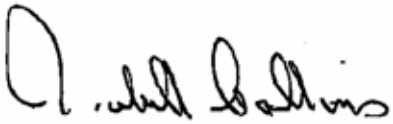
The Secretary
Senate Community Affairs Committee
PO Box 6100
Parliament House
Canberra ACT 2600

The attached submission to the *Senate Select Committee Inquiry into Mental Health Services in Australia from the National Mental Health Consumer and Carer Forum* is submitted on behalf of the National Mental Health Consumer and Carer Forum by:



Ruth Carson
Carer Co-Chair
NMHCCF

Isabell Collins
Consumer Co-Chair
NMHCCF

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Submission to the Senate Select Committee Inquiry into Mental Health Services in Australia from the National Mental Health Consumer and Carer Forum

Executive Summary

The NMHCCF supports the COAG National Mental Health Plan, the consequent increased investment into mental health in Australia and the greater emphasis on community services and recovery.

Despite some increased rhetoric about consumer and carer participation, there are still very limited opportunities for these groups to have real input into national policy development and implementation.

The National Mental Health Strategy has not provided the consumer and carer partnerships or service focus that it aims to achieve.

The COAG National Action Plan has failed to capitalise on the opportunity to use consumer and carer participation to shape appropriate and measurable service improvements.

An understanding of and commitment to meaningful consumer and carer participation at all levels of policy development and implementation needs to be supported to ensure that the destructive current practice of tokenism is identified and eliminated.

Human rights for mental health consumers remains a critical issue in the delivery of services and can only be addressed through stronger leadership, an appropriate allocation of resources and genuine accountability in the form of demonstrated and measurable action.

This strategy should be applied in particular to

- the practices of seclusion and restraint in acute mental health services;
- the clarification of privacy and confidentiality provisions for consumers and carers which are an identifiable barrier to recovery in many cases.

The Australian Government's *Welfare to work* initiative works to undermine the COAG National Action Plan and the National Mental Health Strategy. A whole of government approach is required to review the initiative in consultation with consumers and carers.

Introduction

The National Mental Health Consumer and Carer Forum (NMHCCF) was established by the Australian Health Ministers Advisory Council (AHMAC) in 2002 in recognition of the continued need for mental health consumer and carer involvement at the highest level

of policy development. It provides a mechanism for mental health consumers and carers to come together to foster partnerships and to ensure the input of consumers and carers into the activities of the mental health sector including the reform of mental health policy and service delivery in Australia.

The NMHCCF is funded under this agreement by AHMAC, through state and territory and Australian Government contributions, to be an independent voice for consumers and carers. It reports to AHMAC's Mental Health Standing Committee (MHSC) through the Mental Health Council of Australia (MHCA), which auspices the NMHCCF.

This submission

The NMHCCF understands that the terms of reference of this inquiry relate specifically to consideration of the outcomes of the COAG National Action Plan on Mental Health agreed upon at the July 2006 meeting of the Council of Australian Governments (COAG); the extent to which the action plan assists in achieving the aims and objectives of the National Mental Health Strategy;

The small budget of the NMHCCF and the relative lack of real involvement of the mental health consumer and carer sector in the development and implementation of national and state/territory policy in relation to services in the mental health sector means that consumers and carers are not necessarily well informed of opportunities to input to national policy development. Currently the mental health consumer and carer sector relies on the dedicated participation of already overloaded volunteer consumers and carers to become acquainted with government and bureaucratic processes for which politicians, career public servants and mental health service managers are well trained, comprehensively resourced and highly paid. Therefore a detailed analysis by the NMHCCF of issues such as the following is not possible:

- whether the COAG initiatives are meeting the recommendations of the Select Committee on Mental Health, as outlined in its report *A national approach to mental health – from crisis to community*
- how well COAG initiatives are being implemented if at all,
- whether this investment is making changes to health outcomes for consumers and carers
- the percentage and distribution of budgets across jurisdictions.

Nonetheless, the NMHCCF considers it a fundamental right of consumers and carers to provide input about services and that it is crucially important that the voice of consumers and carers is heard and valued. This is because the ongoing debate between governments and service providers about what constitutes improved or even adequate service delivery in the mental health sector in Australia already lacks appropriate input from the voices of those who are its target. Therefore the NMHCCF highlights the following issues of importance to consumers and carers and as a prelude to its comments the NMHCCF acknowledges the good and tireless work undertaken by many practitioners and clinicians working within mental health services who despite lack of leadership and systemic support to do so, continue to work with consumers and carers as equal partners in their health care.

