

SCHIZOPHRENIA, NEGATIVE SYMPTOMS, AND SOCIAL POLICY

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Source: *International Journal of Mental Health*, Vol. 17, No. 1, PERVENTING DISABILITY AND RELAPSE IN SCHIZOPHRENIA: II. Psychosocial Techniques and Working With Families (Spring 1988), pp. 106-110

Published by: Taylor & Francis, Ltd.

Stable URL: <http://www.jstor.org/stable/41344488>

Accessed: 06-10-2016 07:10 UTC

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## **SCHIZOPHRENIA, NEGATIVE SYMPTOMS, AND SOCIAL POLICY**

MARTIN GITTELMAN

Since the end of the Second World War, social policy with regard to the mentally ill has been in a state of change. Some trends are already clear; others seem less so. In the industrialized countries, we have moved away from reliance on the custodial hospital toward a greater or lesser development of largely, but not exclusively, treatment and housing arrangements in the community. In many places this has meant return to the family, particularly in the case of the young mentally ill. In retrospect, we realize that the impact of this change in social policy on the family should have been evaluated and planned for as early as the 1950s. Our failure to do so has meant years of neglect and waste of one of our most important social and rehabilitative resources. In terms of both social and fiscal policy, our current interest in the negative symptoms of schizophrenia and in the role of the family in caring for its mentally ill members might well be termed "tardive" intervention.

In few of the Western industrialized countries is the situation of the mentally ill deemed to be truly satisfactory; almost nowhere have the mentally ill reached the simple goal of relative equality of opportunity with those not burdened by mental illness; in some countries the changes have been equivocal. In addition to the relatively lower priority accorded psychiatric care in comparison with other health sectors, rehabilitation of the mentally ill continues to suffer from a low status. An underlying and continuing problem has been failure of the public and the professions to perceive the mentally ill as disabled and requiring rehabilitation. They use no crutches or canes, and their handicap

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generally is not readily and visibly apparent. Moreover, mental illness is often conceived of as transient, disability being understood and anticipated only in relation to mental retardation or dementia; hence, the emphasis in research, service, and training has been largely on treatment.

Of course, treatment has been the central concern in most areas of health care, to the neglect of other aspects that could be productive not only in reducing and preventing morbidity but also in returning patients to optimal functioning. In some countries health care has become distorted because of reimbursement systems—e.g., surgery is reimbursed at a much higher rate than, say, health education and promotion involving cardiac rehabilitation or promotion of reduction in cardiac risk factors. In U.S. mental health care, hospitalization for acute illness is reimbursed at a much higher rate than aftercare. Such payment systems do not necessarily “fit” the needs of individual patients. Despite compelling evidence that maintenance medication protects against relapse, few hospitals pursue a policy of aggressively following up at-risk former patients. It is often up to the patient to be “compliant” and to seek out treatment. In one recent study in a large metropolitan area, only 1% of patients treated for acute mental illness were found to have received any aftercare in the same hospital during a one-year follow-up survey [1].

Findings of this nature illustrate our traditional interest in the so-called “positive,” florid, or productive symptoms of mental illness and neglect of the persisting, disabling, “negative” symptoms. The positive symptoms usually include states such as anxiety, hallucinations, delusions, and thought disorders. The negative symptoms, observed in chronic mental illness, are ones such as apathy, abulia, and withdrawal. It is, of course, the positive symptoms that, by their very nature, cause problems in society, which probably accounts for their being the object of more attention and clinical intervention than the negative ones. The latter, though they are the source of severe social and vocational handicaps, have suffered from relative inattention, by any criteria—funding, service delivery, amount of research devoted to them, etc. We have, in effect, been treating *only half the illness*. This has resulted in a population of mentally ill people who, though no longer confined in mental hospitals, suffer disability that causes them

to be unemployed or underemployed, isolated, ill housed or homeless, and disadvantaged in every way. But into this picture of neglect and poor or no aftercare have entered movements and developments that are influencing, and will continue to influence, the care and rehabilitation of the chronically mentally ill.

