2. Interest Groups and Human Rights

The theoretical framework of this thesis is a combination of interest group theory and human rights. This chapter begins with a discussion on the use of interest group theory as an analytical framework. Interest group theory is then examined in relation to the political aspects of controversies over schizophrenia. The general principle of using human rights as a tool of activism is discussed before relating human rights specifically to problems that arise from the practice of psychiatry.

Interest Group Theory

In her book <u>Tainted Truth: The Manipulation of Fact in America</u>¹ Cynthia Crossen devoted a chapter to 'Drugs and Money'. She related a series of events which took place in the late 1980s to illustrate the way in which research funding from pharmaceutical companies can sometimes influence the way in which medical researchers interpret their scientific findings.

The circumstances involved two researchers who had worked on the same biomedical project. One of the researchers became concerned when the project was expanded, with extra funding from a drug company, so that tests could be conducted on the efficacy of a drug manufactured by the donor company. At the conclusion of the project the two researchers disagreed about the interpretation of results. Conflicting articles were submitted to the New England Journal of Medicine. One article said the drug was efficient, (although it only worked in 30% of cases), the other said it was inefficient. Only the positive findings were accepted for publication and while the published author's career continued to prosper, largely with drug company funding, the dissenter's career plummeted. Reviewing the situation afterwards the dissenting scientist observed: "The ultimate goal of the pharmaceutical industry is to make money The goal of medicine is curing people. One is self-interest, one is altruism. It's an intersection of two different social systems."

Advocates of scientific purity might argue that, providing the published material received the proper peer reviewing, the above story only indicates that better scientists receive better funding. They could also argue that proper scientific training is sufficient to overcome the bias³ or temptation to corruption that is implied in the story. However, at the same time, they might agree with the dissenting scientist's belief that medical research is primarily motivated by altruism rather than self-interest. And herein points the way to deep confusion within the scientific identity. Analysts who have researched the way in which commercial, political and social influences

¹ Cynthia Crossen, <u>Tainted Truth: The Manipulation of Fact in America</u> Simon and Schuster, New York, 1994.

² <u>Ibid.</u>, p. 166.

³ Paul R. Gross and Norman Levitt, 'A higher superstition? A reply to Steve Fuller's review', <u>History of the Human Sciences</u>, Vol. 8, No. 2, 1995, pp. 125-130.

impinge on scientific and technological outcomes have developed a number of theoretical approaches to explain why scientific knowledge often appears to be tainted. Interest group theory is one of these approaches.

Interest group theory has its origin in political science. The study of political groupings which lobby governments and exert pressure on public policy making has been a central feature of politics discourses for the past half-century:⁴

With a long intellectual heritage, the pluralist tradition, in its extreme form, views government as a neutral identity which arbitrates group conflict by forming public policies in response to group pressure.⁵

In political activities, interest groups may have formal or informal organisational structures and are amalgamations of individuals or organisations which share a common interest or demand that can be represented before policy makers or knowledge brokers. Interest groups may campaign independently but readily join coalitions of like-minded groups when such an alliance improves the chances of success.⁶ Exclusive access to decision-makers isn't necessary for success and interest groups often find it is the securing of exclusive access to members and finances that is most essential in finding a niche in the political landscape.⁷ Despite some debate about nuances of meaning, interest groups are also commonly referred to as special interests, private interests, pressure groups, organised interests, or lobby groups.

Political scientists usually make a distinction between interest groups and social movements. Social movements are generally thought of as linking individuals across broad-ranging topics of general concern. Interest groups, on the other hand, are usually more narrowly focused and depend on drawing organised support from within a larger social movement. While interest groups usually have specific public policy goals, and focussed lobbying tactics to achieve them,⁸ social movements provide the broader background of public sentiment or discontent from which interest groups draw their significance.

⁴ Martin J. Smith, <u>Pressure</u>, <u>Power and Policy</u> Harvester Wheatsheaf, New York, 1993, p. 3.

⁵ Daniel J. B. Hofrenning, 'Into the public square: explaining the origins of religious interest groups', <u>The Social Science Journal</u>, Vol. 32, No. 1, 1995, pp. 35-49.

⁶ Marie Hojnacki, 'Interest groups' decisions to join alliances or work alone', <u>American Journal of Political Science</u>, Vol. 41, No. 1, 1997, pp. 61-88.

⁷ Virginia Gray and David Lowery, 'A niche theory of interest representation', <u>The Journal of Politics</u>, Vol. 58, No. 1, 1996, pp. 91-112.

⁸ Ken Kollman, 'Inviting friends to lobby: interest groups, ideological bias, and Congressional committees', <u>American Journal of Political Science</u>, Vol. 41, No. 2, 1997, pp. 519-545.

Unlike social movements, the dynamic focus of interest groups, and the competitive arena in which they operate, tend to make them unpredictable. So much so that public relations consultants, who are often required to manage the issues raised by interest groups, have recently been advised, apparently in all seriousness, that "[c]haos theory is particularly useful for structuring emerging social concerns and interest-group behaviour."

Although political science has developed considerable expertise in understanding the way in which interest groups function in the broad political landscape, ¹⁰ it appears this discipline is less deft when it comes to understanding the "concept of the scientific estate" and the way in which interest groups function in that more restricted territory. While discussing typical attitudes held by political scientists, science and technology studies (STS) scholars, Cozzens and Woodhouse, have observed that,

Scientific claims are generally accepted as unproblematic truth; but, when controversy arises, science policymaking is perceived as being so much like any other kind of political activity as to be unworthy of special attention. The discipline treats the politics of the sciences as if they were about as worthy of study as the politics of Albania.¹²

In an effort to fill this gap in academic research, STS scholars have adapted interest group theory to explain how scientists go about their work. According to Woolgar scientists constantly adjust their research in the light of "the potential presence or absence of interests in the work and activities both of others and themselves". Responding to Woolgar, Callon and Law have argued that Woolgar's "ethnomethodological preoccupation with the essential reflexivity of discourse" was, at the time they were writing in the early 1980s, only one of two competing "notion[s] of social interest for the social study of science." The other notion was the more conciliatory "Edinburgh" approach which agrees "that interests are theoretical constructs reflexively imputed to data, but argue[s] that there is

⁹ Priscilla Murphy, 'Chaos theory as a model for managing issues and crises', <u>Public Relations</u> Review, Vol. 22, No. 5, 1996, pp. 95-114.

