Being

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# Indefinite detention of people with cognitive and psychiatric impairment in Australia

## Submission to the Senate Standing Committees on Community Affairs

**12 April 2016**

# Being | Mental Health & Wellbeing Consumer Advisory Group

**Being | Mental Health & Wellbeing Consumer Advisory Group (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.

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# Introduction

BEING is pleased to provide input into the Inquiry about Indefinite detention of people with cognitive and psychiatric impairment in Australia ('the Inquiry'), held by the Senate Community Affairs References Committee ('the Committee').

BEING regularly engages with mental health consumers to inform our policy work. We do this through a range of activities, such as face to face discussions, online surveys and consumer forums. In June 2012, March 2013, May 2014 and November 2014 we consulted with mental health consumers in NSW, including male consumers in the NSW forensic mental health system. Feedback from these activities, as well as from our ongoing work with mental health consumers, has informed our views in this submission. Where possible, we have also included quotes and real life stories from consumers to illustrate specific concerns.

We'd like to highlight some gaps in the feedback that informed our submission. Although we have engaged with mental health consumers under the age of 18, the feedback we received that was relevant to this inquiry was from people over the age of 18. Our discussions about the forensic mental health system are mainly informed by our engagement with male forensic consumers. We recommend the Committee seek feedback from a range of mental health consumers, including people under the age of 18, and female forensic consumers.

Our submission focuses on and makes recommendations in relation to the following Inquiry Terms of Reference:

> b. the experiences of individuals with cognitive and psychiatric impairment who are imprisoned or detained indefinitely;

We thank the Committee for considering our submission and look forward to opportunities to further contribute to the inquiry.

# 1. Indefinite detention in the forensic mental health system

NSW has the largest number of forensic patients of any Australian jurisdiction (over 400 at April 2015).[1] Forensic consumers' experiences vary depending on the security level of the facility they are in, and the location of the facility.

Forensic consumers have told us that there is much uncertainty about how long they will be held in forensic mental health services. There are no release dates for people in the forensic system. People also feel uncertain about what their rights are and what they need to do to get out of the system. This leads to feelings of frustration and powerlessness. People can be detained for much longer periods in the forensic mental health system than if they had been detained in the prison system.

## Clog in the forensic mental health system

Forensic consumers have experienced long delays in their transitions to lower security level facilities and to the community. People are having to stay in higher security facilities longer than might be necessary, while waiting for a bed to free up in less acute units. People said you could be at the 'beginning' of the forensic system even if you had already been there for 2-4 years. You might be eligible to move to the next step towards community reintegration, but due to 'bed blockage', you could be waiting another 2-4 years before a bed is available for you. During this wait, people's mental health can deteriorate because they are in an environment that is far more restrictive than appropriate to their needs, and they are not getting the appropriate level of support for their stage of recovery. This subsequent deterioration in mental health can lead to the person being detained in the system for longer.

> **Luke's experience:** 'Luke' has been in the forensic hospital for 16 years. He has a loving family waiting for him and willing to support him. Even though the hospital has consistently assessed him as presenting only low risk, they have not released him. He said the hospital also can't move him through to a lower security unit because there are no beds available there.
>
> *"We are like animals in a cage and the doctors are zoo keepers. One patient has been over 15 years in the system and one woman's been 17 years"*
> - **Forensic consumer, 2014**

[1] NSW Mental Health Tribunal, Submission no. 3, Senate inquiry into the Social Services Legislation Amendment Bill 2015, 22 April 2015: http://www.aph.gov.au/DocumentStore.ashx?id=9e2b12ab-4296-47cc-9607-4dca5562c845&subId=350536

**Recommendation 1**
The Committee to identify and address factors in forensic mental health systems across Australia, including barriers to consumers moving through the system, that cause forensic consumers to be detained longer than necessary.

**Recommendation 2**
The Committee to consider how state and territory laws could limit the period of detention that can be imposed on a forensic consumer.

