NSW Consumer Advisory Group – Mental Health Inc.

Moving beyond 'beautiful rhetoric': views from consumers and carers on the proposed NSW Mental Health Commission

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NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG)
501/80 William St, East Sydney NSW 2011
Ph: 02 9332 0200, Fax: 02 9332 0299, www.nswcag.org.au

Authors

Ka Ki Ng, Policy Officer
Tara Dias, Policy Officer

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Newtown Neighbourhood Centre
Morrisett Forensic Hospital
Psychiatric Rehabilitation Australia
WEAVE

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NSW Consumer Advisory Group - Mental Health Inc.

NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) is the independent, state-wide organisation representing the views of people with a lived experience of mental illness at a policy level, working to achieve and support systemic change.

NSW CAG exists to ensure that policy makers hear the perspectives of mental health consumers across NSW. We work from the premise that the participation of mental health consumers in systemic advocacy leads to the development of more effective public policy in the area of mental health. Participation is a fundamental human right as enshrined in Article 25 of the *International Covenant on Civil and Political Rights* (ICCPR).

NSW CAG's vision is for all mental health consumers to be able to participate meaningfully in society and to experience fair access to quality and recovery focused services which reflect their needs. 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 funded by the Mental Health and Drug and Alcohol Office, NSW Department of Health.

Background and summary

NSW CAG commends the NSW Premier and the NSW Minister for Mental Health for their commitment to improving mental health services in NSW. NSW CAG welcomes the opportunity to comment on the proposed NSW Mental Health Commission (MHC). This important initiative has the potential to create the change that consumers have been advocating for, or as one participant told NSW CAG, represents a possible way to move beyond the current 'beautiful rhetoric'.

As the state-wide organisation representing mental health consumers in NSW, NSW CAG believes that the proposed MHC must be informed by the needs and perspectives of people who are affected by mental illness, including people with a lived experience of mental illness and those who are supporting them. To ensure people affected by mental illness play a role in informing the development of the MHC, NSW CAG conducted an online survey consultation and a number of targeted face to face consultations during the first three weeks of July 2011.

NSW CAG's consultation process aimed to find out what people wanted the MHC to do which is outlined in the section 'Leading Change: preferred functions of the MHC.' Participants told us that they wanted the MHC to drive systemic change; to promote a partnership approach of care (involving consumers and carers in decisions); and that they wanted the MHC to also have a role in educating the community and raising awareness.

NSW CAG was also interested in finding out how consumers wanted to participate in the MHC, which is covered in 'Consumer participation in the Mental Health Commission: the why, how and what.' Consultation participants told NSW CAG that consumers need to be actively and genuinely engaged by the MHC. Participants told NSW CAG they wanted an inclusive and accessible Commission and that the Commission must have numerous structures that support consumer participation.

In undertaking the face to face consultations, NSW CAG sought input from a diverse spectrum of people, including young people, adults with a mental illness living in the community, adults in forensic mental health care, women who recently exited from prison or rehabilitation, people living in boarding houses, older people, and people with an intellectual disability. Consultations were also conducted in Sydney and two regional NSW locations which were not visited by the NSW Mental Health Taskforce during its community consultations.[1]

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[1] NSW CAG endeavoured to consult with consumers from culturally and linguistically diverse (CALD) communities. NSW CAG was informed by services that the short timeframe for consultation and the July school holiday made accessing CALD consumers difficult.

NSW CAG's comments and recommendations in this report are based on feedback from 234 consultation participants throughout NSW who identified as consumers (someone with a lived experience of mental illness), carers (families and friends of people living with a mental illness or disorder) or who identified as both consumer and carer.

As NSW CAG is the peak body for mental health consumers, face to face consultations focussed on hearing from people with a mental illness.

In addition, this report is informed by NSW CAG's core work of hearing from consumers of mental health services in NSW, including information from:

- over 1,000 people (consumers, carers, service providers and other interested people) on our Network who are accessible via the internet;
- regular face to face consultations with consumers within each Area Health Service across NSW; and
- our knowledge base derived from consulting with consumers of mental health services in NSW over the last 17 years.

NSW CAG makes the following recommendations:

Recommendation 1:

NSW CAG recommends that the proposed MHC acknowledges, considers and learns from work that has been done to improve mental health outcomes in Australia and abroad.

Recommendation 2:

NSW CAG recommends that the MHC drives the uptake of person centred and recovery oriented model of care across the mental health system in NSW, and that it provides resources and training to increase the capacity of services to implement the uptake of this model of care.

Recommendation 3:

NSW CAG recommends that the NSW MHC be mandated to develop and set up plans and strategies to implement the government's vision for the mental health system in NSW, and that the plan and strategies are reviewed at regular intervals.

Recommendation 4:

NSW CAG recommends that the NSW MHC maps the specific needs and gaps in service provisions in NSW to inform its plans and strategies, and that the MHC be empowered to allocate resources accordingly.

Recommendation 5:

NSW CAG recommends that the MHC develops education resources, including training modules, on evidence-based best practices on how to work with and support people with a mental illness, and that such resources be made available to individuals and services that work with people with a mental illness.

Recommendation 6:
NSW CAG recommends that the MHC assess the quality of services against the *National Standards for Mental Health Services 2010* and on the basis of the assessment assist services to meet those standards.

Recommendation 7:
NSW CAG recommends that the MHC work with services for people with a mental illness to establish strong links between these services to enable integrated care and service delivery.

Recommendation 8:
NSW CAG recommends that the MHC develops and implements structures that incorporate at its core functions consumer and carer participation.

Recommendation 9:
NSW CAG recommends the MHC to develop resources for community education to promote mental wellbeing and reduce stigma against people living with a mental illness.

Recommendation 10:
NSW CAG recommends the MHC develops an extensive education campaign to demystify the mental health sector and encourage individuals to access mental health support as soon as the need arises.

Recommendation 11:
NSW CAG recommends that the MHC works closely with the HCCC to improve its ability to handle individual mental health care complaints.

Recommendation 12:
NSW CAG further recommends that appropriate information from individual mental health care complaints be fed back to the MHC to be used for identifying system issues and solutions.

Recommendation 13:
NSW CAG recommends that the Commission work to improve outcomes for all people with mental illness, including those with complex needs, as this group is among the most vulnerable in the community.

Recommendation 14:
NSW CAG recommends that the MHC takes a broad view of determinants of mental health, supports a wide range of projects and activities to improve outcomes for consumers and collaborates with other sectors to improve outcomes for all consumers.

Recommendation 15:
NSW CAG recommends that the MHC has a mandate of improving outcomes for those with a lived experience of mental illness as well as improving wellbeing and mental

health of all people in NSW and that it uses inclusive language and terms to achieve this.

Recommendation 16:
NSW CAG recommends that the MHC promotes its existence widely and in a variety of formats, along with information about how consumers and carers can contact them.

Recommendation 17:
NSW CAG recommends that the MHC provides a number of ways that consumers and carers can contact them and consider online forums, a free call number and/or a physical location that consumers and carers can visit.

Recommendation 18:
NSW CAG recommends that the MHC sets clearly defined objectives and outcomes and commits to regular and open reporting on its progress.

Recommendation 19:
NSW CAG recommends that the MHC has a number of structures to encourage consumer and carer participation.

Recommendation 20:
NSW CAG recommends that the MHC regularly holds face to face consultations with consumers and carers.

Recommendation 21:
NSW CAG recommends that the MHC has regular consultations with consumers and carers to find out what the current issues are. Consultations need to be: held regularly throughout the state (and ensure they are held regularly in regional, rural and remote NSW); provide consumers with choice in how they speak to the MHC (group or one to one); need to be held where consumers are (at mainstream mental health services as well as other community services).

Recommendation 22:
NSW CAG recommends that the MHC has an advisory committee with significant and separate consumer and carer representation, with consumers and carers who have diverse backgrounds.

Recommendation 23:
NSW CAG recommends that the MHC reimburses participants for time and expenses involved in sitting on the committee.

Recommendation 24:
NSW CAG recommends that an advisory committee should be only one way of several that consumers and carers can provide feedback to the MHC.

Recommendation 25:

NSW CAG recommends that the MHC considers how existing and new structures could be used to promote consumer participation, including training in systemic advocacy; increased support for consumer workers; supporting participation at the service level; and linking in to complaints/monitoring systems.

Recommendation 26:

NSW CAG recommends that the MHC provides online mechanisms to encourage participation for younger consumers and carers and for those in regional and rural areas.

Recommendation 27:

NSW CAG recommends that if the MHC uses surveys to engage with consumers and carers it should offer other ways to participate and provide feedback to the MHC.

Recommendation 28:

NSW CAG recommends that the MHC has identified roles for people with a lived experience of mental illness within the Commission, including the role of Commissioner.

Further information on the consultation methodology is provided in Appendix A. Breakdown of the survey responses, including participants' demographics, is provided in Appendix B. Comments from online surveys, posted surveys and face to face consultations can be found in Appendix D.

Part 1: Leading change: functions of the Mental Health Commission

Mental Health Commissions can serve a variety of functions. They can advocate for individuals through complaint handling or can advocate at the systemic level through activities such as policy reform and agenda setting, service development, monitoring and evaluation, and community education.

Main issues regarding mental health services

To identify how the proposed MHC can improve the mental health system, NSW CAG asked consultation participants to identify issues that were most important to them in terms of mental health services. The survey contained a list of seven options to illustrate some of the possible functions of a MHC. These options were drawn from past consumers' feedback about mental health services. Survey participants were invited to select any of the seven options and to comment on any other related issues. Participants in the face to face consultations were invited to discuss any issues that were important to them in relation to mental health services, and where it was helpful, the options on the survey were used as examples to encourage discussion.

