

submission

Submission by Privacy NSW
on the

Review of the Mental Health Act 1990 Discussion Paper 1: Carers and Information Sharing



privacy**nsw**

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Review of the Mental Health Act 1990

Discussion Paper 1: Carers and Information Sharing

About Privacy NSW

Privacy NSW is the Office of the NSW Privacy Commissioner. The Privacy Commissioner is the holder of an independent statutory office, created by Parliament under the Privacy and Personal Information Protection Act 1998. Privacy NSW is responsible for the administration of the *Privacy and Personal Information Protection Act 1998* (PIIP Act) and the *Health Records and Information Privacy Act 2002* (HRIP Act) that commences on 1 July 2004.

The functions of the Privacy Commissioner include making public statements about any matter relating to the privacy of individuals generally, and publishing reports and recommendations about any matter that concerns the need for, or the desirability of, legislative, administrative or other action in the interest of the privacy of individuals. This submission reflects the views of Privacy NSW. It does not necessarily reflect the views of the NSW Government.

Our experience in the issue of carers and information sharing

This submission draws on Privacy NSW's considerable expertise in providing advice and dealing with enquiries and complaints relating to mental health information privacy. In 2002-03, 35 (16%) of the 221 formal complaints finalised by Privacy NSW were regarding the handling of information about a person's health. Of these, 15 (7% of the total) were specifically about mental health information. We also received 2,848 informal enquiries in 2002-03, of which 298 (10%) were about the handling of health information.

In developing our best practice guide, Privacy and People with Decision-Making Disabilities,¹ Privacy NSW consulted with a wide range of stakeholders about issues of concern relating to the privacy of people whose capacity to make decisions is in question as a result of such conditions as mental illness. These stakeholders included public sector agencies, people with disabilities and their representative organisations, support persons of people with disabilities, community-based organisations, and health and legal professionals. We have also attended and/or spoken at numerous public forums exploring the privacy interests of people with mental illness and the interests of others in accessing information about them (Office of the Public Guardian and Attorney General's Department NSW Capacity Roundtable Consultation, March 2004; 28th International Congress on Law and Mental Health, September 2003; Confidentiality and the Rights of Carers, Law Week May 2003; Confidentiality and Criminal Negligence, Law Week May 2003).

From this experience we know that applying privacy legislation in the mental health sector requires a careful balancing of interests between those seeking to protect their information privacy and those who want access to another's personal

¹ (February 2004) online at: www.lawlink.nsw.gov.au/pc.nsf/pages/guidelines

information. We have observed that there is considerable confusion among service providers, carers and consumers about how privacy legislation applies in practice. We are aware that 'privacy' is sometimes used as a ready excuse for the complex ethical, clinical and legal issues facing service providers when handling information about a person with a mental illness. However our experience is that, once equipped with some factual information about how the principles in privacy legislation are intended to apply, problems that may appear intractable can be worked through by service providers, carers and consumers in an open, sensitive and privacy-respectful manner.

Overview of our position

Privacy NSW welcomes the opportunity to comment on the issues raised by Discussion Paper 1: Carers and Information Sharing (DP1). Confidentiality and, more recently, privacy are fundamental to the integrity of the therapeutic relationship between patient and professional. This can be seen particularly in the case of mental health when information is shared within trusted relationships to enable care and treatment. At the same time confidentiality and privacy protect information from disclosures that may have adverse or discriminatory effects for the individual to whom the information relates.

Privacy is sometimes regarded as being in conflict with the interests of carers and members of the public who may want or need to know information about an individual's health status. This is an unfortunate perception. Privacy is not an absolute right. Privacy laws recognise this by providing for exemptions to enable information to be shared when it is reasonable and/or necessary to do so. Privacy laws do not stop people caring for each other, or prevent information being shared when it is necessary for the safety of individuals or the public. However privacy laws do require that government agencies and organisations are open about their information handling practices and accountable to individuals and the wider community for decisions that impact upon privacy.

