



# Review of the Guardianship Act 1987: Submission for Question Paper 2 to the Law Reform Commission of NSW

31 January 2017

# BEING

**BEING is the independent, state-wide peak organisation for people with a lived experience of mental illness (consumers). We work with consumers to achieve and support systemic change.**

BEING's vision is for all people with a lived experience of mental illness to participate as valued citizens in the communities they choose. Participation is a fundamental human right as enshrined in Article 25 of the International Covenant on Civil and Political Rights (ICCPR). We work from the premise that the participation of consumers results in more effective public policy and facilitates individual recovery.

Our work is guided by eight principles:

- Principles of recovery underpin all our work
- Recognition of the importance of a holistic approach
- Collaboration and team work
- Flexibility, responsiveness and innovation
- Consultative and participatory processes that have consumers at the centre
- Promoting equity and positive images to address discrimination and prejudice
- Accessible and approachable for all
- Promotion of professionalism and quality practice

BEING is an independent non-government organisation that receives core and project funding from the Mental Health Commission of NSW.

Find out more at <http://www.being.org.au>

501 / 80 William Street  
Woolloomooloo NSW  
2011

ABN 82 549 537 349

P: 02 9332 0200

F: 02 9332 6066

E: [policy@being.org.au](mailto:policy@being.org.au)

**This submission was compiled on behalf of BEING by:**

Elena Sutcliffe, Policy Officer

Jaime Comber, Policy Officer

Kirsten Gibbs, Policy Officer

### **Acknowledgements**

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# Introduction

BEING is pleased to comment on Question Paper 2 on decision-making models for the Review of the Guardianship Act 1987 NSW (the Guardianship Act) by the NSW Law Reform Commission (the Commission). In March 2016, we submitted our Preliminary Submission, which focused on the principles of a supportive decision-making model, fluctuating capacity and a person's own definitions of capacity.

We thank the Law Reform Commission for considering our submission and we look forward to opportunities to further inform the review process. We have responded to the specific sections of Question Paper 2 below<sup>1</sup>.

Firstly, we would like to make four general recommendations that apply to decision-making models. These include:

- Supported decision-making is fundamental to recovery
- A spectrum of decision-making options
- A model that works with fluctuating capacity
- A culture shift towards supported decision-making.

## Supported decision-making is fundamental to recovery

We strongly endorse the adoption of a supported decision-making model in the Guardianship Act. By making decisions for themselves, consumers are able to shape their own lives. Every time a person makes a decision they draw on their strengths and exercise their autonomy. Many consumers are able to make decisions, but require support to get information, fully understand their options and communicate their choices.

People with mental illness have a wide range of decision-making capacities. Some people have fluctuating capacity over the course of their lives. Others have the ability to make some types of decisions with support but do not require support for others. A system that only gives the option of substitute decision-making cannot allow for these nuances. Under such a system, it is inevitable that a large amount of decision-making will be taken away from people who have the skill and desire to make decisions.

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<sup>1</sup> Please note throughout this submission we use the terms "consumer" and "person with a mental illness" interchangeably to refer to people living with mental illness. We refer to people receiving assistance with decision-making as "consumers", and refer to those providing support as "supporters" or "co-decision-makers".

Supported decision-making aligns with recovery-orientated principles. Recovery means different things to different people, however the Australian Health Ministers Advisory Council defines it as “being able to create and live a meaningful life”<sup>2</sup>.

**Recommendation:**

1. The Guardianship Act should adopt a supported decision-making model as the primary framework.

**A spectrum of decision-making options**

A major limitation of the current model is the ‘one-size-fits-all approach’. To maximise the ability of a person to shape their own life, the decision-making model should be tailored to their current capacity to make decisions. In our preliminary submission, we talk more in detail about definitions of capacity. We support the continuum of decision-making options recommended in the Victorian Law Reform Commission Report<sup>3</sup>. This includes autonomous, informal, supported, co-decision and substitute decision-making options.

**Recommendation:**

2. The Guardianship Act to include a spectrum of decision-making options, with supported decision-making as the preferred option for those needing assistance.

**A model that works with fluctuating capacity**

For this model to function well, there needs to be a clear, straight-forward and accessible way for consumers to change between decision-making options should their capacity increase or decrease. People with mental illness often have the best insight into their own decision-making capacity, and recognise when it is decreasing.