Consultation participants told NSW CAG that a diverse range of issues were important to them in relation to mental health services, the top three issues were:

- the quality of services,
- access to services, and
- being treated with respect and dignity.

A detailed discussion on consultation participants' feedback about issues important to them in relation to mental health services are provided in Appendix C.

NSW CAG recognises that the issues identified as important by the consultation participants are not new *per se*. Many of the issues are documented in past reports. For example, the Mental Health Services (MHS) Conference in 2000, which was attended by over 200 people experiencing a mental illness in Australia and New Zealand, identified 23 most important issues affecting people with a mental illness or disorder, and solutions to these issues.[1] Although there may be variations in the way they are expressed, the issues arising from NSW CAG's consultations are in substance reflective of the 23 issues from the MHS Conference. To avoid 'reinventing the wheel', NSW CAG strongly recommends that the new MHC acknowledges, considers and learns from the tremendous range of research, ideas and initiatives that have already taken place to improve mental health outcomes in Australia and abroad.

Recommendation 1:
NSW CAG recommends that the proposed MHC acknowledges, considers and learns from work that has been done to improve mental health outcomes in Australia and abroad.

Preferred functions of a NSW Mental Health Commission

To ensure the proposed MHC will effectively improve mental health outcomes in NSW, NSW CAG believes the functions of the MHC must be relevant to the needs of people with a lived experience of mental illness and also the needs of those who are supporting them. To identify what functions are most relevant, NSW CAG asked consultation participants what they would specifically like the MHC to do. Participants were provided with a list of five options that described some of the possible functions of a MHC and they were asked to select as many of the options as they saw fit. Many of the participants in face to face consultations also shared with NSW CAG their reasons for selecting particular options.

Findings from NSW CAG's consultations show that participants wanted the MHC to have the following functions:

- drive systemic change: shifting the focus to a person centred and recovery oriented model of care and improving the quality of services,
- actively involve consumers and carers in decision about mental health services and policies, and
- community education and awareness raising.

Drive systemic change

A majority of survey participants (69%) indicated the MHC should drive systemic change and lead changes in service improvement. One consumer articulated that the MHC should provide the vision and set the agenda for the mental health sector rather than focus on the day-to-day oversight of services.

Consultation participants told NSW CAG that the MHC should drive system changes in two broad areas:

1. shifting the focus of the mental health system from the traditional model to a person centred and recovery oriented model of care, and
2. improve service quality.

Systemic change: shifting the focus to a person centred and recovery oriented model of care

'The mental health services need to […] treat me as a person in a holistic way so I don't have to wait until I am so unwell I need to go into hospital again.'

(NSW CAG Consultation Participant, 2011)

Consultation participants told NSW CAG that the mental health system needs to become focused on providing holistic care to people with a mental illness to support them to live

meaningfully in the community. Consultations indicated that the current system is inadequate and ineffective at addressing the long term needs of people with a mental illness. Some of the common criticisms by consultation participants about the current mental health system include:

- it is crisis driven,
- it is focused on medical diagnosis and treatment of the mental illness,
- it is over-reliant on medications as a solution to mental illness,
- clinicians are the experts and people with a mental illness are passive recipients of services.

Consumers complained to NSW CAG that medication is being used by many mental health clinicians as the answer to every problem. One consumer pointed out that people with a mental illness can have bad days just like anyone else. However, if a person with a mental illness is having a bad day when he or she presents at a mental health service, the person is likely to be treated as though he or she is having a mental health crisis. The person is likely to be given unwanted intervention, when all that the person needed is to have someone to talk to.

NSW CAG's face to face consultations found that consumers would like the mental health system to adopt the following characteristics:

- focuses on supporting people with a mental illness to live meaningfully in the community,
- recognises people with mental illness as whole persons with diverse needs,
- considers medical treatment, including the use of medications, as one of many options to support recovery,
- recognises people with a mental illness as experts on their own care needs,
- provides ongoing support throughout the journey to recovery.

These characteristics correspond to a person centred and recovery oriented model of care, whereby, service providers work in partnership with individual consumers and their support network to enable the consumers to achieve their goals and to live a meaningful and fulfilling life.[2]

Feedback from NSW CAG's consultations indicated that person centred and recovery oriented care is practised by some services, but this is done sporadically across NSW. NSW CAG found during the face to face consultations that a significant number of consumers were unaware of the concept of recovery. This finding reflects that consumers do not currently have equal access to person centred and recovery oriented care.

Recommendation 2:

NSW CAG recommends that the MHC drives the uptake of person centred and recovery oriented model of care across the mental health system in NSW, and that it provides resources and training to increase the capacity of services to implement the uptake of this model of care.

Systemic change: improve the quality of services

A majority of survey participants (73%) told NSW CAG that the quality of mental health services is important to them, and many held that service quality needs improvement. Feedback from face to face consultations suggested that the MHC needs to drive the improvement of services for people with a lived experience of mental illness in the following areas:

- services need to be adequately and appropriately funded and resourced,
- staff need to be properly trained,
- services need to be supported to improve service delivery, and
- strengthen coordination between services.

Services to be adequately funded and resourced: NSW CAG heard from consultation participants that services supporting people with a mental illness are not being sufficiently funded and that poor funding and resource allocation is affecting services' ability to perform their functions properly. A number of consumers felt that the services they access are declining in both quality and capacity, and many thought that services are over-stretched and under-resourced. One consumer told NSW CAG:

> *'Our grants money is $200 000 per annum. Current contract ends on 30 June 2010. Inflation – the slow and real loss of buying power. [This service] has been given the same amount of money for the past 5 years. This means that we have had to manage on less and less actual buying power. We have had to cut services because of this in order to survive. This is NOT sustainable. We need an immediate increase in our grant to offset the effects of inflation.'*
>
> *(NSW CAG Consultation Participant, 2011)*

NSW CAG recognises that the NSW mental health system would benefit from significant increase in its funding and resources, and it would also benefit from resources being allocated effectively to where it is needed. The New Zealand MHC has a blueprint to guide mental health service development for the implementation of the New Zealand Government's *National Mental Health Strategy*. It considered the needs of people affected by mental illness as the starting point for describing service quality requirements. From that, it developed the resource guidelines to inform the New Zealand Government on how to achieve the outcomes in its Strategy.[3] The Western Australia MHC goes one step further by having a mandate to map out gaps in service provisions and then having the power to allocate resources accordingly.[4]

Recommendation 3:

NSW CAG recommends that the NSW MHC be mandated to develop and set up plans and strategies to implement the government's vision for the mental health system in NSW, and that the plan and strategies are reviewed at regular intervals.

Recommendation 4:

NSW CAG recommends that the NSW MHC maps the specific needs and gaps in service provisions in NSW to inform its plans and strategies, and that the MHC be empowered to allocate resources accordingly.

Staff to be properly trained: consultation participants told NSW CAG that many staff working in mental health services are not properly trained to support people with a mental illness. Discussions with consumer workers as well as clinicians revealed that although clinicians and case workers have the academic qualifications to work in the sector, they are expected to learn on the job how to work with people with a mental illness. They are expected to learn through observing other staff members and from direct interactions with consumers in a form of trial and error. This means that many people working in the mental health sector are not necessarily aware of any of the evidence-based best practices, and that bad service delivery practices can be passed down from one staff member to the next unchallenged.

Consultation feedback indicated that consumers generally considered service staff as 'good people wanting to make a difference', but consumers were concerned that good intentions are being lost though lack of appropriate staff training. To give an example, consumers in a forensic mental health unit told NSW CAG that they are receiving free legal representation at the Mental Health Review Tribunal's hearings, but their right to legal representation remains unfulfilled because rather than advocating for their interests, the lawyers often follow the instructions from the clinicians rather than from the consumer. The consumers told NSW CAG that they would like the lawyers to be made aware of their professional duties as legal representatives of consumers, and to receive training on how to effectively obtain instructions from people with a mental illness.

Recommendation 5:

NSW CAG recommends that the MHC develops education resources, including training modules, on evidence-based best practices on how to work with and support people with a mental illness, and that such resources be made available to individuals and services that work with people with a mental illness.

Supporting services to improve quality: an overwhelming majority of consultation participants told NSW CAG that the quality of mental health services need improving, yet the least number of participants (52.3%) selected 'ensuring quality service delivery – conduct a formal audit of all service providers' as a preferred function for the MHC. It emerged during the face to face consultations that many consumers were afraid that the auditing of services would lead to services being shut down. This widespread belief amongst consumers that 'bad service is better than no service' is reflective of the severe shortage of services for people with a mental illness.

Some consumers, however, told NSW CAG they wanted the MHC to inspect services and assess their performance. Consumers in one focus group suggested the MHC should conduct random surprise visits to keep services honest. Most of the consumers who supported the auditing of services stressed that the assessment outcomes should

be used to help services improve their quality and should not be used to shut down services.

Consultation feedback suggests that the MHC should assess services to identify areas for service quality improvement. To improve service quality at a systemic level, NSW CAG recommends that the MHC uses the *National Standards for Mental Health Services 2010* as the baseline for this assessment.[5]

Recommendation 6:

NSW CAG recommends that the MHC assess the quality of services against the *National Standards for Mental Health Services 2010* and on the basis of the assessment assist services to meet those standards.

