



SCHIZOPHRENIA

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**Papers presented at a Symposium on Schizophrenia
and Human Rights**

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Human Rights Issues relating to Schizophrenia

Mr Brian Burdekin,
Federal Human Rights Commissioner

I would like to begin by sincerely thanking the Schizophrenia Australia Foundation for working together with the Human Rights and Equal Opportunity Commission in the organisation and presentation of today's symposium. My colleagues on the Commission are acutely aware of some of the problems faced by people with schizophrenia, and some of the problems faced by their families, friends, and professionals working in the field. I am sure many of you know my colleague, Commissioner Quentin Bryce, and of her specific interest and involvement in this area. Unfortunately Quentin cannot be with us here today. From a personal point of view, however, I value highly this opportunity to share with you the Commission's particular human rights perspective on the area. For those of you who may be unfamiliar with the Human Rights and Equal Opportunity Commission, I propose to begin by briefly outlining its structure, functions and mandate.

Human Rights and Equal Opportunity Commission

The Commission was set up by the Federal Government in December 1986. It is composed of a part time President and four full-time Commissioners: The Human Rights Commissioner, the Race Discrimination Commissioner, the Sex Discrimination Commissioner and the new Privacy Commissioner. In addition to administering the Racial Discrimination Act, the Sex Discrimination Act and the Privacy Act, the Commission's wider human rights responsibilities are provided for in the Human Rights and Equal Opportunity Commission Act. This Act defines 'human rights' by reference to several international human rights instruments, including:

- The International Covenant on Civil and Political Rights
- 43. The Declaration of the Rights of the Child
- The Declaration on the Rights of Mentally Retarded Persons
- The Declaration on the Rights of Disabled Persons

In discharging its human rights responsibilities, the Commission's powers include the following:

- To receive and conciliate human rights complaints

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- To review existing and proposed legislation
 - To conduct and co-ordinate research and educational programs
 - To intervene in Court proceedings that involve human rights issues
- 41) To work with and consult appropriate persons and organisations for the promotion of human rights
- To prepare guidelines for the avoidance of practices which violate human rights
 - To report to the Federal Government on laws that should be made and action that should be taken by Australia in relation to human rights matters

Human Rights and Schizophrenia

Of the four international instruments which define human rights for the Commission's purposes, two are particularly relevant in relation to people with schizophrenia. These are the International Covenant on Civil and Political Rights; and the Declaration on the Rights of Disabled Persons. The Covenant on Civil and Political Rights expressly requires that everyone is to enjoy all the civil and political rights set forth therein. The Covenant does not distinguish between people or types of people at all. Governments which are party to the Covenant have undertaken to ensure that all men, women and children enjoy their civil and political rights. These rights include the right to:

- protection of the inherent right to life;
- liberty and security of the person;
- freedom from cruel and degrading treatment or punishment;
- freedom of expression, movement, association and assembly;
- equal treatment under the law; and
- effective remedies if these rights are violated.

The Declaration on the Rights of Disabled Persons applies to 'any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities'. Among the specific rights enunciated are the rights to:

- respect and dignity;
- assistance to enable self reliance where possible; and
- protection from discriminatory treatment.

The Commission considers, for these purposes, that 'people with disability or disabilities' includes people with psychiatric or mental disorders.

Ignorance and Fear

This statement sounds simple enough but it by-passes ignorance and cuts through definitional issues to ensure that the rights of those with mental disorders are

recognised. The general area of disability is beleaguered by definitional problems. The public confusion between mental illness and intellectual disability is one example. Schizophrenia itself is widely misunderstood. These sorts of confusions and misunderstandings have a detrimental effect on the lives of people directly concerned, in terms of the political and public support they receive and the basic rights they enjoy. The majority of the community at large and politicians need considerable guidance in this area. Our Commission has found that basically all the forms of discrimination we deal with arise from ignorance and/or fear. The important role of community education cannot be underestimated. We share a responsibility to inform and guide our community, and to press for appropriate political, legal and social responses. The Commission's work in relation to the specific area of mental disorder/psychiatric disability has basically two elements; at an individual level, handling and investigating complaints; and at a broader level, research and preparation of submissions on public policy questions.

Complaint Handling

The Commission's complaint handling procedure is one based on the principle of conciliation. It is carried out confidentially and relatively informally. The Commission receives numerous enquiries and complaints from people with psychiatric disabilities. These enquiries and complaints generally involve allegations of discriminatory treatment in employment or of human rights breaches in different types of institutions. The complaints are dealt with, in the first instance, on an individual basis. The objective is to achieve a mutually agreeable resolution. Sometimes, however, a pattern emerges from the individual complaints and a broader issue comes to the Commission's attention. Let me cite an example.

From Complaint to Policy: Public Employment Practices

During 1987 a government employee, with a history of schizophrenia, complained to the Commission alleging discrimination on the ground of disability. The complainant had undergone a medical examination and the Commonwealth Medical Officer had subsequently recommended against his permanent appointment to the Australian Public Service. The recommendation was accepted by the department and the complainant was advised that his appointment was to be terminated on medical grounds. Over the ensuing months the Commission received a number of complaints of a similar nature. Employees with histories of mental health problems were failing to meet the medical standard for permanent appointment to the Australian Public Service. From the Commission's investigations it became apparent that there were problems with the medical assessment procedures followed by the Commonwealth Medical Service and individual departments. The complaint cases also highlighted problems of interpretation and use of the guidelines on medical standards contained in the Handbook for Commonwealth Medical Officers. During the course of our investigating each of the individual complaints, a review of the Handbook for Commonwealth Medical Officers commenced. The Commission prepared a submission to this review, and in addition circulated it to the Public Service Commissioner and the Heads of all Commonwealth Departments. The principal recommendation of the Commission's submission was that there should be no mandatory requirement for a physical/medical examination as a prerequisite for permanent appointment to the Australian Public Service, except that (a) where a job

has an identifiable medical risk, an examination should be used as a preventative health measure (though it should not be used to screen applicants and exclude them from employment); and (b) where an applicant is being assessed for admission to the superannuation scheme some form of medical assessment might be required for that purpose.

Prisons and Institutions

Also through its complaint handling functions, the Commission was alerted to the treatment of certain prisoners and hospital patients around Australia. As a result, our work in this area led to research and preparation of a submission to the Kennedy Commission of Review into the Queensland Prison System. The Human Rights and Equal Opportunity Commission considers that prisoners with mental disorders have an equal right with others to be treated with humanity and respect for their inherent dignity. They also have special attributes and special needs which must be addressed by prison administrations. Principle 6 of the Declaration on the Rights of Disabled Persons provides:

Disabled Persons have the right to medical, psychological and functional treatment...to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the process of their social integration or reintegration.

Prisoners with mental disorders must also receive special protection within the prison. Principle 10 of the Declaration on the Rights of Disabled Persons provides:

Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature.

The Commission considers it essential that specific programs be developed for the benefit of such prisoners — and that these should be developed by, or in consultation with, professionals with relevant expertise and experience. These professionals also need to be involved in the delivery of such programs. The Commission is also keenly aware of some of the problems faced by people with mental disorder in institutions other than prisons. In the near future the Commission will be making a submission to the New South Wales Royal Commission into Chelmsford Private Hospital and other mental health services in NSW. In that submission, we will point out what has been obvious for a long time to those most concerned with mental illness: institutions have often been the locations of major abuses of rights but deinstitutionalisation programs, as important as they are, are failing because of inadequate funding and follow-through services by governments. Deinstitutionalisation is a valuable concept — but it will fail if it is implemented uncritically or as a cost saving measure. The costs of proper care are high, whether institutional or community-based. Deinstitutionalisation properly implemented is not cheaper — but in many cases it is better.

Homeless Children

I will be releasing the results of a National Inquiry into Homeless Children within the next 24 hours in Sydney. Without pre-empting that Report and its conclusions, I can tell you one of the most disturbing findings which emerged from the hearings in every State: there is now an increasing number of children and adolescents suffering from mental illness among the population of our homeless young people. Our findings in this regard are entirely consistent with those of the 1988 Report of the United States National Academy of Sciences and National Institute of Medicine. Copies of the Commission's Report will be available to participants in this seminar at a later date. You will see that it makes recommendations on the special needs of homeless children with mental disorders.

Protecting Rights

There are many people in Australia today who believe that human rights are adequately protected by the common law. This is unfortunate. It is unfortunate because it is patently untrue in many cases. The common law's assistance and protection in the area of mental illness has been negligible. More specifically the common law has never protected, to any significant extent, and does not now protect the rights of those with any form of disability, physical, intellectual or psychiatric. It is these people, among other groups in our society, who have suffered and continue to suffer from our neglect, our indifference, ignorance and sometimes brutality. In the face of this inadequacy on the part of the common law, the need for legislative protection became clear. Over the years, each State and Territory developed mental health legislation to provide the protection. These laws, however, lack uniformity, are imprecise and suffer from shifting definitions and concepts. Existing mental health laws, especially those on detention and appeal mechanisms, require urgent review.

More recently, legislators have sought to protect the rights of those with a disability through anti-discrimination laws. Some, but not all, Australian States have taken such action. Again however, there is considerable divergence between the jurisdictions. In relation to disability specifically, different States cover different disabilities and different unlawful actions. In October last year the Human Rights and Equal Opportunity Commission welcomed the initiative taken by the Western Australian Parliament in adding new disability provisions to its anti-discrimination Act. The legislation carefully defines 'impairment' to include 'mental disorder'. This is now the most effective disability discrimination law in Australia and provides an excellent example for the remaining Australian jurisdictions (including Queensland) currently without comparable provisions or even legislation.

Legislation has a very important role to play in this area, but legislation does not exhaust protective possibilities. Legislation can interfere with, if not violate, certain of our basic human rights. The enshrinement of certain human rights in the Constitution is a clear and viable alternative, although a very unlikely one in the foreseeable future.

International Law

In the absence of such Constitutional human rights guarantees in Australia, international law has a particularly important role of play. The International Instruments developed by the United Nations continue to contribute to the

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enunciation and protection of people's rights. There are two relatively recent international developments which are specifically relevant for us here today. The first is the development (by the U.N. Sub-Commission on the Prevention of Discrimination and the Protection of Minorities) of a draft body of principles, guidelines and guarantees for the protection of the mentally ill and persons suffering from mental disorders. This draft is still being debated and reviewed. The second relevant development relates to disability in general. The same U.N. Sub-Commission, in 1984, decided to include 'human rights and disability' on its agenda. A comprehensive study into the relationship between human rights and disability was subsequently commissioned and is to include analyses of forms of discrimination against persons with disabilities, of institutionalisation and institutional abuse, and of economic, social and cultural rights as they relate to disability. The Special Rapporteur's preliminary and intermediate reports have been presented to the Sub-Commission; the final Report is due in 1990. Two findings of the preliminary reports which are particularly relevant to Australia are that:

- a Draft Convention on the Human Rights of People with Disabilities has been proposed; and
- there is an obvious need for comprehensive statistical data and for internationally agreed definitions.

The Human Rights and Equal Opportunity Commission is monitoring these developments and intends to contribute substantially to them, internationally and nationally. We are relative newcomers to the issue and our role is still evolving. Hopefully our perspective, energy and powers will prove effective.

On behalf of the Commission, I want to conclude by emphasising the very high value we place on opportunities such as this, to work in co-operation and consultation with organisations such as the Schizophrenia Australian Foundation and the State Schizophrenia Fellowship bodies. The Commission hopes to continue to do so whenever possible and appropriate, in the interests of all Australians whose rights require protection.

The Right to Treatment

Dr John Grigor
Director of Forensic Psychiatry Unit
Victorian Health Department

Schizophrenia is a brain disease in the same way that Alzheimer's disease is a brain disease. It is not romantic. It is not in any way illuminating or ennobling. It is an illness which affects the frontal lobes of the brain which, on average, are some 20% smaller than normal controls and it is an illness which profoundly affects the psychic life of the individual.

We had no effective treatment for Schizophrenia until the 1950s. We still have no cures. In 1951 while searching for a better antihistamine to act as a premedication, it was found that chlorpromazine (a Phenothiazine) appeared to have a calming effect. It was trialled in France, then in England where it was marketed by the May and Baker Pharmaceutical Company as Largactil. By 1955, Largactil reached Australia. Older psychiatrists still talk about the profound impact this drug had on psychotic patients, some of whom were in straight jackets or were rocking back and forth talking gibberish or who had to be fed with a spoon. Within a few weeks, up to 70% improved sufficiently for doctors to seriously consider strategies for discharging them from the hospital and returning them to the community. And so the great move from asylum to community began.

In the 1960s the programs in the hands of doctors, were seldom formally evaluated but their success accorded with the everyday experience of psychiatrists of the time. Regrettably however, State Governments in Australia and elsewhere were seldom able to ensure that the mental health dollar followed the patient into the community.

