

## 5: Medical Model: Interest Groups and Human Rights Imperatives

This chapter discusses the various interest groups that support the medical model and examines their motivation and level of influence. An analysis is made of a campaign by some of these interest groups to extend involuntary treatment in NSW. The human rights imperatives associated with the medical model are examined with particular attention to the UN Principles on mental illness, the right to treatment and the concept of informed consent.

### Interest Groups

A powerful coalition of interest groups support the psychiatric profession in the belief that schizophrenic symptoms are signs of mental and/or neurological pathology. In broad terms the coalition consists of consumers of mental health services (voluntary patients and patient's relatives), the pharmaceutical industry and the State.

People who manifest schizophrenic symptoms are often viewed as being socially disruptive and potentially dangerous, both to themselves and other people.<sup>1</sup> This widespread perception gives rise to a State responsibility to control this type of person. In past times and in other cultures there have been a variety of ways by which the State has discharged this responsibility, usually through banishment or some form of incarceration.<sup>2</sup> The current method is for the State to provide mental health services and for mad people who are thought to be potentially disruptive or dangerous to be controlled by using psychiatric treatments. To facilitate this form of control the State enacts and enforces mental health legislation which empowers medical practitioners to identify the type of people in question and, if they are unwilling to cooperate, to incarcerate them involuntarily in mental hospitals and impose forced treatment on them.<sup>3</sup>

These arrangements have one major advantage and one major disadvantage for the State. The advantage is that the human rights complaints which inevitably arise from a situation in which a large number of non-criminal citizens are stripped of their civil liberties can be deflected by

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<sup>1</sup> M. S. Humphreys, E. C. Johnstone, J. F. MacMillan and P. J. Taylor, 'Dangerous Behaviour Preceding First Admission for Schizophrenia', *British Journal of Psychiatry*, Vol. 161, 1992, pp. 501-505.

<sup>2</sup> Michel Foucault, *Madness and Civilisation: A History of Insanity in the Age of Reason* Vintage Books, New York, 1965.

<sup>3</sup> For a discussion on the mental health policies practised by the governments of various countries see, Kathleen Jones, *Experience in Mental Health: Community Care and Social Policy* Sage, London, 1988.

assertions that the control is actually only care and treatment for a medical condition.<sup>4</sup> The disadvantage is that the State has to underwrite the cost of most mental health expenses.<sup>5</sup>

The costs of schizophrenia are substantial. In the United States researchers working for the National Institute of Mental Health estimated the total cost of schizophrenia for a single year — 1991 — at \$65 billion. This estimate was based on an assumption that the lifetime prevalence of schizophrenia for adult Americans was 1.5%. The costs were broken down into direct and indirect components. Direct costs were related to expenditures on treatment for both inpatients and outpatients as well as costs incurred by the criminal justice system. These direct costs were estimated at \$19 billion dollars. Indirect costs were based on estimates of lost productivity and were broken down into \$24 billion for wage earners, about \$4 billion for homemakers, about \$4 billion for individuals in institutions, \$7 billion for people who commit suicide and \$7 billion for people who could not work because they were required to take care of schizophrenic family members.<sup>6</sup>

Research and training expenditures on schizophrenia involve a substantial annual outlay. In the United States for 1991 they were estimated at \$71 million. This figure was comprised of \$51,302,000 in direct grants from the National Institute of Mental Health and approximately \$20 million from state governments, private institutions and pharmaceutical companies.<sup>7</sup> The size of this schizophrenia research industry has allowed psychiatric researchers to become an influential interest group supporting the medical model.

Members of the psychiatric profession, in general, are broadly trained in medicine before individuals take up psychiatry as a medical specialisation. Although the training of psychiatrists produces two branches of treatment — the talking therapies and the biomedical treatments — all students of psychiatry are taught, as a matter of course, that the symptoms of schizophrenia have a pathological cause.<sup>8</sup> Most psychiatrists find that their professional interests give them little cause to question this teaching. Psychiatry continues to hold a dominant position within an increasingly competitive mental health industry.<sup>9</sup> But the medical training of psychiatrists can only be expected

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<sup>4</sup> A. Buchanan, 'A Two-Year Prospective Study of Treatment Compliance in Patients with Schizophrenia', *Psychological Medicine*, Vol. 22, No. 3, 1992, pp. 787-797.

<sup>5</sup> T. G. McGuire, 'Measuring the Economic Costs of Schizophrenia', *Schizophrenia Bulletin*, Vol. 17, No. 3, 1991, pp. 375-388.

<sup>6</sup> Richard Jed Wyatt, Ioline Henter, Megan C. Leary and B. A. Edward Taylor, *An Economic Evaluation of Schizophrenia — 1991*, Neuroscience Research Center, Neuropsychiatry Branch, National Institute of Mental Health.

<sup>7</sup> *Ibid.*

<sup>8</sup> See for example, Donald W. Black, William R. Yates and Nancy C. Andreasen, 'Schizophrenia, Schizophreniform Disorder, and Delusional (Paranoid) Disorders', in John A Talbott, Robert E. Hales and Stuart C. Yudofsky, eds., *Textbook of Psychiatry*, American Psychiatric Press, Washington, 1988, pp. 357-402.

<sup>9</sup> Kathleen Jones, *Experience in Mental Health: Community Care and Social Policy* Sage, London, 1988, p. 35.

to continue to provide psychiatrists with a competitive edge over rival professionals like psychologists so long as medical explanations for abnormal psychology prevail.

Like the psychiatric profession, the pharmaceutical industry has strong commercial interests in ensuring the continued dominance of the medical model for schizophrenia. The medical model provides the rationale for drug therapy and, in turn, the pharmaceutical industry provides an extensive range of neuroleptic products from which prescribing psychiatrists can choose. In the United States the pharmaceutical industry openly funds the main psychiatric professional organisation, the American Psychiatric Association,<sup>10</sup> which receives "30% of its total budget from drug company advertising in its many publications".<sup>11</sup>

Pharmaceutical companies pay through the nose to get their message across to psychiatrists across the country. They finance major symposia at the two predominant annual psychiatric conventions, offer yummy treats and music to conventioners, and pay \$1,000-\$2,000 per speaker to hock their wares. It is estimated that, in total, drug companies spend an average of \$10,000 per physician, per year, on education.<sup>12</sup>

The pharmaceutical industry also selectively funds scientific research into the side effects of neuroleptic drugs as well as research and development of new products.<sup>13</sup> Drug company sponsorship of clinical trials is a major source of revenue for many psychiatric researchers. This flow of money provides strong incentives for further promotion of the medical model but it also casts doubt on the quality of the findings:

This spring, the New York Post revealed that Columbia University has been cashing in. Its Office of Clinical Trials generates about \$10 million a year testing new medications- -much of which is granted to the Columbia Psychiatric Institute for implementing these tests. The director of the institute was being paid \$140,000 a year by various drug companies to tour the country promoting their drugs.<sup>14</sup>

Pharmaceutical companies advertise their products<sup>15</sup> openly in psychiatric journals often competing for space with scientific research reports in the same areas of treatment for which their own drugs

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<sup>10</sup> Peter Breggin, Toxic Psychiatry Fontana, London, 1993, pp. 426-429.