Strengthen coordination between services: participants told NSW CAG that as part of service quality improvement the MHC should establish better linkages between various services supporting people with a mental illness, including the linkages between mental health services and community support services. One consultation participant succinctly expressed this concern:

> *'My adult child lives independently (with considerable support from family when well and complete support when unwell). We have never used community health services as we've been advised by our GP that access is very poor, long waiting lists, limited visits possible. My daughter struggles to pay for a private counsellor, but does need that support. Her disability employment service does not liaise with her mental health worker or GP and the support is fragmented. Service delivery needs to be more integrated so that they speak to each other and can refer to each other rather than me acting as the advocate and go-between.'*
>
> *(NSW CAG Consultation Participant, 2011)*

Another participant highlighted the need for better coordination between inpatient care and community care, to support transition to living in the community: '*I have found the after hospital care is almost NON existent*'.

Recommendation 7:

NSW CAG recommends that the MHC work with services for people with a mental illness to establish strong links between these services to enable integrated care and service delivery.

A partnership approach: consumers and carers being involved in decisions about mental health services and policies

NSW CAG's consultations found that consumers and carers not only want the MHC to be leading the mental health sector's developments, but they also want to be actively involved in decisions about the developments to ensure mental health policies and services are relevant to their needs. One area that consumer participants said they

would particularly like to be involved in is the decisions on where funding and resources should be directed.

Feedback from consultations indicate that 'active involvement' from consumers' perspective means being in a partnership with decision makers and being involved at every stage of the decision making process. Consumers told NSW CAG that they should be consulted about issues of concern; they should be participating in identifying and implementing solutions to those issues, and they should also be informed when change has actually occurred.

Based on the consultations and NSW CAG's past experiencing advocating for better mental health care, NSW CAG asserts that to effectively improve mental health outcomes in NSW, the MHC must be informed by the views and experiences of those who are using the mental health system. This means the MHC must incorporate strategies to hear from consumers and carers, and it must be able to transform the information gathered into actions.

Beyond the consultations, the MHC must also be engaged in two-way communication with consumers and carers by keeping them informed about any developments in the mental health system, so they are aware of the developments and can provide feedback about the changes. This two-way communication is significant because NSW CAG's consultations found that there is a level of 'consultation fatigue' amongst consumers and carers. Some participants told NSW CAG that they have been consulted many times before about issues concerning mental health services and ways to improve the mental health system, but had seen very little being done to address those concerns over the years. Some consumers who have extensive experience working in the mental health sector pointed out that while the consumer movement has led to improvements in the mental health system, these improvements are often not communicated to the consumers and carers.

Consultation participants' feedback on the best ways for the MHC to engage with consumers and carers will be discussed in Part X: Consumer participation in the MHC: the why, how and what.

Recommendation 8:

NSW CAG recommends that the MHC develops and implements structures that incorporate at its core functions consumer and carer participation.

Community education and awareness raising

One hundred and twenty four participants (57%) indicated that the MHC should deliver community education and awareness programs. Feedback from face to face consultations indicated that consumers saw community education as a strategy to overcome stigma against people with a mental illness and to encourage access to mental health services.

Participants in the face to face consultations stressed that they would like the MHC to reduce the level of stigma against people with a mental illness. Some suggestions from consumers about what the MHC can do to improve community awareness and understanding are:

- start when they are young: some participants suggested that the MHC should play a role in ensuring school children are educated about mental health and mental illness so that children can become more attuned to their mental health needs and can grow up understanding mental illness as normal human experience.
- a central point for information and resources: some participants suggested that the MHC should become the central location for information about what services are available and how to access these services.

In addition, some consumers told NSW CAG that they did not want to access mental health services because they were afraid that services would treat them inhumanely. Feedback from consumers who have extensive experience working in the mental health sector revealed that stigmatisation of mental illness extends to mental health services. Many people associate being in a mental health service as being treated inhumanely. Participants told NSW CAG that the MHC needs to educate the community about what happens at different types of mental health services, and what consumers and carers can expect from these services. They suggested that demystifying the mental health sector would promote service transparency and accountability, and would also address some of the barriers that are discouraging people from accessing services.

Recommendation 9:

NSW CAG recommends the MHC to develop resources for community education to promote mental wellbeing and reduce stigma against people living with a mental illness.

Recommendation 10:

NSW CAG recommends the MHC develops an extensive education campaign to demystify the mental health sector and encourage individuals to access mental health support as soon as the need arises.

Individual complaint handling

The question of whether the MHC should handle individual complaints about service providers were raised at a number of face to face consultations.[2] The majority of participants responded that the MHC should direct its attention to driving systemic changes. Participants in one focus group pointed out individual complaints in NSW are currently handled by the Health Care Complaint Commission (HCCC). Although the participants felt that the HCCC is ineffective at handling mental health care complaints, they nevertheless insisted individual complaints handling should be retained by the

[2] This question was not asked in NSW CAG's survey.

HCCC. They preferred that the MHC improves the HCCC's ability to address such complaints rather than to take over the responsibility of complaints handling.

On the basis of this feedback, NSW CAG considers the HCCC should continue to handle individual mental health care complaints, and where appropriate, information from such complaints should be fed back to the MHC to be used for identifying systemic issues and solutions.

Recommendation 11:

NSW CAG recommends that the MHC works closely with the HCCC to improve its ability to handle individual mental health care complaints.

Recommendation 12:

NSW CAG further recommends that appropriate information from individual mental health care complaints be fed back to the MHC to be used for identifying system issues and solutions.

Part 2: Consumer and carer participation in the MHC: the why, how and what

Why consumer and carer participation is important

'We are the experts.'

(NSW CAG Consultation Participant, 2011)

'We need to be heard.'

(NSW CAG Consultation Participant, 2011)

NSW CAG believes that consumers must be active and equal participants in all aspects of service delivery, policy planning and system reform. The value and importance of consumer participation at all levels of service delivery and the policy cycle is well documented.[6] The MHC must ensure that mental health consumers and carers are at the centre of any MHC, and must genuinely engage with a wide range of consumers in order to improve mental health services and policy.

How to support participation

From our consultations, NSW CAG has identified three features to facilitate consumer and carer participation. These issues are:

1. Be inclusive: people told NSW CAG that for a MHC to work, it must be inclusive of all people with mental health issues, regardless of formal diagnosis, dual diagnosis, culture, ethnicity or geography. This approach acknowledges the complex nature of wellbeing and enables the MHC to have a broad mandate.

2. Be accessible: consultation participants told NSW CAG that the MHC needs to be widely promoted, that people wanted to know how to contact the MHC, and that they wanted options about how to contact the MHC.

3. Be effective: consultation participants wanted to know that the MHC is committed to making substantial changes and that these changes will be communicated openly and transparently to consumers.

How to do it: be inclusive (don't box us in)

'Surely the Commission is for EVERYONE with the lived experience of mental illness…'

(NSW CAG Consultation Participant, 2011)

'…Not everyone can be put into little boxes.'

(NSW CAG Consultation Participant, 2011)

NSW CAG asked consultation participants what the scope of the MHC should be, or in other words, who is the target audience of the MHC? This question elicited a fair amount of confusion among consultation participants.

Consultation participants wrestled with the tension between wanting to ensure that all who needed the MHC were able to access/benefit from it and not wanting to dilute the role or purpose of the MHC. In the end however, most participants responded that they wanted the Commission to have a wide scope.

Consultation participants told NSW CAG that they wanted the MHC to be as inclusive as possible. They wanted to ensure that the work of the MHC included people along the mental health spectrum, ranging from those with mental health issues to those with severe mental illness and/or complex needs. They noted that the MHC would have to tackle social issues that impact mental health. Lastly, participants wanted the MHC to work to foster improved mental health for everyone in the community, regardless of geographic location, culture/ethnicity, age or other factors.

The MHC needs to support people with complex needs: consumers told NSW CAG that the Commission should support people with mental illness and who have complex needs. Consultation participants fed back that the question ('What should be the scope of the Mental Health Commission?') was confusing to them, which is evident in the data below where only 79% of respondents said that the scope should be people with a lived experience of mental illness. Data from surveys show that participants thought that the MHC should also consider the needs of those with mental illness and:

- drug or alcohol dependence (53%),
- at risk of or experiencing homelessness (51%),
- have an intellectual disability (42%).

The qualitative data from focus groups, face to face interviews and online surveys provided greater insight into these statistics. These comments show a more inclusive view of the scope of the MHC and that the MHC should be for anybody with a mental illness, including those who have complex needs. As one consultation participant, said '*A simple answer is to include anyone with a co-morbidity of any type*.'

Most participants acknowledged the complex interplay between mental illness and the above conditions and/or experiences. In addition, consultation participants noted that people with complex needs are among the most vulnerable. As one participant said those with dual diagnosis *'…are often shunted from one "sector" to another, between health, disability, mental health and ageing.'*

NSW CAG notes that other Mental Health Commissions have taken similar approaches in recognition that those with complex needs are marginalised.[7] For example, WA's Mental Health Commission is a partner in a trial project 'People with Exceptionally Complex Needs'[8] which provides support to those who have one or more conditions (mental disorder, acquired brain injury, intellectual disability and substance abuse problems).

Recommendation 13:
NSW CAG recommends that the Commission work to improve outcomes for all people with mental illness, including those with complex needs, as this group is among the most vulnerable in the community.