**Sara’s experience:**

Sara lives with depression and with a chronic physical illness. The intensity of her depression varies, and when it is severe she has trouble making decisions. Her mind feels cloudy and it is difficult to understand different options. She recognises these periods and talks to her psychologist, her support worker and her friends, who help her think through her choices and come to a decision. She does not want a substitute decision-maker, as she wants to make choices for herself, but she does sometimes need support.

Several consumers have expressed to us a desire to ensure that, during times of reduced capacity, decisions are made that represent their prior will and preference.

<sup>2</sup> Australian Health Ministers’ Advisory Council (2013). *A National Framework for Recovery Oriented Mental Health Services: Guide for Practitioners and Providers*. Retrieved from:

[http://www.mhima.org.au/pdfs/Recovery%20Framework%202013\\_Guide\\_practitioners\\_providers.pdf](http://www.mhima.org.au/pdfs/Recovery%20Framework%202013_Guide_practitioners_providers.pdf), p. 2.

<sup>3</sup> Victorian Law Reform Commission (2012). *Guardianship Final Report 24*. p. 55.

This planning can be enabled by using tools such as Wellness Recovery Action Plans<sup>4</sup>. Wellness plans are plans developed by consumers in which they identify triggers and early warning signs of mental illness, and develop action plans for how they want others to support them at these times. People providing decision-making assistance can assist consumers with creating Wellness Plans, act as support when Wellness Plan is activated, and be privy to the Wellness Plan in order to help the person recognise when they may be experiencing symptoms that may reduce their capacity to make certain decisions at this time.

### Recommendations:

3. The Guardianship Act to allow and support a person to select the best decision-making framework for them.
4. The Commission to research further and to encourage the use of tools that assist with fluctuating capacity.

### A culture shift towards supported decision-making.

Over the course of a day, we are all required to make a large number of decisions, and rely on getting information and support from those around us to make these decisions. This is especially the case for people experiencing mental illness, who need to make complex decisions about their healthcare and how they can best recover. Consumers are required to trust healthcare professionals and service providers to give them clear, correct information and support them in making decisions that reflect their preferences. When supported decision-making has been trialled, it has sometimes fallen down due to the preconceptions of healthcare providers where they have assumed consumers have reduced capacity and are not able to make decisions<sup>5</sup>.

Consumers will have most autonomy in a community that understands and implements supported decision-making principles. To build this capacity, services need to:

- Adopt a person-centred and supportive approach to decision-making
- Start with the assumption a person has capacity
- Be trained in how to act as supporters and prioritise the preferences and autonomy of the consumer.

We would like to note that moving to a supported decision-making model will be something that will take time for services and the community to fully understand, embrace and enact.

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<sup>4</sup> Wellness Recovery Action Plan, and WRAP, are the registered trademarks for a recovery model authored and designed by Mary Ellen Copeland. See <http://mentalhealthrecovery.com/wrap-is/>

<sup>5</sup> Davidson, G., Kelly, B., Macdonald, G., Rizzo, M., Lombard, L., Abogunrin, O., ... & Martin, A. (2015). Supported decision making: a review of the international literature. *International journal of law and psychiatry*, 38, pp. 61-67.

## Recommendations

5. The Commission to explore and implement ways to make this transition work smoothly.

# 5. Formal supported decision-making

## Question 5.1: Formal supported decision-making

BEING supports creating the option to formalise supported decision-making relationships. This formalised relationship would have a number of benefits, including:

- Giving supporters more options, with consent of the person, to help consumers access information
- Outlining the rights and responsibilities of the relationship
- Connecting people without informal support networks to supporters.

It is also important to recognise the value of having informal supported decision-making arrangements. Many people with a mental illness already have informal supported decision-making arrangements in place during times of reduced decision-making capacity. Consumers should not be required to formalise an informal relationship that is working well. This could cause unnecessary disruption to a person's life, or place an unnecessary burden on the relationship with the supporter, which is a concern for many consumers.

### Recommendation:

6. The Guardianship Act to provide the option to formalise supported decision-making relationships, however there should not be a requirement to formalise supported decision-making relationships that are working well.

## Question 5.2: Key features of a formal supported decision-making model

One of the key features we would like to highlight for this model to function well is the flexibility to change between decision-making options. Consumers have expressed to BEING that they have found the substitute decision-making system difficult to navigate and have been placed under Guardianship against their knowledge. They have then had difficulty challenging this or changing this when it is not working for them. As mentioned previously, there needs to be a clear, straight-forward and accessible way for consumers to change between decision-making options.

