



REVIEW OF THE MENTAL HEALTH ACT 1990

Discussion Paper 1: Carers and Information Sharing

February 2004

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Part 1: Review of the Mental Health Act 1990

1.1 Background to the Review

The Mental Health Act 1990 was passed by the NSW Parliament in May 1990 and commenced shortly thereafter. At the time it was passed the Act was considered by some to be a high water mark in Australian mental health legislation in relation to the recognition it gave to the rights of persons with a mental illness. Prior to its introduction, the legislation had also been the subject of extensive consultation with both those with a direct interest in its provisions – most notably consumers, carers and health professionals – as well as the broader community.

Seeking the involvement of the community has always been a key feature of legislative reform in this area. The 1990 Mental Health Act was one of the first pieces of legislation in NSW to include a time limited review clause, with section 304 requiring the Minister to review the new legislation and report on that review to Parliament within 2 years of the commencement of the Act. The Mental Health Act Implementation Monitoring Committee was established by the then Minister to undertake the review in accordance with this provision. The Committee, which was chaired by Anne Deveson¹ included wide ranging membership from service provider and community groups to ensure consultation with the community remained a central part of the review process.

The Committee conducted the first, and to date only, review of the current legislation, focusing on issues arising from its implementation. The Final Committee Report was provided to the then Minister in August 1992². The recommendations in the Report provided the basis for a series of amendments to the Act passed in 1994 and 1997. There has been no substantive amendment of the Act since.

The Act has now been operational for thirteen years, and remains largely as passed in 1990. In the years since, however, there have been changes in the NSW Health system, changes in the way mental health services are organized and provided, and new regulatory developments such as privacy laws, which have directly impacted on the legislation. Given these changes, it is now appropriate to revisit the Act in a comprehensive manner and consider whether amendments are necessary to make it more effective and more responsive to the current needs of the community.

Clearly, some of the changes described above raise questions which go beyond the confines of the Mental Health Act itself, to the manner in which mental health services are provided, funded and administered by government. Many of these broader questions have been subject to recent comprehensive consideration and discussion, through the work of the NSW Parliamentary Select Committee on Mental Health which reported to Parliament in December 2002.

The Committee was established by the Legislative Council in December 2001, with extensive terms of reference to review provision of mental health services including funding, quality, staffing levels and community participation in those services.³ Over the following twelve months, the Committee received 303 submissions and heard evidence from 91 separate witnesses⁴. The Final Report, and its 120 recommendations represents a detailed picture of community concerns in relation to mental health services. It therefore provides an important context to this legislative review. In addition, while the focus of the Committee's inquiry was on service delivery, it made some recommendations for changes to the Mental Health Act, primarily based around its community participation terms of reference.

It is recognised a comprehensive review of the Mental Health Act must involve extensive consultation with consumers, carers, and health service providers. To ensure this in October 2003 the Department of Health wrote to a range of stakeholders seeking their views on issues to be included in the review. The issues raised as part of this consultation have provided a useful tool in guiding the work to date. The review will occur by way of two issues papers, each focusing on a key aspect of the legislation. The Papers to be issued will be:

Paper 1: Carers and Information Sharing
addressing information sharing issues identified by the Parliamentary Select Committee and the impact on mental health services of developments in privacy law.

Paper 2: Operation of the Mental Health Act
looking at the general terms of the Act, including current admission processes, to consider mechanisms to improve access and care as well as looking at the forensic system, including the structure for review and release of forensic patients.

1.2. Issues Paper 1

The current Paper is designed to raise issues involving the use and sharing of information in NSW Health, as it impacts on people with a mental illness and their carers, friends and relatives.

It is considered timely to address these issues in the light of developments in privacy regulation since 1990, and the concerns raised by both the Report of the NSW Mental Health Sentinel Events Review Committee⁵ released in December 2003 and the Parliamentary Select Committee during its public hearings. The Sentinel Events Committee made specific recommendations⁶ identifying the need to ensure carers have sufficient information to enable them to be involved in important care decisions. The Committee has requested this be implemented by April 2004. It should be noted that the current review of the Mental Health Act 1990 is the appropriate process to address these recommendations.

The work of the Parliamentary Select Committees has proved particularly useful in developing this Paper, with the key issues raised for comment drawn from material collected by the Committee and the discussions and recommendations in Chapter 6 of the Committee's Final Report. The Paper outlines a range of options to address the information sharing issues raised, with submissions and comments sought on those options.

Comments sought by 30 April 2004

Comments on the issues raised here are invited by 30 April 2004. It is proposed that once comments have been received and considered on both Issues Papers in the Review, a consultation draft Bill will be developed. Further consultations will then occur on this draft prior to introduction into Parliament.

**Comments should be directed to Legal and Legislative Services
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Part 2 : The Debate on Information Sharing

2.1 Privacy and Confidentiality in the NSW Health System

Information about a person's medical status has always been considered by the community as highly sensitive information. Over the years the law has developed a range of safeguards to prevent the improper release of such information, first through common law duties of confidentiality imposed on health professionals, and more recently through statutory privacy schemes designed to regulate information use and disclosure. In each case, policy and law makers have sought to achieve a fair balance between the individual patient's autonomy and right to control who may access information about him or her, and the community's need to safeguard the health and safety of individuals and the public and promote safe and effective health service delivery.

