National Health and Hospitals Reform Commission

Submission Cover Sheet

Please complete and submit this cover sheet with your submission to:

By email: talkhealth@nhhrc.org.au
By mail to: PO Box 685 Woden ACT 2606

A. Details of the person or organisation that prepared this submission

Date of submission: Friday 6th June 2008

Who prepared this submission?
☐ Individual ☑ Organisation

For individuals:

Name of individual:____
Street address: ____
Mailing address (if different from above): _____________________________
Phone (daytime): ____
Fax: ____
Email: ____

For organisations:

Type of organisation. (Please tick all that apply)
☐ Consumer group
☐ Government agency
☐ Private company
☐ Professional body
☑ Other non government organization
☐ Other (Please specify) _______________________________________

Geographic focus of organisation. (Please tick all that apply)
☐ Nationwide
☑ Statewide (Please specify State/Territory) _NSW
☐ Metropolitan
☐ Rural / regional
☐ Remote

Please specify the particular sector focus of your organisation (if applicable). ________Mental Health Consumer systemic advocacy

Purpose/s of organisation. (Please tick all that apply)

☐ Research
☐ Education
☐ Service provision
☑ Advocacy - systemic
☐ Other (Please specify) ____

Name of representative: Karen Oakley
Position within organisation: A/Executive Officer
Name of organisation: NSW Consumer Advisory Group – Mental Health Inc.
Street address: Suite 501, 80 William Street, Sydney NSW 2000
Mailing address (if different from above): As above
Phone (daytime): 02 9332 0240
Fax: 02 9332 0299
Email: koakley@nswcag.org.au

Please note that in making a submission you agree that it may be made public.

B. Response to draft principles

☑ This submission specifically comments on the draft principles developed by the Commission to shape Australia's future health system. (Please tick if this applies)

C. Response to key themes

This submission specifically responds to the following key themes taken from the Commission's Terms of Reference. (Please tick all that apply)

☑ A greater focus on prevention to the health system
☑ Improving frontline care to promote healthy lifestyles and prevent and intervene early in chronic illness
☐ Improving Indigenous health outcomes
☑ Integrating and coordinating care across all aspects of the health sector, particularly between primary care and hospital services around key measurable outputs for health
☑ Improving the provision of health services in rural areas
☐ Integrating acute services and aged care services, and improve the transition between hospital and aged care
☐ Reducing inefficiencies generated by cost-shifting, blame-shifting and buck-passing
☑ Providing a well qualified and sustainable health workforce
☑ Maintaining the principles of universality of Medicare and the Pharmaceutical Benefits Scheme, and public hospital care
☐ Maximising a productive relationship between public and private sectors
☐ Providing a more seamless experience across public and private services
☐ Providing advice on the framework for the next Australian Health Care Agreements (AHCAs), including robust performance benchmarks
☐ Addressing the escalating costs of new health technologies
☑ Increasing access to services
☐ Addressing the growing burden of chronic disease
☐ Providing for an ageing population

☐ Managing the escalating costs of new health technologies
☐ Addressing overlap and duplication including in regulation between the Commonwealth and states

☑ Other (Please specify): Community Mental Health service provision, consumer participation, recovery orientation to service provision, culturally appropriate services, addressing stigma towards people with mental illness

Submission to the National Health and Hospitals Reform Commission

June 2008

NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG)
501/80 William St, Sydney 2000
Ph: 02 9332 0200, Fax: 02 9332 0299, email: gmalins@nswcag.org.au

6th June 2008

National Health and Hospitals
Reform Commission (NHHRC)
PO Box 685
Woden, ACT 2606

To Whom It May Concern:

Regarding: Advice relating to the NHHRC Principles to shape Australia's health system and Terms of Reference

Please find attached advice from the NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG) to the National Health and Hospitals Reform Commission, relating to the Principles to shape Australia's health system and the Terms of Reference.

NSW CAG is the independent, statewide organisation representing the views of mental health consumers and carers at a policy level, working to achieve and support systemic change. Our vision is for all mental health consumers and carers to experience fair access to quality services which reflect their needs.

Our submission makes clear the opinions and perspectives of the consumers we have consulted. It is our hope that this Commission will take this advice in stride and that it will result in concrete changes to the Australian health system generally and mental health services specifically.

Please do not hesitate to contact me should you wish to further discuss any of the advice provided in this submission.

Yours sincerely

Karen Oakley
A/Executive Officer

1 Summary

The basis of this advice

NSW CAG exists to ensure that the perspectives of mental health consumers and carers across NSW are heard by policy makers. 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 forwarded the NHHRC Terms of Reference and Principles to mental health consumer workers across the eight Area Health Services in NSW on our database. The following advice is based on the answers received from consumer workers and on NSW CAG's experiences, including information gathered during consultations with consumers throughout NSW.