### Recommendation:

7. The Guardianship Act to outline a timely and easy to navigate process for changing between decision-making options.

### Question 5.3: Retaining substitute decision-making as an option

#### Substitute decision-making: a last resort only

BEING strongly advocates that substitute decision-making should be a last resort. There should also be established parameters, as this arrangement entails a significant decrease in a person's autonomy.

Before appointing a substitute decision-maker, every possible step should be taken to find an alternative decision-making option. When a substitute decision-making agreement does exist, it is vital that the substitute decision-maker:

- Is guided by the will and preferences of the consumer
- Consults them regarding decisions
- Is available to discuss decisions with the consumer, and;
- Is transparent about the decisions that are made.

Furthermore, a substitute decision-making agreement should clearly outline what types of decisions this arrangement applies to. Arrangements should be regularly reviewed, as they can leave people with mental illness vulnerable to exploitation.

We would also like to make the following points about substitute decision-making for mental health consumers:

- BEING has heard from consumers who felt that substitute decision-makers made choices based on their own values, rather than the preferences of the consumer. As a result, the person with mental illness life was shaped in a way they did not want. Current legislation says decisions should be made based on the "best interest" of a person, BEING recommends this be replaced by the term "will and preference" to prioritise the agency of the consumer.
- The choice of substitute decision-maker should be guided by the will of the consumer. When they are not able to express a choice, the person chosen should be someone who is best able to understand the person's preferences and consents to taking on this role.
- Some consumers have expressed a wish to relinquish their decision-making for some types of choices, for example to protect themselves in times of reduced capacity. Consumers should be allowed to choose substitute decision-makers if they wish. They should be provided with assistance to outline these arrangements and these should be regularly reviewed.
- Co-decision-makers and substitute decision-makers should approach any decision with a supportive mindset, and use supported decision-making wherever possible to maximise the autonomy of the consumer.



In relation to substitute decision-making we make the following recommendations:

**Recommendations:**

8. The Guardianship Act to designate substitute decision-making as a last resort option, stating that every other option must be explored first.
9. The Guardianship Act to require that substitute agreements outline which types of decisions they apply to.
10. In the Guardianship Act the term “best interest” be replaced by the term “will and preference” to prioritise the agency of the consumer.
11. A review process for substitute decision-making arrangements should be developed to safeguard people against exploitation.
12. Assistance should be provided to consumers who wish to relinquish some decision-making to help them outline arrangements that work for them. These arrangements should be regularly reviewed.
13. The Guardianship Act to emphasise the importance of supportive decision-making even when substitute or co-decision-making arrangements are in place.

**Question 5.4: Other issues**

**A unified body of legislation**

There are a number of different pieces of legislation that touch on concepts of substitute and supported decision-making. These include the:

- Mental Health Act 2007 (NSW)
- National Disability Insurance Scheme Act 2013 and;
- Guardianship Act 1987 (NSW).

The concepts of the supported decision-making framework need to be aligned across these Acts. This is vital to assist consumers in navigating these complex pieces of legislation and to ensure that decision-making rights guaranteed under one piece of legislation are not taken away under another. These issues have been identified in other jurisdictions introducing a supported decision-making model<sup>6</sup>. BEING agrees with the recommendation of the Victorian Law Reform Commission to develop greater overlap between the Mental Health Act and the Guardianship Act<sup>7</sup>.

**Recommendations:**

14. Concepts of, and access to, support and supported decision-making should be aligned across the Mental Health Act, NDIS Act and the Guardianship Act.

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6 Davidson, G., Kelly, B., Macdonald, G., Rizzo, M., Lombard, L., Abogunrin, O., ... & Martin, A. (2015). Supported decision making: a review of the international literature. *International journal of law and psychiatry*, 38.

7 ... p.35

15. The Commission to further explore the complexities of integrating the Mental Health Act, NDIS Act and the Guardianship Act in line with the Victorian Law Reform Commission recommendations.

### A smooth transition to supported decision-making

BEING recognises that changing from substitute to supported decision-making is a significant cultural change for both supporters and consumers. Davidson (2015) noted that a change in legislation around supported decision-making in England was not adequately implemented due to insufficient time and resources for staff, insufficient staff training and conflict between staff and service users<sup>8</sup>. Comprehensive training and resources are vital to make sure on-the-ground supportive decision-making takes place.