Debates about the right to privacy of information focus on the potential misuse of health information, with additional community concern generated by the opportunities offered by new technologies to link the records of individuals held by different organisations. The debate often emphasises the primacy of patients' autonomy, linking their right to decide who will see information about their medical and health status to their right to consent or refuse treatment.

Concerns about inappropriate disclosure are also heightened in relation to certain categories of health information, such as information about sexual health, genetic characteristics or mental health, given that these types of information have the potential to be highly stigmatizing. As a result, such information has often attracted higher levels of protection as privacy policy has been developed⁷.

Questions are now arising however as to whether the current balance in the law adequately addresses some issues arising in respect mental health services, particularly in how that balance appears to impact on those family members, friends and other persons who provide day to day care and support for persons with a mental illness. These questions were highlighted by the NSW Select Committee on Mental Health Services. The Committee identified the ability of carers to obtain information about a family member with a mental illness as a critical concern of individual carers and carer groups who gave evidence or made submissions to the Committee. As the Committee's Final Report noted :

*"While evidence from carers, families and rehabilitation services endorsed the right of mental health service users to confidentiality and privacy, where a serious mental illness was involved, many families, carers and NGOs expressed frustration with the inconsistent application of privacy and confidentiality principles."*⁸

Concerns expressed to the Committee went both to possible problems with the laws on confidentiality and privacy as well as to how the current law actually

works – or does not work – in practice. The purpose of this Paper is to explore some of these issues, and raise for comment suggestions for legislative change which may be available to deal with both aspects of the problem.

The Paper therefore concentrates on two questions :

- Does current legislation properly *permit* the disclosure of information to carers, either on specific issues such as informing family and friends of admissions, to the more general provision of information on ongoing care or treatment?
- Does current legislation *support* carers involvement in treatment planning and ongoing care issues, including facilitating the consideration and use of patient information provided by carers in planning and management of the health care of mental health clients?

In considering these questions, the paper seeks to identify legislative options which may be available to encourage a culture of involvement for families and others involved in providing care to persons with mental illnesses.

2.2 The Privacy debate in Mental Health Service provision

The general terms of the broad privacy debate have already been outlined above. It is worth recognising however, that a range of additional specific questions and issues arise when the balance between public and private interest is considered in the context of mental health information and mental health service provision. These issues provide the context in which any discussion about amending the Act needs to occur. Some of these issues can be seen to suggest grounds for maintaining or increasing privacy protections in this area, while others recognise competing public interests which, in limited circumstances, would support additional grounds for disclosure. The various arguments are set out below to give background to the options raised in the Paper.

2.2.1 The nature of “mental health information”

As already noted above, information about a person’s mental health, their access to mental health services or admission to a psychiatric facility is generally considered to be highly sensitive information. While progress has been made in breaking down long held misconceptions and prejudices, the situation remains that the general community is not well informed about mental illness. Those who have a mental illness can still be subject to discrimination in their workplace, in service provision and simply in day to day living. The law recognises the vulnerability of these individuals, with legislation such as the NSW Anti-

Discrimination Act providing a means to address such discrimination. The fact remains however, that information about mental health status can be extremely stigmatising. Given this, there are strong arguments that existing privacy protections need to be maintained.

2.2.2 Capacity

The general privacy debate on health information sees patient autonomy, the right to decide on treatment and the right to decide who will see information about their medical and health status as a primary consumer right. This right is however based on the presumption that the person will have the capacity both to exercise the right and understand the consequences of their decisions, and be in a position to take responsibility for them.

This is a presumption which cannot always be relied on when providing mental health care. Mental illness can mean a person lacks capacity for long periods of time or may suffer episodes where their capacity is impaired due to their illness. While substitute decision making processes can address some of these issues, a broader question also arises as to whether society, through the law, should intervene and dictate decisions on when sharing of information is appropriate.

A similar question lies at the heart of mental health legislation, whereby society has effectively intervened via statute to dictate circumstances where care and treatment must occur. The argument follows therefore that similar intervention may be justified in relation to information sharing, when information can be a critical factor in determining care and treatment decisions.

2.2.3 The “therapeutic alliance” with the patient

Patient openness and willingness to provide full details of their illness is critical to providing effective treatment for mental illness. A relationship of trust between patient and provider is required to encourage such openness. It may be argued that an expansion of the circumstances in which personal health information can be disclosed to family members and carers without the patient’s consent has the potential to erode the relationship of trust between the patient and health service provider. This may result in a reluctance to provide confidential information with a consequential adverse impact on care.

2.2.4 Reliance on Care in the Community

Beyond the more general discussion on the broad principles which should be applied in determining the balance between the individual and society in this

area, there are also more practical arguments to consider, arising directly from the way services are increasingly provided to persons with a mental illness.

Service provision models have changed considerably since the Mental Health Act was passed. The care for mentally ill persons has increasingly moved into the community with a wide range of services provided by Non-Government Organisations (or NGO's) and family and friends. As the health system places more reliance and responsibility for day to day care on such groups and individuals, it follows that this expanded role requires participation in care decisions, something which can only be achieved with access to necessary information. Indeed, it could be argued that community and family carers should be seen as part of the care team, along with professional care providers such as case managers, social workers, nurses and medical practitioners, in their information needs.