## Lacking person-centred rehabilitation

Forensic mental health systems offer different programs that aim to help people reintegrate into the community. The programs and approaches vary across the different forensic mental health services. When we talked with consumers from one forensic mental health service in 2012, the service offered set work programs. For example, there was a work program to volunteer at a library for a certain period of time, and then the person could progress to work on something else like packing boxes for items that would go to the supermarket. People could choose to participate or not participate in these work programs. However, as the programs served as steps for people to work towards going back to the community, when people chose not to participate (for whatever reason), they then might not move through to the next stage of the system. This created a rigid pathway that people have to go through to exit the forensic system, and may not offer rehabilitation suitable for each individual.

When we consulted consumers at another forensic mental health service in 2012 and 2014, people felt uncertain about what they needed to do to get out of the system. Many people had done every rehabilitative program available at that facility, but were still stuck in the same place. So, over time, these activities became pointless to them. People said they wanted meaningful feedback from staff about their progress, and to be more informed about their rights. For example, one forensic consumer said that the feedback he gets is really vague and meaningless, such as “you’re doing alright, just keep doing what you do”. He said he would like feedback to point out areas he was doing well in or needed more work on. There was a lack of communication and information to consumers about their rights and what they need to do to be released.

The experiences from the two different forensic mental health services indicate that services need to involve forensic consumers more in working towards reintegrating the individuals back into the community. For example, the rehabilitation programs offered should be flexible to meet the different needs and recovery goals of

individuals. Services should also have meaningful discussions with individuals about their progress through the forensic system.

### Recommendation 3

Forensic mental health facilities to offer rehabilitation programs that are person-centred and recovery-oriented. For example, by customising each person's rehabilitation program based on their recovery goals and needs.

### Recommendation 4

Forensic mental health facilities to look at improving staff's ability to give meaningful feedback and communicate with consumers to navigate the forensic mental health system.

### Recommendation 5

The Committee to consider people's experiences from a range of forensic mental health facilities, as practices vary across facilities and locations.

### Recommendation 6

State and territory bodies governing forensic mental health systems to ensure meaningful involvement of forensic consumers in the decisions affecting them.

## Feeling frustrated with review processes

Forensic consumers have also expressed to us their frustrations about the NSW Mental Health Review Tribunal's review process. Under the *Mental Health (Forensic Provisions) Act 1990* (NSW), the Tribunal can make orders about the treatment, care, detention and release of forensic consumers. Forensic consumers have told us that they feel that the reviews are a meaningless process in which they don't have any power. They would like the tribunal to consult and involve them in the process more.

One person talked to us about his experience of going in front of the tribunal 30 times over the past 15 years. He felt exhausted because nothing ever seemed to change. Another person talked to us about how he 'did everything right' including attending sessions on anger management, alcohol and other drugs. He felt that he was not progressing out of the forensic system. He felt that he could not get a fair hearing by the Tribunal.

We are aware that the Mental Health Review Tribunal was developing a Self-report form for consumers to provide their own views to the Tribunal. Although we have been unable to confirm its implementation at services, we would recommend trialling and evaluating the impact of this Self-report. We would also recommend ensuring

there are mechanisms that enable consumers' meaningful involvement in their own tribunal review process.

### Recommendation 7

The relevant bodies making and reviewing orders about forensic consumers to consider trialling a self-report form for consumers to submit their own views to the body, and the body to respond to the self-report during the review.

## Being moved backwards in the system

Forensic consumers feel that they are expected to perform like they are functioning normally. These expectations are unrealistic as being detained indefinitely in a hospital 24/7 is not a normal way to live. It is inevitable that people will feel frustrated, and might sometimes behave in ways that staff may view as aggressive, such as by kicking a chair and stomping off.

