Submission

No 9

INQUIRY INTO THE OPERATION OF THE HEALTH CARE COMPLAINTS ACT 1993

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28th November 2008

Mr Mel Keenan The Committee Manager Committee on the Health Care Complaints Commission Parliament House Macquarie Street Sydney NSW 2000 Email: <u>chccc@parliament.nsw.gov.au</u>

Dear Mr Keenan

Regarding: Inquiry into the Operation of the Health Care Complaints Act 1993

The NSW Consumer Advisory Group – Mental Health Inc (NSW CAG) is the independent, statewide organisation representing the views of mental health consumers at a policy level, working to achieve and support systemic change. Our vision is for all mental health consumers to experience fair access to quality services which reflect their needs.

We would like to thank the Parliamentary Joint Standing Committee on the *Health Care Complaints Act* for providing NSW CAG with the opportunity to comment on the on the operation of the Act.

Please find in the following pages our submission in relation to the charter.

Yours sincerely

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Karen Oakley A/Executive Officer

1. The basis of this advice

NSW CAG exists to ensure that the perspectives of mental health consumers across NSW are heard by policy makers. To enable our representation of mental health consumers and to advocate for systemic change, NSW CAG conducts a range of consultations with consumers, carers, service providers and other stakeholders throughout NSW. For the purposes of this submission NSW CAG emailed the three key focus areas for this inquiry to our network of more than 500 people including consumers, carers and service providers from throughout NSW. The following comments and recommendations are based on the responses received and NSW CAG's core work and experience with consumers of mental health services in NSW.

2. The need for an effective, efficient and impartial system that works for the consumers of health care services

NSW CAG supports the role of the Health Care Complaints Commission as an independent body to manage health care complaints. Indeed, the importance of the perception of impartiality is imperative to the success of the Health Care Complaints system. However, NSW CAG has heard from mental health consumers concerns that the current system does not provide the independence and impartiality required. Whilst NSW CAG acknowledges the need to involve and work with registration bodies and Area Health Services (AHS), concerns expressed by consumers are that when complaints have been assessed by the HCCC and passed on to the relevant AHS and registration bodies, the complaints are not adequately considered nor addressed. In some cases this leads to a perception of a "cover up" or "a sense of sweeping things under the carpet" and a feeling of distrust of the system as well as frustration and further disempowerment. As noted by PIAC, these are genuine concerns (2008, p. 8).

NSW CAG recommends that the HCCC oversees the processing of complaints to their conclusion, in consultation and collaboration with relevant registration bodies and/or AHS. At a minimum NSW CAG recommends that the HCCC remains informed of the processes being followed by these bodies or Services and the key contact point with the complainant. These recommendations would assist in providing mental health consumers with a trust in the system and a sense of safety in progressing with a complaint. The implementation of this recommendation may therefore decrease some of the barriers faced by mental health consumers when accessing and using the health care complaints system. Further, the referral of a complaint to a registration body and/or Area Health Service or other organisation adds a level of complexity to the mental health consumer. It can result in confusion as to processes, whom to contact for information, what processes are being followed and what can be expected. The recommendation that the HCCC either oversees or remains informed of processes and is the key contact with the complainant would reduce this complexity and barrier.

From the perspective of consumers, the current health care complaints system as auspiced by the Commission is highly complex. Part of the complexity stems from a lack of adequate communication about the system and the processes. It is unlikely to be widely known by mental health consumers that after assessing the complaint, there are five or six possible pathways, depending on whether the complaint is about a service or a practitioner, the majority of which do not directly involve the HCCC. When a complaint is then referred to another body or organisation, this may lead to confusion. Furthermore, whilst important at some level to ensure delineation of responsibilities, and potentially greater impartiality, having four divisions within the HCCC adds further complexity to the system. This is most likely to be the case if a complaint is passed from one division to another, with consumers becoming unclear as to whom they should be dealing. NSW CAG therefore recommends that each consumer be provided with one contact person within the HCCC who remains with the case to its completion, and provides liaison with the consumer.

An issue that was raised during consultations is the timeliness of response by the HCCC. It was felt that the current system is slow to act on complaints and respond to complainants. NSW CAG appreciates that the Act states that the Commission will decide on the action to be taken within 60 days, and that this is required in many circumstances to ensure a considered and informed decision. However, NSW CAG also advocates for more regular contact with complainants to inform them of the progress of their complaint and provide reassurance that their complaint is being considered.

NSW CAG recommends that:

- The HCCC remains at least informed of, or oversees the full complaints process
- The HCCC remains the key contact point for complainants throughout the process
- Each consumer be provided with one contact person within the HCCC who remains with the case to its completion, and provides liaison with the consumer
- That regular contact be maintained with complainants to inform them of their complaint and provide reassurance that their complaint is being considered.

