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**Response to the Review of the Mental Health Act 1990: NSW Health.**  
**Discussion Paper 1: Carers & Information Sharing.**

Dear Sir,

Thank you for providing the Mental Health Co-ordinating Council (MHCC) with the opportunity to contribute to the review of the NSW Mental Health Act 1990.

MHCC is the state peak body for non-government organisations (NGOs) working for mental health throughout NSW. MHCC represents the views and interests of over 140 NGOs in the formation of policy, and acts as a liaison between the government and non-government sectors. Our member organisations specialise in the provision of services and support for people with a disability due to mental illness.

In putting this document together, MHCC has consulted member organisations, stakeholders, consumers and carers.

MHCC strongly supports a review of the Mental Health Act. Whilst the Act as it exists attempts to address the issue of confidentiality, we welcome clarification of the processes that protect the rights of consumers to privacy, and address issues surrounding family and carers 'right to know' - the contentious issue between reconciling the consumer's right to confidentiality and the carer's need to know.<sup>1</sup>

The new *Health Records and Information Privacy Act 2002* (HRIP Act) commences on 1<sup>st</sup> July, 2004. MHCC is supportive of the determinations of this Act around protecting the privacy of individuals while at the same time allowing for limited disclosure of information to immediate family.

MHCC contends that the term 'carers' should be used rather than the term 'immediate family' as is the case within the HRIP Act and that the definition of 'carer' be defined as in The National Mental Health Plan 2003 – 2008:

*"Carer: A person whose life is affected by virtue of a family or close relationship and caring role with a consumer."*

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<sup>1</sup> **Furlong, M. and Leggatt, M.** (1996). *Reconciling the patient's right to confidentiality and the families need to know.* Australian and New Zealand Journal of Psychiatry, Vol 30, pp 614 – 622.



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The HRIP Act allows for limited disclosure to immediate family about a person's health without consent if the disclosure is necessary to prevent a serious and imminent threat to the life or health of the individual or another person. MHCC supports this approach and feels that the Mental Health Act should be amended to make it consistent with the HRIP Act. The wording in the HRIP Act protects the rights of consumers while at the same time allowing for recognition of carers. We would see interpretation of the HRIP Act as indicating the need for clinicians to be educated and supported to be able to make an informed professional judgement as to the level of carer involvement that is considered to be therapeutic for individual consumers and their ongoing mental health.

MHCC feels very strongly that *it is not enough to amend the Mental Health Act, it is also necessary to change the processes used by staff* in mental health so that the assessment of carer capacity and the support and involvement of carers is integrated into their work.

MHCC has identified a number of principles and processes in relation to the concept of carer involvement:

- Carers are critical to the care and wellbeing of many consumers.<sup>2</sup> Support of carers and the facilitation of their involvement is an integral part of best practice in mental health care.<sup>3 4</sup> Each Area Health Service needs to assess the ways in which mental health staff assist carer/consumer relationships. They should also produce guidelines for staff related to the involvement of carers;
- Due to individual differences in each family situation, it is difficult to achieve desired outcomes by across the board legislation on its own. Consequently legislation needs to be flexible enough to facilitate individual assessment of each consumer's situation by mental health clinicians. Assessment and clinical judgement processes should be further developed and improved by educational programs;
- It is essential that the willingness of carers to participate in a consumer's care, is assessed on an individual basis. It is also essential that carers who are willing to be involved in the consumer's care are individually assessed for their capacity to be involved. This would include an assessment of the carer's other commitments and time constraints, distance from the consumer, degree of understanding of the consumer's needs and ability to assist the consumer. Mental Health staff should be aware of issues surrounding the stigma of mental illness for both consumer and carer. Assessment guidelines should be available to assist staff in handling carer assessment in a supportive manner with maximum sensitivity. For example, staff need to be sensitive to the fact that the initial contact that they have with carers is often at a time of great stress for the consumer and carer. Consequently this may not be the best time to make a definitive assessment of the carer's willingness and capacity for involvement in the consumer's care. The assessment needs to be ongoing so that allowances can be made for crisis points as well as changes in the carer's availability due to other events or commitments that may arise from time to

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<sup>2</sup> **Australian Health Minister's Advisory Council's National Mental Health Working Group.** (1997) *National Standards for Mental Health Services*. Canberra: Commonwealth of Australia.