Improved education and guidance for mental health service providers is the key to making privacy laws work alongside other obligations to consumers. A better understanding of privacy laws is also one step in improving communication between carers, consumers and service providers.

Interaction of privacy legislation and MHA

DP1 notes that privacy laws have been passed since the *Mental Health Act* (MHA) in 1990, and that this is among the reasons why a review of the MHA is now appropriate (para 1.1). Privacy NSW agrees that it is appropriate to consider how privacy laws operate alongside other obligations of service providers in the mental health sector. However the enactment of privacy legislation does not affect the specific legal obligations of service providers under the MHA or other laws. This is because the privacy protection principles in the PPIP Act and HRIP Act are subject to a range of specific and general exemptions within these Acts, including where another law reasonably requires or contemplates non-compliance with the privacy protection principles.

Privacy legislation should not be regarded as a substitute for confidentiality or secrecy provisions that are commonly contained in other legislation. The PPIP Act and HRIP Act only apply to 'personal information' and 'health information'; they do not protect other types of information that may not fall within these definitions. Moreover there is a risk that the extensive exemptions to the privacy protection principles under the PPIP Act and HRIP Act may not afford appropriate protection for information that is handled in the course of the administration of specific legislation such as the MHA and other health legislation.

Section 289

For the reasons above, Privacy NSW does not support removing s289 of the MHA. Similar confidentiality provisions are contained in the *Health Administration Act 1982* and the *Public Health Act 1991*. The purpose of these confidentiality provisions is to ensure that information obtained in the specific context of health administration and services is subject to high level protection against disclosure. This continues to be particularly important in the case of information about an individual's mental health, which if inappropriately disclosed may adversely impact upon an individual's personal, social and professional relations - despite efforts to remove the stigma associated with mental illnesses.

As with the privacy protection principles in the PPIP Act and HRIP Act, the confidentiality rule in s289 of the MHA is not absolute; information may be disclosed in certain circumstances as set out in s289. Guidance for health workers about the circumstances in which disclosure is permitted should be the subject of more detailed policies of service providers. Anecdotal evidence of service providers referring to s289 as the reason for refusing carers access to information (DP1: 3.5.2) is not a sufficient basis for removing s289. If s289 is misunderstood or misused in circumstances where information may in fact be lawfully disclosed, the solution lies in education and support for staff in decision making relating to information handling, rather than in removing a critical legislative safeguard.

Disclosure of information

As noted above, the privacy protection principles in the PPIP Act and HRIP Act are subject to a range of exemptions. Both the PPIP Act and the HRIP provide that agencies may disclose information 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. The HRIP Act, due to commence operation on 1 July 2004, also provides for exemptions to the general rule against disclosure in a range of circumstances set out in Health Privacy Principle 11. In addition, agencies may adopt Privacy Codes of Practice under the PPIP Act and HRIP Act that further modify the application of the privacy protection principles by providing additional exemptions from the standard of compliance normally required.

DP1 states:

It could be argued that the various categories of authorised disclosure set out in the HRIP Act, particularly the "directly related purpose" exemption provides sufficient legal authority to allow information sharing with carers (3.2.3).

Privacy NSW agrees with this as a general statement. However the 'directly related secondary purpose' test would not allow information to be automatically or indiscriminately disclosed to carers. If a person has capacity to consent but refuses the disclosure of their information to carers, or would not reasonably expect the information to be disclosed, the exemption does not apply. As the Guidelines on Privacy in the Private Health Sector by the Federal Privacy Commissioner stress, health service providers need to take care not to go beyond the understanding and expectations of the individual regarding disclosures of information.² While health service providers would not usually need to seek additional consent for necessary disclosures, this will depend on the circumstances of the case and the needs and wishes and the individual.³

DP1 notes that NSW Health has adopted a Privacy Code of Practice under the PPIP Act (para 3.2.1). This Privacy Code of Practice enables agencies to disclose personal information *to immediate family members where the information is necessary to provide appropriate care or treatment or is made for compassionate reasons* (Clause 6). The HRIP Act contains a similar exemption (Health Privacy Principle 11(1)(g), as noted by DP1 at para 3.2.2). The exemption is subject to the following conditions:

