



NSW Consumer Advisory Group – Mental Health Inc.

**Mental health consumers' knowledge and experiences of
complaint mechanisms**

Tara Dias, Senior Policy Officer

February 2012

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 an independent, non-government organisation which receives core and project funding from the Mental Health and Drug and Alcohol Office, NSW Ministry of Health.

Executive Summary

NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) welcomes the opportunity to provide comments to the Health Care Complaints Committee’s Inquiry on complaints handling in New South Wales.

Our submission responds to the second term of reference, in regards to the awareness and understanding that mental health consumers have of the complaint handling systems and processes available to them in the hospital system and in relation to external systems.

Being heard and having complaints considered is a serious issue for mental health consumers. Our submission outlines issues and barriers for mental health consumers in understanding and using complaint mechanisms and is based on face to face and online consultations with 97 individuals.

In general, consumers told us that they had little knowledge of the processes for raising issues or making complaints about health services locally or through external mechanisms such as the Health Care Complaints Commission. Most of those who did have knowledge of the complaints process told us that they felt there was significant barriers that affected their ability to make complaints.

Consumers also told us that had little knowledge of the role or functions of the Health Care Complaints Commission. Consumers told us that they wanted the Commission to have a higher profile in the community and that they wanted the Commission to engage with and educate the mental health sector.

Our recommendations to improve consumers’ knowledge of and satisfaction with complaint mechanisms are listed below.

NSW CAG Recommends:

One: that the HCCC develop further resources specific to mental health consumers about complaint mechanisms that are easily understood through the use of plain English and translated into other languages with suitable cultural considerations.

Two: that the materials that are made available to people (online, brochures, other printed documents.) are easily attainable and engaging. This means they must be easy to find on the website, visually inviting and be straight to the point.

Three: that the HCCC focus on working with the mental health sector (consumers, advocates and services) to strengthen knowledge of and confidence in using local and external complaint mechanisms.

‘No one ever tells you your rights and responsibilities as a consumer of a service. No one ever gives you a document with a complaints procedure in writing. Services are ill equipped for managing complaints. Besides...I am sure that they see the complaint as a manifestation of symptoms [of mental illness].’

(NSW CAG Consultation Participant, January 2012)

Four: that the HCCC further distribute 'Not Happy with Doctor?' to mental health services throughout NSW and consider developing other materials that educate mental health consumers about their rights regarding services.

Five: that the HCCC examine and consider ways it can improve communication with consumers during the assessment phase of the complaints process.

Six: that all HCCC staff are required to participate in training on mental health.

Seven: that during the assessment process, before the HCCC refers complaints back to the local organisation, permission is gained not only from the organisation but also from the consumer.

Eight: that the HCCC provides feedback to the public on mental health complaints by each local health district. The report would give a list of issues and a measure of successful, pending and unsuccessful outcomes.

Introduction

NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) welcomes the opportunity to provide comment on the Inquiry into Health Care Complaints and Complaints Handling in New South Wales.

Our organisation works with mental health consumers to ensure that their views are considered in policy making and in service improvement (one example of this is the MH-CoPES Project¹). We are aware that there are specific issues that people with a lived experience of mental illness (mental health consumers – referred to in this document as ‘consumers’) face when raising issues and making complaints, both at the service level and to external bodies such as the Health Care Complaints Commission.

In order to provide current feedback regarding the knowledge and awareness that mental health consumers have around health complaint handling systems and processes, we consulted with 97 people throughout NSW in December 2011-January 2012.

In order to capture a diversity of views, we had an online survey and face to face consultations in a range of environments (inpatient, community mental health and NGO managed services). Face to face consultations were held in Greater Sydney and regional areas (see Appendices A, B and C for more information).

This document is divided in to three sections:

1. Awareness and understanding of local complaint mechanisms
2. Barriers to making complaints
3. Knowledge and satisfaction of the Health Care Complaints Commission (HCCC).

The main themes that emerged from our consultations were that consumers didn’t have a lot of information about complaint mechanisms, either in hospital/health settings or with external systems. Even when consumers are armed with information about complaint mechanisms, there are still substantial barriers to lodging complaints.