<sup>3</sup> **Australian Health Ministers.** (2003). *National Mental Health Plan 2003 –2008*. Canberra: Australian Government.

<sup>4</sup> **Australian Health Minister's Advisory Council's National Mental Health Working Group.** (1997) *National Standards for Mental Health Services*. Canberra: Commonwealth of Australia, p 12.

time. Similarly, if the carer is very distressed or completely exhausted due to a prolonged period of intense stress, it may be necessary for the carer to have a break before taking up the caring role again.

- Education and support must be available for carers to assist them in understanding and coping with the situations and processes involved in having a family member with a mental illness. Education and support is also needed to equip families and carers with the knowledge and skills necessary for them to assist in the provision of care and support to the consumer. This should occur before the consumer is discharged.

Carer assessment, involvement and support should be included as items in the consumer's care plan so that each consumer's situation in relation to carer involvement is assessed on an individual basis. Further, it is essential that clinicians ensure that information is communicated to carers that have a genuine involvement. Clinicians must be made aware that other people such as employers or lawyers involved in legal or custody cases may present themselves as carers in order to obtain information about the consumer against the consumer's wishes.

MHCC notes that the above principles are in accord with the National Mental Health Plan 2003 - 2008, which aims to recognise and support the role of carers, and to structure services recognising the efforts of carers and ensuring that the mental health and wellbeing of carers is maintained. The plan also advocates for improved information sharing with carers.

MHCC notes that references to carers in the Mental Health Act occur in various parts of the Act and, therefore, it can be difficult to locate them. Consequently MHCC would like to see a separate section in the Mental Health Act that included all information relating to carers and which included a reference to a carers' policy document. The carers' policy document should include the principles and processes identified above. There has long been confusion in this area. A separate section or appendix that included all relevant information and was supported by a relevant policy document would be a useful step in reducing confusion and promoting consistency of application in this critical area.

The proposed Carers policy document would need to include a review of the criteria against which a person is deemed capable of giving informed consent, and the development of guidelines that will better assist clinicians in decision making processes.

The document should include the proposal that every effort should be made on the part of clinicians, to obtain consent from the consumer to disclose information at a time when they are well enough to do so.<sup>5</sup> <sup>6</sup> In addition policy should also be developed to guide clinicians to encourage consumers to consider who they would like to nominate as their carer/s and what information they would like to be shared with their carers. This should be documented in the consumer's file.

MHCC will now focus on the specific sections highlighted in Discussion Paper 1: Carers and Information Sharing.

### **3.5.1 Amend the Act to allow limited disclosure of confidential information about clients of mental health services without the consent of the client.**

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<sup>5</sup> Privacy NSW. (2004). *Best Practice Guide: Privacy and people with decision making disabilities*. Sydney.

<sup>6</sup> Australian Health Minister's Advisory Council's National Mental Health Working Group. (1997) *National Standards for Mental Health Services*. Canberra: Commonwealth of Australia.

***Comments sought in particular regarding:***

***Should the legislation be amended to allow sharing of information in these general circumstances?***

MHCC recommends that **Principle 10(c) of the Health Privacy Principles of the HRIP Act, Limits on use of Health Information**<sup>7</sup> be incorporated into **Section 289 of the Mental Health Act, Disclosure of Information;**

Principle 10(c) supports disclosure of information in situations where:

'It is reasonably believed to be necessary to lessen or prevent;

- a serious and imminent threat to the life, health or safety of the individual or another person,

or

- a serious threat to public health or public safety.'

MHCC contends that Principle 10 (c) of the HRIP Act is appropriate in this situation. If a person is placed under the Mental Health Act they have by definition the potential to pose a serious and imminent threat to the life, health or safety of themselves or another person or to public health or safety. It must be noted however that the issue of consent applies. Individuals must be assessed for their capacity to consent to the sharing of information. Application of the Mental Health Act alone does not negate an individuals rights to withhold consent to disclosure of their personal information. This must remain a judgement made by clinicians trained in assessing consumers' capacity to consent and supported by policy guidelines.