- (i) the disclosure is limited to the extent reasonably for those compassionate reasons, and
- (ii) the individual is incapable of giving consent to the disclosure of the information, and
- (iii) the disclosure is not contrary to any wish expressed by the individual of which the agency is aware

Therefore the above exemption only applies in cases where a person does not have the requisite capacity to consent. Individuals with capacity retain the general right to consent or refuse consent to the disclosure of their information to third parties, including family. This is entirely appropriate. There is no reason why persons with mental illnesses, where they can exercise capacity, should have their wishes overridden (other than in accordance with the circumstances provided in the exemptions to the privacy protection principles).

Disclosure of information without consent

DP1 proposes an option to amend the MHA to allow limited disclosure of confidential information about clients of mental health services without the consent of the client (para 3.5.1). It is not clear from DP1 whether this proposal is intended only to apply in situations where a person lacks the capacity to consent to the disclosure of their information, or whether it applies more generally, including to clients with the capacity to consent.

Privacy NSW has serious concerns if the proposal would enable service providers to override the legitimate wishes of clients who have the capacity to give or refuse consent to the disclosure of their information. The right to give or refuse consent to

² November 2001, p16; online at: www.privacy.gov.au/health/guidelines/index.html#1

³ Ibid, p17

the disclosure of one's personal information underpins the fundamental right of all individuals to respect for their autonomy. People with disabilities, including mental illnesses, have no lesser expectation than anyone else to this right. This is affirmed in the United Nations Declaration on the Rights of Disabled Persons⁴ (1975) which protects the equality of people with disabilities in relation to civil and political rights enjoyed by others. This principle is reflected in domestic disability law, including the Disability Services Act 1993 (NSW), that recognises specific entitlements of people with disabilities. These include the right of people with disabilities who receive services to be provided with those services in a manner which results in the least restriction of their rights and respects privacy and confidentiality.⁵

The principle of consent-based treatment has long been fundamental to the therapeutic relationship between patients and health workers. If a person retains the capacity to give or refuse consent to the disclosure of personal information, their wishes may only be overridden in the kind of limited circumstances recognised by the exemptions to the privacy protection principles. Disclosure of personal information without consent is a matter for professional judgement in all the circumstances of a particular case. Individuals who do not wish their information to be disclosed to relatives may have valid reasons, whether simply a personal choice or to protect their health and safety. An automatic statutory requirement to disclose information to carers (or an express or implied right of carers to obtain information) would undermine the right of people with mental illnesses to decide who has access to information about them.

What if a person lacks capacity to consent?

Individuals who lack the capacity to give or refuse consent to the disclosure of their information are entitled to the same protections of their personal information as anyone else. Privacy NSW recognises that service providers must balance complex clinical, ethical and legal considerations in cases where a person lacks capacity to consent to the disclosure of their information.

Neither statutory nor common law provides clear answers to many of these dilemmas. This may be frustrating but is not necessarily inappropriate. The 'right answer' to the question of when information about an individual who lacks capacity can be disclosed should be determined on the basis of all the circumstances the particular case. Privacy NSW's best practice guide on Privacy and People with Decision-Making Disabilities⁶ seeks to assist agencies in these difficult circumstances.

It is not possible to legislate for good judgement. The temptation to introduce an automatic notification requirement or other 'quick fix' should be carefully scrutinised. Legislative provisions that authorise the disclosure of information without appropriate limits may ignore the complexities of each case and unreasonably undermine the privacy rights of people with mental illnesses.

⁴ Online at: www.unhchr.ch/html/menu3/b/72.htm

⁵ Disability Services Act 1993, Schedule 1 Principles and application of principles

⁶ Above, 1

The way forward

Privacy legislation attempts to strike an appropriate balance between the protection of personal information and the circumstances in which information can be shared. Privacy NSW recognises that it is not always easy to strike this balance in practice. Service providers may be assisted in this process by organisational or sector-wide policies and guidelines that provide practical assistance while promoting compliance with the blunt instrument of the law.