Part 3 : Disclosure – Sharing Information with Carers

One factor that became apparent from both the evidence given to, and conclusions reached by the NSW Select Committee was the considerable confusion that exists as to the exact limits and content of privacy obligations in NSW, and how they interact with the provisions of the Mental Health Act. The Committee particularly noted :

... the current inconsistent application of privacy and confidentiality principles in the NSW mental health system in relation to patients, guardians, families, carers, and other service providers...⁹

Before examining further the issue of legislative change, it is therefore useful to outline how privacy law currently impacts on information sharing in mental health services in NSW and the current provisions of both mental health and privacy legislation.

3.1 The Mental Health Act

The Mental Health Act already contains a limited number of provisions which allow for the sharing of information with the relatives of persons who have a mental illness. The current provisions are as follows:

3.1.1 Notifying relatives of a Magistrate's hearing

Section 38 of the Act deal with persons who have been admitted as an involuntary patient under the Act, and requires them to be brought before a Magistrate to determine if they are a "mentally ill person" under the terms of the Act as soon as possible. In addition, the provision has a notification to relatives clause, which reads:

- (3) *The medical superintendent must, in accordance with the regulations¹⁰, do all such things as are reasonably practicable to give notice to the following persons of the medical superintendent's intention to bring the person in respect of whom any such advice is furnished before a Magistrate:*
- (a) *the nearest relative¹¹, if there is one, of the person or a relative nominated by the person,*
 - (b) *the person's guardian, if any,*
 - (c) *any personal friend or friends of the person, up to 2 in number.*

Section 38(4) however limits the scope of the notification, stating:

Notice need not be given to the nearest relative or any personal friend of the person if the person objects to it being given.

Concerns have been raised that the terms of subsection (4) may inappropriately limit notification being made to relatives, particularly given that the capacity of the person being held is very likely, at this point of time, to be compromised by their illness. The provision also focuses on notification of a “relative” or “nearest relative” of a person, rather than carer. While the “near relative” and “nearest relative” are defined at some length in the Act, linking notification to the caring role played by a person may be a more appropriate approach.¹²

3.1.2 Opportunity to attend and appear at a Magistrate’s inquiry

Under section 41(4), a Magistrate’s inquiry is to be open to the public unless the person brought before the Magistrate (or their representative) objects and the Magistrate upholds the objection. Subject to such an objection therefore, a relative or carer who has been notified of the hearing may attend. In addition, section 43(2) provides:

A person who is the nearest relative, if there is one, the guardian or a personal friend of, or a relative nominated by, the person brought before the Magistrate may, with the leave of the Magistrate, appear at an inquiry.

The Act therefore allows a limited right for a relative or other person described in the provision to appear and speak at the Magistrate’s inquiry. Again, such a right is limited as it depends on the discretion of the Magistrate and, as with the other notification provisions of the Act, focuses on the relatives of a person rather than those involved in their care.

3.1.3 Notification of transfers

Sections 78(1) and (2) deals with the transfer of persons who are held in a hospital as temporary patients or continued treatment patients. Under section 78(3):

an authorised officer or medical superintendent is required, before making an order under subsection (1) or arrangements under subsection (2), to do all such things as are reasonably practicable to give notice:

- (a) *to the nearest relative, if there is one, of the patient or a relative nominated by the patient, or*

- (b) *if there is no such relative, to a personal friend of the patient who is either known as, or is said by the patient to be, his or her personal friend,*

of the proposal to transfer the patient and the reasons for the transfer.

Unlike the notification occurring at the time of the Magistrate's hearing, which allows the person detained under the Act to object to the notification, section 78(4) only allows notice *not* to be given in circumstances where the transfer constitutes an emergency. In this case the notice is to be given "as soon as practicable" after the transfer is made.

3.1.4 Discussion

The terms of the above provisions very much reflect discussions at the time the 1990 Act was passed. The categories of persons recognised as entitled to information therefore do not tend to reflect the same groups of people who may now be said to have an interest in the information – particularly where they are the mentally ill person's ongoing care provider in the community. The point at which information is required to be shared under the Act and the kind of information which can be given may also not reflect patient and carer needs.

There is also a degree of internal inconsistency with the provisions, not only in relation to who can be given the information, but also the constraints imposed around when the information can be given, and when and how the views of the person admitted under the Act are to be addressed. Finally, as the evidence before the Select Committee suggests, there appears to be a degree of uncertainty and lack of knowledge about the availability of these mechanisms for accessing information.

3.2 Privacy legislation

3.2.1 Privacy and Personal Information Protection Act 1998

The current law applying to the NSW public sector is the Privacy and Personal Information Protection Act. This Act, which commenced operation in July 2000, introduced a set of Information Protection Principles which regulate the collection, use and disclosure of personal information. Section 19 of the Act deals with disclosure of personal health information, and provides only very limited circumstances in which this type of information can be disclosed. These are:

- where the person to whom the information relates has expressly consented to the disclosure¹³;

- where the consent of the person to whom the information relates cannot reasonably be obtained, and the disclosure is made to a health service provider involved in the care or treatment of the individual¹⁴;
- Where the disclosure is necessary to prevent a serious or imminent threat to the life or health of the individual concerned or another person¹⁵.

