Attachment 2

REVIEW OF THE MENTAL HEALTH ACT 1990

Discussion Paper 1: Carers and Information Sharing

Submission

Comments on the issues raised in this Discussion Paper have been requested. We believe that we are able to contribute in an informed way, based upon our experiences in caring for our daughter, diagnosed firstly with Bipolar Disorder and then Schizophrenia. For one and a half years after the initial diagnosis but while she could still work and look after herself, we were involved in her care on a regular but sporadic basis. Once she was committed to a Mental Health Unit at a Sydney Hospital after two suicide attempts, we were involved on a daily basis, until she absconded some three months later and committed suicide.

Overall, we believe that we would have been much better equipped to help our daughter if we had received more input and had more discussion, with the treating psychiatrists. A part of the information that we needed but did not have, was a better insight into the disease itself, its salient characteristics and progression, and the medications and other treatments used and their likely outcomes and limitations. Surprisingly, this topic was not covered in the Review. Provision of this information should be entirely non-controversial since it does not involve patient confidentiality issues. On the patient confidentiality issue itself, we have a very clear view. We would rather have our daughter alive with some of her rights having been set aside than dead with her rights (uselessly) preserved intact.

Our comments on specific issues raised are as follows:

2.2.2 Capacity. We completely agree with the sentiments expressed in the last paragraph of this Section. There is an obvious parallel between intervention to schedule a patient and intervention to provide crucial information to a carer.

2.2.4 Reliance on Care in the Community. Our experience, in seeing our daughter daily over the three months that she was hospitalised, with her many visits home with the responsibilities for us that this entailed, makes it clear to us that it is **vital** that the carer be considered and treated as part of the care team.

3.1.1 Notifying relatives of a Magistrate's hearing. We agree that it would be most appropriate to notify the carer, often but not always a relative, of these hearings.

3.1.4 Discussion. It is clear to us that the ill person's interests are currently not being served by the conditions and constraints of the 1990 Act. Both the person who can receive the necessary patient information and the information itself need to be much better identified and defined.

3.2.3 Discussion. We agree that the Mental Health Act needs to be revised to recognise and to define the role of non-professional carers. Unless this is done, the carer's ability to help the patient will be severely limited.

3.3.1 Health service providers' common law duties. Once the **legal** identification of a carer and his/her rights and responsibilities has been achieved (see below) and the accompanying modifications made to the MH Act, then it should be relatively easy to resolve the legalities concerning disclosure to carers.

3.4 A need for change? We strongly agree that the law relating to carers needs to be clarified for some issues and revised for others.

3.5.1 Boxed proposals. Legislation should be amended to allow sharing of information as described. This should be on an ongoing basis, at least weekly, and immediately after any 'signal event' in the patient's treatment or response. The patient should be told of the disclosure.

3.5.2 Boxed proposals. Repeal Section 289, but give guidance to medical superintendents by stating in the Act their obligation to inform carers of admission or discharge of a patient, or of any other 'signal event' arising in the treatment of a patient. The patient should be told of the disclosure.

3.5.3. Amend the Mental Health Act... No, an interim Court order should not be required. This would impose an expensive, unnecessary and unhelpful (to the care of the patient) obstacle to dissemination of necessary information to carers. It would also open the process to inconsistent interpretation by judges and counter-productive legal battles.

4.2.1. Recognition of the role of carers in the MH Act. We strongly agree that a 'culture change' in the attitude of health professionals to carers is needed; too many of these depreciate the efforts and abilities of carers in a misguided and unproductive effort to support the clinical cabal.

Section 4 (1) (b*)* of the Act should indeed be altered to expand the reference to "community care facilities" to recognise the role of a carer. This is especially important, given the limitations in availability of these facilities.

Section 4 (2) (a) needs to be amended to qualify the misleading phrase "in the least restrictive environment" to include "consistent with the patient's welfare". It was just such a misguided policy of "least restrictive environment" at the Mental Health Unit that allowed our daughter to abscond without let or hindrance, and then to commit suicide. An External Review into the circumstances of her absconding strongly supported the imposition of much stronger security measures in the Unit, as a matter of urgency.

Section 4 (2) (b) Who judges the "minimum necessary in the circumstances"? Our experience was that the treating clinicians were unable to correctly make this judgment for our daughter and erred on the side of inaction rather than caution. As we stated at the outset, we would rather have had our daughter's "rights" contravened, with the more important criterion of her safety placed at the forefront instead. Your "rights" have little value when you are dead. Mentally ill patients are **mentally ill**, and need to be protected from themselves, as in any case their admission to a mental health unit implies. In our view, the Act's caution on this issue of restriction of liberty, though well meaning, is misguided and gives the wrong guidance. The most important "right" that a mentally ill person (or an outside person coming into contact with a violent patient) has is **the right to life**, and all other considerations should be subservient to this.

4.2.2 Inclusion of carers in discharge planning. Certainly it is essential that the carer must be consulted in the discharge planning phase. In the case of our daughter, the consultant psychiatrist decided to discharge our daughter without consulting us and long before she was, in our view, ready for discharge. His misjudgment of this was made plain when a week later, she expressed her ongoing suicidal ideation and her discharge had to be cancelled. Section 293 (1) is not sufficiently onerous in emphasising the responsibility of the medical superintendent to ensure that care outside the hospital is available to a patient whom he/she wishes to discharge.

5.2 Who is a carer? **Our suggestion is that a single primary carer should be identified at the time that the patient is scheduled, and simultaneously given legal status by the scheduling magistrate.** In most cases it will be obvious who this person should be, and the magistrate should be given discretionary powers for any cases where there is contention. **Under these arrangements, there is no need to exclude anyone from this role in the Act, and it automatically ensures that the carer is 'legitimate'.** If more than one carer wished to be involved, it would become the responsibility of the primary carer to judge the merit of this, and what form it should take. The carer should have the right to access patient information at all times and under all circumstances, not just when the patient "lacks capacity". Otherwise, who is to judge the patient's capacity? – certainly not the patient, and even the clinicians couldn't guarantee their judgment.

5.3 What sort of information should be covered? We believe that there should be no limitations on the information available to a carer. It would be impossible to define in advance for all cases what information is necessary for the carer and what is not, and further more, any limitation would be open to abuse by the treating staff. If the carer has legal status as suggested in the previous section, many of the concerns about this lack of limitation would be alleviated. Additionally, it could be required of a primary carer that he/she formally agree to protect the information and the interests of the patient.