people in prison should be more readily provided, and VCAT should consider conducting hearings at hospital inpatient units to make it easier for a person detained under the MHA to participate in the hearing.

## 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 authorising psychiatric treatment and place of residence decisions for a person who is unable to make their own decisions due to mental illness?**

A complex issues that requires more detailed options and opportunity for analysis and debate

The MHLC has long-advocated for equal rights and opportunities to exercise them for people with mental illness and other members of the community. This includes having the option, if the person so chooses, to appoint someone they trust to make decisions on their behalf if they themselves are unable to do so. The MHLC maintains that a fusion model is the most human-rights compliant option, reinforcing the need to afford people with mental illness the same rights in relation to decision-making, exercise of their autonomy and safeguards for when they lack capacity to make a particular decision/s.

Overall, however, we found it very difficult to respond to this question in such a way as to contribute to an informed debate. The interaction of mental health and guardianship laws is an incredibly complex issue and we were disappointed that, despite calls for the Commission to fully explore the option of fusing mental health and guardianship laws, the Commission's response has been to dismiss a fusion model without giving the community a real opportunity to discuss and respond to what are both philosophical and practical issues.

We recognise this may be largely a result of the Commission's restricted reference in relation to mental health, as the terms of reference denied the Commission the ability to review the MHA and any real chance of a 'root and branch' reform of capacity-based laws. The Commission's preferred option C – to provide for the "limited use of guardianship laws" to enable personally-appointed proxy decision-makers to consent to or refuse psychiatric treatment, left many questions unanswered.

For example, if a person did have an 'enduring guardian' making decisions for them, would all aspects of their advance directives be interpreted in accordance with guardianship laws? What about in those areas where the enduring guardian did NOT have clear decision-making authority – would the advance directive be interpreted under guardianship or mental health laws? What if there wasn't a proxy decision-maker appointed – would that mean the directive defaulted to the mental health act, or only when the person "lacked capacity"? What about the period before they were deemed to



lack capacity, but might have needed extra support – would this be a guardianship or mental health law issue? What about living arrangements? Do these directive only become a mental health act consideration once the person is made an involuntary patient? What if the advance directive is designed to be implemented so as to avoid the need for such an acute crisis to manifest itself in any event? Take, for example Merinda Epstein's advance directive (Appendix 2). Who takes responsibility and under which law, for implementing her advance directive, or supporting her in accordance with that directive? How will mental health clinicians know which law to comply with and for which 'patients' in their care? What kinds of safeguards might apply to decisions by enduring guardians for psychiatric treatment if a person does not have an advance directive to guide their decision-making?

By comparison, the draft fusion model law developed by Daw, Dawson & Szmukler to which the Commission referred, was a more detailed and comprehensive model. The authors had invited commentary principally from experts in the legal, policy and psychiatric fields with experience in numerous jurisdictions including Scotland, the US, the UK, New Zealand & Northern Ireland. The notable exception from the range of commentaries was, unfortunately, a consumer perspective, however, the exercise - published in an entire edition of an international journal - was designed to prompt public debate, as it did, with commentators expressing a range of views about the desirability and workability of the proposed model, in some cases making suggestions for amendment. We do not propose to endorse the particular model devised by these authors. Devising a fusion model is not as simple as merely transposing mental health treatment decisions on to an existing guardianship framework or vice versa. In our view, it must involve building from the ground up a model which has the UN CRPD at its core and that incorporates the strengths of each system, striving for an empowering, progressive and non-discriminatory framework. Without something more substantial to comment on and respond to, the exercise is disappointingly hollow.

The question of the interaction between these laws was a particular focus of the consumer consultation forum we conducted. As our report concluded:

Participants felt that the interaction of these laws was a very complex issue which required more thorough exploration with people with the lived experience of mental illness. A common remark was that this was the forum was the first time many participants had had the opportunity to explore this issue in

any great detail and consider the consequences and impacts of different possible legislative frameworks.<sup>31</sup>

From the consultation with consumers we concluded that:

Even if the two laws remained separate, [consumers] were not confident that the two respective reviews would necessarily result in consistent laws and rights for people with mental illness [compared with] other non-psychiatric illness.<sup>32</sup>

As one person commented about the Commission's preferred option (C):

It's token concern for the rights of people labelled with mental illness – the Commission is acknowledging that Option A is inherently discriminatory and that Option B would put us on a par with at least other people with disability, but [yet] the Commission says the fusion model is a 'step too far' – that's for the community to decide.<sup>33</sup>

#### Inconsistencies between the reviews of mental health & guardianship laws:

In our view, the gap between the rights enjoyed by people with mental illness compared with others in the community – even people with other, non-psychiatric disabilities – appears to be reinforced by these concurrent law reform processes. In particular, the discrepancies in the process and likely directions and outcomes of Commission's review of Guardianship, and the Department of Health's review of the *Mental Health Act 1986* (Vic) (MHA). The timing and outcome and relationship of both these reviews occupied much discussion at the MHLIC's consumer forum in May and provoked much frustration among mental health consumers. Consumers to whom we spoke were reluctant to embrace reforms in guardianship laws where it was unclear to what extent they would be affected by a mental health act, assuming it continues to exist.

In our view, two key areas of reform were given only token or limited recognition in the Exposure Draft Mental Health Bill. Those were first, advance directives (called 'instructional directives' by the Commission; 'advance statements' by the Department of Health), and second, nominating someone as a supporter who could have access to information (called a 'supported decision-making arrangement' by the Commission; 'nominated person' by the Department of Health).

---

<sup>31</sup> Appendix 1, p 2.

<sup>32</sup> Ibid.

<sup>33</sup> Ibid.