<sup>11</sup> Loren R. Mosher, 'Are Psychiatrists Betraying Their Patients?', Psychology Today, Vol. 32, Issue 5, September 1999, p. 40.

<sup>12</sup> Ibid.

<sup>13</sup> Michael F. Conlan, 'Drug research advances reported by industry group', Drug Topics, Vol. 140, No. 5, 1996, p. 122.

<sup>14</sup> Mosher, op.cit.

<sup>15</sup> Duff McDonald, 'Smile with Prozac - and laugh to the bank with Eli Lilly', Money, Vol. 25, No. 4, 1996, p. 88.

are being recommended. Because their role is driven by the normal market concerns for the promotion of product sales there is often a certain amount of confusion concerning the difference between scientific findings and sales promotion.

This point can be illustrated by a recent report of research undertaken into the efficacy of an atypical neuroleptic called risperidone. Unlike conventional neuroleptics which only block dopamine receptors in the brain risperidone also blocks serotonin receptors. Risperidone was approved for use in the US in 1994. The pre-approval research used a sample of 388 people who were undergoing treatment for schizophrenia with conventional neuroleptics, but who were failing to respond to the drugs. Some were given an increased dosage of a conventional neuroleptic, some were given a placebo, and some were given risperidone. After eight weeks the researchers found that the patients given risperidone were more improved than those in the other two groups.<sup>16</sup>

However, there were two problems with this research. The first was that the criteria for judging ‘improvement’ was simply a matter of awarding the patients daily points on the basis of their observed willingness to cooperate and interact socially. The second problem was that one of the authors, Richard Meibach, was identified in a subsequent article as being an employee of Janssen Pharmaceutical Research Foundation, the research arm of the manufacturer of risperidone.<sup>17</sup> The wholly subjective nature of the observations of patient improvement, together with the conflict of interest of one of the observers, must cast some doubt on the scientific validity of these findings. This type of conflict of interest is a constant feature of pharmaceutical industry involvement in discussions about schizophrenia.

The appellation of ‘consumer’ of mental health services has come to be used in recent years to describe a fairly diverse interest group.<sup>18</sup> Consumers divide into primary consumers — i.e. patients or people in receipt of psychiatric treatment, and secondary consumers — usually meaning the relatives of patients. However, the patients themselves can also be divided into voluntary and involuntary patients. A major problem of identity has arisen from a tendency by supporters of the medical model to hold the group identity of involuntary patients hostage within the collective description of ‘consumers’. It should therefore be understood that inclusion in the category of ‘consumers’ is not equally convenient for all the interests that are associated with it.<sup>19</sup>

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<sup>16</sup> Stephen R. Marder and Richard C. Meibach, ‘Risperidone in the treatment of schizophrenia’, American Journal of Psychiatry, Vol. 151, No. 6, 1994, p. 825.

<sup>17</sup> Editorial, Science News, Vol. 145, No. 25, June 18, 1994, p. 398.

<sup>18</sup> Margaret Leggatt, ‘Schizophrenia: The consumer’s viewpoint’, in Graham D. Burrows, Trevor R. Norman and Gertrude Rubinstein (eds), Handbook of studies on Schizophrenia. Part 2: Management and research, Elsevier, Amsterdam, 1986, pp. 43-53.

<sup>19</sup> Karen Moscynski, ‘Tips for writing on mental illness. (political correctness is in order)’, Writer’s Digest, Vol. 76, No. 11, 1996, pp. 62-64.

Some of the most enthusiastic supporters of a pathological interpretation of schizophrenia are the relatives of patients.<sup>20</sup> Madness tends to generate intense levels of fear in both the people who experience it<sup>21</sup> and the people who witness others undergoing the experience.<sup>22</sup> This fear plays an important role in galvanising relatives into support of the medical model, and in shaping their goals. The importance of relatives as an interest group lies in their immediacy to the problems that arise when a person manifests unusual thoughts and beliefs. It is usually the relatives who are the first people to become aware when a family member begins to experience unusual mental phenomena. They are often alarmed at the sudden change in the person and frequently become confused and fearful about the situation — fearful both for themselves and for the person manifesting the symptoms. The first inclination of relatives is to seek help and advice and this is usually readily available from the medical profession.<sup>23</sup>

Of the three meta-models for explaining the symptoms of schizophrenia — the medical, mystical and myth-of-mental-illness models — the latter two, mystical and myth-of-mental illness, are likely to seem absurd to relatives.<sup>24</sup> Relatives usually see themselves as managing a crisis situation and these two models might look as if they are designed to exacerbate madness. The medical model, on the other hand, with its ability to medicate and pacify the relative, and to supply a causal explanation that satisfies normal scrutiny, can be highly attractive.

The relatives of schizophrenics frequently belong to support groups which are growing increasingly powerful as mental health lobby groups both in the United States<sup>25</sup> and Australia. A review of some of the literature directed at members of these support groups indicates strong collective support for the medical model. A pamphlet, for instance, published by the Department of Health in New South Wales which was directed specifically at relatives of schizophrenics, lists 13 points of advice on “The Role of Relatives and Friends”. The fourth point is “Help to ensure that medication is taken as prescribed.”<sup>26</sup>

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<sup>20</sup> Patrick Rogers, ‘A sense of purpose. (how family dealt with child’s chronic schizophrenia)’, People Weekly, Vol. 46, No. 3, 1996, pp. 139-142.

<sup>21</sup> P. Chadwick and M. Birchwood, ‘The Omnipotence of Voices. A Cognitive Approach to Auditory Hallucinations’, British Journal of Psychiatry, Vol. 164, No. 2, 1994, pp. 190-201.

<sup>22</sup> D. Titelman, ‘Grief, Guilt, and Identification in Siblings of Schizophrenic Individuals’, Bulletin of the Menninger Clinic, Vol. 55, No. 1, 1991, pp. 72-84.

<sup>23</sup> National Alliance for the Mentally Ill (NAMI), Schizophrenia Pamphlet by: National Alliance for the Mentally Ill, Washington, 1990.

<sup>24</sup> Schizophrenia Society of Canada, Schizophrenia: A Handbook For Families Health Canada, 1997, Available URL, <http://www.mentalhealth.com/book/p40-sc0/.html>

<sup>25</sup> Wes Shera, ‘Managed care and people with severe mental illness: challenges and opportunities for social work’, Health and Social Work, Vol. 21, No. 3, 1996, pp. 196-202.

<sup>26</sup> NSW Health, The Puzzle of Schizophrenia, State Health Publication No. (HTS) 88-016 NSW Health, Sydney, 1992.

Similarly a leaflet published by a relatives' support group called the Schizophrenia Fellowship states categorically that "Schizophrenia is now known to be a biologically-based illness...." An accompanying newsletter from the same organisation, under the heading "Not Taking The Prescribed Medication", recommends to "find a daily routine when tablet taking can become a habit (e.g. breakfast, toothbrushing)."<sup>27</sup> Another pamphlet from the Schizophrenia Fellowship declares its intention to "develop into an effective lobby".