1. COAG National Action Plan

The NMHCCF strongly supports the much needed attention recently given to mental health through the COAG National Action Plan. This includes in particular the focus on recovery, early intervention and prevention and more and better coordinated care and support for people living in the community with a mental illness and their carers.

The COAG initiatives also present an opportunity, with respect to early intervention and prevention, to focus on consumers at risk of becoming a part of the justice system. Many of the people in the forensic system (mental health criminal justice system) are there because they were unable to get clinical assistance at a time when they needed it and this has resulted in a chain of events leading to them committing a serious crime. This is an area of critical need and with current initiatives in early prevention and early intervention, there is an opportunity to build in this focus in the future, provided that appropriate support is given.

The NMHCCF is, however, extremely disappointed that the COAG National Action Plan does not give any stated support to the importance of consumer and carer participation in mental health service delivery, policy development and implementation, nor take up many of the recommendations made by the Senate Select Committee on Mental Health supporting consumer and carer participation, as outlined in its report *A national approach to mental health – from crisis to community.*

2. Success of the National Mental Health Strategy

The importance of consumer and carer participation is well described as an integral part of the National Mental Health Strategy (the Strategy). However, it is clear through the recent opportunities for initial input to the review of the National Mental Health Standards (being undertaken by the Australian Council on Healthcare Standards) and development of the new National Mental Health Policy and National Mental Health Plan under the Strategy (being coordinated by the Australian Government), that consumers and carers feel that the Strategy has failed in a number of key areas.

A continued lack of any formal mechanism to monitor consumer and carer experiences of the implementation of the Strategy and tokenism in consumer and carer participation at all levels has meant that this situation has been left largely unaddressed.

Meaningful consumer and carer participation also informs partnerships that will support prevention and early intervention and it is the basis for an effective recovery model. The COAG National Action Plan has failed to recognise this.

The failures of the National Mental Health Strategy and now the COAG National Action Plan to effectively address mental health consumer and carer participation in the planning and delivery of services are highlighted by the following issues of major concern to the NMHCCF, which need to be addressed as a matter of urgency throughout Australia (these are not in order of importance but linked to each other):

3. Human Rights

Consumers and carers continue to ask that they be treated with dignity and respect and that these principles are given the power to inform service delivery at all levels. The Mental Health Council of Australia reported in 2005 on a national consultation that showed that "pleas for the provision of basic care with dignity were almost universal"[1]

In many instances it is the culture of clinical services which result in human rights abuses. Consumers regularly report that this is worse than anything they experience in the community.

Rights of consumers are acknowledged in the National Mental Health Strategy and in national policy. This has resulted in changes to state legislation, but unfortunately the changes have not translated into any meaningful improvements or respect for consumer rights or any accountability measures to rectify situations where rights are abused. Current accountability measures such as the self implementation of a quality assurance framework against the National Mental Health Standards are inadequate to identify and address human rights abuse in mental health (see below: *2. Quality Assurance and the role of accreditation*).

A more appropriate mechanism for the elimination of human rights abuses would be the consistent collection or examination of sentinel events in the mental health sector. This does not exist. Further, the potentially extremely dangerous practices of seclusion and restraint are still practiced as routine interventions despite the lack of evidence to support their efficacy. Even in the United States, not broadly considered to be a leader in mental health, many professionals have classified seclusion and restraint as a failure of treatment in mental health.[2]

With respect to seclusion and restraint practices, the NMHCCF acknowledges the extremely important work being undertaken by the AHMAC Mental Health Standing Committee Safety and Quality Partnership Group through its *National safety priorities in mental health: a national plan for reducing harm*.[3]

However, until real culture change ensues as part of or in parallel to the implementation of alternatives practices, seclusion and restraint will continue to be a common first line intervention and its inconsistency with human rights conventions will remain unquestioned.

4. Quality Assurance and the Role of Accreditation

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[1] Mental Health Council of Australia, 2005. *Not for service: Experiences of injustice and despair in mental health care in Australia*, Canberra.

[2] United States Department of Health and Human Services, 2003: United States Department of Health and Human Services News, Vol XI, No 2, http://www.samhsa.gov/samhsa_news/VolumeXI_2/article6.htm

[3] Commonwealth of Australia. 2005 *National safety priorities in mental health: a national plan for reducing harm*, http://www.health.gov.au/internet/wcms/publishing.nsf/Content/A6A9123C4FA8E49FCA257230001F3C41/$File/safecov.pdf.

Quality assurance and accreditation processes (currently the only mechanisms that may provide information about the implementation of the rights of consumers as outlined in the National Mental Health Strategy), do little to improve the quality of services. Part of the reason for this is that National Mental Health Standards are often too generalized to be implemented well or measured. Thus accreditation only takes a perfunctory look at services and where negative outcomes are identified, they may easily be ignored or glossed over.