To us, it seems clear that supported decision-making options and advance directives are taken far more seriously and are being explored more thoroughly by the Commission. Whilst we are hopeful there will be stronger support from the Commission than what we have seen in the Exposure Draft Mental Health Bill, the fact that advance directives – particularly ones which go beyond strictly psychiatric treatment - are likely to straddle both laws, makes for extreme uncertainty in the recognition, validity and enforceability of advance directives for a person with a mental illness. As the questions we pose above demonstrate, advance directives are perhaps the most stark example of why consistency between guardianship laws and mental health laws is so important.

#### A human rights-promoting, empowering model

In the MHLC's view, of the options the Commission has proposed, the fusion (option B) model would appear the most human rights compliant. Although we can see the potential for some consumers to embrace the option of a previously unrealised right to enable an enduring guardian to both consent to and refuse treatment, it is unclear how the emergency provisions would apply and whether or not there should be additional safeguards to guard against any coercive measures.

Consumers we spoke to discussed the degree to which guardianship laws might be a more empowering, rights-oriented alternative to a mental health act characterised largely by involuntary treatment. As we found in the consultation report:

There was broad acknowledgement that guardianship laws still have the power to be used paternalistically – both in terms of personally-appointed enduring guardians and VCAT-appointed 'adult guardians'. This was a concern to many participants. It was felt that option C presented a "real risk" of the threat of coercion applying. As one person commented, "The entire mental health system is underpinned by coercion anyway". There was broad support for the introduction of supported-decision-making processes that weren't coercive [such as advance directives themselves].<sup>34</sup>

In Alberta, Canada, we understand that a person may be subject to involuntary treatment in the community on a community supervision order, where treatment decisions are made by a 'guardian' – a responsible member of the community – which is usually a parent, sibling or spouse. We understand that, in essence, personal directives are used by family members to force the person with the mental illness back into

---

<sup>34</sup> See Appendix 1, p3.

treatment for brief periods and that the family member can make a treatment decision, notwithstanding any wishes expressed in the person's personal directive.<sup>35</sup> It is hard to see how this situation is more empowering or more accountable or necessary for protecting consumers' rights. Indeed, some consumers at the forum remarked that a VCAT-appointment of a proxy decision-maker may be no better than what happens under the MHA where the authorised psychiatrist becomes the decision-maker. Others thought if VCAT-appointed guardians could make psychiatric treatment decisions there would need to be some sort of review and oversight of these decisions.<sup>36</sup>

Another area that raised concern by us and also by consumers, was the interpretation & use of the emergency provisions. As we found in our report:

There was a very strong feeling of concern among consumers about how the 'emergency' exception would operate in practice. One consumer consultant noted that psychiatrists/staff in mental health often consider all psychiatric treatment as akin to 'emergency' treatment, even though technically this is not the case.

Other concerns about the emergency provisions included who determines what is 'insufficient time' to contact the person's proxy / 'enduring guardian'. Overall it was felt that in practice, emergency provisions could very easily be used to undermine the empowerment of people with mental illness, for example to dismiss the person's advance directive.<sup>37</sup>

Consumers at the forum were also nervous about whether enduring guardians might step into the decision-making role prematurely and undermine the principle that coercive or substitute decision-making would only be used as a last resort.<sup>38</sup>

Consumers with also keen to explore more the Tasmanian "integrated" model. However, on further consideration it would appear there are additional complexities in any event between the interaction between the MHA and Guardianship laws in that

---

<sup>35</sup> Source – personal email from Terry Romaniuk, Policy & Knowledge Management Counsel, Legal Aid Alberta, dated 18 June 2011.

<sup>36</sup> See Appendix 1, p 3.

<sup>37</sup> Ibid, p 5.

<sup>38</sup> Ibid, p 4.

state.<sup>39</sup> It was interesting to discuss the separation, at least in theory, of detention of a person for their safety and the question of involuntary treatment. We nevertheless have concerns about the impact of CTOs under the MHA in that state operating as conditional discharge orders, which would appear to have the potential to effectively force compliance with psychiatric medication in any event, without an actual ‘involuntary treatment order’ or the review safeguards that might bring.

Conclusion:

In many ways this question prompted us to ask more questions than pose answers, but, all things considered, the MHLC cannot support either separate mental health and guardianship laws (option A) since this provides insufficient certainty nor equality particularly around the recognition of advance directives, capacity as the central criterion for the appointment of a substitute decision-maker, supported decision-making options. Nor can we support the Commission’s preferred option of limited use of guardianship (Option C). In our view maintaining two parallel systems and laws depending on whether a person has appointed a proxy decision-maker or not will be incredibly complex, confusing and potentially unwieldy for mental health clinicians, for mental health consumers and others. There is insufficient detail to determine precisely how the Commission envisaged this compromised system working in practice and it is therefore unclear what lasting advantages there would be under this model.

Although we strongly support fusion model as the most human rights-compliant option, we reiterate our disappointment that, without at least a backbone of a framework for the community to comment upon, it has been a lost opportunity for mental health consumers to achieve at least the goal of equal treatment and rights compared with people with physical or non-mental disabilities.

---

<sup>39</sup> Based on discussion with Anita Smith, President of Guardianship Board, at the Office of the Public Advocate, 10 June 2011.

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

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

We agree with the Commission that the appointment of a guardian for a person subject to the *Crimes (Mental Impairment and Unfitness to be Tried) Act 1997 (Vic)* (CMIUT Act) is not necessarily appropriate, but that the availability of advocacy is critical to the person's ability to exercise their rights to apply for variation to their order and navigate towards greater liberty, privacy and freedom.

**Question 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)*.**

We do not believe that OPA is the appropriate body to provide the kind of legal advocacy required for people detained or otherwise restrained under CMIUT Act. We strongly support the appointment of legal advocates with proven expertise in working for and with people with mental illness and in particular forensic patients of people otherwise subject to the CMIUT Act. Both the MHLC and VLA have the ideal expertise in this respect.