As part of the implementation of the Privacy and Personal Information Protection Act, NSW Health worked to ensure appropriate provisions were included in a NSW Health Code made under the Act to allow for the reliance on substitute decision makers and to extend the “treatment disclosure” noted above, to cover disclosures to health service providers in the private sector. Concerns remain however, as to the adequacy of this legislation to properly reflect the necessary flows of information in the health system.

3.2.2 Health Records and Information Privacy Act 2002

The above concerns were one of the factors which lead the Government to enact the Health Records and Information Privacy Act 2002. That Act effectively removes the regulation of health information from the Privacy and Personal Information Protection Act and establishes a revised set of Health Privacy Principles to regulate health information in both the public and private sector.

While the Health Records and Information Privacy Act is yet to commence¹⁶, once it becomes operational, its terms will determine questions of disclosure of mental health information. The new legislation seeks to fine tune privacy principles to recognise specific health issues impacting on collection, use and disclosure of health information.

Health Privacy Principle 11(1)(g) is one of the revised provisions identified by the Select Committee. This provision allows disclosure if the purpose of the disclosure is to provide the information to an immediate family member of the individual for compassionate reasons. In addition to this provision discussed by the Select Committee, there are also a number of other relevant provisions in the Health Records and Information Privacy Act. These include Principle 11(2), which allows disclosure where the disclosure is “lawfully authorised”, ie, where this is:

permitted (or is necessarily implied or reasonably contemplated) under an Act or any other law (including the State Records Act 1998),

This provision makes it clear that the privacy legislation¹⁷ will accommodate disclosures authorised by the Mental Health Act (either those currently in the Act as outlined above, or indeed, any future provisions added to the Act as a result of this Review).

In addition, Principle 11(1)(b) allows disclosure of information without the consent of the patient where:

the purpose of the disclosure is directly related to the purpose for which the information was collected, and the individual would reasonably expect the organisation to disclose the information for the secondary purpose,

This provision was specifically designed to recognise, that while the primary purpose of collecting health information may be for immediate patient care, there will also be range other activities, consequent upon that care that are of “directly related”, such as, for example, any sharing of information necessary to provide proper medical treatment or provide ongoing care to a patient..

3.2.3 Discussion

It could be argued that the various categories of authorised disclosure set out in the Health Records and Information Privacy Act, particularly the “directly related purpose” exemption provides sufficient legal authority to allow information sharing with carers. On the other hand, it is also recognised that the terms of the Act provide only general guidance, and do not specifically recognise the non-professional carer role. Given this and the strong concerns expressed by carers to the Select Committee, it may therefore be argued that a more explicit legislative statement of their ability to obtain information should be considered.

3.3 Confidentiality

3.3.1 Health service providers’ common law duties

It is generally accepted that health service providers owe patients a duty of confidentiality quite independent of any rights or duties established by privacy laws. The duty is accepted to have roots both in the law of contract, ie, arising from the contract for service between a provider and a patient, and in equity, via the so called fiduciary duty of an individual practitioner to his or her patients.

The law also recognises however that this duty is not absolute and there are circumstances where a provider may “breach” the duty and lawfully disclose information obtained as part of their treating relationship. These situations generally reflect the categories of lawful disclosure recognised by privacy legislation, and include:

- *Where the patient has consented to disclosure, or waived their right to confidentiality.* This may be said to occur for example, where a

information is shared with other health service providers involved in the ongoing care of a patient;

- *Where there is a statutory basis for the disclosure.* There are many examples of situations where legislation imposes a positive statutory obligation on a practitioner to provide information. For example, provisions for the mandatory notification of suspected child abuse, and provisions in public health legislation requiring reporting of certain notifiable diseases. This would also include information provided in accordance with the requirements of the Mental Health Act, outlined at 3.1 above.
- *Where a disclosure is made “in the public interest”.* This recognises that there will be circumstances where the public benefit of certain information being disclosed is sufficient to outweigh the public interest in maintaining confidentiality. The exact nature and extent of this interest, and when it will apply however, remains vague, with the few cases considering the issue generally turning on the very specific facts put to the court.

While it appears likely that law would support disclosures made as a matter of urgency to protect the life and safety of a patient or another person, what they would conclude on the more general question of sharing information with community care givers, as opposed to other health service providers, is uncertain and this question has not been considered by an Australian court.

3.3.2 Discussion

Some of these categories, particularly the concept of a public interest disclosure arguably appear directly relevant to the information needs identified by the Select Committee. At the same time however, it must be recognised that the exact bounds of the confidentiality duty – and the circumstances where it can lawfully be breached – remain uncertain.

3.4 A need for change?

It could be argued that the categories of authorised disclosure contained in the Health Records and Information Privacy Act, along with the specific disclosures sanctioned under the Mental Health Act, in themselves contain sufficient legal authority to allow information sharing with carers. The key issue would therefore be ensuring that individuals working in the health system are both aware of and use the law appropriately, the emphasis being on education. In this regard, it is noted that the implementation of the new Health Records and Information

Privacy Act will be supported by an extensive education campaign, in line with recommendations made by the Select Committee.