1. Awareness and understanding of local complaint mechanisms

Consultation participants were asked:

- *Have you ever wanted to raise an issue or make a complaint with a service?*
- *Have you ever lodged a complaint?*

We wanted to know what people knew about available complaint mechanisms at the service level. We also wanted to know what kept people from making complaints if they had grievances. Consumers told us that they were given little information about their rights and complaints processes. Consumers also said that what information they were given was sometimes confusing.

1.1 Awareness of complaints processes

Mental health consumers consistently told us that they did not raise issues with services or lodge complaints because they were not aware of their rights as a service user and/or didn't know what processes to go through.

Consumers don't know their rights! (NSW CAG consultation participant, January 2012)

'In 25 years of using the mental health system, I've never had anyone say to me "you can make a complaint."' (NSW CAG consultation participant, January 2012)

Some said that this information was never given to them by the service, either verbally or in written form, and other consumers told us that there were significant barriers to understanding how to lodge complaints.

1.2 Barriers to understanding complaints processes

Consumers identified several reasons why they didn't understand the complaints process:

- **Timing:** consumers said that they were often provided with information on rights/complaints mechanisms when being admitted to acute services. Many said that being unwell combined with the side effects of medication made it difficult to read and absorb information.
- **Presentation:** we heard that people found information 'written in legalese,' often in small font and often put in a pamphlet (which may be one of many given to the person).
- **Resources:** services staff, especially in acute wards, are busy and don't have time to give this information verbally or check in to see what questions consumers have.

Consumers also repeatedly told us that they felt most vulnerable when visiting inpatient units and emergency departments yet these were the times when they had the least information about their rights and available complaints mechanisms. Many consumers were also uncertain about the role of mechanisms like the Official Visitors Program.

1.3 Knowledge and awareness of complaint mechanisms -what would help

We appreciate that the HCCC has provided specific information on their website for mental health consumers. We think consumers would benefit from receiving the information in print, taking into account the factors listed above.

NSW CAG also found it difficult to find the “Simple Factsheet – Not Happy with your Doctor?” and the information about “complaints about mental health care” on the website and suggest links to these be in the section about “how to make a complaint” or a link to information you require before making a complaint on the home page.

NSW CAG recommends:

Recommendation One: that the HCCC develop further resources specific to mental health consumers about complaint mechanisms that are easily understood through the use of plain English and translated into other languages with suitable cultural considerations.

Recommendation Two: that the materials that are made available to people (online, brochures, other printed documents.) are easily attainable and engaging. This means they must be easy to find on the website, visually inviting and be straight to the point.

2. Barriers to making complaints

Consultation participants were asked:

- *If you ever wanted to make a complaint but did not, what stopped you?*
- *If you raised an issue or lodged a complaint, did anyone help you?*

Consumers told us that feeling powerless, rather than access to information, was a bigger factor in whether or not they used complaint mechanisms. Feeling powerless in these situations manifested in numerous ways.

We include discussion of these factors here to show the need for the HCCC to play a more active role with the mental health sector, especially in its capacity to handle complaints. If local complaints mechanisms were more effective at resolving complaints, this could have the potential to reduce the number of complaints made to the HCCC.

2.1 Complaints viewed as a symptom of mental illness

Consumers repeatedly and overwhelmingly told us that their complaints were discredited because of their mental illness. Consumers said that they are not treated as equals in the health care system or as one consumer said, she is treated as a 'low person' and complaints have no weight.

'The problem when you are mentally ill is that when you complain about something you are already expected to triple justify every observation, question, concern or requested outcome'
(NSW CAG consultation participant, January 2012)

'Sometimes I feel that because I am a mental health consumer, what I say is not taken seriously because it is easier for the nurse etc. to blame me and my condition, especially in the emergency department'
(NSW CAG consultation participant, January 2012)

Consumers told us that they felt discouraged from making complaints because they are not treated as equals in their health care and that complaints are viewed as symptoms of mental illness.

2.2 Fear of retribution

Consumers also told us that they didn't want to make complaints because they feared retribution. Consumers talked about how they had experienced or had seen other consumers branded as 'troublemakers.'

Consumers said that they often feared that lodging complaints or informally raising issues would limit access to services they needed.

NSW CAG understands this is a common issue for all people who make complaints. For mental health consumers however, making a complaint has specific repercussions. Consumers are more likely to be socio-economically disadvantaged so they have limited choice about where to access services. Consumers may have to go back to the same service they complained about. For consumers living in regional and rural areas, there may only be one community mental health team and generally only one hospital in each area.