The MHLC has extensive experience assisting forensic patients through individual legal advice and representation in relation to reviews and/or applications to vary non custodial supervision orders in the County and Supreme Courts. Many of these referrals come through Forensicare who are pleased with the model of representation developed by MHLC. We are keen to push the limits with these matters, promote the person's thoughts and endeavor to make Charter submissions when appropriate. We have also been actively involved in community legal education sessions for consumers at Thomas Embling Hospital, including, in 2006, publishing a handbook to Mental Illness and the Criminal Justice System. Most recently, we published the results of a research project which explored the experiences of people with mental illness in the Victorian criminal justice system.<sup>40</sup> Our work also puts us in a unique position to comment on systemic law reform and policy issues and spearhead research such as the research into the

---

<sup>40</sup> Available at: [http://www.communitylaw.org.au/mhlc/cb\\_pages/crime.php](http://www.communitylaw.org.au/mhlc/cb_pages/crime.php) (last accessed 1 June 2011)

experiences of people living with mental illness who are involved in the criminal justice system.<sup>41</sup>

The MHLC is keen to increase its capacity to assist people with CMIUT Act matters and urges the Commission to recommend the appointment of advocates from either the MHLC or VLA. In our view it is extremely important for clients to have a choice of either organisation. Criminal matters comprise around about 7% of the MHLC's total advice and casework.<sup>42</sup> Unfortunately however, due to extremely limited resources (approximately one day per week casework & advice) and the often intensive amount of work involved in each case, any increased advocacy would require a substantial injection of funding to the organization to build its capacity in a sustainable manner. We believe that a recommendation for advocacy should be made by the Commission, on the proviso that adequate funding is provided to both MHLC and VLA to meet the additional, unmet needs of this particular client group.

---

<sup>41</sup> See the Project Report, published October 2010, available at:  
[http://www.communitylaw.org.au/mhlc/cb\\_pages/crime.php](http://www.communitylaw.org.au/mhlc/cb_pages/crime.php)

<sup>42</sup> See MHLC's annual report – 2008/09, p 57, available at:  
[http://www.communitylaw.org.au/mhlc/cb\\_pages/annual\\_reports.php](http://www.communitylaw.org.au/mhlc/cb_pages/annual_reports.php)

## **What do mental health consumers want from guardianship laws?**

### **Report from Mental Health Legal Centre's consumer forum (Monday 16 May 2011) and follow-up consumer consultation**

Prepared by:

Catherine Leslie  
Lawyer / Policy worker  
Mental Health Legal Centre

June 2011

#### **Background:**

As a specialist community legal centre that provides legal assistance to people with mental illness including in the areas of guardianship, administration and mental health laws, the Mental Health Legal Centre, was keen to hear directly from consumers what they wanted in reform of guardianship laws. We decided to hold a forum to discuss with mental health consumers some key aspects of the Victorian Law Reform Commission's (Commission) proposed reforms as detailed in the Commission's Consultation Paper.

A total of eight consumers attended the forum, some of whom identified as consumers, others as psychiatric survivors. Many participants had extensive expertise, not only from their respective lived experiences, but also drawn from, in many cases, decades of experience as activists and consumer consultants in the broader consumer movement in Victoria, Australia and internationally. The forum was facilitated by Catherine Leslie, Lawyer and Policy worker from the Mental Health Legal Centre.

A considerable part of the forum was taken up discussing the interaction between mental health laws (Victoria's *Mental Health Act 1986*(MHA)) & guardianship laws including the different timing and nature of the two reviews of these respective laws (the MHA review having been nearly completed by the Victorian Department of Health). The Commission had also considered the interaction between guardianship laws & mental health laws (contained in Chapter 23 of the Consultation Paper) – see Topic 1 below – and it was a great concern that any recommendations made by the Commission which would promote the rights of people with disabilities - in particular around advance directives - might not apply equally to people labeled as having a mental illness, because of a separate mental health act.



## **Topic 1 – Interaction between mental health laws & guardianship laws**

### **General comments by participants –**

Consumers were keenly questioning the need for separate mental health laws which, on their face reinforced the different and discriminatory way in which they were treated as a result of their diagnosis. The Commission’s proposed Option A - no change to the separation between mental health and guardianship laws - was therefore not seriously considered.

There was as a general feeling of disappointment with the way the Commission had approached this topic in chapter 23 of the Consultation Paper. Some people were particularly frustrated by the fact the Commission had identified a ‘preferred’ option (Option C) of a limited use of guardianship laws for “enduring guardians” to make psychiatric treatment decisions<sup>1</sup>, whilst at the same time dismissing the fusion option which would provide all substitute decision-making provisions came under the one, cohesive law (Option B). Some participants also expressed concern about the Commission referring to the ‘desirability of treating people against their will before risk issues are serious and imminent’ as a reason to dismiss the ‘fusion’ model. In terms of Option C, consumers were disappointed the proposals left many questions unanswered. As one person commented:

It’s token concern for the rights of people labelled with mental illness – the Commission is acknowledging that Option A is inherently discriminatory and that Option B would put us on a par with at least other people with disability, but [yet] the Commission says the fusion model is a ‘step too far’ – that’s for the community to decide.

Participants felt that the interaction of these laws was a very complex issue which required more thorough exploration with people with the lived experience of mental illness. A common remark was that this was the forum was the first time many participants had had the opportunity to explore this issue in any great detail and consider the consequences and impacts of different possible legislative frameworks.

Whatever the Commission’s final recommendation, there was a strong feeling that implementing change would be a problem if there were a persistent lack of knowledge about these options in the community. Even if the two laws remained separate, people were not confident that the two respective reviews would necessarily result in consistent laws and rights for people with mental illness and other non-psychiatric illness.

---

<sup>1</sup> And which would prevail over any decision of the authorized psychiatrist under the MHA, thereby bringing the person within the scope of guardianship rather than mental health laws.