Staff may view these behaviours as a part of the person's mental illness symptoms and document these views in the person's medical records and notes. Forensic consumers may not agree with what's written about them, and they have limited access to read or change the medical notes about them. Staff misperceiving behaviours related to frustration with the system or environment as mental illness symptoms can lead to the person being moved backwards in the system. One forensic consumer called this "Forensic Snakes and Ladder".

The Mental Health Review Tribunal can make orders for release into the community with conditions. Some people who have breached a condition have experienced excessive penalties for their breaches. For example, a few people breached conditions involving minor drug or alcohol consumption, and were brought back to the facility and detained for more than five years in the forensic mental health system. People can be subject to periods of detention that are disproportionate to the breach. This adds to people's uncertainty about how long they will be detained in the forensic mental health system.

### Recommendation 8

Forensic mental health facility staff to be more aware of and empathic to the life circumstances of consumers and trained to be able to separate behaviours related to frustration with the system or environment from mental illness symptoms.

**Recommendation 9**

Forensic mental health facility staff trained to engage with consumers and to appropriately support individuals to deal with emotional distress.

**Recommendation 10**

The Committee to consider how to enable forensic consumers to easily access, review and challenge their medical records and the medical notes written about them while at a forensic mental health facility.

**Recommendation 11**

The Committee to consider how state and territory laws can ensure that the period of detention for breaching conditions while on conditional release is appropriate to the breach.

## Feedback from women

We have limited feedback from women about their experiences with the forensic mental health system. Some male forensic consumers have suggested that there aren't as many rehabilitation support options and resources available for women as men. We have feedback from one woman who was in the forensic system for ten years on conditional release.

> **Rhonda's experience:** 'Rhonda' had to attend a Mental Health Review Tribunal hearing every six months, and comply with constant random drug testing for the ten years she was on conditional release. In line with the feedback from other forensic consumers, she felt uninformed about the Tribunal processes, and inadequately involved.
>
> *"Just felt like they were going around in circles, playing me…. there's no direction… you're always getting the impression like they're treating you like you're wrong"*
>
> She felt that her advocate from Legal Aid was on the tribunal's side because they were always saying things like "I'll take this to them [the tribunal] but I don't think they'd agree with that."
>
> She was also living with domestic violence. Although the tribunal and her advocate were aware of this, according to Rhonda nothing was done to protect her and her children. When there were domestic disputes, she was the one who was taken away, sometimes by police. Her children were taken out of her care, and she had to have supervised visits to see them.

While on conditional release, she became involved in a community group. Unknown to her, one of the Mental Health Review Tribunal members was also involved in that community group and could see her participation in it. This helped her get unconditional release and exit the forensic system.

Rhonda's experience highlights the powerlessness that forensic consumers may, and do, experience in the forensic mental health system even when they are not detained in a facility. Rhonda's experience also highlights some issues women with mental health issues may face in relation to domestic violence and care of children.

**Recommendation 12**

The Committee to be informed by feedback from a diverse range of forensic consumers, including women.

**Recommendation 13**

The Committee to ensure there are systems and partnerships across government agencies so that forensic consumers on conditional release are properly supported.

# 2. Indefinite detention in mental health inpatient settings

In NSW, mental health consumers can be admitted to a mental health inpatient unit voluntarily or involuntarily under the *Mental Health Act 2007* (NSW). Mental health inpatient units can be a psychiatric unit in a general hospital, or a stand-alone psychiatric hospital. Some factors that make people feel like they are being indefinitely detained in a mental health inpatient unit include:

- Not being informed about how long they will be staying at the hospital.
- Not being involved in discussions about their own treatment, including discharge.
- Waiting for an indefinite period of time to see a doctor, who has the power to release them from the hospital.
- The hospital having some discretion to push back discharge dates.

There are NSW government policies and guidelines that aim to address some of these factors. For example, the NSW policy directive, 'Transfer of Care from Mental Health Inpatient Services', states that it is essential for services to communicate to the consumer, carers and other relevant parties when the consumer is likely to be

discharged and return to the community.[2] However, this policy doesn't necessarily translate into practice. Mental health consumers' feedback show that there is inconsistent implementation of the policies in inpatient units.