Mental health in this country had remained a State responsibility since the time of federation. In 1901 general health became a federal responsibility, but mental health was left to the care of the States. Most State services have remained chronically underfunded and subject to intermittent scandals, Royal Commissions, Committees of inquiry and so on. So when bed numbers began to reduce as a consequence of effective methods of treatment, mental hospitals seized on the opportunity to refurbish wards, to reduce ward numbers to a manageable size, to engage allied health professionals and to move from a custodial mode of treatment to a therapeutic mode.

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Twenty six years ago as a young doctor, I first worked in a Mental Hospital. Let me describe the ward for which I had responsibility. It had ninety beds, forty-five beds down each side of the long single dormitory. There was insufficient space between the beds for the patients to get in; only between every two or three beds was there a gap. During the daytime, patients were driven out of the ward into an airing court. If it was wet they huddled under a rotunda. The wards were sometimes hosed out with fire hoses. At night the patients were let in again. Bath night occurred on one night per week. There were no individual baths but a small bath house as an annexe to the hospital. The pool was like the green, greasy Limpopo river, virtually a small, tepid swimming pool with steps leading in and out.

Patients divested themselves of ward clothing, were given a piece of bar soap, slowly descended into the pool, washing as they proceeded to the steps at the other end to emerge, dripping, to tea chests of towels and clothing. People only wore institutional clothing. Men did not wear underpants, women wore lisle stockings, pink bloomers, no bra and either summer or winter nightdresses. These were brightly coloured and garish. They came in two sizes, 'much too large' and 'much much too large'. The first to emerge were the best dressed. This was in an era when belts and shoe laces were forbidden because of the potential for suicide.

As 'deinstitutionalisation' progressed, the hospitals devoted enormous energy to hold onto the mental health dollar to do something to improve the state of what the public still perceived as lunatic asylums. In the 1970s what had begun as an empirical and programmatic process became a 'movement', embraced by activists including some psychiatrists, who now saw themselves as having a clear mission to close these hospitals and to treat all patients, if possible, in the community. Part of this arose from the development of the community mental health centre movement. In 1960, John Fitzgerald Kennedy assumed the Presidency of the United States. He was seeking something to characterise his new administration and the community mental health centre concept was seen as an appropriate cause. The essentially psychoanalytic tradition of North American Psychiatry at that time believed that, given the techniques of psychotherapy, one could make people lead substantially happier and healthier lives and prevent the later emergence of mental illness.

Community mental health centres were set up in areas of social deprivation, the ghettos, Hispanic-speaking areas, black minority areas and the 'poor white trash on the other side of the tracks'. The expectation was that a system of community mental health would improve the mental health of the community, reduce marital discord, crime and the frequency of psychosis.

Within psychiatry itself, there were a number of anti-psychiatry psychiatrists. Professor Thomas Szasz who escaped from Hungary in the early 1950s to take up a chair in psychiatry in New York wrote on *The Myth of Mental Illness*. Szasz spoke appealingly to the University Students of the 1960s who are now the decision makers of the 1980s. Dr R.D. Laing, a Scottish psychiatrist wrote *The Divided Self*, and with radical psychiatrists in the U.K. wrote about the mystical experience of schizophrenia. Such writings from within the profession, debunking medical model concepts of schizophrenia and mental illnesses, had a very profound effect on

Western thinking. They were joined by others. Erving Goffman, a sociologist, in *Asylums* proposed that staff subordinated patients to simplify management. Another psychiatrist, Dr Russell Barton wrote on *Institutional Neurosis*, where he postulated that much of the behaviour observed in schizophrenic patients was essentially that of the process of institutionalisation. We now know that non-institutionalisation patients show many of the same aspects of behaviour as those who are hospitalised. Clearly, the bad mental hospital had to go.

But the new community mental health centres were not particularly interested in the people who were now being discharged in increasing numbers from the mental hospitals. They saw them as the products of a bad old system and were much more interested in preventing people becoming mentally ill. If you could get to the children, to marriages which were fragmenting, get into the schools, into marriage guidance, this would reduce the chances of people becoming manic depressive, perhaps stop them developing brain disease. Unfortunately, the premise was wrong, but that was where much creative energy of psychiatry went in the 1960s, attacking the presumed roots of mental illness. Psychiatry was reinvigorated by the community mental health centre movement, but the discharged mental hospital patient was all too frequently ignored.

Another popular set of theories revolved around the effects of inadequate or pathological parenting. With schizophrenia, for example, there were whole series of family theories with descriptions of 'skewed' families and 'schismatic' families and ('schizophrenogenic' mothers, the mother whose behaviour causes the genesis of schizophrenia in her offspring by 'double-binding'. This was described as mother putting her child into a conflictual situation from which he had to make a choice and where either choice was wrong. As a consequence the child would retreat into his own world of fantasy. Many families became terribly demoralised by this assumption of casuality as a consequence of parental interactions.

I can recall families selling their homes in Melbourne and moving to London to go to programs that were supported by Dr R.D. Laing and others, to try and see whether, through family therapy treatment, they could cure schizophrenia in their offspring. The literature was extensive and it has no doubt influenced some of the politicians of today. Non-psychiatrists also contributed: Gregory Bateson, the anthropologist, Theodore Lidz, a psychoanalyst, Wynne and Singer and others.

In addition the Radical Therapy movement claimed that illness was simply a manifestation of a sick society. People with schizophrenia were really behaving in a very sane way and the remedy was not to try and treat the individual but to change society. Psychiatry was seen as a political activity practised by racist, sexist and imperialist therapists who used oppression and deception to further promote alienation.

This then was the scenario of the 1960s which, I suggest, led on to the patients' rights issues of the 1970s and the intervention of lawyers. Fresh from their victories in the U.S.A. in the civil rights movement, the new civil libertarians sought legislative changes in the state mental hospital system. Through the intelligent application of law they sought to force the mental hospitals to modify their treatment approaches.

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They challenged on the basis that the hospitals could not deliver the treatment required and that the patient had a right to expect. They hoped that they would force the hospitals to improve services, but all too frequently, State legislatures decided they did not have the money to bring hospitals up to the required standards. This led instead to the closure of many mental hospitals. The lawyers then turned their attention to attacking the mechanisms of entry into the mental health system. They altered mental health legislation, sometimes to the point in some States in America to restricting involuntary hospitalisation to those who were dangerous to themselves or others. In addition, legal mechanisms were added to the review process. Patients could be legally represented at review hearings and retention in hospital sometimes had to be argued before a magistrate in court. This was a far cry from the recommendations of the Percy Commission in the U.K. in the 1950s which met to draft the 1959 U.K. Mental Health Act. The Percy Commission saw the act as an enabling piece of legislation, as free as possible from legal intervention and constraint. They wanted the process of hospitalisation to be essentially a medical process more closely aligned with medicine than the law. The United Kingdom legislation reflected this and the Australian legislation of the day was essentially similar. There were protections under the Act for wrongful admissions but, by and large, getting into hospital was a relatively easy process.

In the 1980s in some States, patients appear before magistrates with doctors arguing their need for continued retention in hospital. This further blurs the distinction between illness and crime. The new civil libertarian movement has meant that some patients are not admitted at all. Patients' rights are in the ascendancy.

In contrast, other writers have begun discussing the homeless mentally ill, 'rotting with their rights on', sleeping under bridges, untreated but with their rights intact. As Joseph Morissey said

If the first stage of deinstitutionalisation reflected an opening of the back wards, the second stage was marked by a closure of the front door.

The final ingredient was economics. Early studies had suggested that not only was community care better than hospital care, but that it was cheaper. We now know that good community care is almost as expensive as hospital care. At a sociological level these debates were proceeding amongst a backlash to the industrial revolution which had seen the creation of larger and larger institutions, be they factories, hospitals or schools. The post-World War Two period has seen a move away from large institutions to smaller, more accessible facilities. The Victorian Government has as one of its social justice strategies, accessibility to health services. If you support accessibility you may need a mental hospital unit in every suburb. Clearly there has to be some trade off between 'complexity' (because you need large institutions to get complexity in treatment programs) against 'accessibility'.

We are still in an era where small is beautiful, smaller is even more beautiful, and smallest is sublime. In my State the preferred intellectual disability model of care is a group home with five or six residents. This is wonderful, but can lead to increased staff burnout. Such units reduce the complexity of programs while

promoting individual care.

In the 1970s psychiatrists believed that, with modern drugs and 'deinstitutionalisation', primary and secondary prevention would stop the development of long-stay patients. So over a generation, nurses lost the traditional skills of managing the severely disturbed patient. They were often no longer attached to large hospitals. The model unit was often a 30 bed ward attached to a community general hospital where there were no longer sufficient nursing staff, particularly after hours or at weekends, to safely care for the disturbed patient. Increasingly frequently, when the disturbed patient presented to such units the police had to be called because the staff no longer had the coping skills.

In New South Wales, the community mental health centre movement established itself in much the same way as in America. It saw itself as a separate service to the mental hospital service and there was a lot of energy lost at the interface between the mental health centre and the hospital. The centres were reluctant to attend to the continuing care needs of the discharged mental hospital patient. In Victoria the community health clinics were much more closely integrated with after-care and follow-up. There were State by State variations in the relationship between the new services and the old.

In the 1980s in New South Wales Dr John Hoult and his co-workers reported in 1981 and 1983 on a controlled study of psychiatric hospital versus community treatment. They randomly allocated those ill enough to justify hospital admission to a community care treatment team, and the others to routine standard care in hospital. Patients were followed up for 12 months. Hoult showed that the burden on relatives for those treated in the community was initially higher, but was overall less, and the relatives were more satisfied. There was less hospitalisation over the following 12 months, a clinically superior outcome and less cost. This demonstration that acute care was possible in the community led to discussions in New south Wales to accelerate hospital closures. There was brief correspondence in the Australian and New Zealand Journal of psychiatry, some of it questioning whether the results of a highly motivated research team with a dynamic leader offering round the clock support, would be replicated with wider categories of patient care. The researchers had some exclusions including dementia and substance abuse. Others wondered whether the results could be broadly generated throughout the mental health system. Nevertheless, this was important research and Dr Hoult became a valued advisor to the New South Wales Government. Critics have complained that community services were already inadequate and that bed closures were occurring more frequently than the State was able to create community places. Others suggested, cynically, that the government was really interested in the reputed billion dollars worth of mental Hospital real estate. There was, however, little disagreement that good community care was as satisfactory as good hospital care.

The literature on deinstitutionalisation has now confirmed that the closure of mental hospitals has too frequently lead to other forms of institutional care which are often program poor or program absent such as boarding houses, hostels, special accommodation houses, 'sleeping rough', church homes, the prisons and so on. There are as many people as previously in institutions of one sort or another; they no longer are the large mental hospitals of yesteryear. This phenomenon has been

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called: 'transinstitutionalisation', where society has simply switched institutions for many people, and not genuinely placed them into the community.

Meanwhile, the State-employed psychiatrists have voted with their feet. About twenty years ago, 25% of psychiatrists in Victoria were essentially in private practice and 75% were essentially in public practice. Now the situation is almost reversed. It may be of surprise to learn that in one of the world's most heavily doctored countries it has been hard to retain local medical graduates in the Mental Health Systems. It is the same in the United States and Great Britain. In a country which has put up significant barriers to foreign medical graduates, Australia has had to relax conditions of entry so that foreign graduates can be employed in the State Mental Health Services.

Let me talk a little about the training experience of psychiatrists. It is different from the training experience of any other sort of doctor. If you wish to be a specialist, you are obliged to work at least for a period in the State Mental Health System. In a number of States, trainees will be required to present to Medical Review Boards. Involuntary patients in Victoria must be assessed by a Review Board within four to six weeks of admission. The Review Boards are chaired by a legal practitioner and have a psychiatrist and a community representative.

Patients have the right to be legally represented. Quite a deal of time is spent in the preparation of documentation to enable the Review Board to function. A lawyer may ask a young trainee psychiatrist why did he use a particular medication in a particular dose. Did the doctor know that Professor X usually does brain scans in this diagnosis and so on. The young psychiatrist frequently feels intimidated. Many endure the five years of training but the moment they qualify they leave the State system to practice somewhere else. Public Psychiatry is the only area where doctors' practices are reviewed in this quasi judicial context.

In Victoria there is a government supported Mental Health Legal Resources Centre whose lawyers are becoming more adroit by the day. In monitoring treatment we have Community Visitors who have right to inspect premises and with patient consent inspect case notes etc. Case notes are available to the patient through Freedom of Information. Every week I would speak to lawyers. Every few weeks I would speak to the Ombudsman, release documents under Freedom of Information, speak to a lawyer from the Mental Health Legal Resources Centre or speak to Community Visitors or show them round our facility. Once a month I would speak to the Public Advocate. Doctors have become very cautious about what they write down in case notes because many patients will ultimately read them. The words 'sexual intercourse' may be replaced with euphemisms such as 'periods of warm human contact'. The word 'schizophrenia' may be replaced by the terms 'Bleuler's disease', after the psychiatrist who coined the term. So, far from communication being enhanced note writers may develop a private language which need only make sense to other professionals working in close proximity at the time. More time is spent on paperwork. More time is spent organising marginal investigations. The C.A.T. Scan (computerised axial tomography) has limited indications in psychiatry and the cost of the scan is high. The psychiatric indications for a number of investigations are

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limited, but doctors may do them lest they may be accused by relatives or friends or lawyers that perhaps they have not excluded every possibility of some other condition. This is known as the practice of 'defensive psychiatry' and occurs not only here in Australia, but elsewhere where medico-legal practices demand that overinvestigation is the prudent way to proceed. In my view this is neither good medicine nor good psychiatry.