Summary of recommendations

On the basis of the information presented, NSW CAG recommends that mental health be included explicitly by this Commission. Mental health is essential to all types of health, and must be considered fully if a holistic approach to Australia's health system is truly desired. It is also imperative to ensure that consumers participate throughout the reform process. The information below makes clear the opinions and perspectives of the consumers we have consulted. It is our hope that this Commission will take this advice in stride and that it will result in concrete changes to the Australian health system generally and mental health services specifically.

NSW CAG supports the Principles and Terms of References presented by NHHRC, considering them to be a great *starting point* for what in needed to shape the future of Australia's health system, but that needs to be done, particularly in relation to mental health. Concern has been expressed that mental health often galls off the agenda in reforming services. Through this submission NSW CAG aims to bring mental health consumers and their needs to the forefront of considerations by the NHHRC. It considers the Principles and various Terms of Reference.

Two core themes run throughout our consultations and our submission. Firstly, NSW CAG advocates for genuine consumer participation and partnership in all aspects of service provision, delivery, development and policy development and implementation. Secondly, there is a need for challenging negative attitudes towards and stereotypes of people with a mental illness, both among the general community and amongst the health workforce.

NSW CAG makes the following recommendations:

Strategies be developed to:

- Educate staff about the need for, and how to achieve coordinated care
- Encourage case meetings between services, clinicians and consumers
- Reinforce the need for and ensure adequate discharge planning in partnership with consumers and carers
- Educate GPs about the use of care plans
- Accurately inform the public about mental illness and suicide

- Dispel myths, and work to target stigma surrounding mental illness. The most useful strategies to overcome stigma are those which increase people's contact with people living with mental illness (Corrigan, 2004)
- Fund programs where mental health consumers spend time with people in schools, universities, workplaces, the media and other key institutions
- Continue monitoring media representations of mental illness and suicide and lobbying for accurate representations of people with a mental illness

Other recommendations:

- Staff are provided with training in recovery, consumer oriented service provision
- Staff be provided with training by consumers to reduce stigma and to change negative attitudes towards those with mental illness
- Specific investigation into the service needs of people in rural and remote regions of NSW, and service gaps
- Consideration for ensuring infrastructure within services and for people living in remote regions to enable the use of mental health services being delivered using new technologies
- Investment in community mental health services be a priority
- The adoption of recovery oriented services
- Ensuring culturally appropriate services
- That the NHHRC work with the NSW Government to resolve their non-signatory status on the Australian Health Care Agreement allowing physicians employed with public health services to write prescriptions for consumers
- Ongoing consumer participation with the NHHRC
- Consumer representation on the NHHRC

2 Response and Recommendations

NSW CAG exists to ensure that the perspectives of mental health consumers and carers across NSW are heard by policy makers. 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 forwarded the NHHRC Terms of Reference and Principles to mental health consumer workers across the eight Area Health Services in NSW on our database. The following advice is based on the answers received from consumer workers and on NSW CAG's experiences, including information gathered during consultations with consumers throughout NSW.

We would like to thank all who have contributed to our consultations, and our inquiries for this submission, including the Area Mental Health consumer workers, consumers of mental health services, and the Multicultural Mental Health Australia (MMHA) CALD Consumer Reference Group, for providing their input and sharing their expertise and experience.

The Principles

NSW CAG advises the need to ensure consumer participation throughout all the steps of health system reforms. Indeed, it is recommended that Consumer Participation & Partnership be made a core, underlying principle to both the NHHRC and to services throughout NSW and Australia.

- Principle 1. People and family centred: Carers play a vital role in the mental health process, should be, as one consumer worker stated, "informed and involved". Therefore, carers need to be included explicitly within these principles.

  In creating a 'People centred' health care system, more of an emphasis needs to be placed on consumer participation in their care and in health services generally. Likewise, services need to place consumers at the centre of care in order to ensure individualised treatment of care.

