

30 May 2003

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Dear Ms Blamey

Thank you for providing the Mental Health Co-ordinating Council (MHCC) with the opportunity to contribute to the Privacy NSW Stakeholder Consultation: Draft Guidelines under the Privacy and Personal Information Protection Act 1998 (PPIP Act) on Consent and Capacity. 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 100 NGOs in the formation of policy and acts as a liaison between the government and non-government sectors. Our member organisations provide services and support people who have a disability due to mental illness.

MHCC strongly supports the promotion of equal rights and opportunities and the elimination of discrimination against people with disabilities and welcomes the development of improved PPIP guidelines for NSW public sector agencies and NGOs. Privacy and confidentiality laws shape the delivery of mental health services in NSW, from individual primary care through to state-wide data collection. We commend the openness of Privacy NSW to hear the concerns of consumers and providers as they seek to address the very real issues of consent and capacity that often don't match the blunt rules of legislation.

General Comments

The MHCC supports the intentions of Privacy NSW to review the guidelines on consent and capacity to assist agencies in meeting their obligations to people who have a disability and lack capacity at any given time.

Furthermore, the recent *Inquiry into Mental Health Services in New South Wales*, December 2002 addresses a range of issues relating to privacy, confidentiality and information and specific recommendations have been made. In evidence presented to the Committee, carers, families and advocates for people with serious mental illnesses raised questions about whether or not upholding a person's right to privacy was always compatible with delivering appropriate care. An excerpt has been enclosed for your reference. For your information and added referral we have enclosed the chapter on privacy, confidentiality and information taken from the Final Report.

Issues of capacity and consent are highly contentious ones that people are dealing with daily and trying to find a balance between client confidentiality and the value of transferring information for the benefit of that client. Typically, people with capacity issues have significant support needs. Avoiding unnecessary bureaucracy is crucial in order that confidentiality no longer becomes the rationale for pushing out the ever-important carer and withholding important information that will help them assist the person they are supporting. The challenge is finding a mechanism, in which information can be transferred when appropriate for the benefit of that person.



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Specific Comments

1. Guidelines

Whilst the draft guidelines are well laid out, there is a need for simplification of information to ensure correct interpretation and general access to the advised approach.

The inclusiveness of NGOs when referring to agencies is very important to break down the barriers to communication across the sectors and encourage working relationships. It is crucial to ensure there are no double standards between state and non-government agencies to encourage information sharing when appropriate and ensure the same degree of protection to a client, no matter where they find themselves in the system. We are all seeking to address the needs of people with cognitive disabilities and enhance the control of individuals over the way their personal information is handled. Acknowledging this gap in communication and addressing the problem with disclosure between agencies is essential.

2. Consent & Capacity

The complex area of consent and capacity may benefit by addressing the very shortcomings of fixed procedure. Whilst encouraging a guideline approach, decision-making will often require a joint evaluation / assessment.

A workable mechanism for the transfer of information will of course have its concerns with breaches of privacy. A possible audit process for access to health records may be necessary to monitor unauthorised access and use of information.

Our key concern is that the main carer be well considered in order that they are in a position to continue providing appropriate care, (eg. necessary medication) and in some cases to ensure their own personal protection through informed and up-to-date knowledge of the person's changing condition.

2.1 Consent

The right of people with a mental illness to privacy and confidentiality was acknowledged throughout the Mental Health Inquiry 2002. The anguish families and carers experience due to mental health information disclosure restrictions, however, was encapsulated in many personal accounts related to the Committee by witnesses and in submissions.

In reference to your specific guidelines, we believe that when seeking consent from a person, it is not enough to accept a verbal declaration or signature as one's perception of competency can be unreliable when they are actually lacking capacity and consequently are against their best interests. Seeking validity of consent requires a judgement of a person's manner in general and possibly accepting input from long-term providers and carers.

For the benefit of the person and other involved groups, agencies have an obligation to document consent changes to provide a subjective view of the changing nature of the person's ability to make their own decisions. Whilst the NSW Health Mental Health Outcomes and Assessment Tools initiative (MH-OAT) is currently being used as a way of standardising mental health records, there are concerns that such practical quality assurance activities may place unreasonable burdens on clinicians. It is important to remain mindful of not unnecessarily adding to the workload.