It may take time for some consumers to adjust to making decisions for themselves. It is important that we do not assume that consumers will not be able to make decisions in the future because they have reduced capacity at the present time. A trial of substitute decision-making in South Australia, using decision-making agreements, established that consumers can improve their decision-making skills and confidence over time<sup>6</sup>. This will be particularly important for consumers who have not been allowed to make decisions for a long time and as a result may have lost some of their decision-making ability and confidence. All consumers with reduced capacity should be provided with an environment that nurtures their strengths and encourages their ability to make decisions.

#### Recommendation:

16. The Commission to review evidence on how decision-making can successfully be increased and integrate this information into training and material available for anyone assisting with decision-making.

## 6. Supporters and co-decision-makers

### A strong, trusting relationship is the foundation of support

Key components of a supporter and consumer relationship are trust, knowledge, and collaboration. This is the case regardless of whether the supporter or co-decision-maker is a friend, family member, professional or volunteer<sup>9</sup>. When a supporter or co-decision-maker is selected it is important, especially if not a family or friend, that a

<sup>8</sup> – p. 64.

<sup>9</sup> Family and Community Services – Ageing, Disability & Homecare. 2016. *Supported Decision Making Pilot – Background and learnings*; [http://www.adhc.nsw.gov.au/individuals/inclusion\\_and\\_participation/supported-decision-making-sdm-background-learning](http://www.adhc.nsw.gov.au/individuals/inclusion_and_participation/supported-decision-making-sdm-background-learning) p.2

strong relationship is built. Spending time together, learning the consumer's history and understanding their will and preferences, is an important way of building these relationships. This way decisions are genuinely shared through collaboration and partnership<sup>10</sup>.

### **Bill's experience:**

Bill is a 25 year old man with depression. After he was in hospital as a late teenager he set up a power of attorney arrangement with his parents. He is really comfortable with this arrangement as he knows his parents have a thorough understanding of his history and what his preferences are. He understands that not everybody has that with their families, and that if he didn't have his parents he would want to have someone spend the time getting to know him, learning about his past history, and understanding what he wants when he has lowered capacity.

### **Recommendation:**

17. The Guardianship Act to include in the principles of the legislation the importance of trust, knowledge and collaboration in supportive decision-making arrangements.

### **Resources and training**

Supported decision-making will be a new way of working for many consumers, their friends and family, and for public and private services. Some consumers may be accustomed to having people make decisions for them, either formally or informally. Additionally family and services may be accustomed to making decisions for people. Through provision of resources and training, these relationships can be shifted into collaborative partnerships based on support and the autonomy of consumers.

Pilot studies around the world have shown that both supporters and consumers needed training to be able to properly use supported decision-making<sup>11</sup>. The NSW Family and Community Services Ageing, Disability and Home care's pilot study in 2015 found that some supporters still tried to make decisions in the best interests of the consumer, rather than supporting the consumer even when they thought their choices were risky. In the study, the supporters and consumers received resource materials and face-to-face training. They also received ongoing support from training facilitators. The pilot study found that all of the supporters in the program would have benefited from additional training<sup>12</sup>.

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<sup>10</sup> Pathare, S. & Shields, L.2012. *Supported Decision-making for persons with a mental illness: A review*. Public Health reviews. 2012;34: epub ahead of print.

<sup>11</sup> Family & Community Services Ageing, Disability & Home Care. 2015. My life, my decision: An independent evaluation of the Supported Decision Making Pilot.

<sup>12</sup> Family and Community Services – Ageing, Disability & Homecare. 2016. Supported Decision Making Pilot – Background and learnings; [http://www.adhc.nsw.gov.au/individuals/inclusion\\_and\\_participation/supported-decision-making-sdm-background-learning](http://www.adhc.nsw.gov.au/individuals/inclusion_and_participation/supported-decision-making-sdm-background-learning) p.1

Supporting or co-decision-making with someone with a mental illness and/or fluctuating capacity is different to supporting or making a joint decision with someone with an intellectual disability or an elderly person who may have a fixed level of capacity.

Training for supporters, co-decision-makers and consumers should:

- Include specific examples of supporting someone with a mental illness
- Include information on how to recognise signs of fluctuating capacity
- Include specific examples of how to support someone with fluctuating capacity
- Include examples of available planning tools, such as Wellness plans
- Include the language and principles of the National Recovery Oriented Framework<sup>13</sup>
- Be delivered through written resources, face-to-face training, and ongoing support from training facilitators.