In Australia two of the main consumer lobbying organisations are the Schizophrenia Fellowship and ARAFMI (Association for the Relatives and Friends of the Mentally Ill). In the United States the main counterpart is the National Alliance for the Mentally Ill (NAMI) which operates nationally and has some 140,000 members.<sup>28</sup> NAMI's enthusiasm for lobbying on behalf of the medical model has come under criticism for an apparent conflict of interest arising from its acceptance of large donations from drug companies:

The National Alliance for the Mentally Ill, which is pushing to have mental health laws rewritten so that people can be involuntarily hospitalised for refusing to take their medications, received nearly \$1 million in 1995 from more than 13 drug companies.<sup>29</sup>

Since 1995 NAMI's drug company funding has apparently escalated dramatically.

According to internal documents obtained by Mother Jones, 18 drug firms gave NAMI a total of \$11.72 million between 1996 and mid-1999. These include Janssen (\$2.08 million), Novartis (\$1.87 million), Pfizer (\$1.3 million), Abbott Laboratories (\$1.24 million), Wyeth-Ayerst Pharmaceuticals (\$658,000), and Bristol-Myers Squibb (\$613,505).

NAMI's leading donor is Eli Lilly and Company, maker of Prozac, which gave \$2.87 million during that period. In 1999 alone, Lilly will have delivered \$1.1 million in quarterly instalments, with the lion's share going to help fund NAMI's "Campaign to End Discrimination" against the mentally ill.

In the case of Lilly, at least, "funding" takes more than one form. Jerry Radke, a Lilly executive, is "on loan" to NAMI, working out of the organization's headquarters. Flynn explains the cozy-seeming arrangement by saying, "[Lilly] pays his salary, but he does

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<sup>27</sup> Olga Piatkowska and Maria Visotina, 'Coping With Difficult Behaviour: Do's and Don'ts', Schizophrenia Fellowship News, April 1992.

<sup>28</sup> Jennifer Comiteau., 'Taking the lead', Adweek Eastern Edition, Vol. 35, No. 51, 1994, pp. 24-26.

<sup>29</sup> Keith Hoeller, 'Psychiatric Drugs Harm Children', Seattle Post-Intelligencer, April Issue, 1997.

not report to them, and he is not involved in meetings we have with [them]." She characterizes Radke's role at NAMI as "strategic planning."<sup>30</sup>

In Australia an organisation called Schizophrenia Australia has been set up in recent years to lobby governments and educate the public about the medical model view of schizophrenia. The organisation also uses an alternative business name, SANE Australia. In 1998 the focus of their campaign was "Help for Families". Anne Deveson, Deputy Chair of SANE Australia, explained the intention of the campaign:

SANE Australia's Campaign provides help to families effected by mental illness, through information and referral to local services. .... We are also determined to put their needs firmly on the agenda with Commonwealth and State governments. It is unacceptable that of the eight states and territories, six do not yet recognise the unique needs of family and other carers in their mental health strategies.<sup>31</sup>

Schizophrenia Australia/SANE has a glittering array of entertainment/legal and business celebrities listed as its many patrons. However, acknowledgments in its literature make it clear that, like NAMI in the US, the Australian organisation is also largely funded by pharmaceutical companies which manufacture new schizophrenia drugs. Their 1996 "Carers Handbook" states that Schizophrenia Australia's Community Education Program is "proudly supported" by Janssen Cilag, Sandoz, ICI Pharmaceuticals and Eli Lilly. The drug company logos are all prominently displayed for emphasis.<sup>32</sup> Successive editions of SANE News, the organisation's newsletter, carry advertisements stating the "SANE News is proudly sponsored by Janssen Cilag — Supporting care of mental illness in the community".<sup>33</sup> SANE even sends out correspondence on letterheads which state that it is sponsored by yet another drug company, Pfizer.

Laurie Flynn, the executive director of NAMI in the United States, summed up what she called the "synergy" between relatives' support groups and drug companies this way: "The drug companies want more and greater markets, and we want access and availability to all scientifically proven treatments. We don't think drugs are everything, but for the vast majority they are important."<sup>34</sup>

Secondary consumer groups are often the most active lobbyists in campaigns to persuade governments to alter mental health legislation to make involuntary commitment easier. These

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<sup>30</sup> Ken Silverstein, "Prozac.org: An influential mental health nonprofit finds its 'grassroots' watered by pharmaceutical millions", *Mother Jones*, November/December, 1999, Available URL, [http://www.motherjones.com/mother\\_jones/ND99/nami.html](http://www.motherjones.com/mother_jones/ND99/nami.html)

<sup>31</sup> Anne Deveson, 'Help for Families', *SANE News*, Issue 8, Winter 1998, p. 5.

<sup>32</sup> SANE Australia, *Carers Handbook*, SANE Australia, Melbourne, 1996, p. 26.

<sup>33</sup> See for example, *SANE News*, Issue 9, Spring 1998, p. 8.

<sup>34</sup> Silverstein, *op.cit.*

campaigns are sometimes overtly coordinated by members of the medical profession. A common complaint of relatives' groups is a perception that civil liberties protections, which restrict unnecessary and unfair use of involuntary hospitalisation, interfere with their preference to incarcerate mad relatives in times of crisis. A recent campaign by secondary consumers to modify the involuntary commitment procedures specified in the New South Wales (NSW) Mental Health Act might serve as a useful illustration of campaign tactics.

### **Campaign to Extend Involuntary Treatment in NSW<sup>35</sup>**

On 26 May, 1995 a letter from a Dr. Inge Southcott was published in the Sydney Morning Herald.<sup>36</sup> Dr. Southcott's letter told about her anguish as "the mother of a 20 year old schizophrenic man who now lives on the streets". The purpose of Dr. Southcott's letter was to appeal for changes to be made to the NSW Mental Health Act (MHA) so that her son, who she said was "harmless and not suicidal," could be involuntarily incarcerated in a mental hospital and given treatment. Dr. Southcott's proposal was to have a stipulation removed from the MHA which required that a person had to be thought likely to cause serious physical harm to themselves or other people before they could be committed to a hospital involuntarily.<sup>37</sup>

Her letter was followed five days later by an article in the same newspaper written by Anne Deveson.<sup>38</sup> Deveson's article began with a reference to Dr. Southcott's letter and then proceeded to review her own similar experience with a schizophrenic son who she says "killed himself from an overdose of alcohol and sedatives while living on the streets, psychotic, malnourished, vulnerable". Deveson's article went on to endorse Southcott's concern about the difficulties that the requirement of 'dangerousness' causes to the relatives of mentally ill people.

Shortly afterwards two more letters appeared in the Sydney Morning Herald written by doctors. They were both supportive of Dr. Southcott's proposal to amend the MHA. The letters had both been written on the day Southcott's letter was published. One doctor argued that "the criteria for instituting compulsory treatment should be widened"<sup>39</sup> while the other, after affirming the difficulty

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<sup>35</sup> A version of this section has been published as a book chapter. See, Richard Gosden, 'Coercive Psychiatry, Human Rights and Public Participation', in Brian Martin (ed.), Technology and Public Participation, University of Wollongong, 1999, pp. 143-168.

<sup>36</sup> Dr. Inge Southcott, 'Anguish over mental health Catch 22', Letters To The Editor, Sydney Morning Herald, 26 May, 1995.

<sup>37</sup> Mental Health Act 1990, Section 9.(1), NSW Government Information Service, Reprinted as in force at 17 October, 1994, p. 5.

<sup>38</sup> Anne Deveson, "Towards a better treatment of serious mental illness', Sydney Morning Herald, 31 May, 1995.