The MHC needs to consider the social factors impact health: consumers have told NSW CAG during these and other recent consultations that they need government and service providers to take a holistic view of mental health. Participants have told NSW CAG their mental health is impacted by ability to access services as well as the social conditions they experience. Social factors and experiences of stigma, discrimination, unstable/inappropriate accommodation, unemployment and poverty impact wellbeing.

One consultation participant, an Aboriginal Elder, told NSW CAG that the injustice he experienced on a daily basis was enough to damage anyone's mental health. He said: *'I could gather 200 Aboriginal men who are fined beyond the max [by police]…it's impacting on our families. It [injustice] starts in youth and causes breakdowns.'*

Similar parallels can be drawn between the experiences of people from other groups such as newly arrived migrants (especially refugees and asylum seekers) and people at risk of/experiencing homelessness. Experiences of social inequalities and injustice impact physical and mental health.[9] For this reason, the MHC needs to take a wide view what impacts mental health (the social and the medical) and consider community and justice issues and collaborate with other sectors.

NSW CAG notes that the WA and Canadian Mental Health Commissions use this approach. The WA Mental Health Commission has prioritised engaging with people from diverse backgrounds (Aboriginal peoples and people from culturally and linguistically diverse backgrounds)[10] and that the website's language on mental health reflects a holistic rather than medical approach. In addition, the Canadian Mental Health Commission has supported research and is involved in projects on homelessness.[11]

Recommendation 14:
NSW CAG recommends that the MHC takes a broad view of determinants of mental health, supports a wide range of projects and activities to improve outcomes for consumers and collaborates with other sectors to improve outcomes for all consumers.

The MHC should aim to promote mental health and wellbeing broadly: consultation participants told us that the MHC needs to promote mental wellness in the community, in addition to working for improved outcomes for people with a lived experience of mental illness. This aligns with the majority view that the MHC has a role to lay in delivering community education programs (57%).

To achieve this, the MHC will need to consider the best way to do this as how people engage with and identify with traditional mental health terms, specifically 'mental illness' and 'consumer' will be influenced by their age, cultural and or ethnic background, and

other experiences. For example, depending on cultural background, people will conceptualise and speak of their mental health in a variety of ways. In another example, participants told NSW CAG they did not identify as a 'consumer' either because they were only starting to use mental health services or because of negative experiences with mental health services.

This highlights the necessity for the MHC to be flexible and sensitive around the terms and definitions it uses. NSW CAG believes that this will ensure that the MHC is inclusive of all people who need its assistance, regardless of what label they apply to themselves or how they conceptualise their mental health. This approach is one that is reflected not only in the language and approach of the WA Mental Health Commission's website but also the Terms of Reference for its Advisory Council[12] as well as in the Statement of Intent for NZ's Mental Health Commission.[13]

Recommendation 15:

NSW CAG recommends that the MHC has a mandate of improving outcomes for those with a lived experience of mental illness as well as improving wellbeing and mental health of all people in NSW and that it uses inclusive language and terms to achieve this.

How to do it: be accessible (people need to know what the MHC does and how to contact it)

Consultation participants told NSW CAG that once the MHC was formed, they wanted to know what the purpose of the MHC was and how to contact it.

Consultation participants suggested that MHC promote its existence through community radio, pamphlets (in the community and at mental health services) and through advertisements in local papers. Participants told us that promotional materials need to be colourful and engaging to a wide range of people and consider ages of the target audience, varying levels of literacy and diverse cultural backgrounds.

NSW CAG also heard that consultation participants wanted a variety of ways to get in touch with the MHC. These included by phone (free call number), mail, online or by having a physical space that they could go. Having a physical space was very appealing to some participants and it was suggested that it would be one way for the MHC to have a presence in regional and rural areas.

Consultation participants also discussed that when they contacted the MHC they wanted the staff at the MHC to be easy going, or in the words of one consumer, they didn't want to deal with staff who *'have too much starch in their apron.'*

Recommendation 16:

NSW CAG recommends that the MHC promotes its existence widely and in a variety of formats, along with information about how consumers and carers can contact them.

Recommendation 17:
NSW CAG recommends that the MHC provides a number of ways that consumers and carers can contact them and consider online forums, a free call number and/or a physical location that consumers and carers can visit.

How to do it: we want substance, not spin

'… [the] main thing is they've been listening for years, they [government] listen and listen but they don't make changes'
(NSW CAG Consultation Participant, 2011)

From speaking with consumers, NSW CAG heard participants say that they wanted the MHC to make substantial changes and that they wanted regular and open communication about the MHC's progress.

Consumers told NSW CAG that they are disenchanted with Government's commitments to mental health reform. One consumer expressed the general sense of scepticism when she said that this consultation process will probably result in another report and *'we've had so many reports, you may as well put it in the dusty corner with all the others.'*

Other consumers told NSW CAG that there had been many good reports, standards and policies but that they hadn't been implemented yet. This was attributed to sector turnover and changes in government. Still other consumers said that there had been significant progress made, but that this progress hadn't been communicated to the community.

The MHC will need to define objectives and outcomes and show consumers and carers that it is dedicated to making changes, not just creating more reports. It will also need to regularly and openly communicate on its progress against these measures to consumers and carers. These measures are necessary if the MHC is to have credibility with consumers and carers and be seen as a mechanism worth engaging with.

Recommendation 18:
NSW CAG recommends that the MHC sets clearly defined objectives and outcomes and commits to regular and open reporting on its progress.

What structures support consumer participation?

NSW CAG asked consultation participants about how they wanted to provide feedback to the MHC. Consultation participants told NSW CAG that they wanted to be provided with a variety of ways to participate but the majority expressed that they wanted to participate in face to face consultations.

Consultation participants told NSW CAG that they wanted to participate in the MHC through face to face consultations (68%), mental health advisory committee of

consumers and carers (53%); training in systemic advocacy (46%); online forums (45%); and through questionnaires (36%).

Recommendation 19:
NSW CAG recommends that the MHC has a number of structures to encourage consumer and carer participation.

Recommendation 20:
NSW CAG recommends that the MHC regularly holds face to face consultations with consumers and carers.

Option: community consultations

'I think surveys are limited. Also a MH advisory committee is constrained by very few participants. Forums, however, provide an opportunity for large numbers of people to present diverse views and provide much richer data to inform policies and service delivery.'

(NSW CAG Consultation Participant, 2011)

'[We want] community consultation that cuts out the middle man. Send the actual politicians and policy makers to speak with real people with a range of experiences and back this up with all the stats etc…'

(NSW CAG Consultation Participant, 2011)

Overwhelmingly, consultation participants told us that their preferred way of providing feedback to the MHC was through participation in forums or consultations. Approximately 68% of participants told NSW CAG that they wanted to participate in face to face consultations and forums.

As shown by the participants' quotes above, consultation participants saw community consultations and forums as the most democratic way of providing feedback as more views were likely to be presented to the MHC. Consultation participants also saw value in having decision makers themselves participate in consultations.

NSW CAG's core business is listening to consumers and recommends that the MHC considers a number of factors when planning and undertaking consultations. Implementing the following will ensure that the MHC hears from a wide range of people with mental health issues.

Hear from people in regional, rural and remote NSW: service and policy issues may vary for people depending on their location. Regular consultations in regional, rural and remote areas are necessary to hear from consumers and carers in these areas.

Give consumers choice about how they wish to participate: some people may prefer speaking in a group setting but the MHC should also give participants the option of providing feedback one to one. This is an important option to provide as individuals may

be reluctant to share views they worry will be controversial or if concerned about confidentiality.

Go to people using mental health services, don't expect them to come to you: visiting mental health services (such as PHaMs activities or inpatient units) will support more individuals to participate by reducing barriers such as transportation. In addition, if people are already in a familiar environment and with their peers they will be more likely to share their insights.

In addition, the MHC needs to link into broader services that have people who are experiencing mental health issues but who may not necessarily identify as consumers. Examples of these services include: youth refuges, services for women leaving domestic violence, transitional accommodation programs for people exiting prison and activities for people from refugee or refugee like backgrounds. People in these groups have provided valuable insights to NSW CAG about barriers in accessing services and gaps in services.

Use people with a lived experience of mental illness to run consultations: consultation participants told NSW CAG that it was important that they wanted to communicate with MHC staff who were 'not corporate.' They wanted people who had an understanding of mental health issues and who were easy to talk to.

Recommendation 21:

NSW CAG recommends that the MHC has regular consultations with consumers and carers to find out what the current issues are. Consultations need to be: held regularly throughout the state (and ensure they are held regularly in regional, rural and remote NSW); provide consumers with choice in how they speak to the MHC (group or one to one); need to be held where consumers are (at mainstream mental health services as well as other community services).

Option: consumer advisory committee for the MHC

The majority of those consulted (51%) agreed that it would be useful to have an advisory committee of consumers and carers that provide feedback for the MHC.

Consultation participants noted a number of inherent limitations with this type of participation. Participants expressed that a few people cannot represent the diversity of experiences of all consumers. Consumers also expressed annoyance that consumer participation was often viewed as 'consumer or carer'; as one participant said, *'I do not understand the "or" both consumers and carers are needed to represent themselves and their constituency, with adequate feedback and input from their constituencies.'*

If the MHC has an advisory committee it needs to have significant consumer representation (separate from carers) and that consumers are reimbursed for their time and expenses. The Council would also need to encourage representation from people who have diverse experiences (such as the NZ model).

NSW CAG believes that there is value in having an advisory committee but a committee on its own, without other participation structures, is inadequate.