MHCC contends that information relevant to risk to either the consumer, carer, service provider or any other person should be included in such limited disclosure. To facilitate carers in understanding the implications of the information disclosed, MHCC recommends that relevant supporting education and information should also be presented.

***If so when should the information be disclosed?***

**b. With reference to HPP 10(c)** MHCC contends that information should be disclosed as required to facilitate the provision of optimal care for the consumer. **Part of the provision of optimal care includes the utilisation of the insights and resources of carers.**

***Should the person to whom the information relates be told of the disclosure?***

**c.** Every effort should be made to inform the consumer at such time as he or she is well enough. This is a matter of clinical judgement and should be determined by the treating team supported by policy and protocols on determination of capacity to consent.

***If so, should there be exceptions to such an obligation?***

Exceptions to this obligation to provide limited disclosure should only arise if service providers have knowledge of possible risk or harm.

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<sup>7</sup> **Health Records and Information Privacy Act 2002 – Schedule 1- Health Privacy Principles – Website-**  
[www.austlii.edu.au/au/legis/nsw/consol\\_act/hraipa2002370/sch1.html](http://www.austlii.edu.au/au/legis/nsw/consol_act/hraipa2002370/sch1.html)

**3.5.2 Rely on Health Records and Information Privacy Act for general Privacy protection, and replace the general confidentiality provision in the Mental Health Act with specific disclosure provisions.**

**Comments sought in particular regarding:**

**Should Section 289 of the Mental Health Act be repealed?**

No. MHCC recommends that **Principles 10 (c)** (as outlined on page 4 of this submission) **of the Health Privacy Principles of the HRIP Act, Limits on use of Health Information** be incorporated into **Section 289 of the Mental Health Act, Disclosure of Information.**

MHCC believes that incorporating the above principle into Section 289 of the Mental Health Act will provide adequate provision for limited disclosure to carers while safeguarding consumers' privacy and allowing sufficient scope for clinical judgement to be applied.

**Should existing notification provisions in the Mental Health Act be revised to place the onus on the Medical Superintendent to notify appropriate carers?**

Yes, however the points made below also apply here.

**Should new provisions be inserted that require the Medical Superintendent to notify carers or relatives when a person is admitted or discharged under the involuntary detention provisions of the Mental Health Act?**

Yes. It is imperative that specific disclosure provisions are included in the Act to alleviate the stress experienced by carers with regards to involuntary admission and discharge notification. MHCC notes, however, that at the time of discharge it is expected that the consumer be well enough and have the capacity to make decisions around who they would like notified. Exception should be made for people discharged under a Community treatment Order.

**Should the person to whom the information is related be told of the disclosure?**

Yes.

**If so, should there be exceptions to such an obligation?**

Yes. If the consumer is very unwell and the clinician's clinical judgement is that it may be inappropriate to inform the consumer of the disclosure, and may put the consumer at risk of self harm or other person/s at risk of harm from the consumer. However, the consumer should be informed as soon as he/she is well enough.

**3.5.3 Amend the Mental Health Act to enable guardians, family and primary carers to obtain an interim court order for the release of confidential information from the health care provider.**

**Comments sought on this proposal:**

There should be the opportunity for carers to obtain information via a court order if they feel entitled to information that the health care provider is unwilling to give. An avenue of appeal should be available. However, the disclosure provisions of the HRIP Act, together with clear and specific disclosure provisions in the Mental Health Act should ensure that the need for such court

action should be minimal. An education program and policy guidelines related to disclosure would need to be instituted for clinicians and service providers.

#### **4.2.1 Getting the message across – listening to carers.**

**Comments on expansion of “community care facilities” to include the role of community carers in Section 4 of the Act.**

##### **Comments sought on this proposal:**

It is important that recognition of the role of carers is acknowledged in the Mental Health Act. However, we would not support their inclusion in the ‘Object,’ if their role were mentioned in the context of ‘control of person.’

Support is given to the proposal that information may be disclosed to ‘community carers’, provided that the information is reasonably required for the ongoing health of the consumer and provided that the person to whom the information is being disclosed is directly involved in providing care. **The safeguards and principles referred to in other parts of this submission also apply here.**

MHCC would like to see the term ‘community care facilities’ include non-government organisations who are closely involved in the ongoing care of consumers in the community as the primary carer. For the many, many consumers who do not receive care from family and friends, non-government organisations providing supported accommodation, employment programs or other rehabilitation services are the main point of care and support for a consumer.