<sup>39</sup> Dr. Kathleen Bocce, 'Mental health patients' families have few rights', Letters To The Editor, Sydney Morning Herald, 2 June, 1995.



of committing involuntary patients under the existing conditions, went on to demand more mental health resources.<sup>40</sup>

Five days later Dr. Peter Macdonald, the Independent Member of Parliament for Manly, himself a medical practitioner, made a speech in the NSW Legislative Assembly outlining his intention “to lead a crusade”<sup>41</sup> on certain mental health issues over the next few years. He indicated that amendments to the Mental Health Act to widen the criteria for involuntary treatment would be central to his plan.

Several months later, on 26th October, 1995, Macdonald introduced into the NSW Parliament a Mental Health Amendment Bill 1995 which proposed to replace the requirement of dangerousness for involuntary hospitalisation with loosely-worded criteria that would have allowed involuntary procedures to be invoked if a person was thought to be incompetent and in need of treatment.

In his two speeches to Parliament on this subject Macdonald supported his arguments by quoting letters from the mother of a young man with schizophrenia. In this correspondence the mother said she had “last worked in psychiatry in Adelaide in the late 1970s”.<sup>42</sup> She also gave an account of her son’s symptoms:

Our 20 year old son developed a psychosis about three years ago. He was a top student at his school, a promising musician, well-liked and respected by his peers. Our relationship with him was good, and we had hopes that he would be a well-adjusted adult, able to take his place in society. Today he is wandering the beaches and streets of Manly, to all intents and purposes a ‘homeless youth’.

His psychosis takes the form that he believes he has to convert all to Christianity because all are doomed to go to hell. He cannot explain why he believes this and he seems to think that the world is going to end soon. He gives away all his belongings and money to people he believes God is directing him to save, e.g. he gave away \$2000 at Christmas. This was his entire savings.

For a while he was bringing home vagrants and they would spend the night in his bed while he wandered the streets looking for more people to save. We lost various possessions to these people, some of whom were also obviously suffering from psychosis themselves. He deprives himself of sleep as he believes he has to be ‘working’ i.e. evangelising.

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<sup>40</sup> Dr. Robert Dixon, Letter To The Editor, Sydney Morning Herald, 2 June, 1995.

<sup>41</sup> Peter Macdonald, ‘Mental Health Support and Counselling Services’, Legislative Assembly Hansard, 7 June, 1995, pp. 46-47.

<sup>42</sup> Letter to Peter Macdonald April 1994, quoted by Peter Macdonald in ‘Mental Health Bill’, Legislative Assembly Hansard, 26 October, 1995, p. 1.

He has lost all his friends and his relationship with us is under great strain as he puts his ‘work’ before all other considerations. But he is not a danger to himself or to others so he cannot be taken to hospital under the present Mental Health Act.

The doctors involved say he would probably benefit from medication for his psychosis and they want to put him on the clozapine programme but their hands are tied until such time as he deteriorates further and does something to actively harm himself or others. Meanwhile his family suffers, his relationships with all his mates are lost, he loses all his money, he smells, he neglects all that he formerly held dear when he was well.

I think it is a disgrace that our society can let this happen, and I know it is not just my son to whom this is happening. It involves many other youths who are also wandering the streets in the grip of mental illness.<sup>43</sup>

It is clear this mother wanted her son to change back to the way he had been three years earlier. However, from her own account there was every indication that he wanted to remain the way he was. If we were to hear his side of the story it is quite possible he would argue that there was nothing wrong with his mind and he was only expressing his Christian beliefs. A detached observer might argue that it would have been more rational for the mother to change the locks on her doors and lock him out rather than attempt to change the mental health laws to have him locked up. But apparently her MP, Peter Macdonald, supported her approach and he actually used the example of her son as the primary justification for proposing his amendments to the Mental Health Act.

In human rights terms Inge Southcott’s role as an anxious mother campaigning for legislative changes is a matter of some interest. This is because she appeared to be participating in a co-ordinated effort. She also informed Peter Macdonald in a letter that she was a member of a support group called the Schizophrenia Fellowship and that this organisation planned “setting up a discussion group in May to look at further amendments to the Act especially the scheduling clauses”.<sup>44</sup> The scheduling clauses provide the legal framework for involuntary incarceration.

It should be noted that Anne Deveson, the author of the Sydney Morning Herald article which supported Dr. Southcott, helped to establish the NSW Schizophrenia Fellowship and then became the vice-chairperson of the national organisation, Schizophrenia Australia.<sup>45</sup> Deveson has been engaged in high-profile activity on mental health issues in NSW since the 1980s. She chaired a government-appointed committee set up in 1988 to review the Mental Health Act 1983, the findings

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<sup>43</sup> Anon., Letter to Peter Macdonald April 1994, quoted by Macdonald in ‘Mental Health Support and Counselling Services’, Legislative Assembly Hansard, 7 June, 1995, pp. 46-47.

<sup>44</sup> Peter Macdonald, ‘Mental Health Bill’, op. cit., p. 1.

<sup>45</sup> Anne Deveson, Tell Me I’m Here, Penguin, Ringwood Vic., 1991, Facing-cover page.

of which “were integral to the final draft”<sup>46</sup> of the amendments to the 1983 Act. She was also the initial chair of the Mental Health Act (1990) Implementation Monitoring Committee<sup>47</sup> which was set up by the NSW government to report on the efficacy of the new mental health legislation.

Deveson stands out as one of the most influential figures directing recent NSW initiatives in mental health legislation. By occupation she is a film-maker/writer and her expertise in the mental health area is largely based on her experience as the mother of a schizophrenic son. The story of her relationship with this son is poignantly told in her book Tell Me I’m Here.<sup>48</sup> She portrays herself in this story as a frustrated, intermittent, and sometimes reluctant, carer. Her son died in 1986.

Deveson’s subsequent zeal to reform public policy on mental health issues is outlined in the proceedings of a curious Symposium on Schizophrenia and Human Rights jointly sponsored by the Human Rights and Equal Opportunity Commission and the Schizophrenia Australia Foundation.<sup>49</sup> The symposium was held in Brisbane in February 1989. It was curious because at the time there were daily newspaper reports emanating from the Chelmsford Royal Commission<sup>50</sup> exposing psychiatric malpractices. Yet most of the speakers at the Symposium chose to focus attention on a perception that “the right to treatment” should have precedence over “patients’ rights”.<sup>51</sup> This was despite the fact that the human rights principles summarised in the opening address by the Human Rights Commissioner, Brian Burdekin, as being the principles most closely related to mental health issues, did not include a right to treatment, nor rights for relatives to arrange for involuntary treatment, but were all concerned with the rights of the individual to avoid coercion and discrimination.<sup>52</sup>

Deveson’s contribution to the Symposium largely consisted of detailed advice on how members of support groups for relatives of schizophrenic people might be able to manipulate the mass media by winning over journalists to their point of view on mental health issues.

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

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<sup>46</sup> The Mental Health Act Implementation Monitoring Committee, Report To The Honourable R A Phillips MP, Minister For Health On The NSW Mental Act 1990, ‘Preface’, August 1992.