¹⁰ David Lowery and Virginia Gray, 'The population ecology of Gucci Gulch, or the natural regulation of interest group numbers in the American states', <u>American Journal of Political Science</u>, Vol. 39, No. 1, 1995, pp. 1-30.

Susan E. Cozzens and Edward J. Woodhouse, 'Science, Government and the Politics of Knowledge', in Sheila Jasanoff, Gerald E. Markle, James C. Petersen and Trevor Pinch (eds), Handbook of Science and Technology Studies, Sage, Thousand Oaks, 1995, p. 535.

¹² <u>Ibid</u>.

¹³ Steve Woolgar, 'Interests and explanation in the Social Study of Science', <u>Social Studies of Science</u>, Vol. 11, 1981, p. 371.

¹⁴ Michel Callon and John Law, 'On Interests and their Transformation: Enrolment and Counter-Enrolment', <u>Social Studies of Science</u>, Vol. 12, No. 4, 1982, p. 616.

¹⁵ <u>Ibid</u>., p. 615.

nothing obnoxious so long as it is understood that there can be nothing final about this (and all other) explanatory attempts".¹⁶

However, Callon and Law were dissatisfied with both these approaches and they proposed a third view which saw the interest groups surrounding scientific issues as actors who enrol one another in a networking process:

Actors great and small try to persuade by telling one another 'it is in your interests to...'. They seek to define their own position in relation to others by noting that 'it is in our interests to...'. Our view is that they are trying to impose order on a part of the social world. They are trying to build a version of social structure.¹⁷

This view was illustrated by a recent controversy that erupted in the United States over the future of the National Center for Injury Prevention and Control (NCIPC).¹⁸ The NCIPC, a branch of the Centers for Disease Control and Prevention (CDC), was under threat of elimination due to budget cuts. The arguments mounted for and against the budget cuts confirm the Callon/Law observation.

The NCIPC had been engaged in research on the effect of injuries from firearms and had concluded that the existence of guns in the community constituted a hazard to public health. These findings had been challenged by a coalition of interest groups including the National Rifle Association, the Heritage Foundation, and the Doctors for Integrity in Research and Public Policy, who oppose gun control. Together these organisations had publicly argued that the NCIPC's findings were out of date and that the research had been politically motivated. This lobbying had led to the threat of budget cuts. The medical research community, acting on behalf of collective interest, responded by accusing the government of caving in to political pressure and warned that health promoting research should not be influenced by special interest groups.¹⁹

Although the influence of special interests is normally better concealed than it was in this case, STS researchers usually find it is possible to identify a variety of impinging interests when the social background of scientific research is analysed. In their description of actor networks, Callon and Law trace the history of a hypothetical research project to demonstrate how similar projects can be originally conceived and modified by such simple and perennial interests as the need to tailor research to fit publication requirements.²⁰

¹⁶ <u>Ibid.</u>, pp. 615-616.

¹⁷ Ibid., p. 622.

¹⁸ Jerome P. Kassirer, 'A partisan assault on science: the threat to the CDC. (Centers for Disease Control and Prevention)', <u>The New England Journal of Medicine</u>, Vol. 333, No. 12, 1995, pp. 793-795.

¹⁹ <u>Ibid</u>.

²⁰ Callon and Law, <u>op.cit.</u>, pp. 616-620.

In a more recent publication Callon has updated his view and describes four models to explain the "social organisation of science".²¹ He calls his third model "science as sociocultural practice" and discusses how

groups outside the scientific community may be mobilised in the production of knowledge. The border between insiders and outsiders fluctuates and is negotiable. But what is analytically important is to explore the mechanisms by which constraints, demands, and interests outside the circle of researchers influence scientific knowledge.²²

Interests theory appears in the STS literature as a variant that is primarily concerned with class interests. Restivo argues that the use of interests theory for analysing scientific knowledge formation "is not an innovation of modern students of STS. It is a centrepiece of Marxist thought and of the classical sociology of knowledge".²³ He observes that proponents of the theory sometimes have to mount a defence against critics who view the application of interest arguments merely as a "process of imputation."²⁴ Countering this Restivo argues that when interest attribution is carried out appropriately it is "an act of theory."²⁵ Unfortunately he does not go on to detail a method of appropriate attribution.

In discussing an approach to the use of interests theory Abraham has offered some clarification of the problem Restivo was discussing:

inconsistencies in scientist's claims are necessary, though not sufficient, to impute the operation of bias. To demonstrate bias it is necessary to show that scientific knowledge claims are not only influenced by values and interests, but that they are also non-credible.²⁶

Michel Callon, 'Four Models for the Dynamics of Science', in Sheila Jasanoff, Gerald E. Markle, James C. Petersen and Trevor Pinch (eds), <u>Handbook of Science and Technology Studies</u>, Sage, Thousand Oaks, 1995, p. 30.

²² <u>Ibid</u>., p. 43.

²³ Sal Restivo, 'The Theory Landscape in Science Studies', in Sheila Jasanoff, Gerald E. Markle, James C. Petersen and Trevor Pinch (eds), <u>Handbook of Science and Technology Studies</u>, Sage, Thousand Oaks, 1995, p. 106.

²⁴ <u>Ibid</u>.

²⁵ <u>Ibid.</u>, p. 107.

²⁶ John Abraham, 'Scientific Standards and Institutional Interests: Carcinogenic Risk Assessment of Benoxaprofen in the UK and US', <u>Social Studies of Science</u>, Vol. 23, 1993, p. 391.

In relating interest group theory to the political aspects of controversies over schizophrenia it could be said that while the whole mental health system constitutes a broad background social movement,²⁷ the psychiatric profession,²⁸ psychiatric survivors,²⁹ relatives of people who have been diagnosed with schizophrenia,³⁰ civil libertarians,³¹ and the pharmaceutical industry³² are some of the major interest groups active within the larger mental health movement.

Similarly, when interest group theory is applied in a more restricted way by confining the analysis to scientific research associated with the aetiology of schizophrenia, it is anticipated that influences on knowledge formation caused by pressure from interest groups involved in the wider political debate will become apparent. The proliferation of conflicting scientific hypotheses, and the certainty with which a number of diverse theories are currently being promoted, indicates it is a field rich with the ingredients Abraham requires for imputing bias.