3. The need for a complaints system accessible to all

The ability to make a complaint depends on individual's knowledge of the system, and sense of power to complain. For many people with mental illness, their treatment by society, and at times, by the health care system and health care professionals, as well as the illness itself is disempowering. Furthermore, many mental health consumers are unaware of their rights, including the rights to treatment and care, as well as the right to complain. Through the results of the MH-CoPES Questionnaire¹, which is designed to provide a mechanism for mental health consumers to evaluate mental health services, NSW CAG has been made aware that many consumers do not have access to or knowledge of their rights and responsibilities. This disempowerment and lack of knowledge act as barriers to mental health consumers being able to access and utilise the complaints system. The result may be a feeling of being further disempowered by the system that was supposed to provide care, with no apparent pathway for this to be resolved.

In addition, past experience with the complaints system also poses a barrier and sense of reluctance to use the system again. For some consumers who do not feel that the HCCC adequately dealt with their complaint, there is a sense that there is no mechanism available for the resolution of complaints.

NSW CAG has also been alerted to some services, and some staff within mental health services who do not accept or deal with the complaints of consumers. In more severe

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¹ The MH-CoPES (Mental Health Consumer Perceptions and Experiences of Services) Questionnaire is a tool used to collect consumers' perceptions and experiences of services. NSW CAG has been conducting the research component of the MH-CoPES Project. For more information go to <u>http://www.mentalhealth.asn.au/members/nswcag/Projects/Projects MH-CoPES.htm</u>.

Operation of the Health Care Complaints Act, 1993

cases, we have been alerted to mistreatment of consumers as a result of making even an informal complaint. These situations, compounded by a lack of information about the Health Care Complaints Act and system in NSW, pose a further barrier to mental health consumers accessing the complaints system. Indeed, the fear of potential reprisal from making a complaint, including the possibility or threat of extended stays in inpatient units also act to prohibit consumers making a complaint about the health service, their treatment or a health care provider. This barrier has also been documented in the literature (Clark, Scott, Boydell, & Goering, 1999; Crawford & Kessel, 1999; Gill, Pratt, & Librera, 1998; Hansburg, Nelson, Connors, Gill, Grande, & Paley, 1996; Lebow, 1982; Svensson & Hansson, 2006).

To ensure that the complaints system is accessible to all, wide knowledge about the system, process, HCCC and how it can be accessed needs to be made available to all consumers. This information needs to detail clearly what services and people complaints can be made about, the extent of the powers of the HCCC, including what they are there for and what they can and cannot do, explicit information about how to contact HCCC and make a complaint, and about appeals and review processes. This information needs to be provided in a variety of forms including written documents, oral and visual formats, as well as produced in languages other than English to ensure it is accessible to all. From information gathered through the MH-CoPES Project, it is clear that this provision of information cannot be left to the responsibility of mental health services or staff. Further, it must be noted that many mental health consumers do not have access to the internet, and therefore there need to be other means of accessing the information about the complaints system. NSW CAG recommends that the above barriers be considered when developing communication materials and processes to ensure the equality of access to the system. This is in line with Article 21 of the United Nations' Convention on the Rights of Persons with Disabilities, which has recently been ratified by the Australian Government, and which notes that information needs to be provided "in accessible formats and technologies appropriate to different kinds of disabilities" (Article 21, a).

A further barrier to all mental health consumers being able to access the health care complaints system is the requirement that all complaints must be made in writing. Some mental health consumers have impaired cognitive and/or visual abilities either due to the illness, or treatments and medications and low levels of literacy. For some, this impacts on their ability to communicate in writing. During the MH-CoPES Project, it was noted that many people are embarrassed by or reluctant to reveal these difficulties and therefore disengage in any process that requires a written response. This clearly poses a barrier to accessing the health care complaints system. A further barrier is that in providing written documentation some consumers find difficulty in clearly expressing themselves. Therefore the details surrounding the actual complaint may not be adequately expressed in writing for the HCCC to be able to make an adequate assessment of the complaint. In such circumstances, the complainant is clearly disadvantaged and disempowered. There is therefore a need for the provision of mechanisms whereby consumers can verbally document their complaint. This may include through individual advocates within services or through staff at the HCCC. Where this service is available, this needs to be clearly advertised, again using a range of media, to ensure consumers are aware of their options. This recommendation is again supported by Article 21 of the Convention on the Rights of Persons with Disabilities.

While NSW CAG has noted twice the need for individual advocates to assist people in making a complaint or in navigating the system, it must be noted that no individual

advocacy service exists within NSW for mental health consumers. Within some mental health services, there are Consumer Advocates who are employed for this purpose. However, the widely known difficulties for this workforce of limited hours, large workloads, lack of consistent and clear job descriptions, being employed by the service against which they are to advocate, and the lack of adequate training limit Consumer Advocates' abilities to provide such advocacy and services. Further, upon leaving an inpatient service, the consumer is unable to continue to access a Consumer Advocate who is employed to work at that inpatient service. Thus, the continued support required in making a complaint is not necessarily in place. As noted within Article 9 of the Convention on the Rights of Persons with Disabilities, bodies are required to take appropriate measures to provide "other appropriate forms of assistance to persons with disabilities to ensure their access to information" (Article 9, 2f).