What distresses those of us who remain in the public sector is that time spent on direct patient care, is diminished by paperwork, by responding to watchdog bodies, and by a tendency to be tentative about diagnosis and to be tentative about treatment. Some of us defer treatment until we have done the last serum rhubarb test to exclude every obscure medical condition. Patients' rights have gone mad.

What is happening out in the community? The community is increasingly concerned about community violence. There have been some spectacular (fortunately only a few) cases of markedly ill schizophrenic patients who have murdered. I am a forensic psychiatrist and work in the prison system. Although most schizophrenics are non-violent people, a small proportion are murderers and there are some dozens who have committed homicide who are in prison or security hospital. Schizophrenia is a lethal disease in other ways. Ten per cent of people with schizophrenia may ultimately suicide.

Psychiatrists are perceived as having a serious credibility gap. On the one hand, they are claiming through nuclear magnetic resonance imaging and other new techniques that they understand schizophrenia and are improving methods of diagnosis and treatment. On the other hand, the community is seeing more people in the streets showing disturbed behaviour. The National Health and Medical Research Council in 1987-88 surveyed all States and found that there was little information available on the homeless mentally ill. Dr Helen Hermann and co-workers at Monash University surveyed inner city residents in Melbourne and found a very high level of mental illness. The study was extended to prison populations. I had been interviewed on *Four Corners* in 1987 and suggested that perhaps our prison system, collectively, now constituted the State's largest mental hospital. When the front door of the psychiatric hospitals seems closed, people tend to be diverted to the criminal justice system. The evidence is not yet in, but the existence of frank mental illness in the remand sections of our prisons is about ten per cent. Each day I see people in prison who, were it not for the fact that they are intellectually disabled or mentally ill, would not be in prison. They may be incarcerated for trivial matters such as resisting arrest or failing to pay a taxi fare. Yesterday I saw a person in prison who broke a number of windows at a Migrant Hostel. He was very psychotic and had been untreated for two years. When you see psychiatry from this perspective you do wonder whether we have got the correct balance between protecting a person's rights and that person's right to treatment.

I have spent some time outlining the various factors, economic, structural, and legislative that have led to the present complex management of the mentally ill in Australia. There are many interacting factors. One of these is the patients' rights issue which has contributed to an unforeseen situation where I believe that some

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patients are now late hospitalised, undertreated, and their relatives have become demoralised. I do not believe that this is good enough in a caring society. If I become psychiatrically ill and do not recognise my need for help, I hope that someone gets me quickly and efficiently into hospital. I do not have to tell the doctors in the audience that early treatment leads to less morbidity, shorter hospitalisation, earlier re-socialisation and an earlier return to work. God help any of you if you are doctors, or lawyers if you require involuntary hospitalisation. Few will certify a lawyer if he becomes mentally ill. I can recall when I was the psychiatrist superintendent of a young lawyer who wandered unclad around Melbourne for some weeks. He would visit all his friends and talk to them about the love of Christ, stark naked. He stayed out of care because no-one was prepared to certify him and put him in hospital. Eventually the Police Surgeon sent him to hospital where he recovered quickly but developed a profound depression when he contemplated the consequences of his psychotic behaviour. He suicided. This was a decade before the current mental health legislation, but is an example of a tragic consequence of late hospitalisation. People with manic depression, another major psychosis, will, in a state of mood elevation, become hypersexual, wreck their marriages, spend their money and become bankrupt. Do they thank the civil rights lawyers for delaying their entry to hospital?

In addition to these legal concerns, I stress that I believe that there are many changes needed in our State mental health systems. Perhaps we may have to restructure our inpatient units in larger units of one hundred beds, so we can once again safely care for the behaviourally disturbed by having sufficient staff available at all times. I do not believe it is in any way appropriate, as all too frequently happens, for the behaviourally disturbed to be arrested by the police and side-tracked to the criminal justice system. We have to be much more active as psychiatrists and allied health professionals in working with the police and with the courts to divert those people who come to notice, out of the criminal justice system into the health care system.

In the area of patients' rights, we have to redefine these and get a better balance between patients' rights and the right to treatment. I don't believe that psychiatrists who are seen as having a vested interest, can do this alone. The responsibility must fall back on patients themselves and their relatives and friends to demand a better deal. Organisations of Relatives and Friends of the Mentally Ill, The Schizophrenia Fellowship, The Richmond Fellowship, The Alzheimers Disease and Manic Depressive groups have a lead role to play in this ongoing dialogue.

Only when the consumers ask for the right to treatment will politicians and bureaucracies respond by creating the necessary legislative changes.

Schizophrenia and the Right to Civil Liberties

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Civil liberties is one of those phrases that is bound to have people either cheering in the aisles or booing, there is hardly any middle ground. Few people actually take the phrase at its face value. It's become more or less a code word to views that are either supported or rejected by the beholder. This should not be. We should talk about what civil liberties really mean.

What does it mean in its original context? In my view it means speaking of civil freedoms, a set of laws based on the individual's rights. These individual rights in turn are set out in clear and enforceable laws which are given effect by the institutions of Government in our society. In that sense the law, or laws in general, are not neutral. They should always serve some purpose.

Now in this regard I count myself as one of the old school when it comes to talking about civil liberties. I believe that civil liberties includes a question of civil freedoms which ensure human dignity, and which safeguard the individual's right to attain the highest possible quality or standard of life. In this way our understanding of civil liberties has really changed in the latter half of the twentieth century. The most well known example of it is the U.N. Declaration of Human Rights which is part of the international and legal basis for the Human Rights and Equal Opportunity Commission. Civil liberties these days are not just the traditions of the French Revolution - 'liberty, fraternity, and equality'. They include that, but these days they go much further. The U.N. Declaration of Human Rights includes the right to decent standards of education, housing, and employment, as well as human dignity. I talk about civil liberties in a much broader context than just the question of immediate freedom.

The concepts of civil liberties these days are spoken of as positive freedoms in contrast to what were called negative freedom, which stop others from actually interfering with someone else's personal liberty. In this sense I speak of the positive not just the negative civil liberties.

All of *us* have heard that sarcastic description of the American manner of upholding the legal rights of mental illness sufferers as 'dying with your rights on'. Now my view of schizophrenia, as it is with all forms of mental illness and civil liberties, is not 'dying with your rights on' but rather 'living with your rights on' - and that's the way I see it as well in terms of civil liberties. I think it is a false dichotomy to talk about the other person's absolute right to liberty or that person's right to treatment. When I speak of civil liberties I talk about civil liberties in the broader context of having the

right to human dignity and the right to a decent standard of living. That has to be

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translated into the sort of rights to which those suffering from Schizophrenia are entitled.

The rights should be upheld by the right to proper and adequate services of a high standard, including medical and psychiatric services, accommodation, and other forms of treatment from other professional disciplines. Sufferers should have those rights wherever possible while living in the community as a consenting person.

Secondly, there is the recognition of the importance of the wishes of the mental illness sufferer irrespective of the treatment he/she might be getting and putting those wishes into effect as far as possible. And its important, and I'll come back in a little while to say why, to respect the wishes of the sufferer.

Third, and I think this is probably equally as important as the other two points, there is the need for the accountability of those providing involuntary care and treatment, both to the suffering individual and the community at large. I think both of those go hand in hand. I also happen to think that accountability is important not just in terms of respecting the individual; I think that accountability is probably amongst the most effective ways of ensuring and promoting high standards of care and quality standards of care to the consumer.

Now perhaps if I could add a footnote to those three conditions. I also happen to think that in trying to bring that about, having and providing legal representation for mental illness sufferers is the *sine qua non*, the absolute essence, the essential ingredient in breathing life into these rights and conditions.

The mere fact that treatment can be given against the will of the patient or without the consent of the patient, is the fact which distinguishes involuntary treatment from any other area of medicine. It is also again the reason why, like it or not, doctors and lawyers along with all the other professions involved in providing care and support are in it for the immediate future and indefinite future as well. Ultimately in the end, when you do have lawyers and doctors co-operating rather than imagining that they are intractable enemies, the people that benefit are the sufferers. They are the ones after all who are supposed to be at the centre of what this is all about.

When we talk about civil liberties and the system of law that incorporates civil liberties, there must be a mechanism of accountability for the people who exercise the power involuntary treatment, because that power is awesome. They point out quite frequently the situation where they say 'look, I can name to you any number of illnesses, any number of conditions, any number of treatments which are riskier, which have a less sound scientific basis and which should be far more closely supervised than the comparatively well documented and scientifically-based treatment for example, of Schizophrenia through medication'. they will say 'what you should be doing as lawyers if you are really interested in the welfare of society is not worrying about the mentally ill. You should go and pull out various operations which are in their experimental stages'.

Ironically, of course, having said that, one of the operations which is in its experimental stages and which is legally supervised, and which I think is legally supervised correctly, is psychosurgery.

To come back to why psychiatry/mental health should have direct involvement of the law, it is an area where there are directly overlapping duties and interests. On the one hand 'in the laws' you have obvious need to provide care or treatment to someone who is suffering or may be suffering from a mental illness. The other side of that is where it involves involuntary treatment. Now immediately, by definition, you are invoking legal terms when you are talking about involuntary treatment. You've got legal terms when you are talking about involuntary treatment. You've got legal and medical issues immediately intertwined.

You are well aware that historically there have been all sorts of rights guaranteed on paper. We've had legal rights guaranteed from the time of the French Revolution onwards and in many cases those rights of course have not been upheld. In New South Wales, for example, there has been a system of Magistrates hearings for a long, long time - over 70 years - in which any person who is admitted involuntarily to a psychiatric hospital in New South Wales must be presented to a Magistrate. Now again for reasons which I will come to later, merely having the Magistrate's hearing didn't ensure that people who are not mentally ill were admitted to hospitals. It didn't ensure that people who were mentally ill, and may have required hospital treatment, were held at hospital for only as long as it was necessary to treat them there and not for much longer. It didn't, of course, do anything to ensure that standards of care were upheld either.

Now for reasons which I will come on to later, I feel that services that lawyers can offer have to go hand in hand with the sort of services and support that psychiatrists can offer, social workers can offer, and other people in the community can offer. The one thing that has to be realised is that when you want to talk about the human rights and civil liberties of mental illness sufferers you would have to talk about recognising their broader civil rights to a decent standards of life. And this can only be provided by a range of professional disciplines. That includes, doctors and psychiatrists and lawyers. I think that any movement away from that, any attempt to tread a path which has room for one profession and one profession only at the expense of another, is one which is effectively self-serving as well as misleading.

Now I've often had conversations with many friends who happen to be psychiatrists and the issue that always emerges is a clear resentment on their part that for some reason or other, which is unknown to them, their area of speciality, their area of practice - psychiatry, has been singled out for attention by the law. They want to know why is it, for example, if someone has a psychiatric illness whether it be schizophrenia or whatever, that warrants the intervention of the law?

Psychiatric treatment, a medical matter, may be provided to a person with or without that person's consent. The provision of that treatment with or without consent, is very clearly a legal matter. A question of personal liberty is a legal matter. It involves moral questions and it involves political questions.

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It's not a matter that we can dodge whether we are lawyers, psychiatrists, whether we are sufferers of mental illness, or whether we are families or supporters. When you are talking about personal liberty you are talking about not just whether or not the person is to be held in a hospital without the person's consent but also whether the person is to be treated without his/her consent.

They are two very important issues which will emerge later and which we will need to keep in mind. I think the power to treat involuntarily is very correctly a power which is described as awesome because, as unpleasant and as unflattering as it is, the only other group of people in society who have the power to detain someone with or without their consent is the Police. Now I can fully agree that is an unpleasant comparison. In fact I can actually detect the wincing in the audience. Unfortunately it is one of the facts of life. Now! don't say for that reason it should never be done, or that whenever it is done it is an outrageous infringement on the individual. But I think we have to admit and be honest with ourselves that this is what we are doing. Now whether or not it is for the person's own good (although that's a whole different basket of eggs isn't it, who decides exactly what is the best thing for the patient or for the person involved), it is still an infringement of liberty and the law says that every infringement of liberty must be justified. The law does not say every infringement of liberty is illegal or immoral. It says every infringement of liberty must be justified. I think we can agree that the exercise of that sort of power has to be justified.