Realising the potential of a supported decision-making model depends on more than just legislative change. The government must also commit to appropriate funding for these training programs and resources to make supported decision-making a reality.

#### **Recommendations:**

18. Appropriate training and resources to be provided for consumers, supporters and co-decision-makers. This should include specific information on supporting someone with a mental illness and fluctuating capacity.
19. Changes to the Guardianship Act to be accompanied by funding for supported decision-making systems to be implemented. This includes funding to ensure there are well-trained supporters at public or private organisations with sufficient time to properly support consumers.

#### **Culturally sensitive support**

One consumer we consulted was concerned about the vulnerability of consumers who do not speak English and face more challenges when advocating for themselves. Consumers will be best supported by someone who is sensitive to their particular cultural experience and communication styles. Most importantly, supporters should be able to communicate with consumers in whichever language they are fluent. The ability to understand each other well is a central component for supported decision-making.

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<sup>13</sup> Australian Health Ministers' Advisory Council (2013). *A National Framework for Recovery Oriented Mental Health Services: Guide for Practitioners and Providers*. Retrieved from: [http://www.mhima.org.au/pdfs/Recovery%20Framework%202013\\_Guide\\_practitioners\\_providers.pdf](http://www.mhima.org.au/pdfs/Recovery%20Framework%202013_Guide_practitioners_providers.pdf)



### Recommendations:

20. Resources and training to include guidance on a culturally sensitive approach to support.
21. Support to be available in a variety of languages, or accompanied by translation services.

### Supporting the supporters

Studies of supported decision-making have shown that ongoing support provided to supporters also greatly benefits the support they provide to consumers, including addressing gaps in their knowledge of support<sup>14</sup>.

### Recommendation:

22. The Commission to investigate and implement programs that support supporters or co-decision makers.

## Question 6.1: When supporters and co-decision-makers can be appointed

### Choosing your own supporter

Many people with a mental illness experience fluctuating capacity throughout their lives and their recovery process. At times of higher capacity, their insight and ability to make decisions will be such that they can make choices, and communicate these choices<sup>15</sup>. During these periods, a person may want to appoint a supporter or co-decision-maker, with the consent of both parties.

### Bill's Experience:

As Bill went forward in his recovery process, he recognised some of the issues that had arisen while he was unwell and in hospital. He was able to recognise that he was in a period where he could express his wishes and put in place a plan for the future, so that if he was ever in a situation where his capacity was reduced he would have support in making decisions, as well as a modified substitute decision-making arrangement with his parents.

### Recommendations:

23. The Guardianship Act to give consumers the power to choose a supporter or co-decision-maker, and change them if the relationship is not working.
24. The Guardianship Act to allow consumers to appoint a supporter or co-decision-maker if they feel they lack capacity, or may lack capacity in the future, to make decisions.

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<sup>14</sup> Mirfin-Veitch, B. (2016). Exploring Article 12 of the United Nations Convention on the Rights of Persons with Disabilities: An Integrative Literature Review. Donald Beasley Institute: Dunedin.

<sup>15</sup> NSW Ministry of Health. 2015. Dignity, Respect and Choice: Advance care planning for end of life for people with mental illness – A comprehensive guide. p.13

## Assistance choosing a supporter

The majority of people currently falling under the Guardianship Act are assigned public guardians<sup>16</sup>. This may be because they do not have family or friends who can act as their substitute decision-maker or because they prefer not to formalise relationships with their informal supporters. A number of consumers have told BEING they do not have family and friends who could be formal supporters but they do want support.

### **Jamie's experience:**

'Jamie' has bipolar disorder. She feels her only options for a supporter or co-decision-maker are her elderly mother or a friend. She thinks that her mother would find being a formal supporter or co-decision-maker too stressful. She is worried that appointing her friend would be too much of a strain on their relationship, as during times of reduced capacity while unwell, she may be persistent and annoying in her attempts to make financial decisions that she would feel are unwise when well.

There will also be people who will have the capacity to contribute to decision-making with support, but may not have the capacity to appoint a supporter or co-decision-maker. These people may require assistance to appoint a supporter or co-decision-maker. In these cases the Public Guardian should choose someone in line with the consumers will, preferences, beliefs and attitudes. The Public Guardian should, with consent, consult significant people in the person's life to gain a better understanding of who the right supporter or co-decision-maker would be.