## Not adequately informed or involved

Too often, mental health consumers are not informed about when they will be discharged from the hospital. Consumers tell us that they are also not informed about when they can see a doctor to discuss these issues. Some consumers told us that even when they are told when they will see the doctor, this may not necessarily happen, and they may have to wait much longer than promised. These factors make people feel like they are being held in the hospital indefinitely. People from culturally and linguistically diverse backgrounds face particular risks around this due to communication and cultural differences.

Here are some examples of people's experiences:

> **Lee's experience:** 'Lee' said he was involuntarily admitted into a mental health inpatient unit in 2010 and was there for around three months. He didn't know what was happening when he was first admitted, and for months the hospital didn't tell him what was going on and how long he would be kept there. He became very anxious about being held there indeterminately.
>
> **Mary's experience:** 'Mary' contacted us during her involuntary admission at a mental health inpatient unit in 2015. Mary told us that the hospital didn't tell her how long she would have to stay there for. They were also not being clear about what was required for her to get discharged from the hospital and why she hadn't been discharged. She had repeatedly asked to speak to the doctors with the power to make those decisions. Hospital staff told her that she would be able to speak a doctor 'soon' but she had been waiting to speak to a doctor for more than two days. She said that she had a very positive experience at a different inpatient unit before being admitted into this unit. This indicates that practices and people's experiences vary across services and locations.

[2] NSW Mental Health and Drug and Alcohol Office, 'Transfer of Care from Mental Health Inpatient Services', PD2012_060, 14 November 2012, p. 4: http://www0.health.nsw.gov.au/policies/pd/2012/pdf/PD2012_060.pdf

**Lucy's experience:** 'Lucy' was staying at a mental health inpatient unit in 2014. She was only told that she would be discharged on the morning of the discharge date. She felt very distressed because she didn't feel that she was ready to leave the care of the inpatient unit.

Lee's, Mary's and Lucy's experiences show that some mental health consumers are not adequately informed about how long they will be staying at the inpatient unit, and the negative impact this can have on the person.

### Recommendation 14

The Committee to address the factors that lead to mental health consumers feeling like they are being detained indefinitely in mental health inpatient units. This includes the lack of clarity and information about discharge dates and limited access to a doctor.

## Feeling powerless and fearful

People admitted to mental health inpatient units may, and do, feel fearful and powerless because they perceive doctors and staff as having significant power over what happens to them. This includes having some power over how long they have to stay at the inpatient unit. People may feel that staff have the power to punish them, such as by making them stay longer. Due to this fear, people avoid making complaints or providing feedback to the hospital because they don't want to be seen as a 'trouble-maker'.

**Minh's experience:** 'Minh' was staying at an inpatient mental health unit involuntarily in 2014. He believed that a particular doctor was racially discriminating against him by exaggerating his conditions, including at the Mental Health Review Tribunal hearings. He believed this had caused him to be kept in the hospital for much longer than necessary. He had a better relationship with this doctor's superior, and that person was assisting him to get discharged. He didn't want to raise any issue about the other doctor to the hospital, including to the superior officer because he believed the hospital staff wouldn't believe him, and would be on the side of the doctor. He was worried that he would end up being kept for longer if he made a complaint about the doctor to staff or management.

In order to address these feelings, staff need to properly and respectfully communicate to individuals the reasons behind treatment decisions and actions, including why the person needs to stay longer.

### Recommendation 15

The Committee to better understand and address the practical difficulties mental health consumers face in holding staff at mental health inpatient units accountable. This includes ensuring there are clear feedback mechanisms that consumers know about, and a culture where consumers feel safe to provide feedback.