While this position has some validity, it is clear that the confusion and concern over privacy remain widespread in both the general community and among mental health service providers. Part of this confusion clearly arises from lack of clarity in the law, both under statutory privacy schemes and common law duties of confidentiality, as to the extent to which disclosures of information to carers and family are permitted.

This suggests some more formal and specifically targeted legislative change may be necessary. Providing decisive guidance in the Mental Health Act would arguably address potential conflicts which might otherwise arise in deciding if disclosure is appropriate to carers. The inclusion of more specific recognition of information needs in the Mental Health Act may thus serve to emphasise some of these concepts and provide clear direction and support for consumers, carers and health service providers using the mental health legislation.

3.5 Options

It is in this context that the following options for change to the Mental Health Act are discussed. Comments are invited as to the appropriateness and practicality of each of the suggested options, as well as any suggestions for further or alternative change to address the issues raised in this section of the Paper.

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

This proposal is based on Recommendation 33 of the Select Committee Final Report. The Committee proposed that the “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 the further treatment of a client.

The Committee also quoted with approval section 120A of the Victorian Mental Health Act, which also allows disclosure for management purposes, to prevent risk to a person or the public or when a person is missing or dead. As noted above, disclosure for most of these issues will be allowed under the terms of the yet to be commenced Health Records and Information Privacy Act

The question then arises as to whether such an amendment is appropriate as an educative tool, and as a means of clarifying the duty of confidentiality of individual health service providers

Comments are sought on this proposal. In particular:

- **should the legislation be amended to allow sharing of information in these general circumstances?**
- **if so, when should the information be disclosed?**
- **Should the person to whom the information relates be told of the disclosure?**
- **If so, should there be exceptions to such an obligation?**

3.5.2 Rely on the 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

The Select Committee noted much anecdotal evidence that service providers referred to the statutory confidentiality provision in section 289 of the Mental Health Act as their rationale for refusing carers access to information. Thus one alternative means of addressing the information sharing problems identified by the Committee may be to simply remove this confidentiality provision from the Act, and rely instead on the general terms and permitted disclosures of the Health Records and Information Privacy Act. Any gaps in the categories of authorised disclosure under that Act (as discussed at 3.2.2 above) could then be addressed by specific statutory provisions in the Mental Health Act. Disclosures under these provisions would, as already noted, be lawful under the Health Records and Information Privacy Act as they would be “lawfully authorised” by the Mental Health Act.

Some of the specific changes to authorisations to disclose under the Mental Health Act could then include:

- clarification and standardisation of the existing notification provisions outlined above to establish a presumption that the Medical Superintendent must attempt to notify appropriate relatives/carers.
- Insertion of new provisions into the Mental Health Act to allow the automatic notification of a known carer/person responsible when a person is admitted or discharged under the involuntary detention provisions of the Mental Health Act

Such provisions would build upon existing notification requirements, and would provide a straightforward right to information at critical points.

Comments are sought on this proposal. In particular:

- **should section 289 of the Mental Health Act be repealed?**
- **should existing notification provisions in the Mental Health Act be revised to place an onus on the Medical superintendent to notify appropriate carers?**
- **should new provisions be inserted to 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?**
- **should the person to whom the information relates be told of the disclosure?**
- **If so, should there be exceptions to such an obligation?**

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 a health care provider

This option is based on Recommendation 38 of the Select Committee Final Report¹⁸. The aim of the proposal is clearly to provide a mechanism to force access to information in situations where there may be serious fears for a family member. Consideration however needs to be given to the practicality of this option.

Arguably, ensuring the law itself provides clear and appropriate guidance as to the circumstances when disclosure is appropriate, and ensuring service providers are properly educated about these circumstances is a more direct and simple way of ensuring carer access to necessary information. The general disclosure provisions of the Health Records and Information Privacy Act, outlined at 3.2.2 above, accompanied by clear and specific disclosure provisions in the Mental Health Act, would readily achieve that end.

The advantage of the latter approach is that it simply involves compliance with clear statutory rules, and does not require a family to seek resort to a court to have the matter resolved. Court action of any sort is a costly and cumbersome means of progressing these issues, and may therefore not be readily accessible to large sections of the community. As such, there would be strong arguments to limit it to an option of last resort.

Care would also need to be taken in developing any such provision, to ensure that its introduction does not suggest any kind of limitation on other existing rights of access, nor establish a precedent that information can *only* be accessed by such means.

Comments are sought on this proposal.

Part 4 : Getting the message across – listening to the carers

4.1 The Problem

While this Paper has primarily looked at the issue of access by carers to information, the Select Committee also identified the need for service providers to listen to those who provide direct day to day care to family members. For example, the Committee noted evidence from one carer which emphasised the need to include families in assessment procedures:

Clinicians must avail themselves of all available sources of information if they are to do comprehensive information gathering. Thus the family needs to be involved in the suicide assessment procedure...Unfortunately my experiences show that family are not taken seriously or included in the assessment yet they know the person better than any psychiatrist can through a one hour interview¹⁹

The Committee noted that submissions such as this:

emphasised that not only do carers require information from mental health services to provide ongoing care, but they also need the opportunity to provide information when acute care may be required. At present, carers do not appear to have opportunities to either provide input or receive basic medical advice regarding the person they care for. In the case of people suffering from episodic illnesses, carers and families expressed the view that their ability to detect 'warning signs' or rapid deterioration needed be taken into consideration by health professionals, if early intervention is to work.²⁰