Recommendation 22:
NSW CAG recommends that the MHC has an advisory committee with significant and separate consumer and carer representation, with consumers and carers who have diverse backgrounds.

Recommendation 23:
NSW CAG recommends that the MHC reimburses participants for time and expenses involved in sitting on the committee.

Recommendation 24:
NSW CAG recommends that an advisory committee should be only one way of several that consumers and carers can provide feedback to the MHC.

Option: training and other forms of consumer and carer empowerment

'Allow, empower and encourage communities and individuals to drive the changes they know need to be enacted.'

(NSW CAG Consultation participant, 2011)

One survey option for participants under consumer participation was 'training opportunities in systemic advocacy.' Approximately 46% of consultation participants identified that they wanted the MHC to offer training opportunities in systemic advocacy. This training may include components on lobbying, negotiation, relationship and coalition building. For example, NSW CAG is aware that the Mental Health Council of Australia (MHCA) provides systemic advocacy training to consumers and carers.

In addition to training, consultation participants identified that they wanted the MHC to support the following measures in order to better involve consumers in systemic advocacy:

Support for consumer workers: numerous consumers identified that consumer workers play a large role in supporting advocacy at the individual and systemic level. Consultation participants noted that it was often a strain on these roles as workers often are responsible for large geographical areas, may work part time hours and may not have optimal levels of training or support from employers.

Consumer workers can play a key role in providing information about mental health services and policies and facilitating consumer involvement. NSW CAG recommends that the MHC considers additional support for consumer worker roles throughout NSW; consumer workers can help link in consumers to the MHC as well as communicating the MHC's news back to consumers.

Supporting participation at the service level: consultation participants told NSW CAG that they thought that services should be supported to strengthen consumer participation structures. Feedback from committees or councils at the service level could be fed to the MHC when required.

Linking in to existing complaints/monitoring mechanisms: participants noted that the current mechanisms could provide ways to facilitate consumer feedback about systemic issues. These include the Official Visitors Program and the HCCC.

Recommendation 25:
NSW CAG recommends that the MHC considers how existing and new structures could be used to promote consumer participation, including training in systemic advocacy; increased support for consumer workers; supporting participation at the service level; and linking in to complaints/monitoring systems.

Option: participation in online forums

Approximately 45% of those consulted said that they would like the opportunity to engage with the MHC through online mechanisms. This option was particularly popular among younger consultation participants who stated that they were comfortable and confident using this technology. Young people who were consulted also indicated that they valued this option because even if one was feeling anxious or insecure, they would be able to put their ideas forward for consideration, and not worry about how they sounded or looked to others. Online forums can also be a valuable way to engage those outside of metropolitan areas.

Recommendation 26:
NSW CAG recommends that the MHC provides online mechanisms to encourage participation for younger consumers and carers and for those in regional and rural areas.

Option: Questionnaires

Filling out questionnaires was the least preferred choice in engaging with the MHC, with only 36% of participants choosing this option. Participants acknowledged that the information provided through surveys was limited and one consumer pointed out that many consumers are over surveyed and are often having to answer questions in survey form (required by health professionals, caseworkers).

Recommendation 27:
NSW CAG recommends that if the MHC uses surveys to engage with consumers and carers it should offer other ways to participate and provide feedback to the MHC.

Option: consumer and carer representation within the MHC

In addition to the options presented to consumers through the survey, consultation participants told NSW CAG that ideally consumers and carers would be represented within the MHC. Options presented to NSW CAG included:

- that if there is one Commissioner, that individual could be someone with a lived experience of mental illness,
- that if there is a board of directors or if there is more than one commissioner, that consumers are well-represented within this group,
- that consumer and carer representation is separate, as consumers do not wish to be represented by carers,
- that there could be a department for consumers that is located within the MHC,
- that there are other staff members/project officers working within the MHC that are consumers.

Recommendation 28:
NSW CAG recommends that the MHC has identified roles for people with a lived experience of mental illness within the Commission, including the role of Commissioner.

Conclusion

NSW CAG believes that people with a lived experience of mental illness are best placed to inform the development of what the MHC should do. Consultation participants told NSW CAG that their top issues with mental health services are around quality, access and how they are treated as individuals. A MHC has the potential to address this issues by driving systemic change; promoting a partnership approach with consumers and carers; and by playing a role in educating the community and raising their awareness of mental health.

How the Commission operates is just as important as what it does. The values underpinning its functions will also contribute to its effectiveness. Consultation participants told us that they wanted a Commission that had a wide mandate. It should work to improve mental health for people with mental illness, including those with complex needs, and be concerned by the social issues impacting mental health as well as health promotion for the general community. They also told us that they wanted to be able to contact the Commission and have a variety of ways to give feedback to the Commission. Perhaps most importantly, they wanted to be assured that the Commission was more than another good sounding plan. Consumers want action.

In order for the MHC to achieve these outcomes, the Commission must continuously engage with a wide range of consumers and carers from diverse backgrounds. This submission is only one of many steps in hearing the views of consumers and carers on the MHC. The MHC must have a number of ways to facilitate genuine and ongoing participation in order for the MHC to be relevant, effective and credible.

Appendix A: Consultation methodology

Ensuring consumers have a voice in influencing public policy is the core business of NSW CAG. To capture feedback from a diverse range of persons affected by mental illness in NSW about the proposed MHC, NSW CAG provided a few ways that people could participate, including:

- an online survey for consumers and carers,
- targeted face to face consultations with consumers with complex needs who due to various reasons would be unlikely to participate in the online survey, and
- distribution of an electronic copy of the survey that could be printed off and distributed to those unable to participate in online surveys or face to face consultations.

The online survey was promoted widely via multiple communication channels. These included promotion on the website and online forum of peak mental health and community organisations; public notices on popular community online forums, email distribution to all known networks; visiting or telephoning selected services to promote the survey; and promoting the survey to consumer workers in NSW Health services.

Targeted face to face consultations were conducted with consumers with complex needs who were unlikely to take part in the online consultation. To ensure the views from a diverse spectrum of consumers were obtained, NSW CAG conducted a series of targeted face to face consultations in Sydney and two regional NSW locations, with young people, adults with a mental illness living in the community, adults in forensic mental health care, women who recently exited from prison or rehabilitation, people living in boarding houses, older people, and people with an intellectual disability.

The face to face consultations were run either as focus groups or one to one depending on the needs of the participants. Although these consultations were guided by the same questions as the online survey, they were facilitated flexibly to cater for the different needs of the participants. For example, some participants with an intellectual disability had difficulties understanding what a MHC is, and so the questions were asked in terms of how they would like the government to improve services. This approach enables NSW CAG's consultations to be as inclusive as possible. The qualitative data from the face to face consultations also helped to contextual the survey data

NSW CAG also distributed soft copies of the survey to consumer workers throughout NSW as well as other individuals who could distribute surveys in print form. The intention was to be able to reach those who were unable to access the internet or who were unable to attend a face to face consultation. These surveys were returned to NSW CAG via fax and post.

Appendix B: Summary of survey responses

Total number of surveys collected: 234

1. Are you a:

	Number total	Percentage total
Consumer	128	58.7%
Carer	46	21.1%
Both	28	12.8%

2. Gender

	Number total	Percentage total
Male	79	36.2%
Female	130	59.6%

3. How old are you?

	Number total	Percentage total
under 18	6	2.8%
18-25	32	14.7%
26-35	42	19.3%
36-45	33	15.1%
46-55	51	23.4%
Over 55	45	20.6%

4. In which country were you born?

	Number total	Percentage total
Australia	172	78.9%
England	15	6.9%
New Zealand	9	4.1%
Other	10	4.6%

5. What is your cultural background?

	Number total	percentage total
Aboriginal	12	5.5%
Australia not specific	110	50.5%
European	25	11.5%
Maori	6	2.8%
Other	6	2.8%

6. What types of mental health services have you had experience with?

	Number total	Percentage total
in-patient unit	131	60.1%
community mental health service	154	70.6%
private psych or psychiatrist	142	65.1%
forensic mental health unit	12	5.5%

7. What are the main issues for you in terms of mental health services?

	Number total	Percentage total
available any time they are needed	149	68.3%
conveniently located	105	48.2%
Quality of mental health services	158	72.5%
being able to access related services in a coordinated way, e.g., housing, employment services	104	47.7%
being treating by services with respect and dignity	143	65.6%
that service delivery and outcomes are recovery oriented	116	53.2%
being involved in treatment and care planning	120	55.0%

8. What would you specifically like the Mental Health Commission to do?

	Number total	Percentage total
make sure consumers/carers are involved in decisions about mental health services/policies	145	66.5%
provide useful feedback to service providers and to Government	119	54.6%
lead changes in service improvement and drive systemic change	150	68.8%
conduct a formal audit of all service providers	114	52.3%
deliver community education and awareness programs	124	56.9%

9. What should be the scope of the Mental Health Commission?

	Number total	Percentage total
people with a lived experience of mental illness	171	78.4%
carers/family of people with lived experience of mental illness	161	73.9%
people with an intellectual disability	91	41.7%
people who are homeless or are at risk	111	50.9%
People with drug & alcohol dependency	115	52.8%

10. What are the best ways to make sure consumers and carers are involved in decisions about mental health services and policies?

	Number total	Percentage total
questionnaire	79	36.2%
a mental health advisory committee of consumers and carers	116	53.2%
the opportunity to participate in face-to-face consultations or forums	149	68.3%
the opportunity to participate in website or online forums	97	44.5%
training opportunities in systemic advocacy (by and/or for consumers and carers)	100	45.9%

Appendix C: Important issues relating to mental health services

During the consultations, participants told NSW CAG that a range of issues are important to them in relation to mental health services. The following provides details on the comments collected from NSW CAG's consultations.