Now when the police do arrest someone, to go back to that nasty analogy, what happens is that the person is arrested, charged. The law states that that person must be brought quickly and without delay before a court of law, and that a formalised ritual has to be carried out. The information and evidence is then put before a court, and the court then makes a decision as to how the law is going to be applied in this particular case. Now effectively the Mental Health Acts in each State provide mechanisms to carry out that function. It's important to realise that that is what they do. I think also that it's important to recognise that without the Mental Health Acts there is in fact no power to provide involuntary treatment to a mental illness sufferer, none whatsoever! The common law doesn't prescribe a right to treatment, it does not prescribe any other right apart from a very basic right to liberty. Now without a Mental Health Act, those of you who provide care or treatment to sufferers of mental illness would not have any powers whatsoever to treat someone involuntarily.

Now! think that should explain at least why it is that there is a future for both doctors and lawyers in this field. I usually find it is necessary to illustrate the reasons why! say these things, because we often forget what the results can be when the law is overridden, when there is simply a bad or ineffective law or a law which does not uphold civil liberties. One of the most obvious examples of what does happen when there are no real laws governing the involuntary treatment of the mentally ill, is what happened in the Soviet Union under Stalin up until the present time where treatment of mental illness, and the detention of people in hospitals, was effectively used as a political weapon to lock up opponents of the regime.

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It was very clearly used to put forward a very narrow and very restricted interpretation of social normality. After all anybody who criticised Uncle Joe Stalin, must have something wrong with them!

That is what can happen when mental health legislation can be reduced to a mere rubber stamp. Without wanting to take that particular analogy too far, there have been some studies done as to what has happened in New South Wales. Under the present Mental Health Act (this is as recently as 10 years ago), there were two studies done in two hospitals - Rozelle Hospital and Gladesville Hospital in Sydney. Rozelle and Gladesville Hospitals unfortunately have the distinction of being the first places that social researchers always go when they want to do some sort of research or investigation. I want to impress on you that in my view, Rozelle and Gladesville Hospitals were no better or no worse than other hospitals in New South Wales at that time. In 1977, an unpublished postgraduate paper reported that Magistrates' hearings which were effectively to decide whether or not a person should stay in hospital, how long that person should stay in hospital, and possibly what sort of treatment they should receive, were an average of some 3 to 4 minutes. Effectively, a person's immediate future was decided in a period of 3 to 4 minutes. I must say that when! mentioned that to a group of nurses, one nurse said that he simply refused to believe that because he certainly didn't believe it was possible for any hospital to do something in three minutes.

So, first of all the hearings were for a very short period. Second, 89% of persons presented were made the subject of a maximum 6 month order for detention in hospital. In only 5% of those hearings did the treating doctor actually attend the hearing to give the Magistrate direct evidence as to the reasons the person was in hospital, the need for the person's stay in hospital, and the sort of treatment the person would get. In other words, in 95% of cases, Magistrates at that time were making orders to detain people in hospital on the basis of what the Magistrate read on the medical certificates — that and nothing more!

It also occurred in the days when legal representation of patients at these hearings was rare. It was usually restricted to patients who were wealthy enough to afford it, or who had friends or relatives who were willing to go out and do the running around to organise a solicitor or a barrister to attend.

We now have a branch of the Legal Aid Commission of New South Wales which provides legal representation for people who have been involuntarily admitted to hospital and who are presented to a Magistrate's hearing. We have organised a system of representation effectively throughout the Sydney area and in the rest of New South Wales.

Let me give you some examples of things which have come about in the last few years following the establishment of the Mental Health Advocacy Service. Some of these things are patients wearing street clothes at a Magistrate's inquiry, access to all documents presented as evidence including the person's hospital file, medication which is consistent with proper care at a level which does not hinder communication during the legal procedures and the use of an Interpreter. Now I would stress that all of those things are sound psychiatric practice. Perhaps I am sticking my neck out

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in suggesting that legal representation at this sort of hearing might be accepted as sound psychiatric practice. I happen to think it is, but in fact it is not generally accepted as that. There is no obligation on the hospital authorities to carry out those things but they are now generally carried out. I think that as Solicitors representing our clients, we have helped and can take credit for the fact these things are now being put into effect in the hospitals of New South Wales.

Let me go on to discuss with you a couple of examples which I hope would act as eye openers. They are not intended to be a basis to have a go at anyone. They are there to serve as examples of what can go wrong, and how legal representation can help turn things in the right direction.

A young man called P, in his late 20s, had been detained in hospital by a Mental Health Tribunal under the Mental Health Act. That meant that he had already been detained in hospital as a temporary patient for six months by a Magistrate. Before that he'd been a voluntary patient for a further four months so he had been there for well over 10 months. When he saw the Tribunal that reviews people who may become long term patients (continued treatment patients), the Tribunal directed hospital authorities to place the young man in rehabilitation programs in order to prepare him for placement in the community to avoid him becoming institutionalised. Institutionalisation refers to a person who has temporarily or permanently lost the skill to live independently and with dignity in the community. Now the Mental Health Tribunal did have amongst its three members a doctor (G.P.) as well as a psychiatrist, so presumably the Tribunal had some idea of what it was directing the hospital authorities to do.

The Tribunal ordered that the young man be detained for a further three months, asking the hospital to prepare a discharge plan so that the young man could leave the hospital. Now during the whole of the time after the Tribunal's orders, he was detained in a locked security ward at the hospital without any access to rehabilitation programs. Apart from an initial attempt, no effort was made by the hospital to carry out the Tribunal's direction and have him transferred to an open ward for rehabilitation nor to have him placed in the community. At the expiry of the Tribunal's three month order the hospital simply continued to detain him in a locked security ward without any legal laws whatsoever, on the grounds that supposedly he still required involuntary hospitalisation and involuntary hospital treatment.

Four months later, in desperation I might add, the hospital's social work staff, contacted the Advocacy Service asking for a solicitor to intervene on behalf of this young man. They were appalled at the gross illegality of it all. They doubted that he still needed to be hospitalised and they were extremely worried that he may never again be able to live independently in the community as he had before he had been detained in hospital.

As a result of the intervention of the solicitor from the Advocacy Service, hospital authorities were compelled to present P to a Mental Health Tribunal sitting at a nearby hospital. Ironically at the hearing all the evidence presented by the hospital psychiatrist and social worker clearly stated that P was not a mentally ill person in the meaning of the Act. In other words, he did not come within the criteria specified

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by the Act to be detained and also there was real doubt whether he needed to be in hospital at all at that stage. So, needless to say, the Tribunal discharged him. Let me say that I was actually the solicitor who appeared for that man, Mr P. I had organised a psychiatrist's report and an independent social worker's assessment in addition to the hospital's assessment, as I imagined that after holding him for well over one year, the hospital would insist that he needed to be kept in there. I was the one who was most surprised when, at the hearing, the hospital was agreeing to let him go.

Let me give you another example, involving a man who was being detained in hospital suffering from severe depression. The hospital wanted to give the man a prolonged course of ECT. The hospital file indicated that the medical superintendent had gone through the necessary legal process, which in New South Wales at present simply requires the Medical Superintendent personally to make a decision that the person requires ECT for his/her own welfare or benefit. The Medical Superintendent had in fact done that. What was proposed was not just one or two episodes of ECT, but something like 12 treatments. Now, this was so despite the fact that the man's medical history indicated that long-term treatments like ECT were ineffective, caused increasingly severe memory loss, and confusion. It also caused a great deal of distress to him for obvious reasons.

On instruction, we arranged for a second independent psychiatrist to attend the hospital and examine the man to provide a second opinion on the advisability of administering ECT. Despite the clearly expressed wishes of the patient, the hospital refused to cooperate with the request from the Mental Health Advocacy Service to permit the independent psychiatrist to examine the man. The hospital even refused access to the Psychiatrist and proceeded to administer two treatments of ECT. The Advocacy Service made an application to the Supreme Court in Sydney on an *&parte* basis, effectively on an emergency basis, for orders restraining the hospital from continuing to administer the ECT beyond the two treatments that had been given.

On the summons return date, the Court was informed by the hospital's counsel that it did not intend giving any further, treatments of ECT. Ultimately the Court upheld the hospital's and the medical superintendent's right to administer the ECT. The man did recover, but there was no more ECT and he was eventually discharged from hospital. The case is important in my view, because the court clearly stated that in deciding whether or not to administer ECT involuntarily, the medical superintendent was obliged to take into account the patient's wishes. Now! don't say, and the Court didn't say either, that the Medical Superintendent was bound by the patient's wishes. To my knowledge it is the first occasion that a pronouncement like that has been made by a Court involving involuntary treatment in a psychiatric hospital. I'd go further to suggest that the upholding of the client's right to have his/her wishes taken into account now ought to be extended to all areas of involuntary treatment. Again, let me emphasize that it shouldn't necessarily be binding but have to be taken into account Quite frequently, unfortunately, they are not

In addition to these cases, we are currently acting on behalf of a number of involuntary patients, former patients, or their relatives concerning treatment

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received in hospital or in the community. In at least two of these cases, the person who received treatment died in circumstances strongly suggesting treatment which they had received was negligent.

A case currently being investigated by us involves a young man suffering from chronic Schizophrenia who had been successfully placed in a group home and was stabilised under the supervision of a community health care team. A psychiatrist newly placed with that team changed his patient's medication and reduced his dosage without consulting any colleagues whatsoever on that team. As a result, the young man's condition rapidly deteriorated leading to his involuntary admission to hospital. According to his mother the young man was set back several years. He is presently still in hospital receiving treatment.

I think you will agree that these are the sort of areas in which we ought to be involved. It is important to have effective legal advocacy for people suffering from mental illness who are involuntary patients in hospital. It is important in that it plays a positive role in ensuring that breaches of standards don't go undetected. People who are effectively the consumers in our business are dependent for life and limb on the quality of the psychiatric services they receive. Now therein lies the importance of our involvement in those sort of cases - not to 'doctor-bash', not to conduct witch hunts, but to maintain standards for the benefit of the consumers. These sorts of investigations can only be carried out, and the facts of these cases can only be uncovered, by members of the health care professions, including psychiatrists, who have the expertise to determine what should be the appropriate standard of services in any particular case.

Without people like them the scrutiny and accountability that I was speaking of earlier, doesn't exist in reality. Despite what the law might say, despite what legal and medical ethics might say, in every case where we have talked about raising standards we have to talk about having people involved who are prepared to roll up their sleeves and uphold the rights of people who are dependent on these sorts of services.

In an article entitled 'Treatment of the Mentally Ill: Legal Advocacy Enters a Second Generation' (*American Journal of Psychiatry*) the author, Bennet Rubenstein said:

egal advocacy efforts are assuming a second and potentially more controversial dimension, which is the increasing use of law as a means of accountability regarding the treatment and services provided to psychiatric patients. As a result, appropriate standards of medical care, from diagnosis to medication, to the use of restraints, to rehabilitation have emerged, and because such standards now exist, individuals can try and enforce them. That, I believe, is what lawyers and doctors can do together.

I was approached a month or so ago by a woman who formerly lived in Queensland and who had been held or detained in hospital here on two occasions. She told me that it had all been done illegally and she was quite angry about it. She asked me to do something about it. My first reaction was to obtain her written authority and to write to the two hospitals in question, asking them to provide me with information

about her involuntary treatment in hospital and how it was that she came to be brought there. I did this as I have no idea whether or not this woman's case is valid.

This is the reply from the hospital:

It is the policy of this hospital not to release clinical notes of patients, except in the case of a successful third party discovery action or subpoena. We do supply medical reports on patients when supplied with full details of name, date of birth, and specific information about injuries or admissions. We also require a supply of the type of action envisaged and also the names of the parties involved in such actions. Yours faithfully.

When I first read that I was appalled. What it amounted to was the hospital simply, bluntly, and flatly saying through me to a former patient at that hospital, we are not going to tell you much at all about why we brought you in here. We are not even going to show you the legal documents which entitled us to bring you in here, hold you, and treat you for something like 10 days. That's an example of the sort of challenge that I suppose lies ahead of us all.

Advocacy from the Patient's Point of View

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In its broadest sense, the concept of mental health advocacy seeks to ensure that people are treated in a manner that guarantees that their dignity, worth, and rights as citizens are considered and respected within the health care system. Patients as consumers of health care have a right to complain about aspects of their hospitalisation and treatment with which they are dissatisfied. The role of the advocate is to provide the patient, as the consumer of a service, with a recognised avenue for voicing complaints about the quality of the service being offered.

Mental health advocacy is an area where the interests of mental health professionals and lawyers often collide. The conflict between the 'legal rights' and the 'best interests' of the psychiatric patient highlights basic philosophical differences between the legal and psychiatric professions. For the patient advocate, there is no simple solution to this conflict. After all, which is worse: for the patient to be hospitalised and thus suffer the loss of freedom, or to go free and thus suffer the loss of care and treatment?

The patient advocate aims to maintain a balance between the clinical and therapeutic needs of the patient and his constitutional and common law rights as a citizen and, to this end, treats each patient as an individual with specific needs and special circumstances.

The Office of the Patients' Friend is such an advocacy service. **It** serves the patients and their families within the Wolston Park complex, Queensland's largest psychiatric institution. The program was introduced into the hospital in 1977 and at the time represented an innovation in the provision of health services to the mentally ill in Australia. Over the past ten years, an average of ten matters per week concerning patients were referred to and handled by the Office of the Patients' Friend.