The accreditation process highlights time and again that a lack of clarity around appropriate service delivery combined with a powerful service culture, leads to a situation where the evidence of consumers, carers and professionals seeking to improve service delivery is just not heard. In other words, the current system of standards, education and training on their own do little to foster quality services.

Culture change needs to be supported by stronger leadership, an appropriate allocation of resources, and genuine accountability in the form of demonstrated and measurable action if it is to be effective.

5. Meaningful Consumer and Carer Participation not Tokenism

Underpinning the above culture change difficulties is the failure of both the implementation of the National Mental Health Strategy and of the COAG National Action Plan on Mental Health to provide opportunities for meaningful participation of mental health consumers and carers in policy development and implementation at the national and other levels.

The NMHCCF acknowledges that the National Mental Health Strategy seeks to support consumer and carer participation and that as a result there exist a range of welcome initiatives for consumer and carer participation at many levels of service delivery. However, this participation is very often tokenistic, resulting in the poor development, planning and delivery of services and the tendancy to "blame the victim" – that is to blame consumers and carers for failure because they were supposedly involved (but in reality, not in any meaningful way) in the planning, and delivery of services.

This issue has not been addressed under the new funding initiatives available through the COAG National Action Plan. It is unclear whether opportunities to address these issues through the review of the National Mental Health Policy, being undertaken by the Department of Health and Ageing, will be realised. If the COAG National Action Plan is used as a guide, they will not. It would seem that any momentum on consumer and carer participation that was gained through the development of the National Mental Health Strategy has been in steady decline.

Meaningful participation would include:

- National recognition of the need and value of consumer and carer input at the highest level;
- Ensuring that this input is meaningful by strengthening the capacity of the sector to participate (eg training and resources to support networking at a local level so that

consumers and carers are able to participate effectively in community debate on issues that affect them and have the skills and experience to offer effective solutions; ensuring that consumer and carer representation is appropriately valued through the use of financial remuneration).

The Australian Government's own *Principles for the appointment of consumer representatives: A process for Governments and Industry* .[4] provides guidance for individual government departments seeking to engage with consumers and carers and sets out the process for meaningful participation. However these *Principles* are not recognised consistently even within the Australian Government. For example the NMHCCF has recently identified several instances where government departments have a policy of *not* providing remuneration for consumer and carer representation, despite the *Principles'* recommendation to do so. This includes an Australian Government department directly involved in implementation of the COAG National Action Plan.

The NMHCCF is very concerned that under arrangements whereby consumers and carers are not remunerated, the only consumer and carer participation will be undertaken by those consumers and carers who are either employed in the sector or who can afford to donate their time free of charge. This effectively discriminates against the most marginalised consumers and carers.

By not highlighting the importance of consumer and carer participation, COAG have lost an opportunity to utilise consumer and carer input where it is most needed.

In its recommendations in the report: *A national approach to mental health – from crisis to community* the Senate Select Committee on Mental Health included a range of important recommendations to improve mental health through consumer and carer participation. These have not been implemented and the NMHCCF requests that action on these urgently be undertaken if reforms to the sector are to be realized.

6. Privacy and confidentiality

One important example of the need for effective consumer and carer participation in mental health service design and delivery is the awareness-raising and activity undertaken by consumers and carers around privacy and confidentiality.

Carers (including all family members significantly involved in the care of people with a mental illness) regularly encounter major difficulties in their role when they are excluded by imagined and or actual privacy and confidentiality provisions that work against the interests of unwell consumers. In many cases, excluding carers from recovery plans can work against the interests of recovery and risks causing potentially life threatening difficulties for consumers.

[4] Commonwealth Treasury Consumer Affairs Advisory Council, June 2005, *Principles for the appointment of consumer representatives: A process for Governments and Industry*, (http://www.treasury.gov.au/documents/994/PDF/consumer_reps.pdf)

Consumers and carers also regularly face the possibility of critical incidents because unwell consumers travel across state and territory boundaries and lose contact with regular support mechanisms. Privacy and confidentially provisions change across state and territory boundaries, adding complexity to potentially life threatening situations.

While the NMHCCF acknowledges and values the importance of privacy and confidentiality in mental health care and continues to support consumers' control over their care, it is currently working to identify improvements to the implementation of privacy and confidentiality provisions so that consumers are protected and carers can continue to play a role in their recovery where this is appropriate. However, unless these improvements are acknowledged, used by services in planning and implementation and underpinned with the appropriate legislation, a critical safety issue will remain.