2.3 Lack of support to navigate complaints processes

Consumers told us they needed support to go through the complaint process and that it left them frustrated, exhausted and confused. Consumers said they often wanted support to know who to talk to, to know what they needed to do (i.e. write a letter, make a phone call) and to receive guidance on whether or not they had grounds for lodging a complaint.

There is no state-wide mental health specific individual advocacy service for consumers in NSW so consumers rely on assistance from consumer workers, peers, families and carers or non-government support services who are not always aware of the process of making a complaint to a health service or using external mechanisms. We are aware that there are many people who are not able to obtain assistance from informal or formal networks in their geographical area.

We have also heard that some consumers who ring the HCCC for this type of initial support have automatically and inappropriately been referred to the Mental Health Advocacy Service (which only provides support in relation to the Mental Health Act).

2.4 Local complaint processes are ineffective and not credible

Some consumers said that they didn't feel that following a complaints process was beneficial. They said that no real change occurred and attributed this to services that didn't take the time to listen (or who did not have a culture of quality improvement) and slow moving, bureaucratic structures.

'It'd be okay if you raised an issue and they actually listened to you...but it's no use complaining to deaf ears. If they don't listen to you, you know they're not interested in improving the service. You know that it isn't worth it.'

(NSW CAG Consultation Participant, January 2012)

This belief that 'it isn't worth it' is prevalent among a lot of consumers and prevents people from using complaint mechanisms.

2.5 Addressing barriers to using complaint mechanisms

Consumers identified a number of changes necessary to improve use of complaint mechanisms. Consumers told us that services need to adopt a quality improvement approach. As one consumer said, adoption of an 'independent & automatic review process that looks for what could have been done better than who should be blamed or lose face' is necessary.

Consumer involvement in quality improvement initiatives is important and necessary to shift the culture of mental health services. One consultation participant said that services should be required to log all complaints and that the onus should be on whoever receives the complaint to record it (rather than requiring consumers to put grievances in writing). This log should be used to inform quality improvement activities. This would have the effect of reassuring consumers that their grievances are being heard and that services will be transparent and accountable in their care and support of consumers.

In addition, we hear from consumers all the time that they need individual advocacy support. Many consumers know that there is a complaints process but don't know where to start. Given that there is no specific mental health advocacy service in NSW, we believe that other groups likely to support people with a mental illness during the complaints process need training to effectively guide consumers through the complaints process. The table below outlines key stakeholders likely to support consumers through the complaints process and the training that we believe these groups should have.

Stakeholders	Training required	Rationale
Consumers	Rights and responsibilities under Australian Charter of Healthcare Rights, complaints processes at local level, individual advocacy and HCCC	Strengthen ability to self-advocate; strengthen capacity to support peers
Peer/Consumer Workers	Providing individual advocacy services, rights and responsibilities under Australian Charter of Healthcare Rights, complaints processes at local level, individual advocacy and HCCC	Support consumers to self-advocate; provide individual advocacy; promote better understanding of complaints mechanisms; influence shift towards culture of quality improvement; knowledge of where to refer consumers for external expertise/support
Staff in mental health sector	Providing individual advocacy services, rights and responsibilities under Australian Charter of Healthcare Rights, complaints processes at local level, individual advocacy and HCCC	Support consumers to self-advocate; provide individual advocacy; promote better understanding of complaints mechanisms; influence shift towards culture of quality improvement; knowledge of where to refer consumers for external expertise/support
Health Care Complaints Commission staff	Training on mental health, information on individual advocacy support resources specifically the role of Mental Health Advocacy (through Legal Aid)	Strengthen ability to work with consumers to progress complaint; improved and appropriate referrals to community support

The amount of improvement required in this area is substantial. Combined with the high number of mental health related complaints logged with the HCCC, we recommend that the HCCC focus on working with the mental health sector, in the same way that it has previously focussed on working with Aboriginal health consumers and organisations. We believe a training and engagement project, similar to what is listed above, would have sustainable benefits for consumers, the mental health sector and the HCCC.