There was significant interest in exploring further a model whereby the power to detain a person and take them to a place of safety, on the basis of risk (under one act) may be dealt with separately to the decisions about substitute decision-making for all medical (incl psychiatric) treatment and other issues. All personal, non-financial and medical treatment decisions could fall under guardianship laws where the person lacked the requisite decision-making capacity. In this respect, some felt the Tasmanian model mentioned by the Commission deserved some consideration as a “fourth option – D” and that the community have the opportunity to comment on it.

### **Summary of views of participants about option C**

There was a strong feeling that the Commission’s preferred Option C represented a compromise of the rights of people labelled with mental illness, which should not be the case. It was generally felt that, in retaining separate mental health laws under Option C, this would still result in discrimination against people labelled with mental illness.

Some participants felt that the key issue in the question of the interaction of laws was whether people with mental illness can refuse treatment.

There was broad acknowledgement that guardianship laws still have the power to be used paternalistically – both in terms of personally-appointed enduring guardians and VCAT-appointed ‘adult guardians’. This was a concern to many participants. It was felt that option C presented a “real risk” of the threat of coercion applying. As one person commented, “The entire mental health system is underpinned by coercion anyway”. There was broad support for the introduction of supported-decision-making processes that weren’t coercive (see more detailed comments about advance directives below).

In relation to proxy decision-makers more generally, it was generally felt that personally-appointed decision-makers should be separated out from those appointed by VCAT, as there are different issues with each type of appointment. People were generally in support of the ability to choose to appoint someone else to make decisions on their behalf if they had someone trust to make those decisions. On the other hand, participants didn’t want VCAT-appointed proxies to have the same broad powers as if they were appointed by the person. As one person explained:

For one thing, the appointment by VCAT will be done at later stage - possibly if [you’re] unwell, whereas appointing someone yourself would happen when I’m ‘well’

Another person expressed it as, “If we don’t appoint someone, we don’t trust anyone [to make the decision for us]”.

Some participants remarked that a VCAT-appointment of a proxy decision-maker may be no better than what happens under the MHA where the authorised

psychiatrist becomes the decision-maker. Others thought if VCAT-appointed guardians could make psychiatric treatment decisions there would need to be some sort of review and oversight of these decisions.

The appointment of a proxy decision-maker, or enduring guardian, was inherently linked to the making of an advance directive. However, as one person remarked:

If the appointment of an enduring guardian is to ensure an advance directive is followed or honoured – this is an advocacy issue, NOT a guardianship issue

Consumers also stressed that proxy decision-makers should not be able to make decisions on the basis of information or discussions which were not disclosed to the person, in concert with a central tenet of the consumer movement - 'nothing about us without us'.

It was recognised that not everyone has a support person they trust to make decisions for them – those that do are lucky. One person commented that you can't necessarily guard against the situation of a person in their first mental health crisis who may not have appointed anyone. Others thought this situation could be best addressed by inspiring a "culture of advance directives in the community generally". As one person commented:

Best practice psychiatric treatment must involve implementing a person's advance directive.

Participants were concerned about what the Commission was proposing in terms of when an enduring guardian's power to make a decision for the person would effectively 'kick in'. There was concern about the extent to which, in practice, substitute decision-makers ('enduring guardians') might step in prematurely in circumstances which potentially "loosens the criteria" for what might otherwise not meet the threshold for substitute decision-making or involuntary treatment provisions under the MHA. Participants queried whether factors such as 'risk' would have to reach a certain level under Option C, to really be sure that autonomy was taken away from the person themselves truly as a measure of last resort.

In any event, some people were strongly of the view that Option C would be no use for people with mental illness if the Commission's proposals for supported decision-making – such as advance directives and the appointment of supporters - is not put in place first. It was unclear the extent to which the Commission's proposals for supported decision-making would apply to people with mental illness. It was generally felt that, given the way the Exposure Draft Mental Health Bill gave limited recognition to supported decision-making options, people with mental illness would not have the same kind of guarantee (under the MHA) that substitute decision-making would be used only as last resort.

### **Views about the emergency provisions in option C – the ‘exceptions’ to an enduring guardian making the decision about psychiatric treatment:**

Participants discussed how the Commission’s proposed ‘exceptions’ under Option C, to enable treatment by clinicians without consent<sup>2</sup>, would operate in practice. Although it was acknowledged the principle of ‘emergency’ treatment applies to general health, there was a concern about how mental health clinicians would interpret this kind of provision.

There was a very strong feeling of concern among consumers about how the ‘emergency’ exception would operate in practice. One consumer consultant noted that psychiatrists/staff in mental health often consider all psychiatric treatment as akin to ‘emergency’ treatment, even though technically this is not the case.

Other concerns about the emergency provisions included who determines what is ‘insufficient time’ to contact the person’s proxy / ‘enduring guardian’. Overall it was felt that in practice, emergency provisions could very easily be used to undermine the empowerment of people with mental illness, for example to dismiss the person’s advance directive.

There was also a concern about the potential for the emergency provision to effectively prevent someone from refusing treatment under Option C (via their ‘enduring guardian’).

### **Topic 2 – ‘Instructional directives’ (Advance directives)**

The forum participants discussed the Commission’s options for determining the ‘weight’ or ‘enforceability’ of ‘instructional directives’ (the Commission’s term) on a decision-maker who had been appointed by the person (‘enduring guardian’) to make decisions if they themselves were unable to consent to treatment. The Commission’s options were:

- |   |
|---|
| <ul style="list-style-type: none"><li>A. No change (ie. Directive is just one of a number of factors to take into account in determining what is in the person’s ‘best interests’)</li><li>B. Require them to consider directive &amp; provide reasons for departing</li><li>C. Binding but displaceable in certain circumstances</li></ul> |
|---|

Forum participants overwhelmingly dismissed options A & B and preferred Option C, but with some added conditions and authorisation process (see detailed comments below).

---

<sup>2</sup> The proposed criteria that must be satisfied is where: a. there is a serious risk of immediate harm to person or others AND b. there is insufficient time to contact enduring guardian AND c. the powers must be exercised for person’s benefit.