Quality of services

Consultation participants told NSW CAG the most important issue to them is the quality of mental health services. An overwhelming majority of consultation participants said that the quality of services for people with a mental illness needs improving.

> *'...the treatment from some of the hospital staff leaves a lot to be desired. It was disgusting to say the least.'*
>
> *(NSW CAG Consultation Participant 2011)*

Consumers' feedback highlighted that 'quality' from consumers' perspective refers to a number of concerns, including:

- over 1,000 people (consumers, carers, service providers and other interested people) on our Network who are accessible via the internet;
- regular face to face consultations with consumers within each Area Health Service across NSW; and
- our knowledge base derived from consulting with consumers of mental health services in NSW over the last 17 years.
- drug or alcohol dependence (53%)
- at risk of experiencing homelessness (51%)
- have an intellectual disability (42%).
- participation on committees/councils tended to be more tokenistic
- no/inadequate reimbursement for time or expenses (limits who can participate and drains resources of those who do)
- meetings only in metropolitan areas which excludes those from regional, rural and remote areas.
- that if there is one Commissioner, that individual could be someone with a lived experience of mental illness
- that if there is a board of directors or if there is more than one commissioner, that consumers are well-represented within this group
- that there could be a department for consumers that is located within the MHC
- that there are other staff members/project officers working within the MHC that are consumers.
- the appropriateness of the care delivered to consumers, including the appropriateness of treatment and medications,
- the consistency and continuity of care, from inpatient settings to living in the community,

- the attitude of the service providers,
- the actual skills and credentials of the service providers beyond their academic qualifications,
- the physical and social environment of services

Access to services

*24/7 access: c*onsumer participants told NSW CAG it is important to be able to access services when the need arises. Sixty-eight per cent of the consultation participants indicated that they would like services to be available at any time when they are needed. Face to face consultation participants stressed the importance of having access to services that are available 24 hours a day and seven days a week. This is because mental health crisis can happen at anytime and anywhere. One participant told NSW CAG that being able to access support whenever the need arises would not only help reduce the scale of the crisis, it would also give people with a mental illness a peace of mind knowing that support is available whenever it is needed.

Conveniently located: participants also considered important that services are conveniently located. Face to face consultations revealed this issue to be highly significant to consumers in regional locations. Consultation participants in regional areas told NSW CAG that they have to travel long distance to access community-based mental health support. The travelling is costly and time consuming. To consumers who are physically or mentally unwell, travelling such long distance may be simply impossible. Consumer participants told NSW CAG that knowing where they can go, and importantly, having somewhere they can go to get support at all time means they can receive the support necessary to avert the situation from becoming a crisis.

Locality is also of great importance to consumers who are in inpatient mental health settings, including forensic mental health facilities. A number of consumers who have experience with inpatient mental health care told NSW CAG that they felt socially isolated when they were in inpatient care because their family were unable to travel the distance to visit them at the unit. For consumers in forensic facilities, this problem is exacerbated because there are very few forensic facilities, and forensic consumers from all over NSW are placed in these facilities. This means that many forensic consumers are socially isolated because they have no ties to the communities local to the facilities, and their own social support networks are also out of their reach. Consumers told NSW CAG that contrary to improving their mental health, being socially isolated when they are in inpatient units worsens their mental illness.

Treated with respect and dignity

Being treated with respect and dignity was identified by consultation participants as the third most important issue in terms of mental health services (65.6%). Many consumer participants told NSW CAG of their disenchantment with services. They pointed to the grossly imbalanced power dynamics between service providers and consumers – the ‘us

and them' attitude of many service providers. They reported feeling belittled by service providers and their views and expressed needs being ignored. Alarmingly, a few consumers told NSW CAG that they had made serious complaints against staff at inpatient services, but their complaints were dismissed as 'delusions' by the services.

Unsurprisingly, consultation feedback suggested that consumers are more inclined to return to a service if they felt that the service treated them with respect, dignity and understanding. Furthermore, consumers avoid returning to a service that they felt had mistreated them.

Appendix D: Comments from consultation participants

To help protect consultation participants' identities, NSW CAG has provided comments grouped thematically (as opposed to listing comments by consumer). Some comments appear in more than one section. Comments in quotation marks are comments extracted directly from online surveys.

Main issues in terms of mental health services

Quality of services

- Improve mental health services, 'I'm tired of being rescued by parents or carers'.
- Want them to push recovery focus, by ensuring that consumers are receiving the services they require and also that there are physical spaces that support recovery.
- Services supporting people with mental illness need to be better supported – staff continuity very important because it takes a long term to build up trust and rapport.
- Improving quality and attitudes of workforce, one young consumer being told that she's an attention seeking [*****].
- Morisset takes people from all over NSW, but they don't do anything to send the person back to their community. People are expected to work it out somehow.
- At the moment, practitioners receive their uni degree but don't have any practical skills or knowledge. They often have to learn on the job. This leads to huge inconsistencies in approach. It also means that staff are not exposed to new evidence-based approaches.
- Consumer workers need to be properly trained to do their job effectively. For example, they need legal education and training about the mental health system.
- 'Having services for complex cases (e.g. counselling for abuse and comorbid disorders, mental illness and personality disorders etc.), more suicide prevention services and more care in public psychiatric units for suicidal persons. I have seen many people who are suicidal turned away from inpatient services because there are not enough beds, or they are discharged too early when they are still suicidal. This leads to a feeling that public mental health services don't have the resources or the expertise that they need to properly care for patients.'
- 'That in-patient care is in an environment which is conducive to wellness - positive in atmosphere, ensures high standard of nutrition and good hydration as patients are often not able to recognise that they are dehydrated.'
- 'Have empathy, compassion, caring and sympathy.'

- ‘Continuity and consistency of care.’

Access to services

- ‘Access to appropriate services eg. child/youth MH services’
- ‘That the referral process is easy for both consumers and services that refer clients. And that is is recognised that rural people are grossly underserviced and often have transport issues. Also services sensitive to the needs of the Aboriginal community.’
- ‘long term mental health rehab.’
- ‘that they don't cost too much’
- ‘Accessibility, how welcoming they are and positivity within the whole service.’
- ‘accessibility through cost.’
- Need 24 hours community mental health in the community.
- Schools have counselors, but young people won’t use it due to fear of other students finding out.

Availability of choice of services

- ‘availability of services from diagnosis, treatment available when needed not when it can be accessed eg, Better health access program has now been downgraded from a maximum of 18 to possible maximum 12 sessions only under special circumstances where most clients needs are more than those available.’
- ‘Having choice of practitioner is crucial.’
- ‘The availability of appropriate mental health services beyond brief psychiatric treatment focused on medication for people after hospitalisation, not only immediately after returning home or going into community housing, but on an ongoing basis.’
- annoyance with lack of medicare available psychs.
- Biggest problem is the lack of acute services for young people, just nowhere to send them when they need services.
- ‘Having services for complex cases (e.g. counselling for abuse and comorbid disorders, mental illness and personality disorders etc.), more suicide prevention services and more care in public psychiatric units for suicidal persons. I have seen many people who are suicidal turned away from inpatient services because there are not enough beds, or they are discharged too early when they are still suicidal. This leads to a feeling that public mental health services don't have the resources or the expertise that they need to properly care for patients.’

Appropriateness of care

- nobody has the time for what you need, they just want to medicate you and/or look at you like you're a freak – sometime just needed someone to talk to and let things out.
- medication is treated as the answer for everything, but the medication makes people sick and affect their ability to function on a day to day basis.
- trying to force them to be admitted into inappropriate care facilities (story of place in X where woman showed up, thought she was going to a short term care facility and was freaked out by the people who were really unwell, making sounds like dogs. She felt quite misled about the purpose of the place she was being taken too and felt pressured to go).
- services aren't addressing core problems.
- Not having appropriate levels of support, being only able to access services when at crisis point.
- story of the woman in X prison show said, 'I'm hearing voices' the staff said, 'you should speak to them' and then the woman ended up killing someone.
- medication makes people sick and affect their ability to function on a day to day basis.
- people are given stronger dosage than they needed and this turns them into zombie and stop them from being able to speak up for themselves.
- Need to stop relying just on medication and make available other forms of support.
- Limited forensic units in NSW. Patients come from all over NSW, many of them have no access to family while they are here. Can't get leave if they have no where to stay – the hospital needs to check and approve the accommodation before they could get leave. Social isolation which can cause stress, depression and more.
- Should shift focus from institutional care to community care models. People currently stay in acute unit for up to 6 months because there is nothing in the community to move them to, this actually damages their mental health, and it also means those in the community needing acute care can't get in either.
- At James Fletcher hospital, patients are asked to fill in a survey to review services, but it's long and complicated. For people who are unwell, it's like having to sit an exam.
- lots of hot potato passing at the moment – going from one service to the next because their treatment isn't working – no real attempt to look at why treatments aren't working.
- 'Follow up support.'
- 'The mental heath services need to be all of the above to treat me as a person in a holistic way so I don't have to wait until i am so unwell I need to go into hospital again.'

- ‘I have found the after hospital care is almost NON exsistant and the treatment from some of the hospital staff leaves a lot to be desired. It was disgusting to say the least.’
- ‘being told what side effects to medications whole of body, whole of life being supported.’