NSW CAG recommends:

Recommendation Three: that the HCCC focus on working with the mental health sector (consumers, advocates and services) to strengthen knowledge of and confidence in using local and external complaint mechanisms.

3. Knowledge and satisfaction of the Health Care Complaints Commission (HCCC)

Participants were asked:

- *What do you know about the Health Care Complaints Commission?*
- *What has been your experience in dealing with the HCCC; were you satisfied with the process? What was good, bad and what could be improved?*

Less than 15% of those we consulted knew about the HCCC and those who went through the HCCC complaints process were dissatisfied with how the HCCC handled their complaint.

3.1 Knowledge of the HCCC

When added together, complaints related to mental health (mental health services 5.4% of all complaints; psychiatry complaints 2.1% of all complaints; and psychology complaints 1.8% of all complaints) make up 9.3% of all complaints received by the HCCC in 2010-11.²

If added together, these complaints would rank third in the list of all complaints received by the HCCC, following the service areas of general medicine and dentistry.

These figures show there are problems with mental health service delivery but we believe this figure is deceptively low because:

- most consumers we spoke to (approximately 85% of those surveyed) said that they had never heard of the HCCC
- we were told by some consumers that when contacting the HCCC, they were directed to the Mental Health Advocacy Service, even though their complaint was not related to their rights under the Mental Health Act.

The HCCC needs to raise its profile within the mental health sector. During our consultations, we provided the HCCC's resource 'Not Happy with the Doctor?' which consumers told us was useful. As recommended in Section 2, the HCCC should also engage and train consumers and the mental health sector (both government and community managed services) about the HCCC. We believe if this was done in consultation with the service and the mental health service was able to provide information about local complaints processes then this would be beneficial to everyone.

3.2 Satisfaction with the HCCC

Of the small number of consultation participants who did use the HCCC, they told us that they found the HCCC to be ineffective. We are aware, from consultations we held on other issues, that consumers generally felt that the HCCC didn't handle complaints specifically about *mental health services* very well.

One reason, as illustrated in the case study below, is due to lack of communication.

'Betty's' story: Betty is a mental health consumer who has had numerous frustrations with mental health services. With the support of a consumer worker, she identified that she wanted to lodge a complaint with the HCCC. Betty told us that she has written six letters to the HCCC (about the same issue). She has received no response. Betty said, *'I feel frustrated and my voice has been quashed.'*

(NSW CAG Consultation Participant, January 2012)

The HCCC should look at ways to improve how they communicate with individuals as they progress through the complaint process. As mentioned earlier, we also recommend that all HCCC staff be required to participate in training about mental health and working with people who have a mental illness.

We are aware that the HCCC aims to be an impartial body. Consumers however told us that they thought that the HCCC gave more weight to services than to consumers. For example, one consumer said that she knew that mental health complaints are given back to mental health services to be resolved. This is concerning, because many consumers feel that most mental health services are not equipped to resolve complaints. Before the issue is referred back to the local service, the HCCC needs to communicate with the consumer to ensure this is appropriate.

The HCCC needs to adopt a mechanism to report back to the public on mental health complaints. This should be done by local health district, be made available to the public, and include a list of issues and a measure of successful, pending and unsuccessful outcomes. This will provide transparent reporting for consumers that the HCCC is managing complaints from consumers.

NSW CAG recommends:

Recommendation Four: that the HCCC further distribute ‘Not Happy with Doctor?’ to mental health services throughout NSW and consider developing other materials that educate mental health consumers about their rights regarding services

Recommendation Five: that the HCCC examine and consider ways it can improve communication with consumers during the assessment phase of the complaints process

Recommendation Six: that all HCCC staff are required to participate in training on mental health

Recommendation Seven: that during the assessment process, before the HCCC refers complaints back to the local organisation, it not only get the permission of the organisation but also the consumer.

Recommendation Eight: that the HCCC provides feedback to the public on mental health complaints by each local health district. The report would give a list of issues and a measure of successful, pending and unsuccessful outcomes.

