

# Voluntary schizophrenia organisations

## Attitudes and experiences

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I previously reported (O'Shea, 1989, 1992) on the experience of national voluntary Huntington's disease (HD) and Alzheimer's disease (AD) organisations. This series of enquiries stemmed from an observation of Black (1988) that the medical profession in general offered little support to voluntary groups, a statement which has been largely supported for both HD and AD organisations in the first two parts of this trilogy. This paper examines the experiences and attitudes of (mostly national) schizophrenia organisations.

### The study

Ten contact organisations (addresses supplied by the Schizophrenia Association in Ireland-SAI) were sent an explanatory covering letter and a slightly modified form of the questionnaire used previously (O'Shea, 1989, 1992). The latter enquired about when and by whom the organisation was founded, affiliations with other groups, the helpfulness of the medical profession and politicians (both scored from 'very poor' to 'excellent'), the methods used to advertise and fund the group, and the sources of referrals, with specific reference to psychiatrists and general practitioners (GPs). The respondent was asked to indicate where schizophrenic patients are treated, to rate the availability of in-patient respite care ('unavailable' to 'very good') and to state where this is based, to say if psychiatrists understand carer distress and to list the main sources of such distress. He or she was asked to list the perceived advances in the management of schizophrenic patients during the past 20 years, and in what areas he or she saw important advances developing over the next two decades; the perceived role of genetic counselling in schizophrenia; the most difficult schizophrenic mental symptoms and behaviours with which carers have to cope; and the type of official assistance received by carers in the domestic environment.

The respondent was asked to rate the explanation and advice ('very poor' to 'excellent') given by psychiatrists to relatives and other carers of schizophrenic patients; to describe the organis-

ation of the group at various levels; and to say if patients attend its meetings. Details and comments were sought on all aspects of the questionnaire.

### Findings

According to the German Association of Self-Help Groups (Berlin), there is no national schizophrenia association in Germany. No replies were received from the USA or from the National Schizophrenia Fellowship (NSF/UK - Surrey). Completed replies were received from the SAI (Republic of Ireland - ROI), the Schizophrenia Association of Great Britain (SAGB) based in Wales (here taken to represent England and Wales - E & W), the National Schizophrenia Fellowship in Northern Ireland (NI) and in Scotland, Schizophrenia Fellowship Incorporated (New Zealand - NZ), the Canberra Schizophrenia Fellowship (CSF - for Australia) and the Canadian Friends of Schizophrenics in Toronto (CFST - for Canada). Seven English-speaking countries are therefore represented. A synopsis of each reply follows.

#### England and Wales

The SAGB, founded by Gwynneth Hemmings in 1970, is associated with the NSF/UK, MIND, and with various international organisations. Medical and political help are rated as 'very poor'; psychiatrists fail to educate patients and their relatives and do not prescribe 'scientifically', whereas politicians do not understand schizophrenia and are perceived as being responsible for the imprisonment of many patients. A wide variety of methods are used to advertise SAGB, except that meetings are not held with medical personnel (reasons not given). Funds are raised through trusts, subscriptions, other donations, and fundraising events. The SAGB has its own Institute of Biological Psychiatry and its own research programmes. Referrals to the SAGB come from psychiatrists, GPs, citizens' advice bureaux and similar agencies. Acute treatment

of patients occurs in general or psychiatric hospitals. There is little or no respite care available. Psychiatrists do not appreciate the stresses on carers, a response that was shared by every respondent. The SAGB agreed with the other respondents on the chief sources of this stress: concern over the future of persons suffering from a chronic, incurable disorder; the psychopathology, inertia, unemployment, violent propensities (hidden from professionals) and unpredictability of patients; lack of information on the illness and training of carers to cope with it; lack of domestic finances and monies to develop services; and difficulties with overseeing medication. Lack of insight and poor ability to conduct a rational conversation were seen as being particularly difficult to live with.

The situation over the past 20 years has deteriorated for patients and their families. The SAGB would like to retain psychiatric hospitals and have them fitted out with pathology laboratories. Genetic advice is to be distrusted, although advice about at-risk status is acceptable. The only time that official assistance in the home is forthcoming is when research is being conducted on 'expressed emotion'. The SAGB has a geographically localised organisation, and patients do attend its meetings.