Without consumer and carer input, services have historically operated as service delivery operations rather than consumer and carer focussed recovery operations. While services continue to be planned and implemented in this way, they will continue to overlook opportunities for the strategic and often cost-neutral service improvements that working directly with consumers and carers can provide.

7. Review of Welfare to Work

Simultaneous to the development of the COAG National Action Plan, the Australian Government's *Welfare to work* policy was introduced and is being implemented by the Australian Government through Centrelink. While the NMHCCF recognizes that this policy is no longer being implemented under the name *Welfare to work*, many of its provisions are still in operation.

People with a mental illness who are able to do so, want to work and know that work forms an integral part of their recovery and maintenance of their wellbeing. Work is also their right as members of the Australian community. However, the *Welfare to work* provisions mean that people with mental illness who want employment need to take large risks when they access the current employment system – jeopardizing their ongoing access to the Disability Support Pension (DSP) if or when it is again needed. The lack of flexibility of the *Welfare to work* provisions is a disincentive to work and result in a loss of opportunities in the workforce.

In effect, the *Welfare to work* provisions are undermining the COAG initiatives which are seeking to support people with mental illness to participate fully in community life. These provisions also include a penalty system that treats people with a mental illness unjustly and inadequate long term support for people with mental illness.

Welfare organisations around the country have condemned the *Welfare to work* provisions and the NMHCCF is currently working to make representations to MPs on fixing the inequities of the policy for mental health consumers in the lead up to the next election.

Centrelink have advised that a review of the policy will be completed by the end of 2008. Mental health consumers feel that this is too long to wait for a policy that is causing problems right now.

The NMHCCF requests that as part of its recommendations, the Senate Community Affairs Committee seeks the assistance of COAG to address the inconsistencies of these policies and that the Committee use the expertise of mental health consumers and carers to inform a review of the implementation of the *Welfare to work* provisions to address the significant issues around disclosure, the episodic nature of mental illness and the lack of skills and training of job capacity assessors so that the policy becomes sufficiently flexible to meet the needs of people with mental health issues in accessing and retaining work; this includes but is not limited to

- Development of an assessment tool that appropriately assesses work capacity
- Ensuring that the system does not impose unjust penalties on already vulnerable people.

Conclusion

In its recommendations in the report: *A national approach to mental health – from crisis to community*, the Senate Select Committee on Mental Health included a range of important recommendations to improve mental health through consumer and carer participation.[5] The following specific recommendations are supported by the NMHCCF:

> "Establish and fund a *National Mental Health Advisory Committee* made up of consumers, carers and service providers to:
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> - advise COAG on consumer and carer issues
> - be an advocate for mental wellbeing, resilience and illness prevention
> - promote consumer involvement in service provision
> - promote the recovery model in mental health
> - promote community and school-based education and stigma reduction, and
> - promote and manage mental health first aid programs aiming for 6% of the population to be trained and accredited, targeting those with the greatest probability of coming in contact with mental health issues – teachers, police, welfare workers, and family carers…
>
> "…Provide recurrent funding to the *Human Rights & Equal Opportunity Commission* (HREOC) to:
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> - monitor human rights abuses and discrimination in employment, education and service provision of those with mental disability
> - liaise with state and federal ombudsmen to identify trends and systemic failures that give rise to complaints, and

[5] Senate Select Committee on Mental Health, 2006, *Final report: A national approach to mental health – from crisis to community*, Commonwealth of Australia 2006.

- investigate discrimination against people with mental illness in Supported Accommodation Assistance Program (SAAP), respite and private and public rental housing,….

"Reform the National Mental Health Strategy (NMHS) to guarantee the right of people with mental illness to access services in the least restrictive environment, to be actively engaged in determining their treatment and to be assisted in social reintegration and underpin those rights with legislation...

"Include in the next NMHS Plan specific, measurable targets and consumer and/or health outcomes that are monitored and reported on annually…." [6]

The COAG National Action Plan was the first opportunity since the development of the National Mental Health Strategy for governments to provide support in these critical areas of need to the sector outlined in this submission:

1. focus on human rights for mental health consumers including the elimination of seclusion and restraint
2. review of the way in which the National Mental Health Standards support the rights of consumers and carers
3. leadership and support for meaningful consumer and carer participation at all levels of policy development and implementation
4. review of the *Welfare to work* provisions.

The NMHCCF recognises that by focussing on early intervention and prevention, COAG sought to make a long term investment for better outcomes for mental health consumers and carers. However, by leaving out initiatives to address meaningful and not tokenistic consumer and carer participation in current service delivery and future policy development the COAG National Action Plan has not capitalised on the opportunity to invest in the most important and powerful resources in the planning and delivery of effective services for mental health consumers and carers: the meaningful participation of consumers and carers themselves.

[6] ibid