However, the plan which has been outlined for this thesis also calls for analysis of the non-scientific "philosophical" aspects of the schizophrenia controversy. This begs the question: Can interest group theory be adapted to analyse philosophical controversies? The answer to this question is simple; when philosophical positions become controversial, of necessity, they also become political. (The same could also be said about scientific controversies.) So that what is being referred to here as the "philosophical level" of the controversy could just as suitably be called the "political level". Therefore it would seem unnecessary to make any adaptive adjustments in applying interest group theory to what is best described as a philosophical controversy.

There might seem to be some problem, however, in the proposal to apply a theory of political analysis to a situation in which the proponents of the differing philosophical positions are not equally engaged in active advocacy of their respective positions. Whereas the medical model of schizophrenia is vociferously pursued by well-organised and well-funded entities that fit any criteria for interest groups, the advocacy of the myth-of-mental illness and mystical models is largely conducted by individual authors who write for fairly vaguely defined audiences of supporters. The problem here is that those who believe in either a non-existent or natural cause for

²⁷ David Mechanic, 'Establishing mental health priorities', <u>The Milbank Quarterly</u>, Vol. 72, No. 3, 1994, pp. 501-515.

²⁸ Stephen W. White, 'Mental illness and national policy', <u>National Forum</u>, Vol. 73, No. 1, 1993, pp. 2-22.

²⁹ See for instance, <u>Dendron News</u>, published by psychiatric survivor organisation, Support Coalition, 1999, Available URL, http://www.efn.org/~dendron.

³⁰ For a description of the relatives' movement in the US see, Peter Breggin, <u>Toxic Psychiatry</u> Fontana, London, 1993, pp. 448-450.

³¹ Bruce J. Ennis and Richard D. Emery, <u>The Rights of Mental Patients: An American Civil Liberties Handbook</u> Avon Books, New York, 1978.

³² Steve Carrell, 'Coming: Host of schizophrenia drugs with lesser side effects', <u>Drug Topics</u>, Vol. 139, No. 14, 1995, pp. 35-36.

schizophrenia might not be consistently active enough to fit some of the more rigid definitions for interest groups.

Fortunately though, there is an interest group model available which is well suited to deal with this problem of disproportion amongst competing advocates. A. Paul Pross, a political analyst, found when he was attempting to dissect the complexities of Canadian politics that the term "interest group" was used widely to describe both politically active and non-active entities, and that this imprecision made analysis difficult. In order to clarify the situation he decided to divide "the entire spectrum of interests associated with any given public policy into three categories: formal interest groups, solidarity groups, and latent interests."³³

These three points on the spectrum essentially represent a diminishing gradation of active advocacy and the scheme is well suited for application to the three philosophical positions on schizophrenia. In Pross' model formal interest groups are structured organisations that are more or less constantly engaged in applying political pressure. Pross preferred to call these "pressure groups". Most of the interest groups engaged in advocacy of the medical view of schizophrenia easily fall into this category.

Solidarity groups, on the other hand, operate without much formal organisation but are still "made up of individuals with common characteristics who also share some sense of identity" and who have "enough group feeling to elicit a common reaction to public events, which may register in individual interventions in public debate".³⁵ The interest groups that advocate the myth-of-mental-illness model for schizophrenia fit fairly easily into this category of solidarity groups.

According to Pross, the third point of the spectrum, latent interests, are more difficult to identify because they,

are comprised of individuals and corporations with interests in common but with no sense of solidarity with one another. They may be extremely active in protecting their individual interests, but do not feel the need to recognise their mutual interest and register a collective voice in order to promote it.³⁶

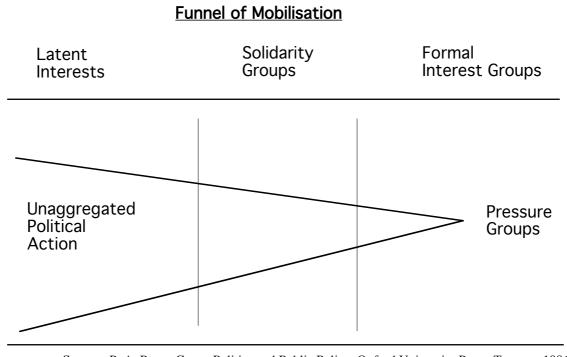
³³ A. Paul Pross, <u>Group Politics and Public Policy</u> Oxford University Press, Toronto, 1986, p. 15.

³⁴ <u>Ibid</u>.

³⁵ Ibid.

³⁶ <u>Ibid</u>.

The advocates of the mystical model of schizophrenia fit well into this description of latent interests. Pross has shown his spectrum of interest groups in diagrammatical form as what he calls "a funnel of mobilisation".



Source: P. A. Pross, Group Politics and Public Policy, Oxford University Press, Toronto, 1986, p. 16.

Human Rights and Activism

The creation, ratification, observation and compliance monitoring of human rights law are political processes in which interest groups are usually deeply involved, and to which interest group theory can be applied as an analytical tool. Human rights advocacy is a well established tactic used for advancing the interests of both individuals and minority groups who have cause to believe they are disadvantaged by existing laws, policies and social structures.³⁷ The technique, in its simplest form, involves identifying one or more articles of human rights law and campaigning for public recognition that past or present conditions violate the rights that are guaranteed therein.³⁸

In respect to the schizophrenia controversy, a situation prevails in which the proponents of the three divergent models each require very different articles of human rights law to assist them in making their respective cases. The refinement of their respective human rights arguments — and the degree of recognition of the arguments by the United Nations (UN), national governments and the general

³⁷ Adelaide G. Farrah and Zachary Elkins, 'Racing toward a new disability strategy', Americas, Vol. 46, No. 4, 1994, pp. 56-58.

³⁸ Gail M. Gerhart, 'Protecting Human Rights in Africa: Strategies and Roles of Nongovernmental Organizations', <u>Foreign Affairs</u>, Vol. 76, No. 2, 1997, p. 200.

public — largely accords with the spectrum of mobilisation illustrated by Pross in the diagram above.