The role and needs of community carers should be described comprehensively (as in the Victorian Mental Health Act – *Mental Health Act 1986*) to provide for the expansion of services that assist carers with the provision of information, education, support and respite; promote self-help and advocacy for people with a mental disorder; and minimise the adverse effects of mental disorders on the individual, the family and community.

#### **4.2.2 Inclusion of carers in discharge planning.**

##### **Comments sought on this proposal:**

Support is given to the amendment and expansion of Section 293(1) of the Mental Health Act, to include the role of a community carer in discharge planning as outlined in DP1, with the proviso that this applies only in instances where it is considered by clinicians to be therapeutic for the consumer and the consumer consents.

#### **5.2 Who is a carer?**

##### **Comments are sought in particular regarding:**

##### **Who should be included as a “carer” for the purposes of accessing care and information?**

Public Guardian, Office of Protective Commissioner and primary carers if directly involved in providing care and support including non-government service providers if they are the primary carer.

##### **Should the categories of carer be limited to those directly involved in care, or expanded to cover close family members and friends?**

Carer categories should only include persons who have extended responsibilities, and are directly involved in providing care and support. They do not need to live with the consumer, however the degree of involvement may intensify when the consumer requires more support.

***Should the right of a carer to access information apply only when patient lacks capacity, or should it apply more generally?***

The right of a carer to access information should only apply when the consumer lacks capacity. The degree of information shared by a consumer with a carer should be decided by the consumer when the consumer is well. Good planning, provision of care and access to information should be collaboratively negotiated when the consumer is well so that provision at other times, when the consumer is very unwell, has already been negotiated and documented in the consumer's file. MHCC promotes the view that clinicians should facilitate this process of advanced directives by consumers when they are well.

***Should a person have the right to prevent access to carers when that person has capacity?***

When the consumer has capacity, his/her right to prevent access to information by carers should be respected.

***E. What sort of protections could be put in place to ensure only legitimate carers and those providing ongoing support could access information and ensure the privacy of a patient is otherwise protected?***

Mental Health clinicians should ensure that they are aware of the consumer's legitimate carers and should only disclose information to them. This process can be facilitated if discussion, agreement and documentation of the consumer's advanced directive in relation to carer involvement is carried out when the consumer is well. Another method would be for clinicians to carry out a carer assessment as described above in MHCC's principles and processes in relation to carer involvement. Clinicians can further safeguard consumer privacy by ensuring that information disclosed is limited to the areas outlined below.

***5.3 What sort of information should be covered?***

***Comments are sought in particular regarding:***

***Should there be limitations on what sort of personal information can be disclosed to 'carers'.***

Yes, information should only be provided to carers if the information is reasonably required for the ongoing health of the consumer and the person who is receiving the information will be involved in providing the care. Additionally, the principles and processes on pages 2 and 3 of this submission, which refer to the assessment, education and support of carers should be followed.

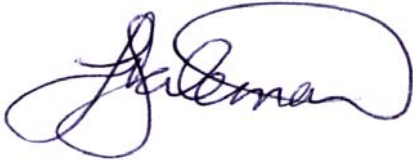
***If so, what form should these limitations take?***

Personal information should be limited to admissions, treatment, medication, legal procedures and discharge planning. When a client is in the community and wants to receive continued carer involvement, a carer should participate in treatment and support planning. Examples of personal information that should not usually need to be divulged would include any information not directly related to the carer's role. Information gained during the course of therapy sessions with

clinicians should be confidential unless there is clinical judgement that not to divulge the information could result in harm to the consumer or others.

Thank you for seeking our involvement in this legislative reform review. We look forward to participating in future discussion papers. Should you wish to discuss any issues surrounding this submission please contact Ann MacLochlainn or myself at MHCC, on 9555 8388.

Yours faithfully,

A handwritten signature in blue ink, appearing to read 'Jenna Bateman', with a large, stylized flourish above the name.

Jenna Bateman  
Executive Officer.