2.2 Capacity

The guidelines on assessing capacity are realistic in their broadness and flexibility. Whilst initial assumptions of capacity or past experiences are unreasonable indicators we believe it is reasonable to assess that a person is incapable of understanding the information or effects of a decision after being provided with support appropriate to their specific circumstances.

We believe that a flexible service delivery approach is necessary that will provide a general guide to treatment, as well as providing room for individual assessment. Whilst the guidelines must not assume the individual will always have capacity to make a decision, they should always be involved in the decision-making process.

The issue of cultural impact is one example where input is required from appropriate groups with specific knowledge and understanding of that person's situation. In this case participation from a family member or understanding support person would be necessary.

There is value in a joint approach, including both the client and groups with knowledge of the client and their changing condition, whilst always ensuring the main carer has significant input. Understanding the changing capacity of the person is important and access to past information or at least freedom of speech between agencies and institutions would be very helpful.

The system should also acknowledge the role of both clinical and community care information, given the importance of relevant non-health information to a person's health. Sharing information between agencies, government and non-government, and encouraging communication for the benefit of the client will help to further address some of the assessment difficulties.

3. What if a person lacks capacity?

When there is a lack of confidence in guardian input or a conflict between carers, other parties who have had ongoing involvement should be consulted. A decision making flow-chart or template of the process to be undertaken may be helpful.

Furthermore, the lack of a substitute consent person is often the case for people without a support network, such as the homeless. In these instances the decision often returns to the Public Guardian, which entirely removes the rights of that individual whilst also hindering agencies from providing suitable assistance.

There seems to be a general lack of clarity by health professionals, concerning current legislation addressing issues around consent. We also refer you to the Mental Health Inquiry and the attached chapter, which includes these very specific issues around consent and guardianship. Just two of the recommendations relating to this topic are:

Recommendation 30

That the Minister for Health and the Attorney General review the Guardianship Act 1987 with respect to people who suffer severe and /or episodic mental illnesses during which they are not capable of making informed consent. This review should include the possibility of enduring guardianship.

Recommendation 31

That the Centre for Mental Health and the Office of the Public Guardian work together to develop an information package for mental health professionals that:

- outlines their obligations as well as the rights of families and carers under relevant mental health, privacy and guardianship legislation, and
- clarifies the existing definitions of 'consent' and 'substitute decision-making' in mental health settings and communicate this clarification to mental health professionals.

In order to highlight the issue of limited disclosure to ensure immediate client care when necessary, we would also refer you to the following recommendation:

Recommendation 33

That the Minister for Health seek to amend the *NSW Mental Health Act 1990* to allow limited disclosure of confidential information about clients of mental health services without the consent of the client. These exceptions to confidentiality would allow information to be disclosed in the following circumstances;

- to guardians, family and primary carers if the information is reasonably required for the ongoing care of a client and the person who is receiving the information will be involved in providing the care and
- where it is required in connection with the further treatment of a client.

Certainly, MHCC supports the entitlement of people with a cognitive disability to equity in regard to the protection of personal information and accurate recording of information. We also acknowledge the greater risk of abusing the rights of people with a disability and the power imbalances that can occur. Moreover, carelessly recorded information that is not rigorously tested and re-evaluated can result in the circulation of false information that results in the incorrect treatment of that client. Consumer participation in reviewing and understanding information should be part of a more co-operative system.

The issues are broad and many and we hope that the recommendations will further inform the proposed guidelines for the benefit of consumers, guardians, and primary carers.

In conclusion, the MHCC appreciates the opportunity to contribute to this paper and commends the accessible presentation of the consultation to date. We acknowledge the complexity of addressing the issues of privacy yet promote the formation of a single simple system that provides user-friendly guidelines. Unfortunately a lack of accessible information on privacy issues remains following NSW Health's recent decision to knock back a training package for health professionals. We also support a system that encourages cross sector collaboration for the benefit of those seeking to retain their rights to privacy, whilst ensuring their own well-being.

Thank you for considering this feedback and if you would like to clarify any points in this submission, please do not hesitate to contact Stephanie Maraz on (02) 9555 8388.

Yours sincerely

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Mental Health Co-ordinating Council

Encl. Legislative Council. Select Committee on Mental Health. *'Inquiry into mental health services in New South Wales'*, Chapter 6, Privacy, confidentiality and information. Final Report. Dec 2002.