The formal interest groups representing the medical model are by far the most advanced. Their human rights case is now greatly assisted by the United Nations' adoption in 1991 of the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care.³⁹ These principles, which will be discussed more fully a little further on, have been incorporated into the UN's human rights regime. The advantages they give the proponents of the medical model are derived from the fact that they specify human rights that are dedicated solely to the issue of mental illness. As such the Principles are generally recognised as the definitive human rights statements that apply to the mental health area to which schizophrenia belongs. Although the Principles do not currently have equal legal status to articles specified in declarations and covenants, they may be upgraded to a higher status in the future.

The interest groups representing the myth-of-mental illness and mystical models gain little comfort from the human rights specified in these UN Principles. As a result they are required to adapt articles of human rights law which have been originally conceived for more general purposes and then interpret them for the specific circumstances encountered when the medical model is imposed on individual schizophrenics. This task is becoming increasingly difficult as national governments in various countries become signatories to the Principles and progressively adjust their mental health legislation and mental health systems to accommodate these Principles. The problem facing the proponents of the myth-of-mental illness and mystical models is that once this process has been completed it is likely that the controversy over conflicting human rights might be declared closed.

In order to convey the seriousness of this situation for the non-dominant interpretations of schizophrenia it is necessary to discuss some background to human rights in general, and also some background about the relationship between human rights and psychiatry.

Background to Human Rights

Human rights are the basic rights all humans hold by virtue of being human.⁴⁰ The precursor of modern human rights was known as 'natural rights'⁴¹ and arose from a belief that human nature required certain liberties in order to fully express itself. The principal determinant of this view of

³⁹ 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), <u>Human Rights and Mental Illness</u>: <u>Report of the National Inquiry into the Human Rights of People with Mental Illness</u>, Australian Government Publishing Service, Canberra, 1993, pp. 989-1005.

⁴⁰ John Dunn, 'Rights and political conflict', in Larry Gostin (eds), <u>Civil Liberties in Conflict</u>, Routledge, London, 1988, pp. 24-27.

⁴¹ Paul Sieghart, <u>The Lawful Rights of Mankind</u> Oxford University Press, Oxford, 1985, p. 29.

human nature was an interpretation of the moral nature of humanity.⁴² These origins of modern human rights are to be found in the thinking of European political theorists of the seventeenth and eighteenth centuries, particularly the English political philosopher Locke.⁴³ At this time a surging middle class was seeking dialectical means by which to out-manoeuvre the various ancient regimes of Europe and 'natural rights' became the basis for the civil and political rights that the middle class claimed in order to achieve this goal.⁴⁴

These bourgeois origins have attached to human rights a somewhat confused legacy. As the largely middle class proponents of natural rights gradually moved out of opposition and into political control the claims for natural rights, particularly property rights, became associated with moves to impede further political change rather than to initiate it. In Britain, by the early 19th century, the language of natural rights had virtually become an exclusive possession of the middle class being restricted to ruling party rhetoric and a sprinkling of liberal reformers who wanted to spread the luxury of property owners' civil and political rights to the masses: "The radical left largely abandoned the language of natural rights".45

Even so, as the voting franchise expanded throughout the nineteenth century, working-class politics continued to develop and increasing pressure was applied to incorporate concerns for social and economic justice into the political mainstream. This process eventually gave rise to a concept of workers' rights. By the end of the nineteenth century, the dichotomy of capital and labour was increasingly seen as a struggle "between the rights of property and the rights of the common man — especially the worker". 46 In modern times this struggle has eventually come to be represented as a tension between middle-class conceived civil and political rights, on the one hand, and working-class conceived economic and social rights on the other. 47

It takes little analysis to expose this development as a false dichotomy. One obvious fault is that the traditional bourgeois emphasis on the civil/political right to accumulate unlimited property clearly belongs more appropriately in the category of economic rights. But the causes of such anomalies are to be found in the long history of middle class struggle to overthrow feudal values and are not of great importance to us now. The matter is only raised here because human rights in their modern

⁴² Maria Borucka-Arctowa, 'Historical Development of the Principles of Equality and Freedom and the Conception of Man', in Gray Dorsey (eds), <u>Equality and Freedom: International and Comparative Jurisprudence</u>, Oceana Publications, New York, 1975, pp. 51-73.

⁴³ John Locke, 'Second Treatise of Government (1689)', in Peter Laslett (eds), <u>Two Treatises of Government</u>, Cambridge University Press, Cambridge, 1967.

⁴⁴ Jack Donnelly, <u>Universal Human Rights in Theory and Practice</u> Cornell University Press, Ithaca and London, 1989, pp. 88-106.

⁴⁵ <u>Ibid.</u> p. 29.

⁴⁶ Ibid.

⁴⁷ Edward S. Herman, 'Immiseration and Human Rights', <u>Third World Resurgence</u>, No. 58, June 1995, pp. 41-43.

context are sometimes viewed with unnecessary suspicion by certain sections of the left because of their long antecedent as a tool of the middle class quest for power.⁴⁸

The modern international human rights regime was established under the auspices of the United Nations (UN) in the wake of the second world war. One of the early objectives of the UN was to draw up an agreement regarding the basic rights of all human individuals which should be respected by all present and future governments. The first products of this dialogue were 1948 conventions concerned with the freedom of association and the prevention of genocide, together with the Universal Declaration of Human Rights. The Universal Declaration was intended as the basis for future international law. This did not eventuate until 1966 when two binding human rights covenants were approved by the UN General Assembly — The International Covenant on Economic, Social and Cultural Rights (ICESCR) and the International Covenant on Civil and Political Rights (ICCPR).

The Universal Declaration, together with the two Covenants, now form the core of a growing international human rights regime and the three documents together are often referred to as The International Bill of Human Rights.⁴⁹ Whereas the two Covenants are considered to be legally binding on the participating nations, the Universal Declaration is of a lesser legal order, although it too is now considered by many commentators to have gained the status of international law through its regular usage to invoke legal, moral and political legitimacy.⁵⁰ Australia, along with an overwhelming majority of the world's nations, has ratified all three documents and has inserted the ICCPR into Australian law by incorporating it in the Human Rights and Equal Opportunities Act.⁵¹

The International Bill of Human Rights has the potential to supply the world with the foundation for an international system of justice in the same way as the United States Bill of Rights has been used as the basis for US justice for the last two hundred years. The principle is that the Bill of Rights defines in law the limits of authority that can be imposed on individuals, as well as the basic necessities that are required by them, so that all individual people, in every place, and at all times, can retain their human dignity.