<sup>47</sup> Ian W. Webster, Chairman of The Mental Health Act Implementation Monitoring Committee, Letter to The Hon. Ron Phillips M. P., Minister for Health, Attached to ibid.

<sup>48</sup> Anne Deveson, Tell Me I’m Here, op. cit.

<sup>49</sup> Human Rights and Equal Opportunity Commission, Schizophrenia: Occasional papers from the Human Rights Commissioner, Number 1, Human Rights and Equal Opportunity Commission, Sydney, December, 1989.

<sup>50</sup> This was a judicial inquiry into psychiatric malpractice at a private hospital in Sydney called Chelmsford.

<sup>51</sup> John Grigor, ‘The Right To Treatment’, in Human Rights and Equal Opportunity Commission, op.cit., pp. 7-14.

<sup>52</sup> Brian Burdekin, ‘Human Rights Issues relating to Schizophrenia’, in ibid., p. 2.

numbers of stories that you plant, you seed, on that particular topic. It's no use just doing a one-off story. It's an ongoing campaign that you have to plan and stage .... there is a need for something to be done about the image of psychiatrists .... we can lobby governments; so we can change political awareness .... we need to start setting a national agenda, and State agendas.<sup>53</sup>

Given the linkages in the sequence of events leading up to the tabling of Macdonald's Amendment Bill it might be fair to assume that Macdonald's 'crusade' is closely associated with Deveson's 'ongoing campaign'.

On 29 November, 1995 Macdonald arranged a meeting at Parliament House with a number of representatives from organisations with an interest in mental health issues. The purpose of the meeting was for Macdonald to consult with stake-holders in order to gauge community support for his amendments. The Bill was still lying on the parliamentary table and Macdonald had to decide whether to bring the matter on for debate during the pre-Christmas session of parliament.

During the course of this meeting Macdonald acknowledged that he had drafted his amendments in consultation with the Schizophrenia Fellowship. A representative of the Schizophrenia Fellowship was at the meeting and presented an argument in support of the amendments by claiming that the removal of the requirement for dangerousness is necessary in order to save people from suicide. He argued that people who have suicidal relatives with mental illness are consistently failing when they attempt to have them committed to mental hospitals. The urgency of his presentation was calculated to induce a belief that the requirement for dangerousness was causing a virtual epidemic of suicide.<sup>54</sup>

On inspection, however, this argument was somewhat paradoxical. There was at the time a provision in the MHA which dealt with suicidal people and permitted involuntary hospitalisation "for the person's own protection from serious physical harm".<sup>55</sup> But this is the very clause which Macdonald was proposing to amend. If it was true that people were having difficulty in committing their genuinely suicidal relatives to hospital then the source of the problem was unlikely to be found in the wording of the Mental Health Act. A more plausible cause would have been the inability of the relatives to convince doctors and hospital medical superintendents that suicide was actually intended.

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<sup>53</sup> Anne Deveson, 'The Social Stigma of Schizophrenia as an Obstacle to the Exercise of Human Rights', in *ibid.* pp. 48-49.

<sup>54</sup> Representative, Schizophrenia Fellowship of NSW, Parliament House meeting room, November 29, 1995, Personal observation.

<sup>55</sup> Mental Health Act 1990, Section 9.(1)(a), *op. cit.*, p. 5.

But even this possibility was not supported by statistical evidence. Normally a person is involuntarily committed to a mental hospital under the direction of a doctor's certificate. But in emergencies, when there is no doctor close at hand to make the order, there is provision in the MHA for relatives and friends to take mentally ill people directly to hospital and ask for them to be involuntarily admitted.<sup>56</sup> In the years 1993<sup>57</sup>, 1994<sup>58</sup> and 1995<sup>59</sup> a total of 174 people were presented at NSW mental hospitals in this way by relatives and friends. Of this number only one person failed to be admitted for not meeting the existing criteria of being both mentally ill and dangerous.<sup>60</sup> It therefore seems likely that the issue of suicide was inappropriately raised in support of Macdonald's Amendment Bill to give it more urgency.

Macdonald decided not to risk putting his amendments to the vote in the busy pre-Christmas session of parliament in 1995. Instead his plan was to negotiate support for the proposal over the new year break and to bring it to a vote after he had cultivated a more certain climate for success when the NSW parliament sat again in April 1996. But in taking this course Macdonald missed his opportunity.

Under instructions from the Labor government, which had observed the lobbying of Macdonald by secondary consumer groups, the NSW Department of Health set about drawing up its own plans for reform of the Mental Health Act. In May 1996 a public discussion paper,<sup>61</sup> including proposed amendments, was circulated and comments from stake-holders and the public were sought. When the government had determined that the tide of public opinion was behind the secondary consumer groups, and that there would be no serious opposition to the erosion of civil liberties, legislative amendments were prepared which made involuntary commitment and longer periods of forced medication in the community much easier. In 1997 a government-sponsored amendment bill was passed which allows involuntary treatment of people who are thought likely to cause "serious harm" to themselves or others. The change had been affected by simply removing the word "physical" from the prior stipulation of "serious physical harm" and then loosely defining "serious harm" to include harm to finances or reputation.<sup>62</sup>

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<sup>56</sup> *Ibid.*, Section 23.(1), p. 10.

<sup>57</sup> Mental Health Review Tribunal, Annual Report, 1993, NSW Government, Sydney, p. 76.

<sup>58</sup> *Ibid.*, 1994, p. 74.

<sup>59</sup> *Ibid.*, 1995, p. 58.

<sup>60</sup> *Ibid.*, 1994.

<sup>61</sup> NSW Department of Health, Caring for Health: Proposals for Reform – Mental Health Act 1990, May 1996.

<sup>62</sup> Mental Health Legislation Amendment Bill 1997, Schedule 1, 1.1 [1], NSW Government Information Service, 1997, p. 3.

## Human Rights Imperatives

The human rights imperatives which support the medical model are not specific to schizophrenia but relate to mental illnesses in general. These generalised human rights imperatives have been codified in recent years and all the most relevant human rights are now specified in the United Nations (UN) Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care.<sup>63</sup> National governments have been encouraged by the UN to ensure their mental health systems are compatible with the UN objectives and the Australian Commonwealth government is advising state governments on any changes that might be necessary to mental health legislation.<sup>64</sup>

Principle 1.1 sets out the right to treatment as being the primary human right on which other rights are based: “All persons have the right to the best available mental health care, which shall be part of the health and social care system.”<sup>65</sup> A number of “Fundamental Freedoms and Basic Rights” are then listed including the “right to be treated with humanity and respect,” “protection from exploitation and discrimination,” and “the right to exercise all civil, political, economic, social and cultural rights as recognised in” other UN human rights declarations and covenants.<sup>66</sup>

The UN Principles then go on to list a total of 25 areas of human rights protection. These include the right for people with mental illness “to live and work, as far as possible, in the community” (Principle 3). This right gives rise to a further “right to be treated in the least restrictive environment with the least restrictive or intrusive treatment appropriate to the patient’s health needs and the need to protect the physical safety of others” (Principle 9).

There is a stipulation that “a determination that a person has a mental illness shall be made in accordance with internationally accepted medical standards” (Principle 4). Confidentiality is protected (Principle 6), standards of care are specified (Principle 8), “medication shall meet the best health needs of the patient” (Principle 10), and informed consent to treatment is required, although paradoxically, only from voluntary patients. The Principles specify that informed consent is not required from involuntary patients, patients who are thought to be incapable of giving their consent or patients who unreasonably withhold their consent (Principle 11).

