MEETING REPORT

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Schizophrenia: breaking down the barriers

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Abstract This paper reviews the key issues presented during the Fourth International Conference on Schizophrenia, which was held in October 1996 in Vancouver, Canada. The main emphasis was placed on the problem of stigma, loneliness and work as well as on the necessity to further elucidate the physiopathology of schizophrenia. Some of the barriers discussed are unlikely to disappear from human societies in the short term with any possible cure for schizophrenia as they are part of any major long-term illness, of which there is a long and ever increasing list.

The Fourth International Conference on Schizophrenia: Breaking the Barriers was held in Vancouver, Canada, in October 1996. The conference was entitled "Breaking the Barriers" to emphasise the fact that many colleagues and patients with schizophrenia describe their experience as "being akin to continually running into walls: economic walls, therapeutic walls, walls of ignorance, walls of prejudice". The conference involved more than 100 speakers from 18 countries. While some of the papers and conclusions are published and others are likely to be published, I shall briefly sketch a personal view of the proceedings.

Plenary sessions alternated with parallel symposia on four major areas: social, cultural, biological and psychological barriers to the care of schizophrenia sufferers. The issue of stigmatisation of schizophrenia was emphasised as being the most important barrier to the care of patients both in the plenary sessions (Prof. JA Talbot, Maryland, USA) and in a symposium by the author, in which it was suggested that the defence mechanisms used by persons with schizophrenia against stigmatisation, i.e. reclaiming (schizophrenics are intelligent) and linguistic intervention (I am a schizophrenia sufferer), should be encouraged to prompt their self-esteem and adherence to treatment. The

high rate of non-adherence to antipsychotic medications as a major barrier to treatment was interpreted primarily in relation to the stigma, poor communication between psychiatrists and family members, and the quality of the physician-patient therapeutic relationship – in addition to the important issues of lack of insight as a phenomenon similar to anosognosia in stroke, side effects of medications and denial in the context of grief over the loss of personal health.

The plenary speeches, each given by a leading authority, were greater in scope than the ensuing discussions. The delegates were generally unanimous on the issue of barriers and if any theoretical tensions developed they were between those who gave a high-quality overview of what the barriers essentially consisted of (Prof. JA Talbott, Maryland, USA) and some delegates and pressure groups who solicited more drastic solutions on the basis of the cutting edge international knowledge and expertise and emphasised the importance of communication between psychiatrists and family members. Tension also developed when some speakers (Dr B Jones Ontario, Canada) went as far as describing the prescription of classical antipsychotics as unethical in view of the professed lower side-effect profile of some novel antipsychotics and the fact that the development of the classical antipsychotics was based on animal models which screened drugs that stopped the animal from moving. It was also suggested that psychiatrists, advocacy groups and the public should unite and put governments under pressure to purchase the new antipsychotics. The opposition came from the author (with large support from other delegates) who mentioned that side effects were not the main reason for non-adherence to antipsychotics; that there was as yet no depot form of the new antipsychotics available; that, although novel antipsychotics have not been developed on the basis of stopping animals from moving, but rather on the basis of their receptor-binding properties, they are likely to sedate animals as well; that many third world countries are, in practice, unable to pay even for imported classical antipsychotics and that, actually, pressure should be put on pharmaceutical companies to reduce the very

high price of these medications for the benefit of some of the most disadvantaged groups in the world community.

Canadian speakers stressed that even in British Columbia (the richest province of Canada) it was extremely difficult to find a bed the same day for a patient with psychiatric illness so it was suggested that a short-term depot such as zuclopenthixol acetate could be used in schizophrenia as a temporary measure to manage the patient in the community for a few days while looking for a bed (Dr R Williams, British Columbia, Canada). American speakers, while admiring the relatively more organised system of health care in countries such as Canada, systematically emphasised the chaotic situation of community mental health care in the US with stunning overviews of the American 'non-system of care' in which large groups of patients remain untreated and vulnerable and a high rate of violent acts are committed by those untreated (reported by Dr E Fuller Torrey, NIMH). This is not astonishing in the US where every second person has a handgun and where the effects of an underlying ghettoisation are deeply felt by those who have an additional reason for being feared and segregated: schizophrenia. In the downtowns of many American cities you would see the picture of this segregation in the contrast between skyscrapers, the site of prestigious banks and financial organisations full of middle-class white collars who speak fluent American English, and the dishevelled beggars and homeless vagabonds with mental illness crawling around these tall overpowering buildings. The effects of segregation based on social fear can be demonstrated by the fact that, in the luxurious and prosperous 'ghetto' of Orange County in California, merely driving an old car is sufficient reason for police patrols to stop the car and investigate why the driver is moving into the area. There is virtually a vacuum for something to happen - home-grown terrorism, riots, religious and ideological extremism and crime – so the violence in patients with mental illness in American has to be viewed in the context of such a social organisation.

As there is nothing equivalent to the NHS in Britain or the health services in Canada in the US, people either have to pay for their own medical insurance, qualify as indigent or be covered under programmes such as Medicare or Medicaid. The borderlines of eligibility for these programmes are relatively high, so many people remain unhelped by any variety of health care. Even for those who have insurance cover, insurance companies in some states, such as California, do not pay for more than 4 days of hospitalisation for psychiatric illness unless the patient has an active plan to commit suicide or has delusions that in practice would lead to homicide.

Hope was instilled by some speakers from NIMH (Dr D Weinberger and Dr E Fuller Torrey) who spoke about large federal and private funds available for research into the neuromolecular mechanisms of schizophrenia and the possibility of a major breakthrough in the years to come while at the same time acknowledging the difficulties in elucidating such a complex and intricate illness or variety of illnesses. Alongside this emphasis on the biological causation of schizophrenia, there was an emphasis (Dr LL Bachrach, Maryland, USA) on the importance of increasing our understanding of the barriers between health care professionals and patients through reading the patient authored literature. Other speakers (Prof Talbot) highlighted the scarcity of funding for research into the sociocultural aspects of schizophrenia, such as the role and importance of stigma, loneliness and work. The fact of the matter is that the latter issues will not disappear from human societies with any possible cure for schizophrenia as they are part of any major long-term illness, of which there is a long and ever increasing list.

There were few participants from the developing world and thus the contributions were not, in general, grounded in the practicalities of everyday clinical work in the cultural and sociopolitical atmosphere of the Third World. All the same, the meeting was arguably the most significant to date on examining the barriers to the care of patients with schizophrenia.