Human Rights, Science and Technology

Although human rights have hitherto been under-utilised as methodology for STS research their usefulness for this purpose is readily apparent. The United Nations has long held the view that

⁴⁸ Dunn, <u>op.cit.</u>, pp. 24-27.

⁴⁹ Leah Levin, <u>Human Rights</u> United Nations Educational, Scientific and Cultural Organisation, Paris, 1982, p. 17.

⁵⁰ <u>Ibid.</u> pp. 12-13.

⁵¹ Human Rights and Equal Opportunity Commission, <u>Report of the National Inquiry into the Human Rights of People with Mental Illness</u> Australian Government Publishing Service, Canberra, 1993, p. 21.

scientific and technological developments can pose a direct threat to human rights. This view was first officially expressed at a 1968 UN conference held in Teheran to mark the twentieth anniversary of the Universal Declaration of Human Rights. The Proclamation of Teheran stated that, "While recent scientific discoveries and technological advances have opened vast prospects for economic, social and cultural progress, such developments may nevertheless endanger the rights and freedoms of individuals and will require continuing attention".⁵²

The conference identified a number of areas for priority consideration: privacy issues arising from developments in recording techniques; the protection of physical and intellectual integrity in the light of advances in biology, medicine and biochemistry; the way in which electronics might threaten people's rights; and "more generally, the balance which should be established between scientific and technological progress and the intellectual, cultural, and moral advancement of humanity."53

Through the 1970s concern about the effect that scientific and technological developments might be having on human rights was a constant feature of UN conferences and a number of studies were commissioned on the subject. A review of these studies in 1982 found that,

Science being itself a part of culture, the essential problem facing mankind in relation to scientific and technological progress, on the one hand, and the intellectual, spiritual, cultural and moral advancement of humanity, on the other, is to decide on the appropriate two-way relationship which should exist between them An investigation of this relationship includes an examination of the impact, both beneficial and harmful, of recent scientific and technological developments upon the rights laid down in the Universal Declaration of Human Rights.⁵⁴

The division of scientific and technological impacts on human rights into beneficial and harmful aspects has since become a standard feature of UN thinking.

There are signs that some professional organisations of scientists are becoming increasingly aware of the human rights obligations of their members. In the United States the American Association for the Advancement of Science (AAAS) conducts a forensic sciences training course designed for

⁵² United Nations, 'Proclamation of Teheran', quoted in Yo Kubota, 'The Institutional Response', in C. G. Weeramantry (eds), <u>Human Rights and Scientific and Technological Development</u>, United Nations University Press, Tokyo, 1990, p. 108.

⁵³ <u>Ibid.</u>

⁵⁴ United Nations, Human Rights and Scientific and Technological Developments, pp. 91-92, quoted in Yo Kubota, 'The Institutional Response', in C. G. Weeramantry (eds), <u>Human Rights and Scientific and Technological Development</u>, United Nations University Press, Tokyo, 1990, pp. 120-121.

doctors, lawyers and other professionals who are working for human rights organisations investigating the activities of repressive governments.⁵⁵

The AAAS also recognises that "[t]he pursuit of knowledge and scientific discovery are enhanced in an environment where human rights are protected." The particular rights the AAAS considers are most pertinent "include the right to education and work; the right to seek, receive, and impart information and ideas; freedom of movement and residence; and freedom of association and assembly". 57

Japanese historian of science Shigeru Nakayama has examined the possibilities of utilising human rights in STS analysis and has devised a system for applying human rights to test scientific and technological developments. His system involves the use of a table which divides science and technology into four types: academic, industrial, defence and service. These divisions are cross-referenced with three essential features of scientific and technological development: the method by which the science is assessed, the nature of the competitive atmosphere in which it is developed, and whether expression of the science is open or classified.⁵⁸ (See table below).

	Academic	Industria1	Defence	Service
Assessors	Peer	Sponsor	Military	Public
Competition	Individual	Corporate	National	None
Expression	Open	Classified	Classified	Open

Source: Shigeru Nakayama, 'Human Rights and the Structure of the Scientific Enterprise', in C. G. Weeramantry, ed., <u>Human Rights and Scientific and Technological Development</u>, United Nations University Press, Tokyo, 1990, p. 138.

Nakayama's purpose is to identify stages of development at which different kinds of science and technology can be assessed for their human rights value. The implication is that some kind of professional self-regulation might be possible which would require scientists and technologists to evaluate their work at various stages of development in order to identify potentially harmful aspects before they actually manifest as human rights problems.

⁵⁵ Kari Hanibal, <u>Taking Up The Challenge: The Promotion of Human Rights. A Guide for the Scientific Community</u> American Association for the Advancement of Science, Washington, 1992, p. 11.

⁵⁶ <u>Ibid.</u>, p. 4.

⁵⁷ <u>Ibid.</u>, p. 5.

⁵⁸ Shigeru Nakayama, 'Human Rights and the Structure of the Scientific Enterprise', in Weeramantry op.cit., p. 138.

Human Rights and Psychiatry

When the international system for the protection of human rights was developed after the second world war, it was largely in response to Nazi atrocities. The Nazis had held a collective belief that the German nation was a living organism and that its well-being was threatened by "useless eaters" and "life unworthy of life".⁵⁹ The German medical profession, 45% of whom belonged to the Nazi Party in the early 1930s, was empowered to tend to the health of the national organism. The psychiatric branch of the profession led the way by "medically killing" some 80,000-100,000 hospitalised mental patients. The expertise the Nazi psychiatrists acquired in killing off their mental patients was later applied to Jewish people.⁶⁰

Even under the legislative frameworks that are typical of most modern democratic societies, psychiatry still treads a particularly fine line between benefiting and harming the exercise of human rights. This is largely because the social objectives of psychiatry and human rights are, to some extent, opposed to one another. While the basic principle of human rights is to set limits on the degree of social authority which is allowed to be imposed on individuals, the speciality of psychiatry is to fit 'difficult' individuals into the social fabric. These fundamental differences sometimes threaten to turn psychiatry and human rights into antitheses, even in the most benign political conditions.