Quality-integrated service delivery

- ‘My adult child lives independently (with considerable support from family when well and complete support when unwell). We have never used community health services as we've been advised by our GP that access is very poor, long waiting lists, limited visits possible. My daughter struggles to pay for a private counsellor, but does need that support. Her disability employment service does not liaise with her mental health worker or GP and the support is fragmented. Service delivery needs to be more integrated so that they speak to each other and can refer to each other rather than me acting as the advocate and go-between.’
- ‘That the referral process is easy for both consumers and services that refer clients. And that is is recognised that rural people are grossly underserviced and often have transport issues. Also services sensitive to the needs of the Aboriginal community.’
- Forensic patients have no support from the Department of Housing NSW. Many felt that assistance for housing is required when transitioning back into the community.
- Forensic patients need specialised support when they are back in the community to help with reintegration as well as continuing their mental health care, but this is currently not available or inadequate.
- teach children and young people about mental health care at school and via extracurricular activities. They then grow up with a better understanding and the stigma can be reduced overtime as these young people grow up.
- ‘That the referral process is easy for both consumers and services that refer clients. And that is is recognised that rural people are grossly underserviced and often have transport issues. Also services sensitive to the needs of the Aboriginal community.’
- ‘That mental health services be queer, kink, poly and sex work friendly.’
- ‘CULTURAL APPROPRIATENESS’

Power dynamics at services

- The ‘us and them’ attitude – this seems to be an entrenched culture within many mental health services, especially in inpatients units. Consumers are disempowered and made to become dependent. Staff should be train to support recovery instead.
- that services want to ‘become part of your life and try to control you’.

- they want to influence you, control you, make you docile – don't want you to speak out because "imagine the things we would say and the compensations they would have to pay"!
- Two participants reported being sexually assault in locked wards, but when they complaint to their psychiatrist, they were disbelieved and told that they were just imagining things.
- consumers saying that services didn't trust them with their own judgements, looking at them like they were crazy.
- 'That the person accessing the services of the mental health service is not retraumatised by the service and the staff. That the consumer is part of the collaborative care team, not excluded. That the consumer be allowed to make informed decisions not be forced into one or another avenue. Also, they must not withhold information for the sake of "making it easier" (my personal experience).'
- 'incompetents of individuals is handled swiftly .when the issue is raised.'
- consumers saying that services didn't trust them with their own judgments, looking at them like they were crazy.
- Afraid to go to community mental health services because if you're having a bad day and acted rudely toward staff, they can call to have to you involuntarily admitted.
- power dynamics are intimidating (especially with gender dynamics).

Service providers' attitude

- 'a lot of people think "mentally ill" and keep them away. That's one of the things they should think about.'
- Stories need to be properly handled and investigated, feels like they aren't taken seriously because of their mental illness, annoyance because of the stigma.
- is aware that many people have experienced sexual, physical abuse, 'these are horrible stories that are hidden. People are treated less than [others]. Their stories are swept under the carpet'.
- Concerned about social determinants of mental health. Says that 'I could gather 200 Aboriginal men who are fined beyond the max…its impacting on our families. It starts in youth and causes breakdowns.'
- The 'us and them' attitude – this seems to be an entrenched culture within many mental health services, especially in inpatients units. Consumers are disempowered and made to become dependent. Staff should be train to support recovery instead.
- Consumer workers as the 'go to' person. Consumers much prefer to speak with a consumer worker and are more likely to be cooperative toward consumer workers than just ordinary staff. This is because they feel that consumer workers can understand and relate to them better, and are less likely to treat them unreasonably.

Funding and resources

- ‘Not enough funding. Not treated as credible as Physical Problems.’
- ‘Staff Shortages in Mental Health should be addressed URGENTLEY’
- ‘To have consumer participation in all levels of the mental health service. The 23BigIssues, see www.nswcv.com.au as the guide to issues important to consumers.’
- ‘That MH services have recurrent and sufficient funding to provide 'quality' services, eg full complement of staff positions.’
- Need to increase funding.
- ‘That MH services have recurrent and sufficient funding to provide 'quality' services, eg full complement of staff positions.’

- support with individual advocacy, especially in regional areas people rely wholly on consumer workers but usually these are part time roles, responsible for large geographical areas – no way they can support everyone.

Problems with the justice system

- One forensic patient highlighted the current six months interval between MHRT reviews as too long. He said many people don’t need to be an inpatient for that long. For those who could benefit from short term inpatient care, overstaying can cause a lot of stress, anxiety, and can lead to dependency.
- Current MHRT review as inefficient. Often the review gets postponed for extended periods because the hospital failed to provide sufficient evidence, and so the consumer hangs in limbo.
- It was felt that many of the lawyers weren’t advocating effectively for clients in MHRT hearings. More training is needed to help lawyers understand their role as representing consumers. The current problem is that lawyers tend to listen to what the clinicians say about what the consumer needs rather than obtaining instructions from consumers. This is a very paternalistic approach.
- problems with police are huge, they treat you like crap, don’t understand mental health issues.
- need mental health liaision officer in police.
- story of the woman in X prison show said, ‘I’m hearing voices’ the staff said, ‘you should speak to them’ and then the woman ended up killing someone.
- There should be a mental health liaison worker at police stations.

How should a MHC work?

- needs to have a regional presence and suggested that it could have offices in regional hubs, in addition want it to be a place where people can physically drop in and talk to someone and get information.

- want to know what types of services are available, often ‘you don’t know what you need until you get it’.
- Commission needs to have a big scope in the things that it looks at, not just clinical services but the services that support people to live quality lives, such as employment. as one participant said, ‘ employment and self-esteem is the biggest thing’.
- recognise that there are lots of groups who need services, as one participant mentioned, people who are in prison.
- want the Commission to provide general mental health resources.
- Address stigma and wider issues.
- Improve mental health services, 'I'm tired of being rescued by parents or carers'.
- Wants to see service providers reporting on outcome based measures
- Not having appropriate levels of support, being only able to access services when at crisis point.
- Improving quality and attitudes of workforce, one young consumer being told that she’s an attention seeking [*****].
- Stigma: ‘I don’t talk to my family about it. We don’t discuss it. I don’t like talking about it…I just want to get on with me life. They look down on you’
- Another main issue is early intervention/prevention – the schools don’t offer good information and in country areas there’s a lot of stigma around mental illness. Want better counsellors and youth services that are welcoming to young people.
- would be good if they played a role with funding, both in providing local funding for projects but also in providing groups with information about what funding is available. Clubhouse members talked about how there was never enough funding and in small communities, often groups were competing against each other for funds.
- don’t reinvent the wheel - the MHC should also draw from work that has been done in the past, eg, the 23 Most Important Issues Affecting People with Mental Illness (2000), and the national mental health objectives from the 2002 National Mental Health Report.
- develop the peer support workforce
- continuing and incorporating the Official Visitor system.
- give consumers a say in how the mental health budget and resources should be spent.
- Lobby for service development and improvement.
- Identify major issues of concerns for consumers and address them, eg, use of seclusion.
- Put in place practices to support recovery and consumer participation.

- Provide the vision and agenda setting for the sector rather than day-to-day oversight of services.
- should audit services, particularly state-wide programs to identify the 'deadwood'.
- should audit services, particularly state-wide programs to identify the 'deadwood'.
- the focus of the MHC should not be on resolving individual complaints about services. This should continue to be the HCCC's role. It is know that the HCCC currently does not handle mental health complaints competently. The focus should be to skill up the HCCC to fulfill this function rather than to create a specific body to deal with mental health complaints.
- people employed by MHC 'we don't want deadwood'.
- need to be independent of funding.
- Government needs to stop filling [their] pockets and start funding services.
- Services are not honest, they need monitoring.
- Mental health is a huge issue and not just for people who have experienced serious trauma or mental health issues but many suffer from depression and anxiety.
- Services need to be monitored, want a Commission to do that, to go into 'places like this' and others like refuges, shelters, local medical services, AMS and carry out continuous, unexpected visits to services, and speak to consumers and staff.
- Staff get comfortable and they cover up for each other when things are not going well.
- I would like the funding situation to be more reasonable.
- people should be compensated if necessary for past wrongs.
- an MHC needs to be separate and independent.
- Annoyance with people having to take meds they don't understand the impacts of, being treated as guinea pigs and lots of pressure from doctors, etc.
- Stories need to be properly handled and investigated, feels like they aren't taken seriously because of their mental illness, annoyance because of the stigma.
- Thinks that health is such an important issue, it is necessary to have enough powers to influence government.
- The need for appropriate training to be provided to staff working in various MH training. This could come in the form of a kit that looks at the Mental Health Act, how hospital systems work and ways in which to provide for forensic patients both in hospital and once they leave. The MHC should develop training resources and consumer reps could be involved in the process.

- The ‘us and them’ attitude – this seems to be an entrenched culture within many mental health services, especially in inpatients units. Consumers are disempowered and made to become dependent. Staff should be train to support recovery instead.
- The MHC should be looking at the bigger picture on mental health, such as focusing on early intervention. For many forensic patients, their offences were committed when they were in a mental health crisis – their crisis and their offence could have been prevented if they were able to access the appropriate mental health care in the community.
- Better training for GP and community workers for early identification – the sooner you identify people who need support and give them the support the better.
- Public education to address stigma and discrimination: housing, Centrelink, schools, telephone companies – everybody, really.
- ‘Broadly rethinking the over-reliance on medication for people with chronic mental illness, particularly those diagnosed with psychotic conditions, and pursue the use of community-based programs and mandatory talking therapies for these people and their families.’
- want them to push recovery focus, by ensuring that consumers are receiving the services they require and also that there are physical spaces that support recovery.
- ‘change laws that treat drug users as useless social deviates instead of them being known to be contributing to society as tax payers and workers in the usual meaning of the word.’
- ‘Community-wide mental health initiatives. We need to develop links between community members and give people the tools to seek help from within their families and social circles. There is too much mental illness to expect the government to address it all. Let's prevent it and maintain positive mental health by creating inclusive, community driven and joyous community activities- for free.’