The expectation of patients in relation to their care and treatment varies according to their psychological needs and, to some extent, the degree of their disturbance. In general, it has been my experience that patients expect:

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- to receive attention to their needs and concerns about their mental state;
- to be given regular and meaningful information about their condition, treatment and progress;
- to have confidentiality maintained.

The first of these expectations is to receive attention to their needs. Present Queensland legislation, the Mental Health Services Act 1974 - 1987, states that no cry for help made by a bona fide patient is rejected. Any patient seeking admission is to be examined and his mental condition assessed. The legislation further states in Section 6 that the least restricted option and least legal formality should be used for the treatment of the mentally ill person.

Treatment is the least restrictive alternative and is an important aspect of the right to treatment itself. Unnecessary restriction of liberty and prolonged hospitalisation does not necessarily equal treatment and can be debilitating for the mentally ill person whose confidence, self esteem, and social skills may be seriously eroded by such hospitalisation. On average about 60% of the patients at our hospital are admitted informally for treatment. The remaining 40% are involuntarily committed or regulated under the provisions of the legislation.

Queensland legislation provides for a mentally ill person to be regulated on the grounds that hospitalisation is the only alternative 'in the interest of his own welfare or with the view to protection of other persons' (Section 18). None would argue that the primary purpose of a person's hospitalisation is treatment, not punishment. The hospital then is charged with the responsibility of providing adequate and appropriate treatment for the patient. This necessitates assessing the specific needs of the patient in consultation with the patient and, where appropriate, his family. It is my opinion that greater consideration to this aspect by the treating staff may well go a long way towards reducing the fear, anxiety of, and hostility regularly expressed by patients who are involuntarily detained.

Optimal care and treatment means that each patient has a right to an individual treatment plan designed for his specific needs. The treatment plan must be individualised with realistic goals and must be regularly reviewed. Long-term patients especially need to be reviewed at regular intervals to ensure that the nature of the treatment they are receiving has continued benefits for them. I see the advocate as an independent monitor of the mental health worker's accountability to the patient. The advocate, being totally independent of the hospital administration, can often provide a neutral or objective assessment of the grievances raised by patients and can relieve the bind staff can face when their loyalties to their employer and their responsibilities to their patients do not coincide.

For patients, issues threatening the quality of life in hospital become very important and can have an effect on the success of any treatment plan. For long-term patients, in particular, the details of routine living have significant impact on behaviour. An important function of the advocate is to monitor the quality of life for patients and ensure that regard for safety, sanitation, comfort, and privacy are maintained.

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The second matter is that of providing regular and meaningful information to patients about their treatment and progress. There is often an expectation on the part of the treatment team that patients delegate maximum responsibility for any decision regarding their treatment to the team who are expected to act in the patient's best interests. The reverse also occurs and often, patients distressed by psychiatric symptoms only too readily share the responsibility for their problem and decisions with staff. This may be appropriate in the initial stages of hospitalisation when treatment for the patient's mental condition is the immediate need. As the patient's condition becomes stable, patients and their families need to be given ongoing information and be allowed to participate as much as is realistically possible in decisions regarding care and treatment. This relieves the fear and anxiety that can result when things are done to patients that affect them which they know little about, and over which they have little or no control. It has been my experience that psychiatric patients generally accept treatment methods, hospital rules and regulations, and even involuntary commitment provided that sufficient time is spent explaining reasons and answering their questions honestly and openly. I see it as especially important that those patients whose liberty is restricted by the provisions of the legislation be given a very clear outline of the conditions under which this can occur.

At this point, I address the very important issue of patient self-determination; that is, the right of the patient to make decisions about matters that concern him. The issue of patient self-determination is complex. On the one hand, certain kinds of decisions, such as the decision to accept help and to change behaviour, can only be made by the patient. Obviously, on the other hand, certain groups of patients, such as the severely disturbed, have limited or no capacity in making decisions. Between these extremes, however, there is a large group of patients capable of making choices and decisions but who are not always knowledgeable about the available opportunities and procedures. Facilitating patient self-determination by extending the patient's knowledge of such opportunities is an important part of the advocate's work.

The image of the helpless, dependent patient must be discarded. Many patients are capable of articulating their needs and dissatisfactions if given the opportunity. Having rights is only the beginning. Patients have to know about their rights if rights are to be of any use at all. They have to know what to do, whom to see, and how to use the administrative machinery to actually implement their rights. It is the advocate's role to ensure that the patient's rightful claims for self-determination are heard and not oppressed within the bureaucracy. Many of the recurring complaints received by our office are from patients who are prevented from exercising their own preferences in managing their lives while in hospital. The result is a loss of freedom of choice. Often, issues are routine day-to-day matters many of us take for granted, such as deciding how much money to have, what to spend it on and so on.

It sometimes happens that a patient, once aware of the available avenues and facilities, does not wish any further action on the issue. The advocate must guard against making the classic assumption of the medical model — that is, that he or she knows what is best for the patient. No advocacy action is undertaken without the

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patient's desire or consent. Where patients are so ill that they are unable to act in their own self-interest, or their capacity to make a decision or communicate a desire is limited then the role of the advocate is to ensure that they receive optimal care and treatment.

Within the general area of the patient's right to receive optimal care and treatment, the patient's right to refuse treatment, especially involuntary medication, is presently an important and controversial issue in psychiatry. This issue raises some difficult questions for the advocate. It can be argued that involuntary treatment conflicts with basic human rights to control one's life and actions. Furthermore, since treatment and/or therapy may have the power to control a person's thoughts and behaviour, then the patient should have protection against it and be able to refuse it. The most difficult situation, in my experience, is when a mentally ill person is competent and not dangerous, needs treatment and yet refuses it, and is involuntarily detained. From the treatment team's point of view, one would argue that to hospitalise a patient against his will and then to allow him to refuse essential treatment is to turn the original justification of hospitalisation into a sham. Under present Queensland legislation, informal patients, that is voluntary patients, who refuse treatment, may discharge themselves. Patients detained under the compulsory provisions of the legislation, however, do not have the right to refuse treatment. In practice, this excludes electro-convulsive therapy, which requires the written consent of the patient. A regulated patient may, however, seek a private independent opinion from a medical practitioner or mental health professional.

The most common complaint raised by patients is involuntary medication, especially in cases where side effects are distressing or insight into the necessity for treatment is lacking. The rights of the mentally ill are not always the same as the needs of the mentally ill. Informed consent is not always possible for the severely mentally ill. If the advocate is to be truly accountable to the patient then a balanced perspective needs to be maintained. When a regulated patient is prescribed involuntary medication, the patient should be informed as to what will be done to him, the reasons for it and its probable effect, and importantly, the side effects. Often, assisting the patient to present his objection directly to the treatment team may result in greater consideration being given to the patient's point of view.

At times, this can result in modification of the patient's treatment plan, but, even when no change takes place, patients appreciate the opportunity to raise their questions and dissatisfactions and have them discussed. It has been my experience that, when no other alternative is available, patients can be helped to accept involuntary medication if they can be shown that those administering treatment believe that it has a definite benefit to the patient and, ultimately, his quality of life. Obviously, a good therapeutic relationship between the patient and the treating doctor is crucial in helping the patient who refuses to be treated.

The patient—therapist relationship demands trust, loyalty, and the maintenance of privacy. The patient places himself in the care of others and reveals vulnerable aspects of his personal life. This brings me to the third expectation of patients mentioned earlier, that is, the right to privacy and confidentiality.

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It is the responsibility of the psychiatric facility and its workers to safeguard a patient's right to confidentiality in all aspects of his treatment, including even the knowledge that the person is receiving treatment. The hospital, of course, is free of responsibility if the information is released with the patient's written consent. In these circumstances, I believe it should be discussed with the patient what information will be disclosed. One of the areas where a patient's right to confidentiality may be threatened is where the issue of public safety is concerned. None would argue that the state has a justifiable right to protect its citizens. Queensland legislation provides one of the conditions for the admission and detention of a mentally ill person to be 'with a view to the protection of other persons' (Section 18). Regulation in these circumstances is usually done as if it were in the best interests of the patient, which of course it may be. In my experience however, patients find this the most difficult position to accept especially when confinement is based on assessments of potential danger to others and not actual history of dangerous behaviour. It is difficult to justify ongoing detention to the patient who does not actually display the predicted dangerous behaviour. As I see it, the role of the advocate in these situations is to ensure that the rights of society to be protected are not valued more than the individual patient's right to return to the community and regain his rights as a citizen.

I would like to share with you some examples of the type of complaint that patients refer to the Office of the Patients' Friend. In the ten years from 1977 to 1987, a total of 4,615 complaints from patients and their families were handled by the Office of the Patients' Friend. For clarification and evaluation, these are divided into seven categories. These are:

1. Care and Treatment issues.

These comprise 13.6%, and include issues such as dissatisfaction with treatment, lack of attention, requests for discharge and quality of life issues such as the ward environment and privacy, quality of the food, hospital facilities and so on. The greatest proportion of complaints within this category are related to inadequate time being spent by professional staff explaining aspects of the treatment or hospitalisation of concern to the patient. I can't stress enough how patients will often accept treatment or restrictions if efforts are made to fully explain the reasons and the co-operation of the patient is sought initially.

2. Mental Health Services Act issues.

These comprise 7% and include assistance with application to the tribunal systems, request for private medical and psychiatric opinions and, prior to 1985, complaints about the censorship of mail. The latter issue is no longer a problem under the new legislation. The greatest number of referrals to our office has involved assistance with and, at times, representation for patients to the tribunal.

3. Information-seeking issues

(12.9%). These involve patients seeking information about legal rights including general civil rights, information about the patient's condition and/or management, seeking advice/support, information about admission, detention, and discharge procedures. The number of referrals from patients dissatisfied with the amount of information available on various issues has decreased over the ten year period. I

believe that this indicates firstly, the effectiveness of the admission contact with all patients by the Patients' Friend. An officer from the Patients' Friend Office contacts all newly admitted patients and their families, and provides essential information. Secondly, there is a greater awareness among all staff at our hospital of the importance of providing information to patients and their families.

4. Property issues

Comprising 4.4% of the total. This includes lost, misplaced, stolen property, collection, despatch, and protection of patients' property. Considering the size of the hospital complex and the number of patient movements within the hospital, property issues comprise a relatively small percentage of referrals to our office.

5. Money issues

(45.3%). These include difficulties with benefits, pensions, problems with private money, misappropriation of money including theft, financial difficulties including loans and some issues involving incapability under Section 55 of our Mental Health Services Act. The greatest concern for patients, by far, involves money issues. Recently admitted patients are often totally unfinancial and our office operates as a lending fund for patients in need.

6. Contacting others

(13.7%). This involves contacting relatives, friends, legal agencies, officials both within and outside the hospital, and sometimes just doing messages for patients. In recent years there has been a significant increase in the number of contacts with legal agencies especially the legal aid office.

7. Maltreatment issues.

This comprises 3.1%, and includes physical and psychological abuse of patients by staff or by other patients. These comprise the smallest number of complaints, but nevertheless, are considered to be the most serious and, often, the most sensitive to deal with.

Apart from the reported contacts by patients where definite actions were taken by the Patients' Friend, there were numerous social contacts where patients come for a talk, to have a cup of coffee, to read the paper, or sometimes to pass the time of day. These informal contacts are an important part of the daily social life especially in long-term patients.

In conclusion, I would like to make some points that I see as crucial for the effective functioning of a mental health advocacy service. I believe that the advocate must be easily accessible and must have time to listen to all complaints. The majority of patients have complaints that involve day-to-day issues easily solved at the local level. I believe objectivity is paramount. Obviously if anyone may complain, some complaints will be irrational and unfounded. I believe diplomacy is essential and if complaints can be settled without conflict then the outcome for both patient and the staff is more desirable. Adversary procedures are out of place in mental health care where relationships between patients and staff should be based on trust with the common goal being the best interests of the patient. Systems are not perfect however. An advocacy service, such as the Office of the Patients' Friend by its very existence

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acknowledges the most important right of the patient and that is, the right to complain.

A Parent's Experience

Mr Orme Hodgson

President

Schizophrenia Fellowship of South Queensland Inc.

Before opening the meeting today I would like on behalf of the Schizophrenia Fellowships of Queensland, that is of North Queensland, Central Queensland and South Queensland, to thank the Human Rights and Equal Opportunity Commission and the Schizophrenia Australia Foundation for getting this symposium together.