While identifying the problem, the Committee also accepted evidence which clearly indicated this was not primarily a legislative issue, as the NSW Consumer Advisory Group (NSW CAG) submitted :

While we note that the Mental Health Act precludes the giving of information to carers by mental health professionals without consumer consent, the Act does not preclude the right of carers to give information.²¹

The NSW CAG did go on to suggest however, that there were grounds to propose adding such a right to the Mental Health Act, stating :

The rationale for adding this right for carers and advocates flows from the Mental Health Statement of Rights and Responsibilities (Australian Health Ministers 1991, p 18, para 1-3). This states very clearly that carers/advocates have rights to initiate contact and give relevant

information to service providers. This request should not contravene issues of confidentiality but is often denied carers on that ground.²²

Even accepting the conclusions reached by the Committee, it must be recognised that legislation cannot simply require health practitioners to automatically include carers or require information from them to be collected and used. Ultimately, care and treatment decisions must rely on the judgement of health professionals to ensure appropriate clinical decisions are made on appropriate grounds.

The question is how best to design a legislative right “to initiate contact” which ensures there will be a meaningful involvement of care providers in the ongoing treatment and care decisions and that pertinent information from carers is properly incorporated into the clinical decision making process.

4.2 Options

The Department welcomes comment on the following options.

4.2.1 Recognition of the role of carers in the Mental Health Act?

A key aspect of the work of the Parliamentary Select Committee was to demonstrate forcefully the major support and care role undertaken by community carers, particularly family and friends, of persons with a mental illness.

As can be seen from the foregoing discussion, many of the frustrations expressed by these groups to the Committee are as much related to a lack of understanding by health service providers about the options available under the current law, as to difficulties in the law itself. In seeking to address this aspect of the problem, it needs to be recognised that legislative change generally can only go so far to modify behaviour, and particularly in relation to the issue of ensuring carers are more closely involved in care decisions, may not of itself fully achieve this aim. Thus, providing a right “to be heard” will not necessarily mean providers will automatically collect and use information provided by carers.

There is, however, one additional legislative option which may assist in ensuring service providers recognise the role of carers and the information they can provide. It would also support the type of culture change which the findings of the Select Committee suggest is required.

Chapter 2 of the Mental Health Act contains four sections setting out the objects of the Act, the objects of the Department of Health under the Act and the functions of the Director General of the Department of Health. The main objects clause is section 4, which states:

- (1) *The objects of this Act in relation to the care, treatment and control of persons who are mentally ill or mentally disordered are:*
- (a) *to provide for the care, treatment and control of those persons, and*
 - (b) *to facilitate the care, treatment and control of those persons through community care facilities and hospital facilities, and*
 - (c) *to facilitate the provision of hospital care for those persons on an informal and voluntary basis where appropriate and, in a limited number of situations, on an involuntary basis, and*
 - (d) *while protecting the civil rights of those persons, to give an opportunity for those persons to have access to appropriate care.*
- (2) *It is the intention of Parliament that the provisions of this Act are to be interpreted and that every function, discretion and jurisdiction conferred or imposed by this Act is, as far as practicable, to be performed or exercised so that:*
- (a) *persons who are mentally ill or who are mentally disordered receive the best possible care and treatment in the least restrictive environment enabling the care and treatment to be effectively given, and*
 - (b) *in providing for the care and treatment of persons who are mentally ill or who are mentally disordered, any restriction on the liberty of patients and other persons who are mentally ill or mentally disordered and any interference with their rights, dignity and self-respect are kept to the minimum necessary in the circumstances*

Section 4 has had a role in influencing the way in which providers and practitioners fulfill their roles and obligations under the Act. An amendment to this provision, to (for example) expand the reference to “community care facilities” to recognise the role of community carers – such as family and friends – would provide significant support and recognition of the role played by these groups, and would provide legislative guidance in the interpretation of the other provisions of the Act.

It is accepted that the above suggestion may be subject to criticism. In particular, some may argue that providing for the role of carers in the objects clause would impact on or diminish the rights of persons with a mental illness, and may discourage them from accessing services. At the same time the information available to date, particularly from the findings of the Select Committee, suggest that enhancement and recognition of the carer’s role may well lead to improved outcomes for persons with mental illness ensuring more streamlined care and timely access to treatment.

<p>Comments are sought on this proposal.</p>

4.2.2 Inclusion of carers in discharge planning?

Currently, section 293(1) of the Mental Health Act requires:

- (1) *If a patient is discharged from a hospital, the medical superintendent or the administrator (if it is an authorised hospital) must do all such things as are reasonably practicable to ensure that the person discharged is provided with appropriate information as to such follow-up care as may be available.*

The original aim of this provision was to provide for some continuity of care of the person after discharge into the community and to emphasise the need to properly plan for this ongoing care. One option would be to amend and expand this provision, to include a role for any community carer in the discharge planning phase. This would provide an opportunity not only for carers to obtain information about ongoing care issues, but to provide information and input into the discharge planning process.

Comments are sought on this proposal.