## When voluntary becomes involuntary

Hospital staff can have the power to detain voluntary patients and reclassify them as involuntary.[3] Mental health consumers have told us that they were alarmed and concerned that despite admitting themselves as a voluntary patient, staff have prevented them leaving the mental health inpatient unit when they asked to. People's feedback indicates that they do not feel adequately informed about their rights before they admit themselves voluntarily. It also suggests that there is often some miscommunication between staff at inpatient units and consumers. These factors can make the person fearful and frustrated about not knowing what is going to happen to them.

> *"You come in voluntary and think that you can either go on leave or discharge yourself, but then the nurse goes "no, you haven't been seen by the doctor". So sometimes I think "what is the difference between voluntary and involuntary?" because if you come in voluntary you expect that you can leave but that is not the case and the nurses do not explain it to you. And when you go to see the psychiatrist, unless they say, "yeah, you're leaving", it's never discussed with you afterwards, it's never discussed with you "this is what we're going to do"… nothing's explained. I don't see any difference."* – Mental health consumer, 2014

Another person called us while in a mental health inpatient unit in 2014. She said she had admitted herself because she didn't have money for food and needed somewhere to stay, and the hospital agreed to admit her on that basis, but now they wouldn't let her leave. She wanted someone to advocate to get her released from the hospital.

Amendments to the *Mental Health Act 2007* (NSW) legislation require mental health inpatient units to give voluntary patients a statement of their rights from 31 August 2015.[4] We don't have consumer feedback yet about the actual impact of this change on people's understanding of their rights, and services' enforcement of these rights.

[3] *Mental Health Act 2007* (NSW), s10.
[4] *Mental Health Act 2007* (NSW), s74A.

**Recommendation 16**

The Committee to consider mechanisms to ensure that people are fully informed of their rights and the risks of self or voluntary admission into a mental health inpatient unit.

# Summary of recommendations

1. The Committee to identify and address factors in forensic mental health systems across Australia that cause forensic consumers to be detained longer than necessary.
2. The Committee to consider how state and territory laws could limit the period of detention that can be imposed on a forensic consumer.
3. Forensic mental health facilities to offer rehabilitation programs that are person-centred and recovery-oriented. For example, by customising each person's rehabilitation program based on their recovery goals and needs.
4. Forensic mental health facilities to look at improving staff's ability to give meaningful feedback and communicate with consumers to navigate the forensic mental health system.
5. The Committee to consider people's experiences from a range of forensic mental health facilities, as practices vary across facilities and locations.
6. State and territory bodies governing forensic mental health systems to ensure meaningful involvement of forensic consumers in the decisions affecting them.
7. The relevant bodies making and reviewing orders about forensic consumers to consider trialling a self-report form for consumers to submit their own views to the body, and the body to respond to the self-report during the review.
8. Forensic mental health facility staff to be more aware of and empathic to the life circumstances of consumers and trained to be able to separate behaviours related to frustration with the system or environment from mental illness symptoms.
9. Forensic mental health facility staff trained to engage with consumers and to appropriately support individuals to deal with emotional distress.

10. The Committee to consider how to enable forensic consumers to easily access, review and challenge their medical records, and the medical notes written about them while at a forensic mental health facility.
11. The Committee to consider how state and territory laws can ensure that the period of detention for breaching conditions while on conditional release is appropriate to the breach.
12. The Committee to be informed by feedback from a diverse range of forensic consumers, including women.
13. The Committee to ensure there are systems and partnerships across government agencies so that forensic consumers on conditional release are properly supported.
14. The Committee to address the factors that lead to mental health consumers feeling like they are being detained indefinitely in mental health inpatient units. This includes the lack of clarity and information about discharge dates and limited access to a doctor.
15. The Committee to better understand and address the practical difficulties mental health consumers face in holding staff at mental health inpatient units accountable. This includes ensuring there are clear feedback mechanisms that consumers know about, and a culture where consumers feel safe to provide feedback.
16. The Committee to consider mechanisms to ensure that people are fully informed of their rights and the risks of self or voluntary admission into a mental health inpatient unit.