Psychiatry has little trouble in establishing its potential benefit to the exercise of human rights when 'difficult' individuals acknowledge that they have a mental disease and seek treatment for it. A specific article of human rights law that psychiatry can enhance in this way is Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). Article 12 concerns "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."

The second part of this article specifies "The steps to be taken by the States Parties to the present Covenant to achieve the full realisation of this right shall include those necessary for: (d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness".⁶² The human rights sentiments expressed in Article 12 are the basis for the 'right to

⁵⁹ Robert Jay Lifton, <u>The Nazi Doctors: Medical Killing and the Psychology of Genocide</u> Basic Books, New York, 1986, p. 46.

⁶⁰ Ibid., pp. 34, 134-144.

⁶¹ United Nations, 'International Covenant on Economic, Social and Cultural Rights', Article 12 (1), reproduced in Satish Chandra, ed. <u>International Documents on Human Rights</u> Mittal Publications, New Delhi, 1990, p. 16.

⁶² <u>Ibid.</u>,

treatment' which is often promoted by advocates of the medical model as being the most important human right in regard to psychiatry.⁶³

But the 'right to treatment' can have a hollow ring to it when psychiatry is practised on people against their will. Many 'difficult' people deny they have a mental illness or, if they are willing to acknowledge it, prefer not to have it treated. The human rights problems for psychiatry largely arise from the tendency of most modern industrial societies to have mental health laws which empower psychiatrists to make clinical judgements about the mental health of the people they encounter in their work and to impose treatment on them, without their consent, if it is thought necessary.

Involuntary mental patients often find themselves in a situation in which they are incarcerated for an indefinite period without being charged with a criminal offence, interrogated, coerced into changing their thoughts and beliefs, subjected to painful and uncomfortable treatments if they cannot or will not make the required mental changes, and denied freedom until their identity has been sufficiently modified. It is in this context that questions arise about whether certain psychiatric practices might violate other human rights.

Soviet Psychiatry

Perhaps the most blatant example of human rights abuse by psychiatry in recent times occurred in the Soviet Union. In the last couple of decades of the Soviet regime, the communist authorities viewed a growing epidemic of political dissidence as a malign social force and Soviet psychiatrists were empowered to assist in dealing with it.

As early as 1974, psychiatrists in the West had become curious about reports of the high prevalence of schizophrenia in the Soviet Union — 5-7 per 1,000 population compared to 3-4 per 1,000 in the UK.⁶⁴ In due course it was revealed that Soviet psychiatrists had discovered a unique form of mental disease to fit the profile of political dissidents. They called the condition "sluggish schizophrenia, a form of schizophrenia where the symptoms are subtle, latent or only apparent to the skilled eye of the psychiatrist".⁶⁵ Soviet dissidents who "wanted to reform the system and claimed that they had the personal vision to do it were exhibiting the text-book symptoms of sluggish schizophrenia."⁶⁶ Soviet psychiatrists became so deeply involved in the control of political

⁶³ See for example, John Grigor, 'The Right To Treatment', in Human Rights and Equal Opportunity Commission (eds), <u>Schizophrenia</u>: <u>Occasional papers from the Human Rights Commissioner, Number 1</u>, Sydney, 1989, pp. 7-14.

⁶⁴ J. K. Wing, 'Psychiatry in the Soviet Union', British Medical Journal, 9 March 1974, p. 435.

⁶⁵ David Cohen, <u>Soviet Psychiatry: Politics and Mental Health in the USSR Today</u> Paladin, London, 1989, p. 24.

⁶⁶ <u>Ibid.</u>, p. 44.

dissidents that a whole system of special mental hospitals was established which they ran in cooperation with the KGB.⁶⁷

When the full situation became apparent to the international psychiatric community, there was widespread condemnation of the Soviet practice. In order to pre-empt inevitable expulsion from the World Psychiatric Association (WPA), the Soviet professional organisation, the All-Union Society of Neuropathologists and Psychiatrists, resigned from the WPA in 1983.⁶⁸ The WPA responded to the resignation by announcing that the Soviets would be welcome to return if they provided "evidence beforehand of amelioration of the political abuse of psychiatry in the Soviet Union".⁶⁹ It is worth noting that the WPA considered that 'amelioration' was all that was necessary to bring the Soviets back into line with international standards. Perhaps what prompted this conciliatory approach was the general perception amongst western psychiatrists that, despite the abuses, "the concept of disease employed in the former USSR was similar to its counterpart in the UK and USA in being strongly scientific in nature."

UN Principles on Mental Illness

The Soviet use of psychiatry for political purposes was the catalyst for a more general investigation into international psychiatric practices by the UN Commission on Human Rights. In 1977 the Commission appointed a "Sub-Commission to study, with a view to formulating guidelines, if possible, the question of the protection of those detained on the grounds of mental ill-health against treatment that might adversely affect the human personality and its physical and intellectual integrity".⁷¹ The primary task given to the two Special Rapporteurs the Sub-Commission subsequently appointed was to "determine whether adequate grounds existed for detaining persons on the grounds of mental ill-health".⁷²

The UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care⁷³ did not emerge until more than a decade later. Unfortunately, despite the

⁶⁷ <u>Ibid.</u>, pp. 102-120.

⁶⁸ A. L. Halpern, 'Current Dilemmas in the Aftermath of the US Delegation's Inspection of the Soviet Psychiatric Hospitals', Paper presented at the Emerging Issues For The 1990s In Psychiatry, Psychology And Law, <u>Proceedings of the 10th Annual Congress of the Australian and New Zealand Association of Psychiatry, Psychology and Law, Melbourne 1989</u>, p.11.

⁶⁹ C. Shaw, 'The World Psychiatric Association and Soviet Psychiatry', in Robert Van Voren (eds), <u>Soviet Psychiatric Abuse in the Gorbachev Era</u>, International Association on the Political Use of Psychiatry, Amsterdam, 1992, p. 50.

⁷⁰ K. W. M. Fulford, A. Y. U. Smirnov and E. Snow, 'Concepts of Disease and the Abuse of Psychiatry in the USSR', <u>British Journal of Psychiatry</u>, Vol. 162, 1993, pp. 801-810.

⁷¹ Kubota, <u>op.cit.</u>, p. 115.

⁷² Ibid.