Why is consumer participation important?

- ‘things in NSW are led by psychiatrists….they have to move away from the medical model and move to holistic delivery of care and support recovery’
- Consumers are the expert on how people with a mental illness should be treated, and they should be regarded as such.
- consumers should be leading the change, and change should be done in a team effort by consumers and clinicians
- ‘we are the experts’
- ‘we need to be heard’
- need to support consumers, including consumers with disability, to speak up because many people are intimidated to do so due to the inherent power imbalance
- ‘They tell us to speak out. They hear us but they’re not really listening.’

Scope of MHC

- ‘Difficult question because to include homelessness and AOD excludes other groups eg forensic consumers. A simple answer is to include anyone with a comorbidity of any type.
- ‘I am disturbed by the inclusion of "people with intellectual disability". Surely people are people. If a person has a mental illness (and also happen to have ID) then why should they be singled out or excluded? Furthermore, I am unsure if drug & alcohol dependency is a mental illness. If it is, then why single them out too? Surely the Commission is for EVERYONE with the lived experience of mental illness. having said that, I do think it is important that the Commission (or someone) oversees the issue of homelessness. If the Commission is responsible for addressing this awful situation then if there are homeless people without mental illness they can be referred to the suitable support services, however, if the homeless person has MI the Commission was keep initiate suitable supports for them - possibly overseeing specific housing projects’
- ‘domestic and family violence related mental health issues’
- ‘people who have arrived in Australia who are refugees and who have been in detention. Aboriginal people’
- ‘Those in the Commission should get off their butts and experience all types of mental health situations as no 2 are the same.There fore NOT everyone can be put into little boxes.’
- ‘change laws that treat drug users as useless social deviates instead of them being known to be contributing to society as tax payers and workers in the usual meaning of the word’
- ‘what are you on?’
- ‘all of these issues impact on ones state of mental health'
- the Commission needs to hear from everybody, all those different groups have a lot of stress and things going on in their heads’

How

- frustration from consumers: they feel that they have been advocating for change and for changes such as MHC for years without recognition and with current government having no sense of history of what consumers have been advocating for
- hearing from consumers requires a separate process to hearing from carers. There is a tendency to treat both as coming from the same side, when they in fact have very different perspectives. Consumers’ voices tend to be drowned out by carers.
- carers are sometimes not helpful to the consumer'
- aside from hearing from consumers, the MHC also needs to keep consumers informed about its work through strategies such as making public meeting minutes, holding regular forums, regular news sheet.
- held up MH-CoPES as a model, where consumers were involved in every step of the planning, design and implementation
- Community-wide mental health initiatives. We need to develop links between community members and give people the tools to seek help from within their families and social circles. There is too much mental illness to expect the government to address it all. Let's

prevent it and maintain positive mental health by creating inclusive, commuinty driven and joyous commuinty activities- for free.

- the MHC needs to have clear outcome measures and be open about its progress in achieving them'
- The MHC should have a free call phone number for people to contact them if they have an issue.
- written materials to consumers need to be in big colourful letters, in layman's terms
- transparency and accountability is paramount.
- Prevention strategies and care for those who have a dual diagnosis. these people are often shunted from one "sector" to another between, health, disability mental health and ageing.
- there must be financial reward for participating in the committee
- consumers should be leading the change, and change should be done in a team effort by consumers and clinicians
- Engagement of consumers – need ways that are friendly to young people, regular questionnaires through service providers, have staff administer
- Consumers need to have a voice and be heard – not just a survey – don't want to be just a statistics.

Access to MHC

- Wants the Commission to have regular visits to regional/rural areas
- Wants the Commission to publicise itself through a variety of means and emphasised that they need to be appropriate to people's ages and needs (online, through phone, word of mouth/through services, media (TV/community radio)
- Need more one stop shops for all consumers and carers (physical place to go)
- Want to be communicated with through a range of means including videoconferncing, newsletters, regular consultations, flyers/phone access
- MHC needs to promote its consultations widely, via multiple channels, including newspapers, TV ads, internet

Substance not spin

- Government and politicians need to meet with carers and consumers to understand a bit more.
- "Main thing is they've been listening for years, they listen and listen but they don't make changes. I guess there have been changes but they've been slow and slow".
- we've had so many reports, may as well put it in the dustry corner with all the others'
- there's a lot of rhetoric that's all very beautiful but there's nothing to back it up'

Community consultations

- We need to feel comfortable – at present won't go to mental health services, especially community mental health because doesn't trust them
- Need to cast a wide net because a lot of people who need help won't go to mental health services, they don't feel confident or comfortable doing so. For example, GPs need to be trained to support people with mental illness and know where to refer them to
- Thinks that the community should be involved broadly by any Mental Health Commission
- That there is a physical location that consumers can go to in order to talk to someone from the Commission, this needs to have extended hours and the staff need to be friendly and accessible, they want people who have ' not too much starch in their apron', places needs to have nice surroundings
- Importance of face to face contact and consultation
- 'Community consultation that cuts out the middle man. Send the actual politicians and policy makers to speak with real people with a range of experiences and back this up with all the stats etc. Allow, empower and encourage communities and individuals to drive the changes they know need to be enacted
- 'I think surveys are limited. Also a MH advisory committee is constrained by very few participants. Forums, however, provide an opportunity for large numbers of people to present diverse views and provide much richer data to inform policies and service delivery'

Consumer advisory committees

- If there is a Committee that has consumers and carers on it, some of them need to be from regional/rural areas. Also they need to be supported to participate (such as funding for travel)
- 'Have separate consumer and carer advisory committess and separate opportunities for consumers and carers'
- Great to have consumer advisory groups and in have consumers setting in committees, but past experience suggest that the approach is mostly tokenistic. One consumer said he was asked to sit on a hospital board but was never paid for his work, and then because he said something the board didn't like, so they wouldn't even given him petrol money to get there. They say they want consumer participation but then make it impossible for consumers to get there. Another consumer also reported similar experience that the government would only keep consumers on if they don't cause trouble
- Consumer Committee: committee members should come from a range of backgrounds, country/city, old/young, male/female, NGO/government, etc.
- Support the idea of a consumer committee that drives the Commission, needs to have a wide range of consumer experiences on that that Committee, including people from diverse geographical areas and have diverse experiences

Consumer representation within the commission

- Suggested that the MHC should have a Director, Spokesman and Consumer Advocate and one or more of these roles should be filled by people with a lived experience of mental illness

- That the Commission should have consumers involved
- a good proportion of the staff at the new MHC should be people with a lived experience of mental illness. There must be enough identified consumers in the MHC to make sure they can be heard: an ‘equal play field’.
- That the Commission needs to have a figurehead that inspires trust in the public and is also influential
- Must be a Consumer Advisor and/or Commissionon the MH Commission
- ‘Have consumers employed in the commission and to have a consumer department inthe commission’
- ‘Have some genuine Carers on the commissiona AND actually LISTEN to what they have to say after all we are the ones with the 24/7 experience that text books CANNT supply’

Online forums

- online services are more appropriate in this day and age.'
- websites/technology are really good avenues for people who are feeling anxious

Surveys/questionnaires

- Consumers need to have a voice and be heard – not just a survey – don’t want to be just a statistics.
- Surveys in services - need to protect privacy and confidentiality – was asked to fill in survey in hospital, an envelope was attached but there wasn’t glue to seal the envelope.

Other ways to support consumer participation

- Opportunities for discussion and giving peole an opportunity to express their views and experiences. All experiences are different and beign heard validate a person's experience in a way which promotes healing.'
- To involve NGO"s that have the peer links in place already
- ‘Paying people to participate in focus groups, developing a NSW peak body of consumers (if there isn't one already)’
- ‘an oppoortunity to make complaints and have them heard by someone with independance and authority ie a mental health ombudsman’
- ‘I do not understand the 'or' both consumers and carers are needed to represent themselves and their constituancy, with adequate feedback and input from their constituancies. see what the MHCA does in terms of sustemic advocacy and training consumers and carers.’
- ‘Recruitment of more consumer workers across the state’
- ‘POLICY REVIEWS INVOLVING CONSUMERS, CARERS AND COPMI’
- ‘different methods will suit different people's personalities and also fit in with their availability’
- Services need to have consumer groups and they need to be independent from any and all health services in order to provide a strong consumer voice. When complaints are

made collectively, they should be dealt with in a timeframe that is adequate. Those who are involved in decision making processes should have a time in which to respond.

- forum set up and facilitated by NGO – need to be independent of the government.
- Inpatient services to have consumer/peer support groups and to have NGO reps coming to the group's meeting regularly, maybe every 3 months. They should have an established relationship with the group, so that the group feel comfortable giving feedback about services. They should then feed the information back as appropriate to bring about change.
- Consumers felt that there could be more training provide for them in developing ways in which to advocate for themselves and other patients.
- Some felt there needs to be more funding for workers who assist in consumer groups, especially in remote and regional Australia.

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