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<sup>63</sup> United Nations Commission on Human Rights, ‘Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care’, in Australian Human Rights and Equal Opportunity Commission (eds), Human Rights and Mental Illness: Report of the National Inquiry into the Human Rights of People with Mental Illness, Australian Government Publishing Service, Canberra, 1993.

<sup>64</sup> Fiona McDermott and Jan Carter, eds., Commonwealth Department of Human Services and Health: Issues for Research, No. 4, Mental Disorders: Prevention and Human Services Research, Australian Government Publishing Service, Canberra, 1995, p. 3.

<sup>65</sup> United Nations Commission on Human Rights, *op.cit.*, p. 990.

<sup>66</sup> *Ibid.*, pp. 990-991.

A list of “Rights and Conditions in Mental Health Facilities” are specified (Principle 13), along with the required “Resources for Mental Health Facilities” (Principle 14). “Admission Principles” are at first covered in a general way (Principle 15), eg. “Access to a mental health facility shall be administered in the same way as access to any other facility for any other illness”, and then more specific conditions are given for “Involuntary Admission” (Principle 16). The need for a review body, procedural safeguards, patient access to information and a complaints procedure are also specified in various other principles.

Most of these specifications are straightforward ideas that are meant to provide a regulatory framework that minimises the social exclusion of voluntary mental patients and which ensures they receive humane treatment. But the simplicity of these ideas does not always extend to involuntary patients and the standing of the Principles is largely dependent on the willingness of practitioners and proponents of the medical model to ignore the paradoxes that are created for involuntary patients.

There are two human rights specified in the Principles — the ‘right to treatment’ and the ‘right to informed consent’ — which are worth analysing in some detail. When these rights are used to guide psychiatric practice on voluntary patients they appear to simply enforce routine procedures that have long standing in other branches of medicine. But unlike other areas of medicine, psychiatry is frequently practised on involuntary patients and these two human rights have special connotations when they are used to guide coercion in psychiatric treatment. About half the people who receive psychiatric treatment for schizophrenia are involuntary patients.

### **Right to Treatment**

The human rights specification that people with mental illnesses have a right to treatment implies that without this specified protection people in need of psychiatric treatment might be denied access to it. The implication is that people who have developed some kind of mental illness might go in search of medical treatment but, because of some kind of obstacle like lack of money to pay, a shortage of services, professional incompetence or rejection by the service providers, perhaps because of a discriminatory policy, the person in need fails to get the necessary psychiatric attention.<sup>67</sup>

In this respect the right to psychiatric treatment is a manifestation of the right all people are assumed to have for any kind of urgently needed medical attention. This basic human right, and its limitations, are instantly recognisable when cases of denial are given publicity. A homeless man might be left injured in the street because it is assumed he has no money to pay for hospital

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<sup>67</sup> Richard H. Lamb and J. Mark Mills, ‘Needed changes in law and procedure for the chronically mentally ill’, *Hospital and Community Psychiatry*, Vol. 37, No. 5, May, 1986, pp. 475-480.

expenses and is unlikely to have any medical insurance. Or doctors might publicly debate the ethics of withdrawing expensive life-support from terminally ill patients. As with other human rights the right to treatment is meant to support the needs of the individual when they are threatened by the exercise of social or professional expedience.<sup>68</sup>

In respect to ensuring the right to psychiatric treatment for mental illness the New South Wales Mental Health Act, for instance, specifies that any person may apply to be admitted to a mental hospital in New South Wales.<sup>69</sup> The medical superintendent of the mental hospital can only refuse the person admission if he/she “is not satisfied that the person is likely to benefit from care or treatment”.<sup>70</sup> If the person is refused admission, or discharged prematurely, the medical superintendent can be compelled to review the decision.<sup>71</sup>

After a person has been admitted to a mental hospital the choice of treatment is normally the responsibility of the psychiatrist to whom the patient has been assigned. This choosing of treatment can also sometimes become the basis for ‘right to treatment’ complaints by the patient. In respect to treatment for schizophrenia the choice is usually between various types and brands of neuroleptic medication, on the one hand, and, less frequently, psychotherapy on the other.

An interesting case discussed in the psychiatric literature concerns a complaint made by a patient of a mental hospital in the United States that his right to treatment had been violated because he had been given psychotherapy but not drug treatment. The patient was himself a doctor and had spent several months in hospital only receiving psychotherapy for depression. The psychotherapy was ineffectual and during this time the patient’s marriage ended and other aspects of his personal life were damaged. However, he was subsequently transferred to another hospital where he received drug treatment which he believed was effective. His complaint was that he was initially denied a right to drug treatment. The first hospital was reported to have settled the matter out of court.<sup>72</sup>

However, more frequently it is not the person actually manifesting the symptoms of mental illness who is most likely to complain about a supposed violation of the right to treatment. Complaints about violations of the right to treatment are more likely to be made by the relatives of mentally ill people.<sup>73</sup> But these complaints by relatives usually do not arise from situations where a mentally ill

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<sup>68</sup> Michael L. Perlin, Kerri K. Gould and Deborah A. Dorfman, ‘Therapeutic jurisprudence and the civil rights of institutionalized mentally disabled persons: Hopeless oxymoron or path to redemption?’, Psychology, Public Policy, and Law, Vol. 1, No. 1, March, 1995, pp. 80-119.

<sup>69</sup> Mental Health Act 1990, Section 12, op.cit., p. 7.

<sup>70</sup> Ibid., Section 17, p. 8.

<sup>71</sup> Ibid., Section 19, p. 9.

<sup>72</sup> Gerald L. Klerman, ‘The psychiatric patient’s right to effective treatment: implications of Osheroff v. Chestnut Lodge’, American Journal of Psychiatry, Vol. 147, No. 4, April, 1990, pp. 409-419.

<sup>73</sup> Anon., ‘Eleventh Circuit rules on rights of child committed by parents’, Mental Disability Law Reporter, Vol. 7, No. 3, 1983, pp. 220-221.



person has approached a mental hospital voluntarily and been refused admission. On the contrary, most frequently they concern a somewhat paradoxical situation where the person who is said to be mentally ill denies it and refuses to volunteer for treatment.<sup>74</sup>

When a person's unusual behaviour and thinking patterns give rise to a perception that a mental illness like schizophrenia might be the cause, and the person is unwilling to volunteer for treatment, it is common for relatives and mental health professionals to argue that the person's refusal of treatment is a manifestation of the mental illness. That is, the presence of mental illness has clouded the person's thinking and prevented the person from discerning for himself/herself the urgent need for treatment.<sup>75</sup>

In this situation the person who is said to be mentally ill is handled as if he/she were unconscious. A person who has been seriously injured in a motor accident and rendered unconscious is assumed to both want treatment and to have a right to it. Similarly, a person who has been diagnosed with schizophrenia, and who refuses treatment, is frequently assumed to be so out of touch with reality that the 'real' person has been obscured by the mental illness.<sup>76</sup> In this situation relatives often undertake decision-making roles on the mentally ill person's behalf and assume that if the 'real' person were present he/she, like an unconscious motor accident victim, would both want treatment and have a right to it.<sup>77</sup> This assumption is often made in the face of vigorous objections by the person concerned.

