



NSW Consumer Advisory Group – Mental Health Inc.

***Submission to the National Report Card on Mental Health
and Suicide Prevention***

May 2012

This report was compiled on behalf of NSW CAG by:

The NSW CAG Policy Team:
Ka Ki Ng, Senior Policy Officer
Tara Dias, Senior Policy Officer
Susan Horsley, Policy Assistant

Acknowledgements

NSW CAG would like to thank the individual participants who generously shared with us their experiences and insights.

We would also like to acknowledge the staff at all agencies that gave us the opportunity to consult with the individuals accessing their services.

NSW Consumer Advisory Group – Mental Health Inc.
501 / 80 William Street
Sydney NSW 2011

ABN 82 549 537 349

P: 02 9332 0200

F: 02 9332 0299

W: www.nswcag.org.au

Table of Contents

Table of Contents	3
NSW Consumer Advisory Group - Mental Health Inc.	4
Introduction	5
1. What works.....	6
1.1 What makes the biggest difference	6
1.2 What works best to support consumers	6
1.3 Priority areas.....	7
2. Report Card	9
2.1 Information that would encourage improvement of services for people with mental health conditions	9
2.2 Information that would make services more answerable for the mental health services they provide.....	10

NSW Consumer Advisory Group - Mental Health Inc.

NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) is the independent, state-wide peak organisation for people with a lived experience of mental illness (consumer) in New South Wales. We work with consumers to achieve and support systemic change.

NSW CAG’s vision is for all consumers to be able to participate meaningfully in society and to experience fair access to quality and recovery focused services which reflect their needs. 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 six principles:

- Being person centred and empowering consumers in the interests of consumers;
- Adopting a recovery approach to building positive futures;
- Promoting positive images and reducing stigma and discrimination;
- Enhancing best practice and building understanding of effective approaches to consumer participation;
- Capacity building of our organisation, consumers and services; and
- Promoting professionalism and continuous improvement in our ways of working.

NSW CAG is an independent non-government organisation that receives core and project funding from the NSW Ministry of Health.

Introduction

NSW CAG is pleased to have the opportunity to share information and stories of mental health consumers in NSW with the National Mental Health Commission.

Our core work is to hear from people with a lived experience of mental illness to identify common trends and emerging issues throughout New South Wales and advocate for change.

We are currently talking to consumers throughout NSW about their reform priorities, to inform the incoming NSW Mental Health Commission. So far we've heard from 250 people in face to face consultations in 23 regional or remote towns and in three metropolitan areas. We have heard from another 90 people through our online survey.

This project puts us in a strong position to comment on the National Report Card on Mental Health and Suicide Prevention and the recommendations in this report reflect the current experiences of consumers throughout NSW.

NSW CAG supports the idea of having a National Report Card as we believe it is an important step in having a more accountable and transparent mental health system. We hope this report can help to inform the development of the National Report Card on Mental Health and Suicide Prevention.

1. What works

1.1 What makes the biggest difference

For consumers, having the right support at the right time makes the biggest difference.

Suggestions for what works and what needs to be strengthened:

- People in the community increasing their mental health literacy to recognise that they or someone they care about is experiencing mental health issues
- Feeling able to ask for help and knowing where to go to ask for support in the community
- Being able to find support that is geographical and financially accessible
- Having access to holistic support (ie activities that support wellbeing through connecting with others, peer support activities) in addition to support provided by the biomedical model
- Being treated respectfully by those providing assistance
- Being able to receive support that is tailored to one's needs (including cultural background and age), and this means having access to support services before one is in crisis, support that takes into account other needs that a person may have due to physical health conditions and age, as well as culturally appropriate services.

'People are talked at, they're told, "you are presenting like this", they're not talking with the person themselves' (Consultation participant, 2012)

1.2 What works best to support consumers

Consumers have told us that recovery oriented services are what work best. Some aspects of recovery oriented services include:

- **Having a voice and choice:** People want to drive their recovery and to work collaboratively with others to weigh up options and decide next steps. A number of people said mental health professionals didn't fully explain diagnosis and treatment options, and many also said they were not involved in their treatment and care planning. People said services need to learn to work in partnerships with consumers and carers rather than imposing their decisions on people.
- **Access to holistic services:** People want to be able to access counselling, support from peers, programs for physical wellness and other life skills activities that support their recovery. Overreliance on the medical model of mental health means that many consumers are still being provided with medication only. Many people told us that while medications may address some of the symptoms of mental illness, their experiences of mental illness are often linked to traumatic life experiences that cannot be treated with medication and/or that having access to medication is only one part of what they need for their recovery.