The SAGB decries the lack of a uniform approach to treatment, the lack of knowledge about schizophrenia possessed by patients, the non-communicativeness of psychiatrists with relatives, and the fact that the latter are often ignorant of the diagnosis. It feels that psychosocial models of the disorders "cause damage and retard progress of the medical model".

#### *Republic of Ireland*

The SAI was founded in 1975 by relatives and the staff of the St John of God Hospital, Dublin. It is associated with the Mental Health Association of Ireland and various international schizophrenia groups. Medical help is available, but is generally 'good'. Politicians are not interested in schizophrenia, although assistance from them is 'fair'. Although a wide range of areas are used to promote the SAI, emphasis is placed on giving talks to target groups such as newspaper reporters, police, and welfare officers. There is some state aid. Medical research is not funded. Medical referrals are few in number, most members being sent by social workers (SWs), community psychiatric nurses (CPNs), and welfare officers. Acutely ill patients are treated in a wide variety of settings, varying from the home to psychiatric units or hospitals. Respite care is reasonably available. Community care and psychosocial support systems have been well developed in some areas. Emphasis needs to be placed on carer support, rehabilitation, stress manage-

ment, and public understanding. Genetic counselling has little to offer.

Help at home mainly takes the form of CPN visits. The SAI has national and (23) local groups, and patients usually meet separately from relatives. The chief concerns of the SAI are the abandonment of carers, the premature closure of psychiatric hospitals, the lack of rehabilitation facilities in many rural areas, the lack of public financing in the community, strained communication between carers and psychiatrists, and lack of a voice for the SAI in policy decisions.

#### *Northern Ireland*

Founded in 1982 by carers, the NI group is associated with NSF/UK. Doctors get on well with the staff of the organisation, but less well with their patients. Medical support and education for families leaves something to be desired. Politicians tend to avoid getting involved. A wide variety of methods are used to raise funds and to attract attention, and there is no financial support for research. The chief referral sources are the self, SWs, CPNs, and other voluntary groups. Acute treatment is based in hospitals, chronic treatment occurs in the community and in hostels. There is very little respite care, apart from admission to a psychiatric hospital. The chief recent advances have been pharmacological including depot preparations, and community supports and awareness. Apart from further improvements in these areas, the future may see less institutionalisation and a more 'holistic' approach by doctors. Genetic counselling offers little because of a lack of scientific knowledge. What help there is is confined to CPNs, SWs, and visits to clinics.

The group is organised at a number of levels, and patients do attend meetings.

#### *Scotland*

The NSF in Scotland was founded in 1972 by Frida Middleton, Ian Fraser and Michael Bellby. It is associated with NSF/UK. Medical and political help are both 'fair', although it varies greatly between individuals. The group has recently started to advertise on TV and radio. A variety of official and voluntary sources of funding exist, but, since money is scarce, funding of research is rare. Psychiatrists rarely refer patients, GPs are somewhat better, and CPNs and SWs are the most active referrers. Acute treatment occurs in both general and psychiatric hospitals, whereas chronic treatment occurs in the community, "a few long-stay wards", and hostels. Respite care is uncommon, patchy, and is based in psychiatric hospitals.

Few psychiatrists understand carer distress. Improvements have included our understanding

of schizophrenia and the refined use of improved drugs. Future work should increase our knowledge of the brain and of drugs; advice to carers needs to be improved; and community care should be taken more seriously. Genetic counselling helps those who seek it. Presently, home-based help consists of only one or two visits. The organisation has regional and local branches, patients attending the local meetings.

The provision of services is patchy, families have to cope alone and relatives are ignored by doctors, and the psychiatric hospital, which served us well in the past, is being run down too quickly.

#### *Canada*

The CFST was founded in 1989 by Arthur William Jeffries and Dr Edward Busse, ten years after the Schizophrenia Society of Canada and the Ontario Friends of Schizophrenics, with which it is associated. Medical help is very uneven and politicians shun the problem because of the financial implications. Funding is derived from many sources, and it is planned to fund research in the near future. Referrals are entirely non-medical. Treatment at various stages of schizophrenia is hospital-based, and respite care is rare. The only advance has been clozapine! Future research should stress brain and drug function. Genetic markers may render counselling of use in the future. There is no help from the authorities for home-based care. All levels of organisation are provided by the various associated schizophrenia groups, and patients do attend meetings.