Although this interpretation of the 'right to treatment' generally requires some kind of endorsement by the relatives of the mentally ill person its usage as a justification for psychiatric coercion has become deeply entrenched in the ethical consensus of the whole mental health system. The strength of this consensus is illustrated by the willingness of professionals who are positioned only on the periphery of the mental health industry to also ignore the paradox inherent in the concept. It is argued by social workers in the United States, for instance, that the profession is required to advocate the right to treatment whenever they encounter a mentally ill person who is going untreated:

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<sup>74</sup> M. A. Carroll, 'The right to treatment and involuntary commitment', *Journal of Medical Philosophy*, Vol. 5, No. 4, December, 1980, pp. 278-291.

<sup>75</sup> X. F. Amador, D. H. Strauss, S. A. Yale and J. M. Gorman, 'Awareness of Illness in Schizophrenia', *Schizophrenia Bulletin*, Vol. 17, No. 1, 1991, pp. 113-132.

<sup>76</sup> P. Lysaker and M. Bell, 'Work Rehabilitation and Improvements in Insight in Schizophrenia', *Journal of Nervous and Mental Disease*, Vol. 183, No. 2, 1995, pp. 103-106.

<sup>77</sup> Richard M. Sarles and Norman Alessi, 'Resolved: two-week psychiatric hospitalizations of children and adolescents are useless', *Journal of the American Academy of Child and Adolescent Psychiatry*, Vol. 32, No. 1, January, 1993, pp. 215-221.

if there are means (medications) to treat unrelieved psychosis, failure to use these means is opposed to social work principles. Similarly, failure to advocate for a patient's right to treatment runs counter to fundamental social work principles and the right to due process. There are legal case precedents that ensure the right to treatment for people confined in public psychiatric hospitals. In the 1966 case of *Rouse v. Cameron*, the D.C. Circuit Court ruled that confining a person in an institution for treatment and failing to provide treatment is a violation of the due process clause of the Fourteenth Amendment.<sup>78</sup>

The lack of distinction in this ethical position between the advocacy of treatment for voluntary and involuntary patients brings the paradox of the right to treatment clearly into perspective. The practice of this ethical position apparently requires social workers to advocate psychiatric treatment for people who do not want to be treated. Even if the analogy of likening a mentally ill person to an unconscious person is acceptable there is still the matter to consider of the quality and efficacy of the psychiatric treatment that is generally on offer.<sup>79</sup>

In the case of an accident victim who is unconscious with serious injuries it can be generally assumed that medical attention will more likely be beneficial to the person than detrimental. In fact, the imposition of medical treatment on an unconscious person, who has not given prior consent, imposes on the medical practitioner an expectation that the patient's condition will not be made worse by the treatment. A patient who recovers from such a condition could be expected to show gratitude to the doctor.

However, the limitations of the analogy which likens an involuntary psychiatric patient to an unconscious accident victim become clear when these criteria are applied to the post-crisis mental patient. Unlike the case of the voluntary patient related above, many former involuntary schizophrenic patients have complained that neuroleptic drug treatment did them far more harm than good.<sup>80</sup> Rather than showing gratitude to the psychiatrists involved they are inclined to argue that the coercive interpretation of their 'right to treatment' violated their more fundamental 'right to refuse treatment'.<sup>81</sup>

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<sup>78</sup> Patricia B. Higgins, 'Clozapine and the treatment of schizophrenia', *Health & Social Work*, Vol. 20, No. 2, 1995, pp. 124-132.

<sup>79</sup> Eve C. Johnstone, 'Schizophrenia: problems in clinical practice', *The Lancet*, Vol. 341, No. 8844, 27 February, 1993, pp. 536-539.

<sup>80</sup> See for example, Seth Farber, *Madness, Heresy, and the Rumor of Angels. The Revolt Against the Mental Health System*, Open Court, Chicago, 1993, pp. 164-165.

<sup>81</sup> Simon N. Verdun-Jones, 'The right to refuse treatment: Recent developments in Canadian jurisprudence', *International Journal of Law and Psychiatry*, Vol. 11, No. 1, 1988, pp. 51-60.

## Informed Consent

The right to refuse treatment is embodied in the standard medical procedure of obtaining a patient's informed consent before treatment.<sup>82</sup> The origins of the medical concept of 'informed consent' are to be found in a complex arrangement of cultural inheritance involving moral, ethical and legal considerations. The moral element is concerned with notions of individual autonomy and a person's right to determine what is allowed to be done to his/her own body by a doctor. The ethical part involves the relationship between an individual and a professional expert who has been consulted by the individual and concerns the expectations of duty and trust that surround such a relationship. The legal aspect is concerned with the actual contractual arrangements that have been entered into by the two parties.<sup>83</sup>

The binding together of these separate concepts into a formally stated principle didn't occur until after the Second World War.<sup>84</sup> The trials of Nazi War criminals had revealed many atrocities in the name of experimental science, most of which were performed by qualified doctors, and the Nuremberg Code was adopted by the United Nations General Assembly in 1946 as an international standard to ensure they were never repeated. The first Principle of the Code states that "[t]he voluntary consent of the human subject is absolutely essential"<sup>85</sup> when conducting medical experiments. Although this Code is considered by many to lack the necessary detail for enforcement it is the seminal document for international law in this area and has been subsequently used as a basis for other international agreements of a similar nature.<sup>86</sup>

From these beginnings 'informed consent' has been developed into a fully fledged doctrine to guide the delivery of professional medical services. Although the procedures appear to be deceptively simple to apply on the surface there are hidden complexities. Most of the problems can be easily sorted into two types: those concerning the notion of 'informed', and those to do with 'consent'.

To satisfy the 'informed' half of the doctrine the medical practitioner is required to tell the patient the reason why the treatment is necessary and the expected outcome, together with a description of any possible side effects and, if failure is a possibility, the likelihood of failure and its consequences. Alternative treatments should also be canvassed.

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<sup>82</sup> John A. Robertson, 'Informed consent: a study of decisionmaking in psychiatry', *Science*, Vol. 226, 23 November, 1984, p. 960.

<sup>83</sup> V. Dharmananda, *Informed Consent to Medical Treatment: Processes, Practices and Beliefs*, Law Reform Commission of Western Australia, Perth, 1992, pp. 1-2.

<sup>84</sup> Carolyn Faulder, *Whose Body Is It? The Troubling Issue of Informed Consent*, Virago Press, London, 1985, p. 12.

<sup>85</sup> The Nuremberg Code, reproduced in *Ibid.* p. 132.

<sup>86</sup> George J. Annas, Leonard H. Glantz, and Barbara F. Katz, *Informed Consent to Human Experimentation: The Subject's Dilemma*, Ballinger Publishing Company, Cambridge, Mass., 1977, p. 8.