### **Recommendations:**

25. The Guardianship Act to incorporate the right to at least one supporter or co-decision-maker, who must have the time and skills to help the consumer with their decisions.
26. The Tribunal to appoint supporters or co-decision-makers for a person who has the capacity to make decisions, but not the capacity or ability to select their own supporter or co-decision-maker.
  - o The supporter or co-decision-maker should be chosen in line with the consumers will, preferences, beliefs and attitudes, after consulting with significant people in the consumer's lives.

## Question 6.3: Characteristics that should exclude potential appointees

### Safeguarding against financial exploitation.

BEING has received feedback from consumers and peer workers concerned about consumers being manipulated into making financial decisions that benefit supporters

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<sup>16</sup> NSW, Guardianship Tribunal, *Annual Report 2012-2013* (2013) 39.

or co-decision-makers. Supporters who financially benefit from decisions made by the decision should be excluded.

We anticipate difficulties arising when family members live with the consumer and also act as supporters and co-decision-makers. More feedback needs to be sought regarding how consumers can best be supported by someone who may benefit financially from them. One consumer suggested consumers should have an additional external supporter to provide independent support.

In more serious situations, consumers have told us they are in a position where financial exploitation and abuse is occurring. BEING recommends that the Commission further investigate safeguards that can be put in place to prevent possible financial exploitation.

#### **Sarah and George's Experience:**

Sarah and George both have a mental illness and live at home with their mother. They do not have a formal substitute guardianship arrangement in place, rather they are informally 'supported' in their decision-making by their mother. They are concerned as they feel their mother is trying to control their money to spend herself, and she attempts to bully them regarding financial decisions they make. They would be very unhappy entering into a formal supported decision-making, or co-decision-making arrangement with their mother.

#### **Recommendations:**

27. The Guardianship Act should set up safeguards against financial exploitation, and endeavour to investigate cases where this might be a possibility.
28. The Commission to seek feedback on the issue from consumers and people who work in the community sector of how people can best be supported by a person they live with who is in a position to benefit financially from them.

### **Question 6.4: Number of supporters and co-decision-makers**

#### **The right number of supporters**

Most people get informal support and advice from a number of different people in their lives. People tend to choose to consult with particular people based on their knowledge and understanding of their situation. This is the same for people with mental illness who many also have reduced decision-making capacity. Building a network of social supports with multiple supporters can be an important part of recovery<sup>17</sup>.

Consumers should be able to design a support system that works for them, including choosing the number of supportive relationships they would prefer. If a consumer has

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<sup>17</sup> Ridgway, P., McDiarmid, D., Davidson, L., Bayes, J., & Ratzlaff, S. (2002). *Pathways to Recovery: A strengths recovery self-help workbook*. Lawrence, KS: University of Kansas School of Social Welfare. Pp. 217-220

multiple supporters, all of them should have the same rights and responsibilities so they are all able to fulfil the functions of a supporter.

**Recommendation:**

29. The Guardianship Act to allow consumers to appoint multiple supporters, each having the full rights and responsibilities given to a supporter under the Act.

**Limiting co-decision-makers to avoid conflict and stress**

A key factor in co-decision-making is the requirement for negotiation and for both people to agree to the decision. People with a mental illness may experience stress when making decisions, and this can increase if a decision has to be negotiated and agreed to with others. Having multiple supporters can improve decision-making; however, having multiple co-decision-makers may make decision-making more stressful.

Consumers have also expressed to us the desire to separate financial decisions from other decisions in their lives. One person spoke of the need to ensure that all bills and expenses were paid while unwell, while another spoke of requiring someone to assist with making financial decisions at times when her capacity was reduced. For these decisions, they felt that a co-decision-making arrangement would work for them. Separating out some decision types to a co-decision-maker, while keeping formal supporters for other areas of their lives, was something they felt might be a preferable option. Since it could be a stressful experience, clear parameters on which decisions have to be made with a co-decision-maker, need to be set out.

**Recommendation:**

30. Co-decision-makers to be limited to one person, or one person for a specific area of decisions, with clear parameters to the decisions that need to be decided upon jointly.

**Question 6.5: Public agencies as supporters or co-decision-makers**

While BEING is not opposed to the idea of public agencies as supporters or co-decision-makers, there should be clear parameters around this. We have received feedback that this can be a problem due to the time needed for effective supported decision-making.