- Principle 2. Equity: Equity of services relates to ensuring equal and fair access to adequate treatment and care for all. Through consulting, and as is widely known, people in rural and remote areas of NSW are particularly disadvantaged in this respect. In many such areas, GPs and psychiatrists are flown in. This inhibits immediate care as their appointment schedule is booked, may delay people seeing clinicians when needed. Further, the rapid change with clinicians flying in adds to a lack of continuity of care. Issues of access to services are faced by many consumers or would be consumers of mental health services. We consistently hear of under resourced and understaffed public services which limit the availability of doctors, psychiatrists, social workers, counsellors, and psychologists. While the revised Medicare Benefits Scheme, which includes psychological services, has gone some way to address this, we continue to consistently hear about:

  - Long waiting times to see health service staff

- Costs needing to be paid at the time of consultation, prohibiting many with mental illness who are on low incomes or pensions from accessing these services
- The gap between the Medicare rebate and actual cost
- Restricted treatment options which inhibit individualised treatment
- Restricted numbers of sessions which means people with long term mental illnesses and requiring long term care are not able to get these needs met though this Scheme, creating also a lack of continuity of care

Likewise, access to GPs and psychiatrists is restricted through waiting lists and the costs of the appointments.

In ensuring equitable services, it is also essential that services be culturally appropriate. This is often not the case in mental health services. Further, the Multicultural Mental Health Australia (MMHA) CALD Consumer Reference Group advised NSW CAG that the Equity principle should aim to ensure equity of services for newly arrived migrants, particularly refugees and those people with Bridging Visa E who currently do not receive "access to Medicare nor resources and assistance to go to other services for help" (MMHA CALD Consumer Reference Group).

- Principle 3. Shared Responsibility: Recognising the role that we all play in the health process is crucial for mental health services. Consumers, doctors, specialists, nurses, health staff, and the general public are all connected to the long-term effectiveness of and care involved in Australian health services. Consumer participation and, where requested, the participation of family and carers, is essential in an individual's treatment. As one consumer worker emphasised, this principle is "essential in the recovery process for consumers of mental health services".

  Shared responsibility, participation, and partnership extend beyond individual care. It is essential that these be incorporated into, and realised in practice in service reform, planning, evaluation, and monitoring, as well as policy development. Although this is recognised as necessary both nationally and internationally, genuine opportunities for participation and partnership are still lacking.

- Principle 4. Strengthening Prevention and Wellness: Education and prevention need to have much more of an emphasis within the Australia health system, particularly in relation to mental health. It was emphasised that funding needs to be made for prevention education and consumer organisations, rather than the bulk of the money going to acute, inpatient care. As noted by the MMHA CALD Consumer Reference Group, and supported by NSW CAG, there is a need for public education and prevention campaigns to include consumers and carers as educators.

  A recovery oriented approach to mental health service provision is required in order for this principle to be realised. This is explored further under the Terms of Reference.

Strategies to address community and health workers' attitudes towards mental illness are also required to see this principle released. This will also be explored in the Terms of Reference.

- Principle 5. Comprehensive: Comprehensive mental health services include both inpatient and community services. As discussed in the section 'Terms of Reference,' NSW CAG is consistently informed of inadequate community mental health services.

  The Multicultural Mental Health Australia CALD Consumer Reference Group advised that "a comprehensive system should include primary health care services and specialist staff that are trained and educated in mental health are competent in delivering services to all those in need, including people from CALD backgrounds who may have additional and different needs" than native English speakers. It is also felt that mental health consumers and carers could provide this training and education to both primary health carers and specialist staff (MMHA CALD Consumer Reference Group).

- Principle 8. Recognise broader environmental influences shape our health: Community attitudes about mental illness and stigma towards people with mental illness have a significant impact on a person's recovery. Addressing stigma in both the community and with health workers is vital to improving services and people's health outcomes.

- The Multicultural Mental Health Australia CALD Consumer Reference Group advised that this principle should explicitly include partnerships with non-profits and non-governmental organisations that "work with people from CALD backgrounds, those with mental illness, the homeless, the disenfranchised" (MMHA CALD Consumer Reference Group).

- Principle 11. Transparency and accountability: Several consumer workers stated that there is a strong need for more transparency in the mental health system and in services at the state, area, and local levels. There is also the need for hospital and community health service staff to be held accountable for their treatment of consumers.

- Principle 13. A respectful, ethical system: The term 'holistic' should be used when referring to the "biological, emotional, physical, psychological, cultural, social and spiritual needs" of a person" (NHHRC Principles, p 5; MMHA CALD Consumer Reference Group).

- Principle 14. Responsible spending on health: Consultations have revealed that it is necessary to examine how funding is distributed to ensure that more of it reaches ground-level mental health services.

- MMHA's CALD Consumer Reference Group recommended that a glossary of terms, such as 'community' in Principle 7. Providing for future generations and 'risk behaviour' from Principle 3 Shared Responsibility should be included at the end of the Principles document.