Most of you know me. You know that I am not a doctor, I am not a lawyer but I do have a little intelligence. I did a maths and have some degrees and diplomas from university and! have published some papers mainly on geriatric dentistry and stroke in dentistry. I don't like being talked down to. I find my superiors don't talk down to me and I wear a big chip on my shoulder. I am wearing it today. I do so because of my experiences in the mental illness field. I do so because I am the parent of a schizophrenic daughter who is aged 29 years and who was first hospitalised ten years ago. She was a bright student who had a so called breakdown whilst in her first year of Agricultural Science. Our experience and knowledge of Schizophrenia at that time was absolutely nil. Unfortunately our G.P. had no greater knowledge than we had. He has today, because he has grown up with us. So there was a delay in our daughter seeking specialist advice, delay in obtaining treatment. Again due to this lack of knowledge our daughter was catatonic by the time she saw a psychiatrist. Indeed she was so far down in a state of catatonia that in the psychiatrist's presence she became completely mute and kept on deteriorating from that time. The psychiatrist concerned was extremely alarmed and said the only way out of this to save this girl's life was ECT. Now this ECT was necessary. My daughter was in no condition to give or to withhold consent. Therefore, we the parents, had to accept the responsibility of signing forms as she was put under the anaesthetic. I don't know where this all fits into some people's idea of human rights. Luckily this treatment was immediately successful with no after effects whatsoever. We were given no diagnosis and very little professional advice or information on our daughter's condition over a period of six years, six years of what for her was a stormy public service career, with other short-term jobs.

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It took Joan and I at least two years to come to terms with the horrible situation that we were in. We felt that we were completely bereaved. We were mentally devastated and I and my family just could not find anyone to turn to, not anyone. The system was out there somewhere but God only knows how one in our position at that time could find it. Had our daughter committed some crime it might have been a different story. So that was why in 1985 Joan and I became Foundation Members of the Schizophrenia Fellowship of South Queensland. We have devoted much of our time to that organisation. We were determined to help others through the tangle of initial action, hospital admission treatment and aftercare. The membership of our association in South Queensland is over 900 and growing.

Inquiries we receive about Schizophrenia and about the Fellowship, which would be many times that number, just tell you the number of people out there who are seeking help, seeking assistance. We in the Fellowship are determined that people with schizophrenia and their families can live with some hope for the future and with some support in the present.

I would like to bring you back into our family life again because it has a bearing on yesterday's discussions. Our daughter who is normally an attractive and intelligent young woman had managed to stay in the workforce for a period of just over three years, until she was pushed out by an unsympathetic Commonwealth Public Service Board whose pragmatic and unfeeling letters to her would have made the stoutest person cringe. I feel that if I had those very letters, if I had shown them in public, the Public Service Board would feel they would have some reason to take action against me for libel. They were terrible and these led to her second major episode. We feel they were a contributing factor.

Since then she has had episodes between periods of work and successful study on what we would call the downward trend. The latest climax approached just on two weeks ago as we were receiving help from friends within our psychiatric service here and the help we were receiving was from friends. Those professionals are our friends.

The usual dilemma arose of course. She denied her illness, she was not taking her medication, she was extremely disorganised, she sacked her psychiatrist. That was her right wasn't it? She was paranoid about her parents and the way she felt her parents interfered with her life. Personal hygiene was pretty close to zero. She was in an awful tangle with the CES and the Department of Social Security. Neither she nor they would allow us to help her get benefits which had been suspended for quite some time. We couldn't get any help because we would be transgressing the rights barrier: we would be transgressing the confidentiality barrier. She badly needed treatment but she would not accept it. She was fine, everybody else was sick. Should she be regulated? If so, when should she be regulated? I think there is a different term in other States that regulation isn't there, 'scheduling' I think they call it. Our daughter decided it for us. Knowing in her broken brain that she needed hospitalisation but rejecting the idea, she hopped in her car late on the Thursday night and she took off. Actually this is her usual reaction. It is a cry for help perhaps. Not knowing where she had gone I reported her as a missing person on the Friday although she had taken her dog with her. I feared for her safety, for as you know there

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have been far too many rape murders lately for anybody's peace of mind when their daughter is out there in the dark, late. On Saturday morning we received a phone call from a very distressed son-in-law in Sydney. Our daughter had arrived there. She had arrived there in a car which had been battered and dented in several places which obviously had been pushed off the road a number of times by impatient transport drivers. It must have been a hellish trip for her.

Our Sydney daughter was in hospital with a two day old baby and our son-in-law of course was in no position to deal with a very disorganised schizophrenic. Now, through the NSW Fellowship who like us mount a 24 hour, seven day a week advisory phone service, we contacted the Hornsby Mental Health Emergency Service.

We flew down to Sydney and we conferred with the team down there and this was late on a Saturday afternoon, and the team there offered to have a psychiatric nurse and a doctor available at any time on that Saturday or Sunday to schedule our daughter to a Sydney hospital if it was necessary. Now that was a marvellous service, I know it doesn't exist all over NSW but that is one place it exists and it should exist everywhere in Australia. It is a service which is just not available in Queensland for the average citizen, let alone outsiders from another State.

We got our daughter home and with the aid of a most understanding psychiatrist and nurse from the Eastern Psychiatric Services our daughter was persuaded to enter hospital as a 'voluntary involuntary' patient. Despite Nadia's reservations yesterday, we feel that that is often the only way a sufferer can be regulated from hospital with dignity, and that is one of their rights.

Now there was a jarring note in all this. In our interview with the duties psychiatric nurse at Hornsby it was nicely pointed out to us that we were very lucky our daughter had a safe home and we were able to fly down. She could have been sleeping under bridges and had parents unable to do what we did. Didn't he realise it doesn't matter what strata of society you belong to, we all hurt just the same, we all go down to the same depths of despair and hopelessness and there is no need to talk down to us about it. Now in conclusion I would like to read to you a short statement made by a mother at a conference on Law and Schizophrenia held in Canada recently, and which could apply to the situation here.

We, the families, believe that it is just too difficult to hospitalise our severely ill schizophrenic relatives when they need help and they are too ill to understand their own needs. We also believe that on all too rare occasions when we are able to get our relatives into hospital, they are released too quickly before their conditions are completely stabilised. They are returned to us only to relapse soon again, and we have yet another battle on our hands to find help for them. We are the parents of the throwaway schizophrenics, the disposables, the ones who are the most difficult to treat; who are often, as a result of their disability, unable to ask for or accept help. They refuse it.

Left without treatment they continue to suffer. Relatives must stand by and watch, unable to alleviate the suffering which in the main is ignored by the mental health care system until it is sometimes too late. It seems to be the

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same story the world over. We are the people who are told you can't help those who won't help themselves and we reply under our breath that it seems to us that you won't help those who can't help themselves. We are the people who mop up the blood of our sons and daughters when they have killed themselves, released from hospital all too soon, or not considered sick enough to be hospitalised in the first place, and we are the ones who must scrub from the floor the chalk outline of a beloved son's body after the police have left.

When we ask the psychiatrists why they do not declare our obviously ill relative incompetent, they reply that the Mental Health Act ties their hands. When we ask the bureaucrats and the politicians how such a law can be passed they tell us that the psychiatrists are interpreting the law too narrowly. When we turn to the lawyers they tell us that the rights of the individual are paramount and (even if it destroys the family) black is black, white is white. Human values do not really matter. We are left helpless and hopeless, alone in our struggle to save the lives our our children.

I am not blaming the individual health professional, the individual care giver, the individual lawyer for this state of affairs, but I do blame the legislators and bureaucrats who allow society to develop so that in the name of human rights, that society allows families to be denigrated, disbanded and destroyed.

There is a letter to the editor in the paper this morning, 'Battle to Survive'. 'Sir, After two deaths, Flat 38 is silent at last'. This is in the *Sydney Morning Herald* of February 16, 1989. Such a pathetic headline. The story of the death of two former psychiatric patients portrayed the misery of a couple trying to live in the so-called free society forced on them by the experts.

Would not these two unfortunate people still be alive had they been left in a protected environment? Is that the system which is guilty of causing their unhappiness and subsequent deaths by casting them into a world in which they couldn't cope? If the Government continues to close institutions which have cared for these people, many more of these tragedies shall occur! Again on a slightly different matter in this morning's paper. A politician and Minister of the crown in this State, in relation to the statement by Commissioner Brian Burdekin yesterday on child abuse stated flatly that he considered that all the problems of child abuse, child delinquency are the fault of the families. You can read that in this morning's *Courier Mail*.

I just feel it is time that all you professionals, lawyers, health professionals, indian chiefs, really communicated with each other. It is time you moved away from these standoffs, the standoffs between bureaucrats and the medical profession. It is time you communicated and got together and it is time you communicated more fully. Now some of you are communicating, I know that, but not across the board. It is time you communicated more fully with families. It is time that you stopped talking down to us and it is time you listened to us and for God's sake give us the privilege of a few rights too. Thank you very much.

Schizophrenia and Violence: Rights and Responsibilities

Dr Margaret Leggatt

Director of the Victorian Schizophrenia Fellowship and Secretary of the Schizophrenia Australia Foundation

I have a personal dilemma in giving this paper because **I** would prefer to be talking **about** positive things to do with schizophrenia, and not an aspect of schizophrenia that **I** wish did not exist.

Secondly, because **I** shall be putting the emphasis on the problems for the relatives who care for someone with schizophrenia, **I** am likely to be reported as wanting to return to the bad old days when we supposedly locked everybody up quite indiscriminately. The emphasis on the relatives' predicament is being given in this paper because their plight is still not properly recognised.

Thirdly, we have a situation where psychiatrists are backing off from making decisions to treat someone against their will early on in the development of a psychotic episode, and we are being forced by legal procedures to have to wait until there are chargeable offences, i.e. until danger to self or others can be demonstrated in such a way that it would be acceptable in a court of law. This is creating intolerable stress for families, and unnecessary delays in giving treatment to people with schizophrenia. But, if we are to come to some better solution to the problems created by schizophrenia and violence, we have to accept that we are in a very grey area.

I wish it were clearly black and white. We are trying to make it black and white so that we do not make any wrong decisions. The problem is that solutions in this area of reducing violence, means that some mistakes are going to be made, but **I** think the few mistakes, costly though they may be, will be greatly offset by the improvement in circumstances for a larger number of people. **I** think most of us do not want to even consider the possibility of making mistakes. It is too threatening.

For many years now **I** have adopted what **I** believe to be the correct statistical finding to the question of violence and schizophrenia, namely that violence is no more prevalent in those suffering from schizophrenia than it is in the general community. But my day-to-day experience in the Fellowship has led me to qualify this approach, as **I** find that it appears that more and more violence is being experienced in family environments, violence which is related to the symptoms of mental illness; violence which **I** believe could be prevented or curtailed by appropriate intervention. **I** also

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see as a very neglected human rights issue, the rights of a very large group of people in the community, the caring relatives whose cries for help often go unheeded.

I am not limiting 'violence' in this paper to recorded acts or convictions for violence, as is found in the literature. I include the expression of extremely hostile thoughts as indicative of psychotic states of mind, menacing, threatening behaviour through to actual acts of violence involving damage to property and physical assault.

The reasons for this is that even if someone only thinks violent thoughts, but does not act on them, or even if they only threaten, or behave menacingly, these situations are still frightening and horrible for relatives to have to live with, and the fear is always the same — how or when will the threats erupt into actual violence? Threatening menacing thoughts and behaviours create fear and intolerable situations of stress for relatives.

As a start to tackling this issue I had a look at some of the literature on mental illness and violence, and from this, I have extracted four major points that I want to emphasise because of the relevance they have to the general thrust of this paper, which is to face up to the issue of schizophrenia and violence. I think that we have been pussyfooting around too long, and from the kind of family situations with which we are being confronted in the Schizophrenia Fellowships, we have sound reasoning for wanting the issue of schizophrenia and violence to be addressed more forcefully.

The first group of studies that I will mention, relate to:

1. Prediction.

A large number of studies (summarised by Erskine in an unpublished paper) conclude that the evidence of ability to accurately predict dangerousness in order to determine whether or not someone should or should not be involuntarily hospitalised, is not encouraging, and the American Psychiatric Association is on record as saying that 'the ability of psychiatrists or any other professionals to reliably predict future violence is unproven'.

This point is made because 'when lawyers and sociologists pinpoint the prediction of dangerousness as one of the vulnerable areas of psychiatry, they force the psychiatrist to allow people to be in the community who need more structured care' (Robitscher).

Nowadays, it is danger to others rather than the nature and the severity of illness, and need for treatment, that has become the main criterion for civil commitment (Roth and Kroll).

2. The purported increase in violence.

Robitscher (p.185) states that new studies on the rates of violent crime amongst the mentally ill are showing that former mental patients do have a higher than normal arrest rate, although often for such relatively minor offences as drunken driving, and not usually for major criminal activity. In addition, anecdotal evidence is accumulating, during a period when it has become more difficult to get patients committed, that some patients who are not committed, do go on to commit dangerous acts.

In the section of his paper entitled *Violence and the Liberalization of Care*, Erskine cites Mullem (1987) who shows that studies have tended to find that conviction rates for offences by the mentally ill have increased substantially since 1985. He cites Taylor (1986), Sosowsky (1978), and Hafner and Baker (1982) who claim that deinstitutionalisation has resulted in the apparent trebling of both violent and non-violent offences by the mentally ill over the peak period of change in care in America. The suggestion is that serious acts of violence have been occurring as patients have been abandoned by psychiatric services and have had to fend for themselves in the community.