### **Should 'wishes' been binding?**

There was a resounding 'Yes' from participants to this question, but a recognition that they could be displaced in certain circumstances (see below).

There was also a strong feeling that the enforceability of an advance directive shouldn't be dependent upon there being a person appointed by way of a 'hybrid' directive – ie. appointing an 'enduring guardian' together with the making of instructions/directives. We reiterate the comment made (above) that the appointment of someone to ensure an advance directive is followed or honoured should be correctly framed as an *advocacy* issue.

Some consumers thought it important the framework for advance directives allow for a person to choose the option of deferring some (or all) decisions to the appointed enduring guardian if they chose to do so, ie. Without making explicit instructions. There was general support for the proposition that medical and lifestyle directives should from the outset not have different status. Similarly, consumers were firmly of the view that advance directives should not have different 'weight' under Guardianship and mental health laws.

A common theme in the discussion was that people with psychiatric disability should not be treated differently simply because of the label of 'mental illness'. One consumer pointed out that people should be able to take risks without this necessarily affecting the validity of the advance directive:

[We] should be able to make 'bad' decisions - decisions that others may think are 'bad' – to take risks or [make] decisions we later think are 'bad'.

Consumers were also keen to have control over determining when an advance directive would be 'activated', namely, when the document itself should take precedence over what the person themselves was saying. To this end, some participants proposed the person making the directive should have the option of stating in the document itself when the advance directive might be set aside and their own views take priority. This was understood to mean indicating in what circumstances one's own "capacity" would be diminished (and the directive relied upon) and when "capacity" or autonomy was regained.

### **In what circumstances should/could a person's wishes in an advance/instructional directive be 'displaced' and how?**

Participants were very clear about the need for authorisation by a judicial body, rather than, for example, a second psychiatric opinion, before their advance directive could be overridden. There was widespread support for the fact that the person must be legally represented at a hearing to determine whether the advance directive would be overridden.

It was also very strongly felt that reasons for departing from the directive must be provided in writing and explained to the person.

Because psychiatric treatment can be so intrusive, both physically and mentally and in restricting a person's human rights, participants expressed overwhelmingly the need to implement advance directives as a powerful human rights tool which should not be easily dismissed. As one consumer emphatically explained:

Mental health treatment is unique – violations occur simply by virtue of a person being drugged against their will. Advance directives are in response to this violation and so they need prior judicial authorisation to override a directive.

Consumers cited frustration with “emergency” provisions such as those proposed in the Exposure Draft Mental Health Bill relating to ECT, which undermine advance directives. As one person explained:

Emergency provisions should only be used to contain a person as last resort if necessary, not treat them against their will.

## **Registration of advance directives**

### **General comments:**

This issue was discussed briefly. Many participants supported registration of advance directives, recognising that doctors and clinicians would only be able to implement an advance directive if they know it exists & have access to it. Others believed registration should be an **option** for people. For most participants, the very sensitive nature of the information in the document is an important concern in answering this question.

### **When should an advance directive be registered?**

Participants discussed whether an advance directive should be registered immediately upon drafting it, or at another time prior to its “activation”.

Some people said they would register the document once it was made. One person commented that they

wanted it registered because it adds credibility.

One person in particular was concerned about having to register an advance directive as soon as it was made. This was, to a large degree because she only wanted the advance directive to be access when necessary. She recognised it may be a long time before the directive would be activated but stressed that, “Others should only need to see it when necessary [and] it should be my choice [when I register it].” In saying this, the consumer thought it would be best if an unregistered advance directive were “as binding as if it were on my medical record.”

If revoking or making a new advance directive is complicated it could be a disincentive to actually making one in the first place. Similarly, complicated registration may compound this.

### **Topic 3 - Supported decision-making options put forward by the Commission**

This topic was largely discussed informally with forum participants in subsequent follow-up discussions.

#### **Supported decision-making arrangements:**

Consumers were generally supportive of being given the opportunity to appoint someone to receive information on their behalf and to support them in making their own decisions. In a sense, it can provide certainty to the person and other third parties about who the person wants to be involved in their decision-making and the extent of the authorization.

It was highlighted however that such an option must be a choice. As one person emphasised, “I wouldn’t want things like this to be imposed on me”.

Credibility was also an important consideration for people. As one person remarked, “if [appointing a supporter] is an option, it should have some weight – it needs to have some credibility”.

In terms of VCAT-appointed supporters however, consumers were less keen about this proposal. One consumer pointed out::

it’s almost like taking it out of the person’s control, even though making an order like this would need their consent. Almost like a contradiction. On the other hand, it could be seen to be a less restrictive option for VCAT than just appointing someone to make decisions for me. But it’s like a slippery slope [and] I’m not sure it should have to get to this point.

#### **Co-decision-making arrangements**

In speaking with consumers, we found real reluctance to support this proposal due, in short, to the risk of such an arrangement operating coercively in practice. One consumer thought that, rather than a support mechanism, co-decision-making sounded as if it were a step closer to taking away her autonomy and decision-making ability. She was concerned that “there could be some coercion or clawing back of what the person themselves wants and if they disagree, there’s not much value in it”.

Consumers struggled to see a place for such an option and one person said:

I would find it threatening that the co-decision-maker could sway my decision – threatening my choice, my autonomy. It would feel like it would be stressful & anxiety-provoking.

In her view, requiring agreement between herself and other person was not the same as supporting her to make her own decisions. It was acknowledged that people's views would really depend on the relationship the person has with the co-decision-maker.

### **When would these support options be triggered?**

Consistent with consumers views about advance directives (above), we found support for the need for consumers to have the option of identifying when supporters should be able to exercise their power. As one consumer remarked, "it's not 'supportive' if I don't agree I need support at that time".