- **Trauma informed services:** consumers want services that make them feel safe and need time and space to be able to form trusting relationships with health staff. With many people having past experiences of trauma, it is important that health system moves to a trauma informed focus, support the individual's recovery and to minimise traumatising or re-traumatising people.
- **Coordinated care:** people want clinical and support services to work together. People said services are not always talking to each other, and they are having to retell their stories all the time, and often are getting conflicting information and advice from different services that are meant to be working together.
- **Continuity of care:** consumers want step up and step down options. People want access to support before they are in crisis. Many people said they had no access to service that could help them stay well, and a number of people said the hospital would not admit them until their situation escalated into a mental health crisis. We also heard that many people thought that the follow up support (after discharge) needed to be improved.
- **More non-clinical support in the community:** people said the support they received through community managed organisations (NGOs) was helpful. People value the flexible and tailored support that these organisations were able to provide.
- **Services tailored to one's lifespan:** depending on age and a variety of other factors, people face different issues. For young people, this may mean additional support with considering educational and career goals, and for older consumers, this may mean navigating ageing and disability sector. Services need to be flexible and responsive to peoples' needs across the lifespan.

1.3 Priority areas

In our recent consultations about the NSW Mental Health Commission, we asked people to prioritise what they wanted reformed. The top three priorities were:

1. Improving understanding and reducing discrimination
2. Increased access to recovery oriented services
3. Addressing inequalities (housing, employment, education, social security)

Priority 1: Improving understanding and reducing discrimination

In recent months, we've overwhelmingly heard that the top priority throughout NSW is for improved community understanding of mental health and mental illness. Ideas for how to do this include:

- embed information about mental health into the Australian school curriculum, with consensus that the earlier people start to gain mental health literacy, the better

- people working in health and human services to complete, as part of mandatory training, a course such as Mental Health First Aid
- create strong national campaigns to provide positive promotion around mental illness and encourage communities to discuss issues related to mental health. Examples such as New Zealand's *Like Minds, Like Mine* were cited by consultation participants.

People said this work of improving community understanding is necessary, especially outside of metropolitan centres, as campaigns like this can increase help seeking behaviour.

Priority 2: Increased access to recovery oriented services

As discussed in the previous section, access to recovery-oriented services is a major priority for people throughout NSW.

Priority 3: Addressing inequities (housing, employment, education, social security)

In our recent project, the third priority was a widely defined one that included concerns about housing, employment, education and social security. We have categorised these as 'inequities' that need to be addressed. The issues that were raised were complex and varied, and included Federal and State matters such as:

- the assessment process by Centrelink and how they felt that Centrelink did not understand mental illness
- how people generally felt they were not treated well by Centrelink staff
- scarcity of appropriate, safe and affordable housing
- when using employment programs, people often felt that they didn't have a choice about whether or not to go for a role, regardless of whether that role was for them
- problems with working a certain number of hours, then being ineligible for the Disability Support Pension, but not being able to afford medications without this concession
- the experience of being socially isolated due to living on a fixed income.

While access to mental health specific services and greater information about mental health in the community is necessary, we think that looking at the wider social justice issues faced by people with a lived experience of mental illness should be a priority of the National Mental Health Commission. The National Commission will be well placed to examine and influence issues around housing and homelessness, employment services and social security.

2. Report Card

NSW CAG is pleased that the National Mental Health Commission is going to be providing this annual reporting. We hear frequently from consumers about the need for greater transparency and accessibility of information relating to mental health care and services. We believe this reporting mechanism has the potential to engage a wide range of stakeholders in this change process.

2.1 Information that would encourage improvement of services for people with mental health conditions

Reporting consumers' experience and perceptions of services

Consumers frequently tell NSW CAG that they would like services to understand the range of experiences people have, and listen to people's views and concerns about their practice, so that services know what people want and can keep their service relevant to the people they work with.

Consumers also say that services should reflect on and evaluate their own practices for continual improvement, and also to learn from other services, including those in other countries, about what works and in what circumstances.