- Consultations recommended that an additional Principle could be added regarding Identifying positive current aspects of Health and Hospitals, so that quality parts of the current system are not lost while reforming the health system. This would also be beneficial as it would allow people to learn about success stories in the current health system and in turn perhaps reduce the number of people that avoid the health system in the beginning stages of an illness.

The Terms of Reference

Consumer participation and partnership and challenge stereotypes and attitudes towards mental illness

Two core themes run throughout our consultations and responses to the Terms of Reference. Firstly, NSW CAG advocates for genuine consumer participation and partnership in all aspects of service provision, delivery, development and policy development and implementation. Secondly, it is essential that strategies be implemented to address the stigmatisation of those with a mental illness, both by the general community and by the health workers delivering care.

Better integrate and coordinate care across all aspects of the health sector, particularly between primary care and hospital services around key measurable outputs for health

During our consultations into community mental health services, a consistent theme has been the need for the coordination of care, both within the community services and between community and inpatient services. Information sharing between services and clinicians with the knowledge and consent of consumers is vital. Agreement to the consumer's care plan between services, clinicians and consumers is also essential. Particular aspects requiring focused attention are adequate discharge planning that involves consumers and where requested, carers, and the use of care plans by General Practitioners. It has been highlighted that some GPs are not developing care plans, are not discussing care plans with consumers and that there is a lack of discussion about care plans between service providers, both public and private.

NSW CAG recommends that strategies be developed to:

- Educate staff about the need for, and how to achieve coordinated care
- Encourage case meetings between services, clinicians and consumers
- Reinforce the need for and ensure adequate discharge planning in partnership with consumers and carers
- Educate GPs about the use of care plans

Bring a greater focus on prevention to the health system

Research and strategies to prevent the onset and exacerbation of mental illnesses and suicide have been expanding. However, community awareness about mental illness is essential, where people are able to recognise possible signs of mental illness and seek assistance early. Similarly, expanding suicide prevention campaigns will enable people to recognise signs of suicidal ideation and to seek help for themselves or for others.

Targeting stigma, stereotyping and discrimination is essential for this to become a reality. Lack of understanding and stigma may lead people to not be prepared to consider a possible mental illness.

NSW CAG recommends that strategies be developed to:

- Accurately inform the public about mental illness and suicide
- Dispel myths, and work to target stigma surrounding mental illness. The most useful strategies to overcome stigma are those which increase people's contact with people living with mental illness (Corrigan, 2004)
- Fund programs where mental health consumers spend time with people in schools, universities, workplaces, the media and other key institutions
- Continue monitoring media representations of mental illness and suicide

Provide a well qualified and sustainable health workforce into the future

Consultations with consumers throughout NSW have revealed that staff shortages are restricting accessibility to care, particularly in the community. In some instances we have been made aware of case managers with loads in excess of 50 consumers, which restricts consumer's access to quality care.

Within the mental health sector, there is a consistent difficulty with attracting and retaining staff, particularly in rural and remote areas. This leads to under-provision of care, and a lack of consistency in care.

A well qualified workforce will also be aware of and practicing individualised, recovery oriented care within mental health services. Staff therefore need training in such service provision. It is also recommended that staff be provided with training by consumers to reduce stigma and to change negative attitudes towards those with mental illness.

Improve the provision of health services in rural Australia

Consultations have revealed that rural mental health services are perceived as being in crisis. As noted above, GPs and psychiatrists in rural areas are frequently inaccessible, because there are far more people seeking to assess the services of doctors than there are doctors available. This is true of GPs and is especially noticeable with psychiatrists. It has also been brought to our attention that in rural areas private psychologists often have a 6-8 week waiting time for appointments, again restricting accessibility of services.

It is felt that the problems with the services in rural and remote regions of Australia are complex and difficult, but inadequate staffing is pivotal to the problems and would therefore be crucial to any solutions.

A further problem highlighted by people in rural and remote regions in NSW is access to services. As a result of economic factors, services are often located in large towns. Therefore, for many, access to required services is not available.

As has been discussed, the high rate of staff turnover, and the inconsistency of visiting psychiatrists results in a lack of continuity of care, which is considered highly important in a person's recovery.

NSW CAG recommends that specific investigation be conducted into the service needs of people in rural and remote regions of NSW, and service gaps. Consideration for ensuring infrastructure within services and for people living in remote regions to enable the use of mental health services being delivered using new technologies is also required.

Improve and expand community mental health services

Adequate community mental health services are key to the prevention and early intervention of mental illness, and in consumers being able to recover and stay well in the community. NSW CAG welcomes and supports the development of NSW Community Mental Health Strategy 2007-2012 by the NSW Department of Health. It is crucial that community services are developed alongside inpatient services. There is a perception that there has been and continues to be too great a focus on the provision of beds. Our consultations have revealed that community services which are under resourced, have, on the whole, become more crisis focused. This restricts the availability of services to those requiring ongoing care to remain well.