**Michael's experience**

Michael voluntarily applied for financial management while in hospital. He thought this would make things easier while his capacity to manage his finances was lowered. For him, the paperwork was the least of his problems, the service was what made the experience negative for him. He had a lot of trouble getting in contact with his case manager at the public trustee. He didn't get much time with his case manager, and then the



case manager was changed. 'It was like they lost all of my information when the case manager changed, and they were just as unhelpful as the first person'.

Given the importance of trust, knowledge and collaboration in a supporter/consumer relationship, unless the public agency is able to provide adequate resources and time, having the option of an outside organisation or volunteers would be preferable.

### **Question 6.6, 6.7: Paid workers, organisations and volunteers as supporters and co-decision-makers**

Paid workers, organisations, volunteers, paid and volunteer peer-workers should also be available as options for those people without the option of friends or family. These supporters and co-decision-makers need to be provided the time, resources and training to help them fulfil this role.

There are potential conflicts of interest for each of these options, depending on the system put in place. For example, in the case of a paid worker at an organisation providing a service certain decisions may be financially beneficial to the organisation or worker. Issues around conflicts of interest in all cases need to be explored further, and guidelines should be put in place to avoid these.

Peer workers are a unique and invaluable source of support for people with a mental illness. The ability for peer workers to be appointed to these supporting roles should be encouraged as part of the commitment to increasing the peer workforce, as per the Living Well strategic plan for mental health in NSW<sup>18</sup>.

#### **Recommendations:**

31. Public Agencies, Paid Workers, Organisations and volunteers to all be allowed to act as supporters and co-decision-makers, provided resources and time are available.
32. The Guardianship Act to encourage peer workers and should not exclude them from becoming supporters or co-decision-makers.
33. The Commission to further explore issues around conflicts of interest, and develop guidelines to provide clear parameters on conflicts of interest.

### **Question 6.8: Powers and functions of supporters**

#### **Being part of the process**

For some consumers, having support from family and friends is a vital part of recovery. To be able to provide this support, these important people in the lives of a person with a mental illness need to be included in the process. We have heard from consumers that their chosen supporters have been excluded from discussions, not

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<sup>18</sup> NSW Mental Health Commission (2014). *Living Well: A Strategic Plan for Mental Health in NSW*. Sydney, NSW Mental Health Commission. p.100-101.

given information, and told they didn't need to know. With the consent of the consumer, a supporter or co-decision-maker needs to be able to access all relevant information, and be present during discussions related to the areas they are supporting the consumer in. This needs to be the case even when the consumer is in hospital as an involuntary patient.

**Recommendation:**

34. Supporters and co-decision-makers to be given access to information needed to support the consumer, and be included in relevant discussions and appointments, including when the consumer is in hospital as an involuntary patient.

**Question 6.9: Powers and functions of co-decision-makers**

As with supporters, co-decision-makers need to have access to all relevant information and be included in all relevant discussions.

**Co-decision-makers acting as substitute decision-makers when needed.**

Some consumers with fluctuating capacity have identified co-decision-making as an option they would consider as a modified form of substitute guardianship. BEING has heard from consumers who, during times of reduced capacity, want other people to have control over some decisions but want to remain part of the discussion and decision-making for others. During these times it is very important that the principle of making decisions based on someone's will and preferences rather than best interest is upheld.

**Recommendation:**

35. The Commission to look into ways co-decision-making can work as a modified form of substitute decision-making while maintaining autonomy wherever possible.

**Question 6.10: Duties and responsibilities of supporters and co-decision-makers**

It is essential that supporters or co-decision-makers actively work to support recovery. By incorporating this into the Guardianship Act as a formal responsibility of supporters and co-decision-makers, the importance of the role a supporter or co-decision-maker has in the recovery process can be positively reinforced.

**Recommendation:**

36. The Guardianship Act to include responsibilities of supporters and co-decision-makers based on recovery principles, including:
  - Actively work with the consumer to increase their capacity
  - Identify a consumers fluctuating capacity, and adjust their level of support accordingly

- Act according to the will and preferences, and guidance of the consumer
- Act according to any Wellness plan.

