

Director General.
Legal & Legislative Services
Department of Health
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**Response to the Review of the Mental Act 1990: NSW Health. Discussion
Paper 1: Carers & Information Sharing.**

Dear Sir,

Thank you for providing the Carers Working Group (CWG) with the opportunity to contribute to the review of the NSW Mental Health Act - 1990.

The CWG, established 18 months ago (under the auspices of the Mental Health Co-ordinating Council (MHCC)), consists of stakeholders, consumers, carers and interested parties who wish to respond to the Legislative Inquiry into Mental Health Services in NSW – Dec 2002. This submission reflects the views of the CWG, and is not necessarily representative of the broad MHCC membership.

The Act as it stands, attempts to address the issue of confidentiality and we welcome amendments to the legislation that will continue to protect the consumer rights to privacy. We also value the importance of acknowledging the issues surrounding families and carers 'right to receive information to assist them in their caring role.' Likewise, we welcome 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 CWG considers it critical that the Act allow for information sharing with carers to ensure the development of improved standards of care for mental health consumers in the community. The sharing of information with carers facilitates access to early intervention and treatment for consumers and reduces the risk of the negative consequences of mental illness such as poverty, homelessness and social isolation.

Members of the group include representation from the following organisations, consumers and carers of people with mental illnesses:

ARAFMI NSW
Hope Unlimited (Newcastle)
Carers Support Unit, Schizophrenia Fellowship
WAROMI (Relatives of the Mentally Ill)
Carers NSW
Sutherland Shire Suicide Safety Network
SWS Carers Network
Wentworth Area Carers Network



*Working For
Mental Health*

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*MHCC is the peak
Body for mental health
Organisations in NSW*

In answer to comments sought in the **Discussion Paper 1: Carers and Information Sharing**, the CWG respond as follows:-

THE PREFERRED OPTION OF THE CWG FOR DISCLOSURE OF INFORMATION TO FAMILY AND CARERS IS OPTION 1 OF DP1.

3.5.1

- a. The CWG endorse the “limited disclosure” of confidential information about consumers of mental health services without the consent of the consumer as proposed in Recommendation 33 of the Select Committee Final Report. In particular, they support the disclosure of information which is reasonably required so that a guardian, family or carer is able to provide the ongoing support and care required by the consumer, and where it is required in connection with further treatment of a consumer.

This amendment to the Act should include the proposal that every effort should be made on the part of service providers to obtain consent from the consumer to disclose information at a time when they are well enough to do so.

Information relevant to risk to either the consumer, carer, service provider or any other person should also be included in such limited disclosure.

- b. Information should be able to be disclosed prior, during and after all service delivery to consumers. This should include referral, assessment, care and discharge, and follow-up. Family and carers should be involved at all stages of the process.
- c. The consumer should be told that it is normal procedure for service providers to provide information to family and carers, even if the consumer is deemed unable to fully comprehend this information. Every effort should be made to inform consumers at such time as they are well enough.
- d. Exceptions to this obligation to provide limited disclosure should only arise if service providers have knowledge of possible risk or harm from family or carer. In such instances, alternative care arrangements must be put in place.

THE CWG SUPPORTS OPTION 2 FOR DISCLOSURE OF INFORMATION IN DP1 AS AN ALTERNATIVE APPROACH.

3.5.2

- a. Yes. Section 289 of the Mental Health Act should be repealed.
- b. Yes. Existing notification provisions in the Mental Health Act should be revised to place the onus on the Medical Superintendent to notify appropriate carers.
- c. Yes. It is imperative that specific disclosure provisions are included in the Act to alleviate the stress experienced by carers and family with regards to involuntary admission and discharge notification.
- d. Yes. It is of vital importance that, where possible, the consumer understands that information is disclosed to carers and families in order to support their treatment and recovery progress.

- e. Yes. When clinical judgement supports that it may be inappropriate to inform the consumer of the disclosure, and may put the consumer or other person/s at risk.

3.5.3

If the Mental Health Act were to be amended to facilitate limited disclosure, as discussed earlier in this submission, this proposal will not be necessary and is therefore not supported.

4.2.1

It is important that recognition of the role of carers is acknowledged in the **Objects** of the Mental Health Act. Changes in attitude to carers as part of the whole community based mental health system, are long overdue. However, we would not support their inclusion in the 'Object,' if their role were mentioned in the context of 'control of person.'

We support the proposal that information may be disclosed to families and carers, provided that the information is reasonably required for the ongoing care of the consumer, and that the person to whom the information is being disclosed is directly involved in providing that care.

The role and needs of community carers should be described comprehensively (as in the Victorian Mental Health Act) to provide for the expansion of services that assist carers. This would include 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

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.

5.2

- a. Public Guardian; Office of Protective Commissioner; family and primary carers if directly involved in providing care and support.
- b. Carer categories should be expanded to include persons who have extended responsibilities, and share in the care and supportive roles undertaken by other members of family or carers. They may not live with a consumer, but the degree of involvement may intensify when a consumer requires more support.
- c. When a consumer is well and able to provide detailed information the role of the carer may diminish but the individual will often agree to share information at this time. Good planning, provision of care and access to information should be collaboratively negotiated when a consumer is well so that provision at other times has already been negotiated. The suggested legislative amendment above would cover changes in circumstances.
- d. Yes. A consumer should be able to prevent information being disclosed if that person does not reside with that particular individual and has no contact through any process with a carer, unless past history indicates issues surrounding early intervention, and that this person needs to be informed at all times.
- e. It would be very difficult to legislate for the protection of privacy that would ensure confidentiality was maintained during such times when case management required the sharing of information across numerous service providers and carers. Existing legislative requirements are probably the best that can be expected to support such concerns.

However, the nominated carer/s or change of carer/s should be included in the planning process and incorporated into the ongoing support and care, so that information is only disclosed to those to whom it concerns.

5.3

- a. Yes. As defined in the proposal in the Discussion Paper 3.5.1 that Recommendation 33, “authorised disclosures” would be limited as follows: ***“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 further treatment of a client.”***
- b. Personal information should be limited to admissions, treatment, medication, legal procedures, carer rights and exit planning. When a consumer is in the community and wants to receive continued carer involvement, a carer should participate in treatment and support planning.

Thank you for seeking our involvement in this legislative reform review. We look forward to participating in future discussion papers.

Yours faithfully,

Corinne Henderson
On behalf of the Carers Working Group.