Fuller Torrey, in his latest book *Nowhere to Go: A Tragic Odyssey of the Homeless Mentally Ill* reviews the literature on violence and unequivocally states that it has increased substantially and that we can no longer ignore these facts.

That we have tended to deny mental illness and its violent aspects in the past is obvious from a number of statements in the literature, and from other sources.

3. Denial.

Dr. David Leonard in a letter he wrote to the Victorian inquiry into strategies to deal with the issue of community violence, commented that it was surprising that the link between mental illness and violence received such scant attention in the first document released by that inquiry. He goes on to say:

'I believe there are reasons for this. Mental health workers, very understandably, are anxious to get rid of the stereotype of the homicidal mentally ill madman that exists in some people's minds. It is certainly true that most acts of violence are not associated with illness, and most people with mental illness are not violent.'

Again, Robitscher says that psychiatrists:

'in the interest of decreasing the stigma of being mentally ill have spent a great deal of energy trying to popularise the view that psychiatric patients are no more dangerous than anyone else. But when sued for failing to restrain their patients from committing harm, psychiatrists defended themselves by denying that they had any special expertise in predicting dangerousness.' (p.184)

Brizer (1987), has also stated:

'despite the prevalence of violent behaviour at psychiatric hospitals, the risks of managing psychiatric patients is rarely acknowledged by the profession... Violence is the darkest side of mental illness and suggests the presence of criminality and evil (and we know that we are not dealing with people who are basically evil)... Secondly, those who evaluate and treat violent patients and their victims employ denial to avoid acknowledging an unpleasant reality.'

Another article by Brizer et al, claims that 'unfortunately, ward reports underestimate the true incidence of in-patient violence.'

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A most recent example for me, of denial, relates to the Queen Street murders in Melbourne. When the Victorian Coroner's report was released to the press and the psychiatric assessment had concluded that Frank Vitkovic was a paranoid psychotic, probably schizophrenic, totally out of touch with reality, and insane — and this was written on the front page of *The Age* newspaper, not one person commented publicly that this was not common behaviour for most people with schizophrenia. This occasion should have been used to show:

- what neglect of mental illness can lead to, in other words, appropriate intervention can prevent violence, and most of us believe that Queen Street should have been able to be prevented;
- it would have been an excellent time to highlight that by far and away the majority of the people with schizophrenia are not violent. But nothing was said, and the stereotype of the mentally ill madman remains 100% intact.

4. Management of aggression and violence is geared to professionals in hospitals.

Recent articles in issues of *Hospital and Community Psychiatry* are calling for appropriate training in the management of aggression in psychiatric patients. One article describes 'A Model for Understanding and Managing Cycles of Aggression Among Psychiatric Inpatients'(May 1987). Another article claims that treatment interventions 'are increasingly needed for patients with violent behaviour who make up a growing proportion of the population in public mental hospitals'. Another article 'Training for Battle: Thoughts on Managing Aggressive Patients' points to the fact that the problems of managing the violent psychiatric patient were only officially acknowledged by the American Psychiatric Association in 1974, when the APA issued its task force reports on the clinical aspects of the violent individual. Only in 1984 did APA issue its task force report on the psychiatric uses of seclusion and restraint, and then only partly as a response to court decisions around the country dealing with the right to refuse treatment. These decisions were making it increasingly difficult to forcibly administer medication to patients who refused it; this in turn made seclusion and restraint, more complex and also more common.

So it seems that denial and failure to address issues of violence are resulting in the need to find training and management programs in hospitals for the violently mentally ill. This is in America. My feeling is that in Australia, we are not addressing this issue adequately in the hospitals either, and if we are not adequately dealing with it in the hospitals, how can we expect the untrained families to cope? The management of aggressive patients (or the lack of ability to manage) is being forced upon the community, particularly those in closest contact with the patient. And although this literature survey is far from complete, nowhere did I find any data or references to what families might be facing and having to cope with by way of violent behaviour in their mentally ill relative.

To summarise the major emphases so far. The literature reviewed four major topics and resulted in the following conclusions.

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1. Prediction of violent chargeable acts is unable to be carried out with enough accuracy to warrant involuntary hospitalisation on the basis of possible or future violence alone.

2. There has been a substantial increase in violence amongst the mentally ill population, related to deinstitutionalisation.

3. We are denying the reality of some mental illness and violence, primarily because we want to protect the non-violent mentally ill from continued stigmatisation. We see the mentally ill as 'sick' and not as 'criminal'.

4. Nevertheless, the increase in violence is being felt in hospitals, and staff are needing to be trained in the management of the aggressive patient.

5. Nowhere did there seem to be any recognition of the need to consider how primary carers can or should cope with the atmosphere of smouldering violence which has the potential to erupt into actual and extreme violence against them. Constant expressions used by the relatives under these circumstances is that it is 'like living with a time bomb' or 'living on the edge of a volcano'.

In the Fellowship in Victoria, we are experiencing an increase in the number of calls for help in the situations of ongoing threats of violence, aggressive, menacing, threatening behaviour where effective intervention has not been available for family carers.

Over a two month period, I asked one of the Fellowship's part-time workers to keep a record of calls relating to people with mental illness who destroyed property, inflicted bodily harm, or had given verbal abuse which included threats and gestures, or menacing mannerisms which evoked fear, whether they were intended or not. In all of the following 150 calls, help had not been available when relatives had felt that they needed it. We looked at each of these situations in-depth, and then categorised the stories we had heard into a group of reasons as to why we felt that appropriate help had not been forthcoming.

1. The relatives presented their information quite inadequately. This is not to blame the relatives. In fact I think it is an indictment of professionals in that we have not trained them to know how to give the information we need. We have relatives who do not recognise what I would call really psychotic thinking and behaviour, with elements of real danger. They are frequently inarticulate and do not know how to describe their situations; they feel terribly guilty about complaining about their relative so they understate their problems, they 'assume' that doctors will understand their situation. There are often cultural barriers. So their story is underrated, and what they might be coping with is not fully appreciated, and not fully listened to.

Inaccurate assessments were made because of this; nothing was done, and the situations continued as before, often with reassurance from the professional that they could find nothing wrong. What we found very worrying was that, after extensive talking and listening, we found plenty that was wrong and that was frightening for the relatives. (14 calls).

2. Situations where the psychosis was barely controlled, but behaviour was still very unsuitable. These problems are left to the carers, with the frequently stated words 'there's nothing more that we can do' They are not 'sick enough' to warrant any intervention. This reminds me of the statement by a mother that schizophrenia is the only illness where you have to watch someone deteriorate before you can get any help. (46 calls).

3. Doctors who will not even talk to the relatives, supposedly for reasons to do with confidentiality. When serious mental illness is involved, this I believe, amounts to negligence. The doctors then make judgments on inaccurate information given to them by someone who does not present his symptoms fully often because of lack of insight. (46 calls).

4. Depletion or failure of the relatives' personal resources. The relatives in this category were getting older and their energy and resources were diminishing, making them more vulnerable to the mentally ill person's aggressive behaviour. Common instances of this depletion include situations where the husband has died, and the mother feels she cannot cope alone. The constant apprehension associated in coping with aggression and abuse had totally worn them out, they felt themselves less able to tolerate these circumstances, and because there seemed to be no way out, they had become very frightened, and terrified of anything they might say or do that would cause their son or daughter to be actively violent. (44 calls).

In our survey, 'Coping with Schizophrenia - For the Relatives', nearly half of the sample of 276 families reported serious physical and emotional problems which were seen to be aggravated, if not caused by, caring for their mentally ill relative.

In the last psycho-educational course that we conducted for relatives, the co-ordinator of that program told me that 9 out of 14 of the families were coping with situations of extreme violence, and had been unable to obtain help. As well, in our study *Coping With Schizophrenia: The Relatives' Perspective* which we published in 1987, we found that from a sample of 275 families, 90 families reported having to cope with varying degrees of violence and aggression. We have no way of knowing just what percentage of the total population of people caring for someone with schizophrenia this represents. Maybe families who come to the Fellowship are biased towards the more severe forms of schizophrenia, or those forms of schizophrenia which manifest with violent behaviours, but in a sense whether or not this group is representative, it still represents a lot of our families who are coping with extremely difficult, tense and anxiety-producing situations revolving around the potential, if not the actuality, of violent acts. Why are so many families caring for someone with schizophrenia having to put up with violence and aggression, as well as all the other difficulties associated with schizophrenia? What are some of the obstacles that they see are standing in the way of them obtaining some kind of effective intervention and help for their mentally sick relative?

1. Failure of G.P.s to realise that many people with schizophrenia are unable to recognise their illness, and therefore will not go to a doctor. Relatives are continually faced with the doctor saying to them: 'Your son or daughter, husband or wife must want to come and see me before I can help. Unless he/she comes to me

'I can do nothing.' I think this is an almost insurmountable problem when someone is becoming ill for the first time, because of the inability to distinguish the early stages of schizophrenia from a whole range of common emotional problems, but when someone has an established pattern of serious psychiatric illness, of which the loss of insight is a very common problem, when there is an established pattern of symptoms, and particularly when someone has gone off their medication and in the past relapse has been the end result, then it seems sensible for the G.P. to ensure that that person comes under care again.

2. Then there are the occasions when someone is examined and they show no evidence of psychosis, yet if you talk to the relatives you will be given a whole list of evidence of bizarre behaviour and thinking. But because doctors are reluctant, indeed cannot commit someone on the basis purely of what they have heard from others, again nothing happens. In cases where mental illness is present and cannot be elicited, couldn't a time-related period of observation be made mandatory?

3. Interviews when they occur, are often too short for psychosis to become evident. This is particularly the case if inexperienced interviewers do not know how to elicit crazy thinking and do not ask the appropriate questions after the appropriate questions can be gleaned by talking to relatives first — but so often the relatives are not consulted, or if consulted, often not believed.

4. Mental illness symptoms fluctuate. Often we find the symptoms are not there when examined by a doctor, but return at a later date, when nobody in authority is present — only the relatives, who have to cope as best they can with uncontrollable behaviour.

5. Prodromal symptoms, reappearing often after someone has gone off medication are not enough to enforce treatment. We have to wait again until really crazy stuff is apparent. We often have to wait until a chargeable offence is possible before anything is done — either medically or legally. Most relatives would have preferred something medical (or psychiatric) to have been done earlier.

Roth and Kroll, in their excellent book, *The Really of Mental Illness*, ask that:

The attitude and policies of society should... give due weight to the need to institute psychiatric care at an early stage of illness, to take account of the benefits that patients, their families and the community would derive from such policies. However, the laws relating to mental health in a number of countries have..., given priority to quite other considerations. Danger to others rather than severity of illness and need for treatment has become the main criterion for civil commitment of psychiatrically ill patients to mental hospital... legal intention in decisions relating to treatment has led to a lower standard of responsibility to patients as persons.

Doctors and mental health professionals who perhaps should have the responsibility in early diagnosis have backed off from the mentally ill because there are too many difficulties, too many obstructions in their way. Small wonder too, that we have relatives who are frustrated, angry bitter and

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resentful at the psychiatric and medical profession who by and large they believe have done very little to help them.

Several issues need to be addressed here:

- G.P.s need to be educated in understanding the earlier warning signs of mental illness.
- Relatives need to be listened to and believed as part of the process of making an accurate assessment. All too often, confidentiality is used as a reason for not even listening to what relatives have to contribute.
- Mental Health Acts need to look at the clauses in them that are acting as impediments to the gaining of treatment at earlier stages than is now possible. Because it is now going to be through looking at such processes that much violence relating to mental illness will be eradicated.

Again, harking back to the Schizophrenia Fellowships, I sense that anger is growing at the failure of psychiatric services to adequately help the long—term mentally ill. There is growing anger and resentment at the fact that doctors and lawyers are seen to be fighting amongst themselves for some sort of professional supremacy, rather than having as their major concern the real welfare of patients/clients and their families. Maybe what is needed is an enormous ground swell of complaint from relatives which I believe could be very useful, but which as yet has not happened in Australia and may not happen either.

Amongst a few though, there may be an increasing need to confront the issue of violence in schizophrenia much more openly than we have done in the past. What for example, would you say to inviting Mr. Jack Hinkley to Australia, the father of the young man who attempted to assassinate President Reagan? Since the shooting, Jack Hinkley has gone very public in an effort to educate the community about mental illness and to raise money for research. He states publicly:

If Joanne (his wife) and I had known the early warning signs of mental illness there probably would have been no shots fired.

The purpose of his visit would not be to publicise the fact that his son attempted to shoot the President, but to emphasise what was the end result of ignorance, neglect and failure to treat. Both Hinkley (in the United States) and Frank Vitkovic (in Melbourne) are examples of a lengthy period of avoidance in facing the problems of earlier detection and intervention.

The greatest concern of course in raising the issue of schizophrenia and violence, is the effect on the majority of others with schizophrenia who are not violent. Will they all remain tarred with the same brush? The community already believes, even though it may believe wrongly, that all people with schizophrenia are dangerous. After all, that is the predominant information that the community is given about schizophrenia. I think we face a huge problem of credibility here. We are asking the community to believe that violence associated with schizophrenia is rare, while the only information that is getting through to the community is that people with schizophrenia are

homicidal madmen. If we could show that most of the violence associated with mental illness can be prevented and is therefore unnecessary, that might be a very good way to get the community onside. Maybe confronting the community's entrenched fears is the way to start an education and destigmatisation process.