In this respect, consumers reiterated that supported decision-making is not just about personal appointments, rather it extends to cover a *way* of working. As one consumer described:

[Supported decision-making] is about doctors and case managers etc providing me with the options & discussing them with me, helping me with the emotional part of decision-making and the implementation of my decisions.

Examples of this could be:

Prompting me with questions. Asking me, 'what do you need in order to make that happen?' whether it be coming down to the bank with me, taking me to the housing office etc

### **Training of 'supporters'**

Consumers were strongly in favour of training being offered to people in these supportive roles, but highlighted the importance of people with the lived experience of mental illness doing the training. As one consumer commented:

The content [of the training] needs to be informed by consumers & what consumers say works for them and actually *is* supportive. I hate it when others tell me what is supportive & what's not for me. At the very least, consumers should be co-facilitators in the process of developing & delivering the training



MHLC Submission to VLRC Consultation Paper - Appendix 2  
**ADVANCE DIRECTIVE:**  
**Merinda Epstein\***

---

**Preliminary Principles:**

1. I write this Advance Directive in good faith.
2. I am familiar with my symptoms. I know them better than anyone else including doctors and my family.
3. I am pretty good at knowing what works and what doesn't.
4. I have lived with strange thoughts and mood swings for many years.
5. I am also a very competent person and skills that far outweigh other limitations.
6. I hold a strong belief that caring relationships are almost always reciprocal. I know almost no consumers who are not carers.
7. I do not need to be protected from 'outing' myself. I am already very out both as a nutcase and as a lesbian.
8. I think of myself as a consumer rather than a patient and wish for this to be respected as far as is possible especially when I am not in a clinical setting.
9. I strongly believe in the slogan of the consumer movement: **Nothing about us without us.** I do not want decisions being made about my life that I am not privy to.
10. I have a terror of being caught out as a poseur who has no real mental illness. Telling me things like, 'you seem OK' or 'thankfully this is only a minor overdose' has the effect of making things worse, not better.
11. **FOI:** I have a good crap detector. I care about what people write in my records because I know it influences their practice. I always recover my records through Freedom of Information.
12. I will continue to work for the freedom and human rights of all people diagnosed with 'mental illness'. Please do not pathologise my politics.
13. I recognise that I have a tendency to intellectualise but this has served me well over many years. Having an intellect is not a pathology either.
14. I have a tendency to try to please. Sometimes I prioritise the needs of clinicians over my own needs. Many consumers do this. I don't want to.
15. I have confidence in the clinical capacity of my psychiatrist, Sue, and my G.P. Paul
16. Sue's practice is exceptionally informal which works very well for me. She works out of a dentist's surgery. There are no other medical doctors there and even more importantly for me, no other psychiatrists.
17. Sue doesn't have any secretarial assistance and I find her answering machine unthreatening and reassuring. She always returns my calls.

18. Sue does not always return calls to other medicos. This demonstrates that her priorities are in the right place. However, it makes an Advance Directive even more necessary because I need to let her know who I want her to speak to and who she can keep on ignoring.
19. I get institutionalised quickly. Avoid hospital if possible.
20. I want this Advance Directive filed and made available, with my permission, if I am again admitted to hospital.
21. Emergency departments are dangerous places for me: with symptoms escalating. They are too busy for complex Advance Directives. Sue and I have together written a letter based on my Advance Directive but signed off by her which says, "*Merinda is the expert in her own life, her own symptoms and her own likely outcomes. Even if she appears very distressed always listen to her and **always** take what she is saying seriously. She is the furthest person from an 'attention seeker' or 'manipulator' so please don't use these words when writing about her.*"

## Medical contacts:

**Psychiatrist:** Sue

Phone: ###

Dr Sue

Address: ###

**G.P:** Dr Paul

Phone: ###

Dr Paul

Address: ## Medical Clinic

**Specialist Bariatric Physician**

Dr Margaret

Phone: ####

Address: ###

**Specialist Orthopedic Surgeon**

Dr Steven

Phone ###

Address: ###

**CAT Team:** Northside Mental Health Program Triage

Phone: 1300 ###

(The CAT Team knows me but they are absolutely the contact of last resort. I don't like their involvement unless absolutely necessary).

**Pharmacist:** Sandra: Pharmacist

Phone ###

Address: ###

(I have an arrangement with my pharmacist that she will take over my 'medical drug stash' when I am feeling suicidal.)

## **Part 2: Important information for all clinicians:**

1. **Treating Team:** I am a central part of my 'treating team'. It is not helpful for others, especially clinicians and workers, to talk **about** me. For my mental health I must be part of conversation that are about me. This does not mean being told decisions after they have been made. It means sitting at the decision making table. Furthermore I consider the people nominated below to be part of my 'treating team' although this is a role that is reciprocal, short term and recognized as a way to increase my power in decisions made by the 'treating team'. I have talked to all 'lay members' of my team about this situation.
2. **Talk to each other:** Communication is the central platform of my Advance Directive. I want all clinicians and my pharmacist to talk to each other. I have chosen you all very carefully because you have good communication skills. I expect this communication to take place. Regardless of your specialty my health involves a complex web of interrelated medical experiences. I do **NOT** want any clinician to hide behind an excuse of 'confidentiality'.
3. I want clinical decisions about my mental health to be made **collaboratively** with Chris and I taking the leading role.
4. **Talk to my nominated Support Team:** You not only have my permission but my insistence that if I call for it or if it is needed I expect all clinicians to call on a particular member of my 'personal treating team'.
5. I do not have a '**next of kin**' so this is not a helpful concept.
6. My brother **who is a doctor** know less about my situation than any of the other people I name here. He can be called upon as a last resort only.
7. Let me know what other medicos **are saying about me** so that I am never kept in the dark about my own life. This might need to be done sensitively but it's important.
8. Please show me, with good grace, any letters, referrals or reports and discharge summaries that are written about me.