# Summary of Recommendations

1. The Guardianship Act should adopt a supported decision-making model as the primary framework.
2. The Guardianship Act to include a spectrum of decision-making options, with supported decision-making as the preferred option for those needing assistance.
3. The Guardianship Act to allow and support a person to select the best decision-making framework for them.
4. The Commission to research further and to encourage the use of tools that assist with fluctuating capacity.
5. The Commission to explore and implement ways to make this transition work smoothly.
6. The Guardianship Act to provide the option to formalise supported decision-making relationships, however there should not be a requirement to formalise supported decision-making relationships that are working well.
7. The Guardianship Act to outline a timely and easy to navigate process for changing between decision-making options.
8. The Guardianship Act to designate substitute decision-making as a last resort option, stating that every other option must be explored first.
9. The Guardianship Act to require that substitute agreements outline which types of decisions they apply to.
10. In the Guardianship Act the term “best interest” be replaced by the term “will and preference” to prioritise the agency of the consumer.
11. A review process for substitute decision-making arrangements should be developed to safeguard people against exploitation.
12. Assistance should be provided to consumers who wish to relinquish some decision-making to help them outline arrangements that work for them. These arrangements should be regularly reviewed.
13. The Guardianship Act to emphasise the importance of supportive decision-making even when substitute or co-decision-making arrangements are in place.
14. Concepts of, and access to, support and supported decision-making should be aligned across the Mental Health Act, NDIS Act and the Guardianship Act.
15. The Commission to further explore the complexities of integrating the Mental Health Act, the Guardianship Act and the NDIS Act in line with the VLRC recommendations.
16. The Commission to review evidence on how decision-making can successfully be increased and integrate this information into training and material available for anyone assisting with decision-making.



17. The Guardianship Act to include in the principles of the legislation the importance of trust, knowledge and collaboration in supportive decision-making arrangements.
18. Appropriate training and resources to be provided for consumers, supporters and co-decision-makers. This should include specific information on supporting someone with a mental illness and fluctuating capacity.
19. Changes to the Guardianship Act to be accompanied by funding for supported decision-making systems to be implemented. This includes funding to ensure there are well-trained supporters at public or private organisations with sufficient time to properly support consumers.
20. Resources and training to include guidance on a culturally sensitive approach to support.
21. Support to be available in a variety of languages, or accompanied by translation services.
22. The Commission to investigate and implement programs that support supporters or co-decision makers.
23. The Guardianship Act to give consumers the power to choose a supporter or co-decision-maker, and change them if the relationship is not working.
24. The Guardianship Act to allow consumers to appoint a supporter or co-decision-maker if they feel they lack capacity, or may lack capacity in the future, to make decisions.
25. The Guardianship Act to incorporate the right to at least one supporter or co-decision-maker, who must have the time and skills to help the consumer with their decisions.
26. The Tribunal to appoint supporters or co-decisions-makers for a person who has the capacity to make decisions, but not the capacity or ability to select their own supporter or co-decision-maker.
  - The supporter or co-decision-maker should be chosen in line with the consumers will, preferences, beliefs and attitudes, after consulting with significant people in the consumer's lives.
27. The Guardianship Act should set up safeguards against financial exploitation, and endeavour to investigate cases where this might be a possibility.
28. The Commission to seek feedback on the issue from consumers and people who work in the community sector of how people can best be supported by a person they live with who is in a position to benefit financially from them.
29. The Guardianship Act to allow consumers to appoint multiple supporters, each having the full rights and responsibilities given to a supporter under the Act.
30. Co-decision-makers to be limited to one person, or one person for a specific area of decisions, with clear parameters to the decisions that need to be decided upon jointly.

31. Public Agencies, Paid Workers, Organisations and volunteers to all be allowed to act as supporters and co-decision-makers, provided resources and time are available.
32. The Guardianship Act to encourage peer workers and should not exclude them from becoming supporters or co-decision-makers.
33. The Commission to further explore issues around conflicts of interest, and develop guidelines to provide clear parameters on conflicts of interest.
34. Supporters and co-decision-makers to be given access to information needed to support the consumer, and be included in relevant discussions and appointments, including when the consumer is in hospital as an involuntary patient.
35. The Commission to look into ways co-decision-making can work as a modified form of substitute decision-making while maintaining autonomy wherever possible.
36. The Guardianship Act to include responsibilities of supporters and co-decision-makers based on recovery principles, including:
  - Actively work with the consumer to increase their capacity.
  - Identify a consumers fluctuating capacity, and adjust their level of support accordingly.
  - Act according to the wills and preferences, and guidance of the consumer.
  - Act according to any Wellness plan.