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Note: Articles and unpublished papers are set in roman type in inverted commas.

Published works (such as books, magazines, newspapers etc) are set in italics
(no inverted commas)

The Social Stigma of Schizophrenia as an Obstacle to the Exercise of Human Rights

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I want to talk today about 'The social stigma of schizophrenia as an obstacle to **human** rights' I thought we might first look at the nature of stigma and some of its causes; then very briefly the consequence; and then I want to concentrate on ways in which I think that stigma can be overcome.

I would like to begin by reading the opening passage of Fuller Torrey's book *'Surviving Schizophrenia A Family Manual'*:

Schizophrenia, I said The word itself is ominous. It has been called 'one of the most sinister words in the language'. It has a bite to it, a harsh grating sound that evokes visions of madness and asylums. Is it not fluid like 'dementia' the word from which dementia comes. Nor is it a visual word like 'ecrassé', the origin of 'cracked' and meaning that the person was like a cracked pot. Nor is it romantic like 'lunatic', meaning fallen under the influence of the moon (which in Latin is lunar). 'Schizophrenia' is a discordant and cruel term just like the disease it signifies.

We have had many debates in the time that I have been involved with schizophrenia about the word and about the use of it. Whether we should use it, whether perhaps because of the connotations it brings with it, it's better to call it something else. So great is the stigma attached to schizophrenia that there are still people who debate about its use. In many parts of the United States, fund raising activities are considered better served by using the words 'mental illness' or 'brain disease'. I know there is a whole body of literature about labelling and that often the word schizophrenia is not used to relatives or to sufferers out of protectiveness and confidentiality.

But I think the consequences of not using the word are far graver than from using it. Schizophrenia is an illness like any other and as long as we go on denying the word, that in itself brings a sense of shame. I think it's better to use it, and use it all the time. There are still hundreds of people who feel the stigma of schizophrenia so badly that they continue to hide it in shame. Whenever I write about schizophrenia

or I talk on radio or on television, I will each time get sometimes up to two hundred letters from people, many of whom have never before talked about it to anyone outside their own family or the people that are involved in the illness, because of the shame. That happened very recently with Tricia Goddard in Sydney whose sister had schizophrenia and had killed herself very tragically in England. Trish Goddard started talking about it. She is a television ABC news presenter in Sydney and she was inundated with letters from people all over Australia who had never admitted anything to do with schizophrenia before. And in the Schizophrenia Australia Foundation where one of our primary concerns is to raise public awareness it is extremely difficult to find people, members of the family, who will speak publicly about it.

Sometimes there are very obvious reasons why you can't opt out of protectiveness for the person in family who has schizophrenia. It isn't easy, particularly when you are right in it. You become emotional about it. It's painful, but we must do it.

Consider the consequences for someone who has schizophrenia but who also feels that they can't talk about it because of the stigma. One of the most moving memories in my journey with schizophrenia came about four years ago at a public meeting in Melbourne. Nobody talked about it then. Nobody admitted that they had it. There was a young man in the front of the hall, and 'the experts' had been talking. This young man stood up and he said:

On the way here today I decided that I was going to tell everyone that I have schizophrenia. I have decided it's time that I stopped hiding. I have decided it's time I stopped living a lie.

He was a young man who had episodic bouts of schizophrenia and who each time he disappeared into hospital, when he came back he'd say he'd been on a bit of a holiday, or he hadn't been well, or he had just been working at home. It was this perpetual lie that he and his family felt that they had to live because of the stigma. He described it as 'like coming out of the closet' and from that moment, those in the room stood up and began to talk about their experiences with schizophrenia. There was a sense of great empowerment.

Only one year before, I had been in South Australia where we had a first public meeting to talk about trying to set up a Fellowship or some kind of group and it was inconceivable that anyone would stand up and say 'I have schizophrenia'. The more that people talk, the stronger we become.

Why has this stigma come about? I think in part it is probably a hangover from much earlier times when diseases in general and mental diseases in particular were ascribed to all sorts of religious and supernatural causes. People were said to be possessed by devils and by demons and they were burnt at the stake or herded on to ships and sailed from port to port, the 'Ships of Fools'. So that in our history we carry with us, the fear of the unknown, the fear of what was considered the supernatural.

I think there is something about the fear of losing control of the upbringing that so many of us had, of 'I am the master of my fate, I am the captain of my soul'. We don't

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like to feel we are out of control. We are quite willing to go to a podiatrist for our bunions or a surgeon for appendicitis, but we are still very reluctant to go to somebody when something happens to our minds. So we project that on to others and if we see someone else isn't coping, particularly someone who is seriously disturbed and sometimes quite frighteningly disturbed, inside I think there is that fear that maybe we might be like that. We project and then we reject, and we say 'Why can't they pull themselves together? Why don't they go away and leave us alone?'

I believe that is a community response that we have to acknowledge and deal with. I think it is also reflected in our economic priorities, this fear of our inner world. We spend millions on exploring our outer world and we spend so little on exploring ourselves. We know so little about the human brain, about our potential as human beings. Again I think that is part of the reason why we distance ourselves from mental illness.

There is the guilt, the guilt which was so scarifyingly underscored in the days of Laing and Szasz when families were considered to have a major responsibility for madness. Some of that lingers on and is still projected on to families by professionals. Again I look back to seven years ago when my own son became ill. I think there was less understanding than there is now, but you still have stories from families of being blamed. And it's when you hear, as I still vividly remember a social worker who said to me: "I know you are a very busy woman Mrs Blain, but try to love your son."

There is massive ignorance and that compounds the stigma, compounds the denial, so that when the Schizophrenia Fellowship of Victoria undertook a study to find the relatives' perspective of the illness, it's no wonder that the relatives gave the highest priority to the need to educate the community about mental illness, to lobby governments for improved services for the mentally ill, and to find ways of acceptance for people who have a mental illness.

So if you bring all that together you have a fear of the unknown, a fear of the supernatural, a fear of losing control of our minds and a fear of ourselves. You have guilt and you have ignorance, and you have a fear of violence, which I will talk about a little later.

What are the consequences of this stigma, the consequences of this denial? We know about the shameful neglect, the isolation of sufferers and their families, the lack of funding, the paucity of research, the inadequate services, the needless deaths, the legislative quagmires, we know that. Every single person in this room in some way or other is touched by schizophrenia whether through our family lives or whether through our work. And each in our own way, with our own perspective knows of the frustrations, and knows of the need to break through them.

How do we do that? How do we end the stigma? First of all, there is consumer awareness. We need to empower ourselves, those of us who are concerned as families, those of us who are sufferers. We need to be honest and open about what is happening to us in our lives. We need to tell people what it is really like. We need to have strength, we need to lobby. And if we have to find that strength through our

anger, well and good. But let us find an outlet for that anger otherwise it will be turned in upon ourselves.

There is professional awareness, the lawyers, the doctors, the police, the social workers, the people who often through no fault of their own see only one half of the whole. So you have the lawyer who only comes in at the end of a particular episode. He or she is not there at the beginning. You have the health worker or the doctor who sees the person in the hospital or in the clinic or in the waiting room, but they are not there with the family in the middle of the night when a psychotic episode occurs there with the terror and the isolation and the grief at seeing someone you love fall apart and being unable to hold the pieces together.

In my own case, I found one of the most helpful people was a probation officer, because she came out to the family. I could never get anyone to come out into the home to see what was happening or to meet us. She actually came and she met the other children and she was there at times when there was trouble, when we needed help. She was an advocate for us. There is a need for professional awareness and a breakdown in the isolation between professionals.

There is community awareness. We have talked about the need for a massive public education program. How are we going to do that? Through the media is the obvious response. When I was a member of the Better Health Commission we did a fairly large study to find out where people got their information about health. For over 50% by far the major source of information was the media. So we need to use the media constructively, not to react to the media, but actually to go out and work with the media.

One of the most successful things that we have done on the Foundation, and we did it also on the Better Health Commission, was to set up media workshops. You run a media workshop not necessarily to deal with a specific issue, but to make friends at that most simple of levels, to make friends with the media so that you form a relationship, you communicate, you can talk about what it's like. And in those workshops we identified key members of the media across the whole spectrum. We had the tabloid press, we had the medical researcher from *A Country Practice*, we had news journalists, we had current affairs journalists, we had feature writers. We brought them together with a doctor, a lawyer, Margaret Leggatt from the Schizophrenia Fellowship and people who had schizophrenia and their families. We didn't deal with large numbers of people.

In the case of the Better Health Commission we spent two days working together. With the schizophrenia workshops we spent a day, but they were productive days because if you are working as a journalist you are usually working under pressure particularly in television and radio. You haven't got time to absorb information quickly and if you have people who come to you and say, look we want to make contact with you, you welcome that. It's that kind of groundwork that I think needs to be put in with the media.

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You can also use the media to give information. You can use the media for agenda setting, You can set up programs with the media if you know that an issue is of major concern.

Let's say the Schizophrenia Fellowship here in Queensland decided that its major emphasis next year was going to be legislation. Well you can plan over a year the numbers of stories that you plant, you seed, on that one particular topic. It's no use just doing a one-off story. It's an ongoing campaign that you have to plan and stage. And ask for help from the people in the media as well.

It is not always going to work. It's going to rebound sometimes. There are good and bad journalists just as there are good and bad doctors. Perhaps bad is the wrong word, there are people that are not as adequate in their profession as you would like.

There is the entertainment section of the media that Quentin raised with us yesterday. He said 'Why not get on to the soapies?' Well I believe that A Country Practice is dealing with schizophrenia, and that could be very powerful. A long time ago there was a program called *Number 96* that did more to overcome the stigma and prejudice against homosexuality than all the learned papers in the world, because you saw a couple who were homosexual. You became concerned with the kinds of people they were, and you got to know them.

Films were harder. They take longer to make and are more costly. But after the Year of Disabled, the government did a survey to find out which were the most effective avenues for changing awareness (not necessarily changing behaviour - that's where legislation is so necessary). They found that documentary films were the most powerful.

When it comes to feature films that's maybe another educative process, where you get together the film makers in this country. Like the Children's Television Foundation in Victoria, which was concerned about the enormous changes in the structure of families in Australia not being reflected in films and in television programs. So they brought together some of the top writers, producers, directors of films and television programs in Australia to talk about those changes and to get them to develop the changes through drama. Again that might be very profitable.

I looked at some of the literature on films in the United States and I suspect (remembering the film *Patrick*) that there is a need for something to be done about the image of psychiatrists, because you find they tend to be divided into three groups. There is usually Dr Dippy who goes around making a right proper ass of himself; Dr Evil who is Machiavellian like the Doctor played by Helpmann in *Patrick* and if it's a female psychiatrist she is usually Dr Madonna. Those are the kinds of stereotypes. As far as mental illness is concerned, a survey in 1981 in the United States of films and television programs found that three-quarters of people with mental illness in films were shown as being violent. In terms of the psychiatrists, 25 percent were shown to be Dr Evil.

So an educative process is required.

Human Rights and Equal Opportunity Commission

I've talked about consumer awareness, professional awareness, community awareness, and now political awareness, perhaps the most important of all. I will finish on that note, because I want to talk about how we are going to achieve public awareness, with educating people.

We need resource material, we need media material, we need to have a good data base, and we need to share that nationally.

We need educational material, we need information, and we need advocacy programs that are nationally formulated with State responsibilities, where we are working together instead of carrying on with our own specific needs.

We must work together so that we can lobby governments; so that we can change political awareness. One of the most effective meetings that I have been to was in Syracuse where there was a large meeting of NAMI (National Alliance for the Mentally Ill) and there were well over one thousand people with a number of key speakers. Their political attack was constant and it was properly planned. I think that has been starting at a State level, but we need to now start setting a national agenda, and then State agendas. We need to have forward planning. We need to be lean, efficient and to work together because only then will we overcome the stigma and the prejudice and the denial that leads to the lack of services, that leads to the waste of human lives.

I've thought back often in the case of my own story, of my son who was very ill, and whose illness was quite relentless and which culminated in his killing himself. And it's not one person's fault. Fault is the wrong word. It was a lack of response because there wasn't the understanding there. It was a failure of services. It was a failure of proper supportive legislation. It was the whole of schizophrenia and that's what we have to deal with.

Margaret talked about the violent side of schizophrenia. I think we have to acknowledge that as well because that is the end result. That's what happens when help is not given early enough. That's something that I have also lived with, and where I have rung up for help and been told in the middle of the night with a very violent psychotic young man it's because you are not setting limits. What help is that? And that's because somebody doesn't understand what it is actually like. So again we get back to the understanding, and I think that what has been good about these past two days is that we have a cross-section of people with a lot of energy. I would like to see coming out of these workshops, some quite specific plans that we can follow through, that people can take away with them; so I look forward to the next part of the session.