⁷³ United Nations Commission on Human Rights, 'Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care', op.cit., pp. 989-1005.

brave start, the final document had been so repeatedly rewritten and massaged by numerous committees dominated by psychiatrists that the original focus was lost. The primary tasks of attending to involuntary detention and the risks of treatment were largely buried by cross-referencing and other priorities.

The final version of the 'Principles' adopted by the United Nations General Assembly in 1991 is primarily designed to protect the rights of voluntary patients, not involuntary patients. Principle 1 begins with an assertion of the 'right to treatment'. This right thereafter becomes the basis for most of the other voluntary patients' concerns, like confidentiality and protection against discrimination, addressed by the document.

Where the 'Principles' do address the problems of involuntary patients, it is done in a way that tends to undermine their rights rather than protect them. Principle 11, for instance, deals with "Consent to Treatment" and specifies that "No treatment shall be given to a patient without his or her informed consent, except as provided for in paragraphs 6, 7, 8, 13, and 15." Paragraph 6, however, denies the right of informed consent to involuntary patients: ".... treatment may be given to a patient without a patient's informed consent if the following conditions are satisfied: (a) The patient is, at the relevant time, held as an involuntary patient;"⁷⁴

Involuntary admission is not only permitted under the 'Principles' but the criteria which are specified for correct procedure were considerably less restrictive than those which were contained in the NSW Mental Health Act (MHA)⁷⁵ at the time the Principles were brought into force. Whereas the NSW MHA, at this time, required that a person must be thought likely to cause serious physical harm to themselves or other people before involuntary commitment was permitted, under the 'Principles' a person can be committed merely because "a qualified mental health practitioner" considers the person's condition is likely to deteriorate, or treatment will be prevented, without incarceration.⁷⁶ (It is worth noting that the NSW MHA has recently been amended to bring it more closely into line with the UN Principles.⁷⁷)

The weakness of the UN Principles in relation to involuntary patients invites a speculation: had the Principles been in existence in the 1970s and 1980s would they have deterred the Soviets from using psychiatry for political purposes? The answer to this question is by no means certain.

⁷⁴ <u>Ibid.</u>, Principle 11, pp. 994-995.

New South Wales Parliament, <u>NSW Mental Health Act 1990</u>, <u>Reprinted as in force at 17 October</u>, NSW Government Information Service, Sydney, 1994, Section 9, p. 5.

Vnited Nations Commission on Human Rights, 'Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care', op.cit., Principle 16, p. 1000.

⁷⁷ New South Wales Parliament, <u>Mental Health Legislation Amendment Bill 1997</u>, NSW Government Information Service, Sydney, Section 9, p. 3.

Although Principle 4 requires that diagnosis "shall be made in accordance with internationally accepted standards" and "A determination of mental illness shall never be made on the basis of political, economic or social status" these requirements might have simply guided Soviet psychiatrists to be more circumspect in their definitions.

The Burdekin Inquiry

The UN Commission on Human Rights was not the only official human rights body to be galvanised into action by the Soviet example — only to end up burying psychiatry's darker side beneath a restatement of the 'right to treatment'. The Australian Human Rights Commissioner, Brian Burdekin, in his opening address to the Sydney hearings of the 1991/92 Inquiry into Human Rights and Mental Illness, referred to Soviet psychiatry and said that Soviet human rights abuses in this area had been the catalyst for his own Inquiry.⁷⁹

Burdekin explained that human rights circles in the Western democracies had formed the view that investigations were required into the mental health systems of democratic countries, to ensure that they were beyond reproach, before a full human rights assault could be launched on the Soviet psychiatric system. He said that his own Inquiry had been conceived as part of this project but that while preparations had been under way to commence his Inquiry the issue had gone off the boil because the Soviet Union had collapsed.⁸⁰ This change of affairs probably explains the confusion that subsequently developed in the Commission's priorities over mental health.

The Commission's confusion of priorities is apparent in a number of respects. One of them is the apparent lack of significance given by the Inquiry to the rights of involuntary patients when they conflict with the needs of their frustrated relatives. Under the heading of "Involuntary Detention" the Burdekin Report observed that:

Involuntary detention — for any reason and under any circumstances — is an extremely serious matter involving curtailment of several fundamental rights the most important of which is the right to liberty. The Inquiry received extensive evidence on this subject, particularly from consumers.⁸¹

⁷⁸ United Nations Commission on Human Rights, 'Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care', <u>op.cit.</u>, Principle 4, p. 992.

⁷⁹ Brian Burdekin, Federal Human Rights Commissioner, Opening Address to Sydney hearings, National Inquiry into Human Rights and Mental Illness, June 17, 1991, Personal observation.

⁸⁰ Ibid.

⁸¹ Human Rights and Equal Opportunity Commission, op.cit., p. 230.

Even so, after only one more brief sentence on the subject the report moves on to a lengthy discussion in support of denying the very same "fundamental rights" the Inquiry had just recognised:

Difficulty in Gaining Involuntary Admission — Families and other carers are faced with a dilemma when the person for whom they are responsible has lost touch with reality and has insufficient insight⁸² into his or her condition to accept the need for treatment.⁸³

The Commission's confused priorities become further evident when the terms of reference are carefully analysed in the light of the subsequent course of the Inquiry. The first term of reference clearly listed the classes of people the Inquiry had initially intended to deal with: "To inquire into the human rights and fundamental freedoms afforded to persons who are or have been or *are alleged to be* affected by mental illness, having due regard for the rights of their families and members of the general community".⁸⁴ [my italics]

What is meant by *alleged to be affected* by mental illness is not immediately apparent. An early usage of the term 'alleged mental illness' can be found in a published dialogue between US patient rights activist Leonard Roy Frank and American Civil Liberties Union attorney and mental patient advocate, Bruce Ennis. Ennis explained in the interview that he used 'alleged mental illness' because "I personally have seen no evidence at all that there is such a thing as mental illness".85

The terms of reference made no attempt to define what it meant by *alleged* but it is unlikely that it was used to question the existence of all mental illnesses in the way that Ennis used the term. What is more likely is that in the planning stage of the Inquiry it was thought necessary to distinguish between certainty in the accuracy of diagnoses of mental illness when applied to some people and uncertainty when the diagnoses are applied to other people.