Based on the feedback, NSW CAG suggests the Report Card should report on consumers' experiences and perceptions of different types of mental health services, including areas that are working well and areas that need improvement.¹ The Report Card should also provide information on evidence-based best practices drawn locally as well as from overseas to improve awareness about these practices and to encourage their adoption by services.

Reporting against priorities identified by consumers

As raised in section 1.3, the top three priorities consumers said they wanted reformed are:

1. Improving understanding and reducing discrimination
2. Increased access to recovery oriented services
3. Addressing inequities (housing, employment, education, social security)

All three priorities have relevance to service improvements, and should be addressed by the Report Card.

1. Improving understanding and reducing discrimination

The Report Card should report on key actions taken by the Federal and State/Territory Governments to reduce discrimination of people with a lived experience of mental illness within the human service sector. For example, whether mental health training has

¹ Further discussion about tools to gather consumer experience and perceptions of service is in section 2.2.

become included as part of basic education for people wanting to work in human services, and the uptake of mental health training by people who are already working in these services.

2. Increase access to recovery oriented services

The Report Card should report on the uptake of recovery oriented mental health practice by services, at both a national, and state and territory level, to enable a comparison. This should be set against the National Mental Health Recovery Framework when it becomes available for implementation.

3. Addressing inequities (housing, employment, education, social security)

NSW CAG acknowledges that social inequities faced by people with a lived experience of mental illness are complex and may be harder to measure systemically. However, keeping these issues on the reform agenda is important. We therefore strongly suggest the Report Card should at a minimum identify the range of major social inequities faced by consumers, and report on the key actions being taken by the Federal, and State/Territory Governments to address these issues.

2.2 Information that would make services more answerable for the mental health services they provide

Measuring performance against established standards

To make mental health services more accountable for the service they provide, the Report Card should measure service performance against standards such as the National Standards for Mental Health Services, rather than creating more standards. Many consumers have said there are too many standards and frameworks on mental health, and these are rarely translated into service practice.

Measuring performance based on consumers' perception and satisfaction

Consumers told NSW CAG that service performance measures should focus on people's satisfaction with the service rather than relying on traditional quantitative measures. People said many good programs and initiatives were defunded because their outcomes did not fit the traditional funding measures. Many people felt that more value should be given to consumers' feedback regarding the performance of programs and services.

NSW CAG is working with the Mental Health Drug and Alcohol Office of NSW Health to embed the *Mental Health Consumer Perception and Experiences of Services* (MH-CoPES) Framework into public mental health services. The MH-CoPES Framework is a process for all NSW public adult mental health services to involve consumers in improving their service. Developed by consumers, the MH-CoPES

*'[the] main thing is they've been listening for years, they listen and listen but they don't make changes'
(Consultation participant, 2011)*

Framework establishes a reflective process through which service providers and consumers work together to achieve continual service improvements.²

NSW CAG is also involved in the development of the National Experiences of Care Tool, which is designed to capture consumer experiences of care with a strong focus on recovery.

Other states have their own tools and processes to gather consumer perceptions of services, and one or a combination of these tools would be useful in collecting data on consumer experiences.

To ensure consumers are at the centre of policy and service decision making, NSW CAG also recommends the National Mental Health Commission supports the mental health sector to embed consumer participation mechanisms into their practices, and for the National Report Card to report on this as it progresses.

Information on allocation of mental health resources

NSW CAG has been told by many people that they are frustrated that governments' commitment to mental health reform rarely translates to changes on the ground. Many people express a sceptical view that government makes promises, reports and policies, but services on the ground continue to be inadequate and overstretched. People said they would like governments' mental health funding decisions to be more transparent and accountable.

Based on feedback from consumers, NSW CAG suggests the National Report Card could enhance transparency and accountability of government decisions by reporting on the following:

- Federal, State and Territory mental health budget, with clear information on which government is responsible for which mental health programs and aspects of care.
- An overview of where governments' budgets are being allocated (for example, into hospital inpatient care, hospital run community care, community managed mental health services and support programs).
- Overview on the mental health workforce in Australia and at State/Territory level. This should include the size of the mental health workforce in the public and NGO sector, with a breakdown of the number of psychiatrists, psychologists, mental health nurses, mental health peer workers and other support workers.

To enhance accountability, NSW CAG also suggests the Report Card identifies and reports on gaps in mental health services, and actions taken by governments to address these gaps.

² Information about MH-CoPES is available on NSW CAG website at:
http://www.nswcag.org.au/mh_copes.html