Appendix A: Face to face consultation locations

Face to face consultations were held in January 2012 in the following locations:

Consultation 1: Hunter New England Local Health District at NGO service

Consultation 2: Hunter New England LHD, inpatient unit

Consultation 3: South Western LHD, inpatient unit

Consultation 4: South Western LHD, NGO service

Consultation 5: Illawarra Shoalhaven LHD, NGO service

Consultation 6: Illawarra Shoalhaven LHD, community mental health service

Appendix B: Face to face consultation format and questions

Raising Complaints: Focus Group Questions

- Introduction about who NSW CAG
- why we are interested in hearing about raising issues and making complaints (continuous quality improvement), access to individual advocacy and the Health Care Complaints Commission
- what this information will be used for
- confidentiality and recording what people say

Questions

1. How do you think people generally feel about raising issues with mental health services?
2. What do you think a service can do to encourage people to give feedback?
3. Has anyone had an experience of lodging a formal complaint?
4. If you were raising an informal or formal complaint, what help did you have? And from who?
5. What do you know of the Health Care Complaints Commission?
6. If you've used the Health Care Complaints Commission, tell me about that experience.

Appendix C: NSW CAG online survey

NSW CAG is gathering information from consumers about their experiences in raising complaints or concerns about care and support they have received. For the purposes of this survey, the term ‘consumers’ includes people with a lived experience of mental illness or mental health issues.

The information you provide will be used to inform recommendations we make to NSW Government about improving the Health Care Complaints Commission and may help us with our other advocacy work.

Part 1: Tell us about yourself

Are you a (please tick all that apply)	Consumer:
	Carer
	Other:
Are you	Female
	Male
How old are you?	Under 18
	19-25
	26-35
	36-45
	46-55
	56-65
	Over 65
Do you live in	Metropolitan area
	Regional area
	Rural or remote area

Part 2: Tell us about your experience with mental health and support services

Raising a concern directly with a service

Have you wanted to raise an issue or concern with a mental health service (community, inpatient, private or NGO service)?

Did you raise this issue or concern with the service?

If so, how comfortable did you feel raising this concern?

If you DID NOT raise the concern with the service, why did you decide not to?

Formal Complaints

Have you ever made a formal complaint about the support or care you've received from an:

- NGO
- Private mental health service or facility
- community mental health service
- inpatient mental health service
- other:

If so, which bodies did you make the complaint to?

- the service itself
- the Health Care Complaints Commission
- the NSW Ombudsman
- other:

Were there any groups or individuals who supported you to make the complaint? And who were they? (ie peer worker, advocacy service, family or friend)

Do you have any other comments relating to complaints processes in mental health services (public, private or non-govt) in NSW?

Part 3: NSW CAG is interested in finding out what consumers know of the Health Care Complaints Commission

Are you aware of the Health Care Complaints Commission (HCCC)?

- yes
- no

Have you been provided with information about the HCCC?

- yes
- no

If yes, who provided you with information?

- clinical staff
- NGO staff
- Advocacy service
- peer worker
- Other:

Have you had wanted to make a complaint with the HCCC but did not? What stopped you?

If you did raise a complaint with the HCCC, what was it in relation to?

- Access (delay in admission or treatment or being refused admission or treatment)
- communication and information (wrong or not enough information provided)
- consent (you didn't give consent)
- discharge and transfer (lack of review prior to leaving, delays in discharge or inappropriate discharge)
- Environment and management of a facility (inadequacies in administration, hygiene, staffing, physical appearance of a facility, etc)
- fees and costs
- grievance processes (lack of information about complaint procedures; failure to respond to a concern or complaint)
- medical records (access to records, accuracy of records)
- medication (administering, dispensing and prescribing)
- professional conduct (lack of competence, assault, sexual misconduct)
- reports and certificates (delays or refusal to provide a report)
- treatment (wrong or inadequate diagnosis or treatment)
- other:

Were you satisfied with the way that HCCC handled your complaint?

What was good about the way the HCCC handled your complaint?

How could the process of dealing with the HCCC be improved?

Is there anything related to raising complaints, support and advocacy or the HCCC that you would like to tell NSW CAG?

Would you be willing to provide further information to NSW CAG? If you would, please provide a way to contact you. *This information will remain confidential and the comments you make will remain anonymous.*

¹ MH-CoPES stands for Mental Health Consumers' Perceptions and Experiences of Services. MH-CoPES is a consumer-driven, quality improvement initiative that operates in adult mental health facilities in NSW.

² Health Care Complaints Commission, *Annual Report 2010-11*, Table 16.9, pp 112.