There are at least two ways the Inquiry might have originally intended to utilise this distinction. The first possibility may have been an intention to examine the problem of false positive diagnosis. This is a perennial problem for psychiatry and arises from the subjective nature of psychiatric diagnostic

^{82 &#}x27;Insight' is a Catch-22 device used in psychiatric coercion. A person who rejects the label of mental illness is said to lack insight into their condition. Lack of insight means the condition is much worse than would otherwise be the case and it therefore requires more drastic treatment for a longer period. Critics of psychiatric coercion have likened the demand for 'insight' to that of a torturer's demand for 'confession'.

⁸³ Human Rights and Equal Opportunity Commission, op.cit., p. 230.

^{84 &}lt;u>Ibid.</u>, p. 5.

⁸⁵ Leonard Roy Frank, 'An Interview with Bruce Ennis', in Sherry Hirsch, Joe Adams, Leonard Frank, Wade Hudson and David Richman (eds), <u>Madness Network News Reader</u>, Glide, San Francisco, 1974, p. 165.

techniques and the lack of laboratory tests to confirm most diagnoses. The second possibility may have been an intention to review patients diagnosed with certain varieties of mental illness — like the Soviets' sluggish schizophrenia — which are not generally recognised by international standards but which some psychiatrists may allege to exist. Perhaps the Inquiry had originally planned to investigate both problems. There are well established concerns about Western psychiatric practice regarding both the problem of false positive diagnosis⁸⁶ and the proliferation of new varieties of mental disease.⁸⁷

Regardless of what the Inquiry's original interpretation of *alleged mental illness* might have been it certainly seems appropriate that an Inquiry into Human Rights and Mental Illness should give hearing to any person who might have suffered the discomfort and humiliation of a psychiatric diagnosis, and possibly incarceration and imposed treatment, on the basis of a mere allegation. But despite the nomination of this category in the terms of reference, as it transpired, the Inquiry completely ignored these people. They were not mentioned in the Inquiry's report at all outside of the terms of reference.

In fact the definitions that were eventually adopted by the Inquiry made it impossible to recognise people who *are alleged to be* mentally ill. The Inquiry chose to use the term "consumer" to describe all of the people who are deemed to have a mental illness, thereby implying they are all willing participants in a mental health service industry. This does not necessarily pose a problem for the recognition of people who *are or have been* mentally ill but the description of "consumer" was totally inappropriate for those who *are alleged to be* mentally ill. Neither false positives nor people diagnosed with non-existent diseases could satisfactorily be described as consumers.

The inability of the Inquiry to recognise the *alleged* group is further apparent in a table published in the Inquiry's report which classifies the people who made submissions and were witnesses to the Inquiry⁸⁹ (see table overpage). If the category of "Consumers" is indeed inapplicable for those who *are alleged to be* mentally ill then the only other categories into which they might fit are "Concerned citizens" or "Others". Although these two categories made 68 and 28 written submissions respectively, not a single person from either of these two groups was called as a witness.

⁸⁶ See for example, David Pilgrim and Anne Rogers, <u>A Sociology of Mental Health and Illness</u> Open University Press, Buckingham, 1993, p. 55.

⁸⁷ See for example, Stuart A. Kirk and Herb Kutchins, <u>The Selling of DSM: The Rhetoric of Science in Psychiatry</u> Aldine De Gruyter, New York, 1992, pp. 1-16.

⁸⁸ Human Rights and Equal Opportunity Commission, op.cit., p. 13.

⁸⁹ <u>Ibid.</u>, p. 10.

It seems apparent therefore that somewhere between the time when the terms of reference were drafted and the time when the hearings of witnesses began, a mechanism was deliberately or inadvertently put into place which blocked the people who *are alleged to be* mentally ill from influencing the outcome of the Inquiry.

Interest groups representing the mystical and the myth-of-mental-illness models for schizophrenia would have been greatly disadvantaged by the Inquiry's cold-shouldering of people who *are alleged to be* mentally ill. The breakdown of the Inquiry's participants in the table on the next page indicates a definite slant to favour some interest groups which support medical models for explaining extreme mental conditions like schizophrenia.

The favoured treatment of psychiatrists and profession psychiatric associations is particularly evident in the ratios of their written submissions to the number of their witnesses. This ratio suggests the Inquiry might have solicited psychiatrists as expert witnesses. The opposite indication is apparent for "Consumers" where the number of written submissions was more than four times the number of witnesses. The contrasting levels of influence between these two interest groups suggests they might hold different positions on Pross's funnel of mobilisation.

Burdekin Inquiry Participants

Description	Witnesses	Submissions		
Psychiatrists	70	52		
General Practitioners	1	3		
Psychologists	7	12		
Social, Youth, Welfare Workers	25	23		
Nurses	14	20		
Professional Associations				
- Psychiatrists	11	. 4		
- Social/Welfare Workers	2	5		
- Occupational Therapists	3	2		
- Nurses	4	. 5		
- Psychologists	5	2		
Church Related Organisations	13	15		
Consumers	44	206		
Carers	26	136		
Concerned Citizens		68		
Federal, State or Local Government representatives	73	60		
NGO representatives	159	185		
Others		28		
Total witnesses: 456 Total submissions: 826 (Excluding multiple submissions from individuals or organisations.)				

Source: Human Rights and Equal Opportunity Commission, <u>Human Rights and Mental Illness: Report of the National Inquiry into the Human Rights of People with Mental Illness</u>, Australian Government Publishing Service, Canberra, 1993, p. 10.

Conclusion

Various interest groups are driving the controversy over the cause of the symptoms of schizophrenia by adopting conflicting human rights imperatives to amplify their claims. It is proposed to use a combination of interest group theory and human rights law as a framework for analysing the dynamics of this controversy. Although there is a disproportion in the power and influence of the interest groups supporting each of the three models, Pross's "funnel of mobilisation" is a useful framework for dealing with this disproportion.

Psychiatric practice, in so much as it is concerned with reshaping atypical individuals and fitting them into the social fabric, has the potential to enhance some human rights while endangering others. But all human rights do not have equal significance in international law. The disproportion in the power and influence of the interest groups driving each of the models does not necessarily reflect the relative standing in international law of the conflicting human rights which are separately used to give moral credibility to each of the three models. It is possible that the medical model, by far the most widely recognised of the three models, actually relies on human rights imperatives that have lower standing in international law than the human rights supporting the other two models.