4.2.3 Other mechanisms

While the Paper has outlined two possible options, any additional suggestions for legislative change to address these issues are welcome.

Part 5 : Legislative Options : Setting the Boundaries

5.1 Legislative issues

If it is accepted that the issues raised in Parts 3 and 4 of this Paper should be addressed by legislation, it follows that careful consideration also needs to be given to how the new provisions are framed, both as to whom they allow information to be provided to and as to the kind of information they cover.

5.2 Who is a carer?

The Select Committee inquiries generally looked at the rights of both family and professional caregivers. Many of its recommendations referred generally to access necessary for “guardians, family and primary carers”.

In developing legislation however, those groups will need to be carefully and clearly defined, as the proposals may well give them potentially broad access to sensitive personal information.

Concerns about compromising the privacy of persons with a mental illness would be ameliorated if there is some clear legislative guidance given on this point, to ensure access will be limited to those with a genuine caring or support role in relation to the mentally ill person, and not persons, be they family members or others who may be only peripherally involved in care, and hence have no reasonable grounds for seeking or being provided with the information.

There are a range of terms used in different legislation which may be useful, from the current quite restrictive definitions of “near relative” and “nearest relative” used in the Mental Health Act to the more widely used formulas, designed to address substitute consent situations, such as contained in the Guardianship Act, the Health Records and Information Privacy Act. A copy of the varying definitions are set out in Appendix A to this Paper.

Comments are sought on the following issues:

- **Who should be included as a “carer” for the purposes of accessing care information?**
- **Should the categories of “carer” be limited to those directly involved in care, or expanded to cover close family members and friends?**
- **Should the right of a “carer” to access information apply only when the patient lacks capacity, or should it apply more generally?**
- **Should a person have the right to prevent access to carers when that person has capacity?**

- **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?**

5.3 What sort of information should be covered?

Clearly, the information held by health service providers and hospitals contains a range of details from general information to extremely sensitive details. It may be argued that consideration should be given to ensuring that any amendment, such as those discussed in Part 3 above, only permit the provision of specific information relevant to the carer's role. Seeking to impose such strictures may go some way to addressing privacy concerns about the disclosure. At the same time it should be recognised that this may be a difficult concept to codify.

Comments are sought on the following issues:

- **Should there be limitations on what sort of personal information can be disclosed to "carers"?**
- **If so, what form should these limitations take?**

- **APPENDIX A**

Definitions used to describe carers or substitute decision makers

Mental Health Act 1990

Schedule 1 Dictionary of terms used in the Act

"near relative", in relation to a person, means a parent, brother, sister or child or the spouse of the person and such other person or persons as may be prescribed as a near relative of the person.

"nearest relative", in relation to a patient (in Division 1 of Part 1 of Chapter 7) or in relation to a patient or a person under detention in a hospital (in Part 2 of Chapter 7), means:

- (a) if the patient or person has a spouse and is not separated from his or her spouse by order of a court or by agreement--the patient's or person's spouse, or*
- (b) except as provided by paragraph (c), if the patient or person has no spouse or has a spouse, but is separated from his or her spouse by order of a court or by agreement, the parents or the surviving parent of the patient or person, or*
- (c) ...*
- (d) if it is ascertained, or not able to be ascertained, that the patient or person has no spouse or surviving parent, or no particulars of the name and whereabouts of any such spouse or surviving parent may be ascertained--such person, if any, as, in the opinion of the person concerned to identify the nearest relative, has the care, or custody of the patient or person,*

but, if the person is a person under guardianship within the meaning of the Guardianship Act 1987, means the person's guardian.

Guardianship Act 1987

Section 33A – “person responsible”

- (4) Person responsible for another person**

There is a hierarchy of persons from whom the **"person responsible"** for a person other than a child or a person in the care of the Director-General under section 13 is to be ascertained. That hierarchy is, in descending order:

 - (a)** the person's guardian, if any, but only if the order or instrument appointing the guardian provides for the guardian to exercise the function of giving consent to the carrying out of medical or dental treatment on the person,
 - (b)** the spouse of the person, if any, if:

- (i) the relationship between the person and the spouse is close and continuing, and
- (ii) the spouse is not a person under guardianship,
- (c) a person who has the care of the person,
- (d) a close friend or relative of the person.

(5) **Operation of hierarchy**

If:

- (a) a person who is, in accordance with the hierarchy referred to in subsection (4), the "**person responsible**" for a particular person declines in writing to exercise the functions under this Part of a person responsible, or
- (b) a medical practitioner or other person qualified to give an expert opinion on the first person's condition certifies in writing that the person is not capable of carrying out those functions,

the person next in the hierarchy is the "**person responsible**" for the particular person.

3D. Circumstances in which a person "has the care of another person"

- (1) For the purposes of this Act, the circumstances in which a person is to be regarded as "**having the care of another person**" include (but are not limited to) the case where the person, otherwise than for remuneration (whether from the other person or any other source), on a regular basis:
 - (a) provides domestic services and support to the other person, or
 - (b) arranges for the other person to be provided with such services and support.
- (2) A person who resides in an institution (such as a hospital, nursing home, group home, boarding-house or hostel) at which he or she is cared for by some other person is not, merely because of that fact, to be regarded as being in the care of that other person, and remains in the care of the person in whose care he or she was immediately before residing in the institution.
- (3) In this section, "**remuneration**" does not include a carer's pension.