## **My history and how it impacts on medical interventions today**

### **There are four important issues people need to know about:**

1. I live on my own. My community of friends is fundamental to improving my mental health. If I am admitted to a public acute unit I **must** have clear and uncompromised **access to a public telephone**. Without this I will get more and more isolated, agitated and unwell.
2. My whole **history** is one of survival and not survival of mental illness. I come from a family of 7. Out of seven 6 of us have or have had mental illness of some kind or other. This history affects every aspect of the way I experience services. Psychiatric units bring back terrible memories, ECT likewise. My sister, who took her own life, was sexually interfered with by two different psychiatrists. Is there any wonder I go strange when I am admitted to hospital.
3. I spent much of my 20s in hospital with knee operation after knee operation. It would seem on the service to be a horrible way to spend your twenties but in fact **hospitals became refuges from the mental illness at home**. Sometimes this still affects me when I am admitted to hospital. I can become dependent quite

quickly. This is not 'just' a behavioral thing. It is deep seated and needs to be treated with understanding. I now have a permanent disability.

4. I **self harm** and I don't mind people knowing as long as they withhold their judgment. There are some very good reasons for it but this is one of the areas in mental health where there is least understanding and least compassion. I ask that everyone speak kindly to me about it in an intelligent way.
5. I am intelligent. I have two degrees – one in education and one in sociology. They give me the following which I want people to appreciate:
  - Please don't get distress mixed up with the concept of limited intellect;
  - Sometimes I live in an intellectual place. This is not pathological.
  - My sociological background grounds my critique of institutions of social control including psychiatry. This does not mean I don't appreciate stuff that sometimes exceptional human beings in this sector do and have done for me.

## Part 3. Advance directive for friends and family -

### People who care about me and want to help as best they can

1. I do not have a 'carer'. I do not want one and I would never expect any one person to be one. It is too much to ask of someone and it distorts our adult to adult relationship.
2. Instead I have a number of people with whom I have reciprocal caring roles. I would like all the medical professionals in my life to be aware of these relationships, read this Advance Directive carefully and act on my advice when I suggest I need extra support.
3. **My Mother:** Mum is a 84 and still willing to come across the city by public transport if she is needed. I care for her too and we have a reciprocal arrangement. She would much rather come and stay with me than see me go into a horrible public psychiatric hospital and she has prevented this outcome many times now.
4. **Caterina:** Caterina is both a consumer and someone who helps me enormously with several aspects of my life. She presently has Power of Attorney Financial over my financial affairs. As a consumer she has insight into the power and other struggles that go on when someone needs this sort of help in their lives.
5. **Rachel:** is also a vital member of my team. As a solicitor working in the area of mental health and a friend she is my best assistance if there is any threat of imprisonment or forced treatment.
6. **Sarah:** I have nominated Sarah as my 'Primary Carer'. Even though we do not behave towards each other in 'carer v careee' kinds of roles (I sometimes care for Sarah who has some serious medical problems of her own) However, the title is useful because she is my friend who is geographically closest to me and she is also employed by a university which grants 10 days leave to a 'primary carer'
7. **Rupert, my brother who is a doctor:** He lives in Yarra Junction which is a fair distance and is probably the least informed about my 'illness'. I don't want him to be used as the 'default carer' because he happens to be a medical doctor. I prefer him to just be my brother.

▪ **Marcia** Dr. (CEO of workplace)  
Phone### Address ###  
Email: [marcia@email.com.au](mailto:marcia@email.com.au)

▪ **Stewart** (workplace)  
Phone### Address ###  
Email: [stewart@email.com.au](mailto:stewart@email.com.au)

▪ **Rachel** (Legal Centre – friend)  
Phone### Address ###  
[Rachel@email.com.au](mailto:Rachel@email.com.au)

▪ **Paula** (sister):  
Phone### Address ###  
(Work)[paula@email.com.au](mailto:paula@email.com.au)

▪ **Rupert** Dr. (brother):  
Phone### Address ###  
Email (partner) [cbrownlee@email.com](mailto:cbrownlee@email.com)

▪ **Sarah** (neighbour):  
Phone### Address ###  
Email: [sarah@email.com.au](mailto:sarah@email.com.au)

▪ **Mum:**  
Phone### Address ###  
(Mum is the most likely to be contactable easily but she does not have a car

▪ **Caterina** (friend, Power of attorney)  
Phone ### Address ###  
Email: [caterina@email.com](mailto:caterina@email.com).

## **Part 4. Work Place Advance Directive: How Work Can Help?:**

1. Sometimes when I am really distressed the 'discs'/'voices' are so intrusive that I can not (for a short time) do the things I need to do. This may include contacting Dr Sue and Dr Paul.
  2. I have spoken to Sue and Paul and told them that I have given my permission for the following people to make contact with them on my behalf if things turn pear shaped. I appreciate the readiness of both clinicians to give priority to my wishes in relation to this.
    - My Mother
    - Catherine
    - Rachell
    - Sarah, and
    - Rupert
- I also give permission for Marcia, Stewart (my employers) to contact those named above if I ask them too or if it is really obvious that I need some help.
- If I get crook at work I will generally be aware of it but I may be very shy about telling anyone because I am often ashamed of needing help. If I do ask for help I will really mean it. It is possible that the CAT Team might try to fob off anyone who tries to contact them who is not a doctor. I will attempt to negotiate so that three names from the list above are known to the CAT Team in the instances where neither Dr Sue nor Dr Paul are available.
- It is extremely dangerous for me when I am unwell to be told there is nothing wrong with me and to 'buck up', Those who know me well will know that this is a recipe for self-harm or a suicide attempt because it feeds my own -super pathology -about not deserving help or care from anyone 🍀\* .

### **WHAT NEEDS TO HAPPEN IF I GET CROOK AT WORK?**

1. I need to be taken seriously if I disclose to anyone because it would have taken a fair amount of courage for me to have approached you. I do not mind if someone notices me struggling and asks, 'are you ok?' I'll say 'yes, I'm fine' if everything is going well.
2. It would be best if someone could sit with me if I'm 'off'. I will apologise over and over again. It's tiresome I know, but it is part stupid habit, part illness and part genuine concern that I am putting too many demands on good people. Tell me to shut up and that I am not being too demanding. With a bit of luck you might even get a bit of a laugh out of me if you do this.