NSW CAG recommends that investment in community mental health services be a priority.

Adopt a recovery orientation

A medical approach to mental illness still prevails. While NSW CAG acknowledges the role of these approaches, they restrict consumer's abilities to take control of their illness and lives, and fail to consider the whole person. Services need to move towards a recovery approach to mental illness where:

- The consumer is the centre of the service and care
- Care is individualised to the needs of the consumer
- Consumers, and family and carers where requested, are integrally involved in treatment planning and care
- A holistic approach to care is taken, where individual's social, emotional, spiritual, safety, housing and economic needs are considered and met alongside psychological and physical needs

Provide culturally appropriate services

In ensuring individualised, and person centred care, it is essential that culturally appropriate services are provided.

Multicultural Mental Health Australia's Consumer Reference Group concluded that "More reference should be made [within the Terms of Reference] to the need to have measurable 'evidence-based' better health outcomes for all groups and especially special needs groups like CALD populations and other minority groups such as refugees, those with a mental illness and their carers, the homeless, the unemployed, women, youth and children," and others (MMHA CALD Consumer Reference Group).

Likewise, services that meet the needs of indigenous Australians are also required. During a consultation, it was noted that the mainstream western approach entirely overlooks spirituality, which is central to both Aboriginal and Maori healing.

The Commission's long-term health reform plan will maintain the principles of universality of Medicare and the Pharmaceutical Benefits Scheme, and public hospital care

NSW CAG supports the principles of maintaining the universality of Medicare and the PBS, and public hospital care. It has been brought to our attention by Consumer and Carer Workers, and confirmed by psychiatrists, that NSW has not been a signatory to the Australian Health Care Agreement which allows doctors employed by public health services to write prescriptions for consumers. This creates particular difficulty for people with a mental illness. When discharged from an inpatient service, consumers are provided with medication to last approximately 3 days. To obtain a prescription they are required to visit their General Practitioner. It has been noted during consultations that the shortage of GPs in many areas does not allow people to see the GP before their supply of medication runs out. Some medications also can only be prescribed by psychiatrists. Consumers therefore require a referral from their GP to a private psychiatrist. Private psychiatrists often have extensive waiting lists, and consumers are often unable to get an appointment before their medication runs out. Access to GPs and psychiatrists is also restricted by cost. Many consumers are unable to afford to pay upfront for an appointment with their GP or psychiatrist where these services are not bulk billed. These factors also influence those who see a psychiatrist at a community health service. Where consumers have been stabilised through medication, and where medication is an important component of ongoing recovery, this situation results in considerable risk to the well being and continued recovery of consumers in the community.

The situation is exacerbated for those on Community Treatment Orders, whose condition of remaining in the community often includes a proviso that they continue to take their medication. Not being able to access medication due to public inpatient and community doctors being unable to write prescriptions poses a risk not only to their health, but may result in their being involuntarily scheduled under the Mental Health Act.

Further difficulties are experienced by those in rural and remote Australia, where GPs and psychiatrists are not accessible.

NSW CAG requests that the NHHRC consider this matter and work with the NSW Government to rectify this situation.

The Commission will comprise a Chair, and between four to six part-time commissioners who will represent a wide range of experiences and perspectives, but will not be representatives of any individual stakeholder groups

NSW CAG and consulted consumer workers feel that the Terms of Reference need to clearly define who will be a member of the commission. NSW CAG and our constituents advocate for consumer representation on the Commission. One consumer worker noted that consumers should be included as members of the commission, "at least some of whom come from the mental health sector". Consumers with a sound network to other consumers bring a wealth of experience of using services, and insight into how services need to be improved to adequately meet the needs of those using services. It is well acknowledged that consumer perspectives differ from those of service providers and clinicians (Australian Health Ministers, 1992, 1997, 2003; NSW Department of Health, 1999). Further, consumer participation in all aspects of policy, and service delivery,

monitoring, development and reform are advocated both nationally and internationally (Deane, 1987; Gill, Pratt & Librera, 1998; NSW Health 1999; Perkins, 2001; Rapp, et al, 1993; Campbell, 1997; Prince & Prince, 2001).

An alternative, although less participatory approach to consumer participation in the Commission is close and continual consultation with, and the seeking of advice from consumers and consumer groups. Inclusion of mental health consumers is imperative in the health reform process.

3 References

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