Examples include the Office of the Federal Privacy Commissioner's Guidelines on Privacy in the Private Health Sector,⁷ the Mental Health Privacy Coalition's Privacy Kit⁸ and Privacy NSW's best practice guide, Privacy and People with Decision-Making Disabilities. The Privacy Kit recognises specific areas of concern for mental health providers about how privacy laws apply in practice. Privacy NSW's best practice guide deals with the particular issue of how privacy legislation should apply where a person lacks the capacity to consent to or understand how their personal information is handled.

It is instructive to consider the findings of the New Zealand Mental Health Commission's review of the NZ Privacy Act 1993 and Health Information Privacy Code. These included a lack of clear, consistent and good quality information-sharing policies specifically written for mental health services. The Commission summarised its findings as follows:

The review found that there is confusion and misunderstanding amongst clinicians about the requirements of the Privacy Act and the code, and their relationship with other key pieces of legislation, such as the Mental Health (CAT) Act 1992 and some provisions of the Health Act 1956.

While there has been some improvement in staff awareness of the legislation and the flexibility in how it can be applied, the Privacy Act is still being used as a reason to prevent sharing information that could or should be shared, when in fact the refusal is being made for clinical or other reasons.

The review concluded that information-sharing policies in mental health services are highly variable across [area health services], with significant gaps in some, as well as inaccuracies in others. Currently many of the services rely on their generic [area health service]-wide information-sharing policies.

Some clinicians feel that the information-sharing issues in mental health services are different from the general health information issues faced by the core health service, and that they must have specific policies in place to address the issues they experience in mental health services.

Many services still do not develop effective intervention partnerships with service users and families or significant others involved in supporting the service user. Staff need to see the benefits of working in partnership with service users and families/or

⁷ Above, 2

⁸ The Mental Health Coalition is comprised of the Australian Medical Association, Mental Health Council of Australia, Royal Australian and New Zealand College of Psychiatrists and the Australian Private Hospitals Association (APHA); online at www.spgpps.com/Documents/mhpkit.pdf

those people supporting the service user. They need to find ways to communicate more effectively with all parties involved.⁹

A better understanding of privacy legislation among service providers is a prerequisite to improved communication and partnerships between consumers and carers. Staff who are confident about their obligations will be able to ensure that information is shared when it is appropriate, and protected when it is not. They will be able to give clear reasons to consumers and carers about why they are choosing to either share or not share particular information. For example, the decision to withhold information may be a clinical one, rather than a legal one related to privacy laws. Or it may be related to a person's wish not to involve their family in their care at the present time, however, in the meantime the service provider may provide general educational information or referral to a support network. Privacy legislation should not be used to justify the lack of inquiry being made about the availability of family or community support, or revisiting at an appropriate time a consumer's decision not to involve their family in their care.

Appropriate policies and guidelines, supported by education and training of staff, are essential to this process. As DP1 notes, the implementation of the HRIP Act is being supported by an education campaign. However Privacy NSW is not sufficiently resourced to ensure that this campaign is "extensive" (para 3.4).¹⁰

Conclusion

A healthy culture of involvement for families and others involved in providing care to persons with mental illnesses depends upon a range of complex factors, from the manner in which mental health services are administered and funded, to interpersonal relations within families, to how the wider community regards and treats people with mental illnesses. It is relatively easy to amend legislation compared to effecting change at these levels of social and economic relations.

Legislative reform is no substitute for the changes that will make a real difference to the lives of people with mental illnesses and their families. Moreover, legislative reform that undermines the fundamental human rights of people with mental illnesses, including privacy rights, may adversely affect relationships between consumers, service providers and carers.

⁹12 February 2002 (p.7), online at: www.mhc.govt.nz/publications/2002/Privacy%20Review.pdf

¹⁰ Privacy NSW, with funding from NSW Health, employs 2 full-time officers dedicated to the implementation of the HRIP Act, on a contract basis. At this stage no funding has been allocated for responsibilities arising once the HRIP Act commences on 1 July 2004.