Although this might seem straightforward, doctors frequently complain about problems they face in properly implementing this procedure. From the doctor's point of view the problem is usually in deciding just exactly how much detail of information is necessary to properly satisfy a particular patient. Some patients, it seems, would rather not be told any more than is strictly necessary, preferring to trust in the wisdom of their doctor to make the decisions for them. Others, particularly those who think of themselves as being 'informed' about life in general, and who truly want to understand their situation, want all the information they can get.<sup>87</sup>

The problem for the doctors is knowing which sort of patient they are dealing with. Doctors tend to argue that giving too much information to patients who don't want it only does harm to the patients by increasing their anxiety. Doctors also complain that they are usually too busy to waste time educating those patients who want to know everything. But neither of these arguments is a sufficient defence for doctors when it comes to protecting themselves against litigation for having failed to satisfy the procedure.

Doctors in the United States are perhaps under more pressure in this regard than doctors in most other countries. The so-called "American disease of medical litigation"<sup>88</sup> is largely a result of US courts having built a strong foundation of case law establishing the right of the patient to be properly informed. In the US doctors are sometimes surprised by the extent of the information that courts have decided a patient has a right to know.

A recent case involved a doctor who performed an operation on a woman without informing her in advance that he was HIV positive.<sup>89</sup> In a separate case a doctor failed to inform a patient about the doctor's chronically agitated emotional state which was combined, so the doctor's estranged wife testified, with a dependency on alcohol.<sup>90</sup> In both of these cases the courts found in favour of the patients. This is despite the fact that in both cases the patients appeared to be satisfied with the medical outcome of their respective treatments. It seems that it was the failure to disclose heightened risk that required compensation.

Clinical trials of drugs pose particular problems in regard to satisfying the requirement that participants be properly informed. A recent article warned about the widespread practice of doctors who gain consent from patients for their participation in pharmaceutical trials without informing the

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<sup>87</sup> Faulder, *Op. Cit.*, pp. 22-31.

<sup>88</sup> Sheila A. M. McLean, A patient's Right To Know: Information disclosure, the doctor, and the law, Dartmouth, Aldershot, 1989, p. 2.

<sup>89</sup> Rex Julian Beaber, 'HIV Positive Surgeons Must Tell Their Patients', Health Systems Review, Vol. 26, No. 5, Sept/Oct. 1993, pp. 41-42.

<sup>90</sup> Charles F. Gay Jr., 'New Twist on Informed Consent in Medical Malpractice', Defence Council Journal, Vol. 60, No. 2, April 1993, pp. 311-312.

patients that the doctors are receiving remuneration from the drug companies. The author implied that patients have a right to know what is motivating the doctor.<sup>91</sup>

Clinical trials of psychiatric drugs are particularly problematic in regard to informed consent. People who has been diagnosed with serious mental disorders like schizophrenia, for whom the drugs are designed, are usually assumed to be incapable of making rational decisions. This assumption is the basis for the involuntary treatment that many of them receive. However, pharmaceutical companies are constantly developing new drugs which have to be tested by clinical trials procedures before they are released onto the market. These conditions tend to produce a paradoxical situation whereby people who are deemed by medical/legal procedures to be unfit to make decisions in regard to their need for treatment in the first instance are, all the same, sometimes assumed to be rational enough to give their informed consent to participate in medical experiments.<sup>92</sup> Paradoxes like this sometimes exercise the minds of medical ethicists.<sup>93</sup>

The problem of ‘consent’ is the other half of the informed consent doctrine. But the notion of ‘consent’ doesn’t seem to cause so much anxiety for the medical profession in general as does ‘informed’. Even so, ‘consent’ still has many areas of contention. The main problem area concerns certain categories of people who are considered unfit to give their consent.

The least controversial of those types considered unfit to consent is the medical patient who is unconscious and needs urgent medical attention. In this circumstance it is normal practice to assume “the notion of *presumed consent*, namely that it is a safe assumption that patients would want whatever is medically indicated to minimise or prevent injury, stop the progression of disease, sustain life, relieve pain and suffering, and so forth”.<sup>94</sup>

There are a number of devices that can extend this kind of presumption of consent into more controversial areas. They include *proxy consent*,<sup>95</sup> which is the form of consent given by a third party, usually a relative on behalf of children<sup>96</sup> and elderly people,<sup>97</sup> and “the doctrine of parens

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<sup>91</sup> John La Puma and Jerome Kraut, ‘How much do I get paid if I volunteer? Suggested institutional policy on reward, consent, and research’, Hospital and Health Services Administration Journal, Vol. 39, No. 2, Summer 1994, pp. 193-203.

<sup>92</sup> James Willwerth, ‘Madness in fine print: using mentally ill subjects for psychiatric experiments too often means extracting and relying on their ill-informed consent’, Time, Vol. 144, No. 19, 7 November, 1994, pp. 62-64.

<sup>93</sup> H. Helmchen and B. Muller-Oerlinghausen, ‘The inherent paradox of clinical trials in psychiatry’, Journal of Medical Ethics, Vol. 1, No. 4, December, 1975, pp. 168-173.

<sup>94</sup> Stephen Wear, Informed Consent, Kluwer Academic Publishers, Dordrecht, 1993, p. 135.

<sup>95</sup> Raanan Gillon, ‘Research On The Vulnerable: An Ethical Overview’, in Margaret Brazier and Mary Lobjoit, Protecting The Vulnerable: Autonomy and Consent in Health Care, Routledge, London, 1991, p. 58.

<sup>96</sup> Jenny Morgan, ‘Minors and Consent to Medical Treatment’, in Law Reform Commission of Victoria, Medicine, Science and the Law: Informed Consent Symposia, Globe Press, Melbourne, 1987, pp. 68-76.

patriae, which provides that the state has the duty to care for those individuals who are not able to do so themselves”.<sup>98</sup> The right to give involuntary treatment to mental patients, without their informed consent, is largely drawn from the doctrine of *parens patriae*.<sup>99</sup>

## Conclusion

The interest groups which support the medical model are unified by a common belief that people who manifest symptoms of schizophrenia are in need of care, treatment and control. While care and treatment are often actively sought by voluntary patients, control is usually reserved for schizophrenics who resist psychiatric intervention.

A number of human rights imperatives are used to gain leverage in meeting the objectives of care, treatment and control. The UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care are the basic human rights references for the medical model of schizophrenia. The UN Principles are designed to protect a wide range of voluntary patient rights by ensuring mental patients are treated with the same level of respect and care that is given to other medical patients.

However, control of patients, in the form of involuntary treatment, is not normally found in other branches of medicine. Involuntary treatment therefore necessitates a certain amount of duplicity in the interpretation of human rights, like ‘informed consent’ and the ‘right to treatment’. The usual tactic is to justify involuntary treatment by assuming that a person who resists treatment lacks sufficient insight to comprehend the need for treatment. This assumption clears the way to assert that the person would assent to treatment if the need were properly understood and that the person’s ‘right to treatment’ would be violated without the imposition of involuntary treatment. In this way the medical model can satisfy the perceived need to control certain patients while at the same time appearing to respect their human rights.

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<sup>97</sup> Elizabeth Ozanne, ‘Informed Consent and the Elderly: Professional Defence or Consumer Right?’, in *Ibid.*, pp. 50-67.

<sup>98</sup> Annas, et al, *Op Cit.*, P. 154.

<sup>99</sup> H. Bursztajn, T. G. Gutheil, R. M. Hamm, A. Brodsky and M. J. Mills, ‘Parens patriae considerations in the commitment process’, *Psychiatric Quarterly*, Fall, 1988, Vol. 59, No. 3, pp. 165-181.