To address barriers discussed above, NSW CAG recommends:

- The provision of clear information to be provided to all consumers of health care facilities, including mental health services regarding rights and responsibilities
- The provision of clear information to be provided to all consumers of health care facilities, including mental health services regarding the process for making a complaint and how to access the Health Care Complaints Commission
- All information needs to be made available in a variety of formats, including written, oral and pictorial to ensure access to this information for all consumers who may have cognitive and/or visual deficits, or reading difficulties
- The provision of adequate levels of individual advocacy and support both within mental health services and the community, to assist consumers in making a complaint, and in navigating the system
- The establishment of systems to enable consumers to lodge complaints verbally

4. The need for transparency

As noted under point 1, the impartiality of the health care complaints system is imperative to its effectiveness. Responses from our network concerning the health care complaints system identified that consumers do not consider the system to be transparent. To ensure this is realised, NSW CAG recommends the following:

- That formal written, and where required also verbal, responses are provided regarding all issues within a complaint to the complainant
- That the complainant be informed of any aspect of the complaint that is altered, or deleted as allowed within the Act
- That the complainant be advised of any aspect of the complaint that is disregarded or assessed as not warranting further action with an explanation
- That the complainant be informed of any addition to the complaint unless the provision of this information would breach the confidentiality of another individual
- Complainants be regularly updated on the progress of their complaint
- That external people and bodies continue to assess a complaint rather than internal reviews being conducted by peers
- That all complainants be provided with information, both written and verbal, on how to appeal a decision
- That all reviews of decisions be undertaken by persons not involved in the initial decision
- That all hearings are open, unless there is good reason for them to not be; in the latter case, that the reason for a closed hearing be publicly disclosed, including the informing of the complainant

- That complainants are able to attend and give statements at hearings
- That all aspects of an individual's complaint be considered and responded to

The recommendations under point 1, regarding the continued involvement of the HCCC and the continuity of a contact point for consumers are also important for ensuring a transparent process.

5. Consideration of the NSW Health Care Complaints Commission in light of the discussion paper, *Proposed arrangements for handling complaints, and dealing with performance, health and conduct matters*

NSW CAG supports the proposed National Registration and Accreditation Scheme, and envisages that it will assist in the protection and safety of consumers throughout Australia. However, NSW CAG shares the concerns of the Public Interest Advocacy Centre (PIAC) about the complaints processes for health care practitioners proposed in the *Consultation Paper: Proposed arrangements for handling complaint, and dealing with performance, health and conduct matters* whereby complaints are handled by the relevant national registration body. In particular, we share PIAC's (2008) concerns that the composition of these registration bodies of predominantly professionals reduces impartiality and results in self-regulatory processes. As noted by PIAC (2008, p. 2) the proposed national model moves away from a consumer focussed model that NSW CAG strongly advocates for.

NSW CAG is also concerned that the proposed model increases the complexity of the process from the perspective of consumers. It would result in consumers dealing with a national body that may be viewed as more distant and therefore more inaccessible, rather than a state body. Further, if a complaint is regarding an individual and an organisation this would result in two dealings – one with the national registration body and the other with the state body dealing with the service.

NSW CAG therefore advocates for the continuity of the NSW Health Care Complaints Commission as an independent statutory authority, with the changes recommended in this submission to enhance the current system.

6. Conclusion and summary of recommendations

NSW CAG presents to the inquiry into the Operations of the Health Care Complaints Act 1993 considerations pertaining to the complexities in the NSW health care complaints system, and the barriers within the current system to mental health consumers having fair and equal access to the system.

To address barriers discussed above, NSW CAG recommends:

- The HCCC remains at least informed of, or oversees the full complaints process
- The HCCC remains the key contact point for complainants throughout the process
- Each consumer be provided with one contact person within the HCCC who remains with the case to its completion, and provides liaison with the consumer
- That regular contact be maintained with complainants to inform them of their complaint and provide reassurance that their complaint is being considered.
- The provision of clear information to be provided to all consumers of health care facilities, including mental health services regarding rights and responsibilities

- The provision of clear information to be provided to all consumers of health care facilities, including mental health services regarding the process for making a complaint and how to access the Health Care Complaints Commission
- All information needs to be made available in a variety of formats, including written, oral and pictorial to ensure access to this information for all consumers who may have cognitive and/or visual deficits, or reading difficulties
- The provision of adequate levels of individual advocacy and support both within mental health services and the community, to assist consumers in making a complaint and in navigating the system
- The establishment of systems to enable consumers to lodge complaints verbally
- That formal written, and where required also verbal, responses are provided regarding all issues within a complaint to the complainant
- That the complainant be informed of any aspect of the complaint that is altered, or deleted as allowed within the Act
- That the complainant be advised of any aspect of the complaint that is disregarded or assessed as not warranting further action with an explanation
- That the complainant be informed of any addition to the complaint unless the provision of this information would breach the confidentiality of another individual
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- That external people and bodies continue to assess a complaint rather than internal reviews conducted by peers
- That all complainants be provided with information, both written and verbal, on how to appeal a decision
- That all reviews of decisions be undertaken by persons not involved in the initial decision
- That all hearings are open, unless there is good reason for them to not be; in the latter case, that the reason for a closed hearing be publicly disclosed, including the informing of the complainant
- That complainants are able to attend and give statements at hearings
- That all aspects of an individual's complaint be considered and responded to

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