3E. Meaning of "close friend or relative"

- (1) A person is a "**close friend or relative**" of another person for the purposes of this Act if the person maintains both a close personal relationship with the other person through frequent personal contact and a personal interest in the other person's welfare. However, a person is not to be regarded as a close friend or relative if the person is receiving remuneration (whether from the other person or some other source) for, or has a financial interest in, any services

that he or she performs for the other person in relation to the person's care.

- (2) The President of the Tribunal may issue guidelines, not inconsistent with subsection (1), specifying the circumstances in which a person is to be regarded as a close friend or relative of another person.
- (3) In this section, "**remuneration**" does not include a carer's pension

Health Records and Information Privacy Act 2002

Section 8 – "authorised representative"

- (1) In this Act, "**authorised representative**", in relation to an individual, means:
 - (a) an attorney for the individual under an enduring power of attorney, or
 - (b) a guardian within the meaning of the *Guardianship Act 1987*, or a person responsible within the meaning of Part 5 of that Act, or
 - (c) a person having parental responsibility for the individual, if the individual is a child, or
 - (d) a person who is otherwise empowered under law to exercise any functions as an agent of or in the best interests of the individual.
- (2) A person is not an authorised representative of an individual for the purposes of this Act to the extent that acting as an authorised representative of the individual is inconsistent with an order made by a court or tribunal.
- (3) In this section:

"**child**" means an individual under 18 years of age.

"**parental responsibility**", in relation to a child, means all the duties, powers, responsibility and authority which, by law, parents have in relation to their children.

¹ Ms Deveson chaired the Committee through its initial stages. On her resignation from the chair, Professor Ian Webster was appointed to bring the work of the Committee to a conclusion;

² *Report to the Honourable R A Phillips MP Minister for Health on the NSW Mental Health Act 1990*, Mental Health Act Implementation Monitoring Committee (August 1992);

³ The key terms of reference of the Committee were to “inquire into and report on mental health services in New South Wales and in particular: (a) the changes which have taken place since the adoption of the Richmond Report; (b) the impact of changes in psychiatric hospitalisation and/or asylum; (c) levels and methods of funding of mental health services in NSW, including comparisons with other jurisdictions; (d) community participation in, and integration of, mental health services; (e) quality control of mental health services; (f) staffing levels in NSW mental health services, including comparisons with other jurisdictions; (g) the availability and mix of mental health services in NSW, (h) data collection and outcome measures”. *Legislative Council*, 11 December 2001, 2nd Session, Minutes No.139, Item 19;

⁴ *Inquiry into mental health services in New South Wales Final Report* Legislative Council Select Committee on Mental Health (December 2002), Chair’s Foreword at XV;

⁵ *Tracking Tragedy* First Report of the NSW Mental Health Sentinel Events Review Committee (December 2003)

⁶ *ibid*, see in particular recommendations 14 and 15 of the Report

⁷ Note for example, the current NSW Health Policy of Privacy, at para 8.1 the *NSW Health Information Privacy Code of Practice* specifically recognises the need for extra sensitivity in handling this type of sensitive information.

⁸ *Inquiry into mental health services in New South Wales Final Report* Legislative Council Select Committee on Mental Health (December 2002), paragraph 6.22;

⁹ *Id*, at paragraph 6.36;

¹⁰ Clause 10 of the Mental Health Regulation 2000 simply provides that the Notice must be in accordance with Form 3 of the Regulation, and served on the person or persons entitled to be given the notice

¹¹ This is defined in the Dictionary of terms used in the Mental Health Act. The definition of the relevant terms is set out in full in Appendix A to this Paper.

¹² For a fuller description of these terms, and discussion on the appropriate categories of carers and relatives who may be included in any information sharing provisions, see Part 6 of this Paper.

¹³ s.26(2), Privacy and Personal Information Protection Act 1998;

¹⁴ s.28(2), Privacy and Personal Information Protection Act 1998 and cl.3, NSW Health Privacy Code of Practice;

¹⁵ s.19(1), Privacy and Personal Information Protection Act 1998

¹⁶ The Health Records and Information Privacy Act is due to commence from 1 July 2004

¹⁷ HPP11(2) also reflects existing provisions in the Privacy and Personal Information Protection Act1998

¹⁸ *Inquiry into mental health services in New South Wales Final Report* Legislative Council Select Committee on Mental Health (December 2002), page 111. It should be noted that R.38 deals with broader than simple information sharing, and also proposes a power to obtain a court order to require an urgent assessment of an individuals health status. This part of the Recommendation will be looked at in Issues Paper 2;

¹⁹ Ms Cathy Heyes, Submission 150, quoted in *Inquiry into mental health services in New South Wales Final Report* Legislative Council Select Committee on Mental Health (December 2002), paragraph 6.27;

²⁰ *Inquiry into mental health services in New South Wales Final Report* Legislative Council Select Committee on Mental Health (December 2002), paragraph 6.27;

²¹ Submission 162, quoted in *Inquiry into mental health services in New South Wales Final Report* Legislative Council Select Committee on Mental Health (December 2002), paragraph 6.29;

²² *ibid*