The main concerns of the CFST are the lack of treatment for patients who refuse it, the refusal of hospitals to keep involuntary patients, a lack of hospital beds, and the perceived unhelpfulness of patients' right movements.

#### *New Zealand*

The New Zealand group, which was founded in 1977 by Christine Staniforth and Anne Nooan of Christchurch, is "associated with the Area Health Boards, Manic-Depressive Society, etc." Some doctors have been 'excellent', others fail to help at all; however, things are improving. Politicians are no help whatsoever. Among the advertising techniques used is an 'awareness week'. Minimal gains are derived from public appeals, although there is some financial help from private trusts and official sources. Medical research funding is not possible. "GPs avoid (making) a psychiatric diagnosis", but psychiatrists, citizen's advice bureaux and case managers send patients to the group. Most acute treatment is hospital-based, whereas chronic treatment occurs in the community. Respite

care, in hospitals and staffed houses, is available but not advertised. Psychiatrists' understanding of the problems of carers is improving, and there have been advances in rehabilitation and "a recognition of work as therapy." Advances need to be made in basic research as well as in the release of resources for both the hospital and the community. Any information available to geneticists should be imparted to those that could benefit from it.

The Disabled Persons Community Welfare Act, which offers four weeks per year respite care, is relatively unavailable for psychiatric patients. The New Zealand group is organised in tiers, and, while it is recognised that goals may be different, patients do attend the same meetings as relatives.

#### *Australia*

The CSF was founded by concerned parents in the early 1980s. Its main associated body is the Australian Psychiatric Disability Coalition. Medical interest has been fairly good, but "very little training (is) given in medical schools". Political help is good, mainly because the Coalition has a statutory footing, although funds still have to be negotiated for. "Nine members of community groups recently formed (the) Mental Health Advisory Council, appointed to advise the Minister for Health." Many avenues are used to increase awareness, and funding comes from diverse sources, including an annual 'walkathon'. There is an annual fundraising dinner for the Mental Health Research Institute of Victoria, although no direct funding of research occurs. Referrals come from many sources, including medical. Acute treatment occurs in psychiatric units in general hospitals, whereas, apart from some hostel and group home accommodation, the "vast majority (of chronic cases are) living independently or with families in the community (with) little support". There is little available in the way of respite care, if they are to be accepted in what facilities do exist. The understanding of carer distress varies with individual practitioners.

Facilities and programmes in the community are still "fragmented, scattered over (a) large area with inadequate public transport". Under the Federal Disability Services Act of 1986, the Government has "at last" accepted responsibility for the psychiatric services – this was previously seen as the responsibility of individual states. "New money (is) now gradually becoming available." Genetic counselling is not relevant at present. Home-based assistance from the authorities is confined to "advice". A few patients attend local meetings, but they are generally "uninterested". Canberra is "well served", but

remoter areas are "very isolated and have practically no services".

### Comments

It would have been better had the NSF/UK and US organisations been included in this survey. Nevertheless, some general deductions can be made. There is a strong feeling that most doctors distance themselves excessively from the relatives of their patients. Relatives, who have been seen as one cause of burnout among doctors (Roberts, 1986), often feel isolated and unsupported. Carer distress is largely attributed to the effects of living unrespite with psychologically dysfunctional charges. Lack of political help is chiefly based on financial considerations. The closure of mental hospitals, particularly at the present pace, is decried. Great emphasis is placed on improving our understanding of the disease model of schizophrenia and on pharmacological answers to resistant psycho-social pathology.

The greatest dissatisfaction is expressed by the E & W respondent, whereas the Australian reply, although highly qualified, seems the most optimistic. The Australian situation is similar to that reported for Huntington's disease (O'Shea, 1990).

In general, there appears to be a wish to halt the abandonment of the best aspects of institutional care, and disenchantment with community services. Also, there is a feeling that the law needs to be changed to take account of lack

of insight and non-compliance. Rehabilitation and rural areas are neglected. Finally, undergraduate medical training urgently needs to take account of the families from which patients come.

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