3. Remind me to take a Seroquel (anti-psychotic which I always carry around with me). If I am really struggling, especially with anxiety symptoms like hand wringing and pacing etc I can also take a Valium. I carry these as well.
4. Ring Sue but remember she only has an answering machine. She may be hard to get on to. Ring Paul and ask for advice or get them to ring me back at home.
5. It is most likely that by the time I get to this stage I won't be able to drive. Once someone has been located who can meet me at home send me home in a taxi (I have a half price taxi card). Don't send me home to an empty house at this point.
6. We'll need to organise how to get the car home. This might be a task for either Sarah or Rachel. However, there will need to be some communication about the keys.
7. The only thing I can do until arrangements are made is to stay as calm as possible and if there are no external people around I could sit out the front. A café --away from colleagues perhaps. I will be concerned I'll disturb is the other option at this stage but not on my own. I could rabbit on with whoever comes with me and give the impression I have made a fairly miraculous recovery. At this point, there is a possibility that I'll seem to contradict earlier symptoms. This is normal. It is part of my defense armory. It usually does not mean I am OK.
  - a. Don't worry if I do any of the following (its possible that I will be getting more distressed as time goes on):
  - b. Talk to myself
  - c. Say 'shish' repeatedly
  - d. There are a couple of audible demands I make of the 'voices' even though I can nearly always shut my 'return fire' up or disguise it in a cough or a sneeze. However if people do hear me angrily saying any of the following please try and ignore it because it is not aimed at anyone other than the 'discs' or 'voices':
    1. Shut up;
    2. Piss off;
    3. I'm going to kill you;
    4. I know death;
    5. You are death;
    6. I know what death is;
    7. Don't play with death;
    8. Death is coming;
    9. If you touch me again I will kill you;
    10. Don't touch me;
    11. Don't come anywhere near me;
    12. If you come anywhere near me I am going to kill you, or
    13. Shhh

*(As you can see from this list my repertoire of self abuse is varied and eloquent!!)*
- e. Stair at my right wrist and get very agitated if anyone goes to touch it. I truly believe it is bleeding even though logically I know it is not.
- f. Shake my head a lot
- g. Stare up to the left hand side as if I was listening to a voice coming out of the bats hanging above our desk at our community.
- h. Wring my hands repeatedly.

## Part 5. Reminders to myself

<b>Early Warning Sign</b>	<b>WHAT I NEED TO DO</b>
1. Become pre-occupied with disturbing 'discs' / 'voices' or intruding thoughts	Don't shut my eyes. Try and focus on the here and be present in the room. Recognise that even though these 'voices' might be more dissociative (from past experiences playing themselves out in the present) than 'psychotic' they are still legitimate and I'm not a fraud. If anything, I am the opposite. Remind myself this. Take a Seroquel PRN. Try not to spin off into the past. Ground myself if I can. Ring someone. Dog therapy.
2. Disturbance in sleeping pattern	Make sure the medication is taken early. Revert to taking the anti-depressants in the morning. Try comforting, nurturing things like hot baths with nice smelly things. Cuddle a dog.
3. Believe I am bleeding from my right wrist	Bandage it if this is going to help the secondary fear of getting blood everywhere. Remind myself that this is not real even though it feels real. Try and distract myself.
4. Suicidal thoughts	Work out how strong they are from 1 -10. If they are over 6 ring someone. Whilst she's still able get Mum over. If not, see if Sarah is around. Take all medications to chemist –especially over the counter pain killers. Get my drugs down to the chemist whilst I still can –early on.
5. Obsessive thoughts of hurting myself	Try and look at the feeling behind the wish to self harm. What do I really need? What am I really feeling? Try and fulfill this need. If I am able to ask for help don't escalate my symptoms between asking and help being received in order to justify this. Remind myself that it is sometimes good to ask for help.
6. Constant 'shishing'	Recognise the feeling behind the abusive 'voice' that I am trying to 'shish'. Listen to what is being said rather than trying to shut it up and stop this part of my story from being part of me.
7. Loss of concentration	Stop. Get a cuppa. What am I pre-occupied with that is stopping me concentrating. Are they 'discs' or 'voices'? Going home might be the best course of action if it can help keep a really difficult situation from arising. Be honest with myself and those around me about my capacity at these times. Don't push on and on when nothing is going in.
8. Intrusive exhaustion	Why? Ask myself what sort of exhaustion it is. If it is physical exhaustion go to bed early. More likely it will be emotional exhaustion so be kind to myself. I have a right to be emotionally exhausted sometimes. My head does a lot of hard work.
9. Repetitive flashbacks and abusive thoughts	Recognise and acknowledge the flashback and don't abuse myself for having them. Remind myself that I do not have to make a judgment about the seriousness of the situation that has initiated one or more of the events that seem to always cause this distress. Remember what Dr Sue says about the relativity of trauma. If it's traumatic to me then it is trauma. Don't give myself a guilt trip on top of everything else.
10. Sudden change in mood	Remember I have mixed states often and I get through it. Tell Dr Sue when I next see her and map the changes if I can do it without it becoming a chore. Do some of the things that I know can settle things like Op.Shopping.
11. Taking on too much and not being realistic about what I can and can't do	<b>Constantly check what I am committing myself to and subtract two things!</b> I am always wrong and over optimistic about what I can achieve. Remember the need to over achieve is in the past. I no longer need to make up for the ways I have failed before. Congratulate myself on my achievements as an everyday woman. If I find myself with too much on my plate I need to immediately off load some things. The two most important things work-wise are my two paid jobs. Everything else might need to go. Practice saying 'no' in front of the mirror.