After years of stigma and shame, the families of the mentally ill in many of the industrialized countries have banded together and begun to act as advocates for their mentally ill members, lobbying for adequate services, funding, and research. The National Alliance for the Mentally Ill, formed in the United States in 1980, decades after counterpart families in Europe had organized for similar ends, has moved quickly to establish chapters (now numbering more than eight hundred) around the country to advocate forcefully on behalf of the mentally ill. Much of the impetus for the formation of the family organizations has come from deinstitutionalization and the greater burdens for families that have followed in its wake. It has been said that community mental health care has largely meant care by the families of the mentally ill. But though the family has assumed a much greater burden, it has not received the financial and social support needed to make care of its mentally ill member effective—or bearable for the caregivers (except, it should be noted, in some of the Scandinavian countries, which do reimburse families for care of their mentally ill members).

Family associations, as described by Hatfield [2], want community facilities—housing, vocational training, and other relevant services. They do not want to have to, and in many cases cannot, bear alone the constant burden of caring for their mentally ill members. Some professionals understand the needs of families, but others do not: they fail to comprehend the stress of caring for a mentally disabled person on a full-time basis. We hope this collection of papers will serve to sensitize mental health and social welfare professionals and others to what daily care of a mentally ill person can mean, emotionally as well as financially.

As occurred in the 1950s when the parents of severely disturbed children formed national groups and other groups were organized for various purposes (e.g., the women's liberation movement), a powerful influence for change has begun to be felt in mental health delivery systems. Consumers of mental health services are no longer willing to

accept theories that seem to blame them for the psychopathology of their family members. Today there is a broad consensus that severe mental illness is a biological disorder with psychosocial aspects that can trigger onset and relapses. This change in concepts has made it possible to develop a wide array of consumer education literature and programs, in particular, family rehabilitative interventions, whose vitality and efficacy have been demonstrated by dramatic reductions in relapse and disability rates among the mentally ill [3]. Practical guides on the management of schizophrenia are to be found in most libraries and, like texts on diabetes or chronic back pain, have helped to diminish fear, ignorance, and stigma and, most importantly, have increased patients' compliance with treatment regimens, thereby reducing risk of relapse.

What is especially remarkable about this development is that there has recently been no breakthrough in treatment of the mentally ill, no new drugs or techniques. Like the new high-speed trains in Europe or Japan, which move so silently and with such little vibration that the traveler marvels at their performance, though he realizes that they represent largely further refinements of old technologies, but with renewed attention to comfort and speed, the new strategies in coping with the symptoms of chronic mental illness are designed to minimize the negative. These strategies involve collaboration and sharing of information among professionals, families, and the mentally ill themselves. The effects have been apparent in more compliance of patients with maintenance medication regimes and in a considerable reduction in stress within their families, factors that result in fewer relapses and more effective functioning of both patients and caregivers.

Intervention strategies utilizing education of the mentally ill and their families show great promise in developing countries as well as in the industrialized nations. In the all-too-common situation in which there is no doctor to provide care—often, not even a primary health care worker—all devolves upon the family and the community. Under such conditions, efforts to reach and educate families and to assist them in forming self-help and mutual support groups are essential.

Change does not come easily, and in mental health care many problems have still to be solved. Families want their mentally ill members to be helped to lead “normal” lives, to the extent possible, and to be

able to care for themselves. Mental health professionals tend to eschew the term *education* and prefer to engage in *therapy*. Yet, both groups are evolving new forms of collaboration that may have far-reaching effects, particularly when they join forces to insist on more adequate funding for needed services and research. Advocates, families especially, for care of the mentally retarded have had considerable success. We hope that the efforts of those concerned with preventing relapse and disability of the chronically mentally ill will also bear fruit, and that this collection of articles will make a worthwhile contribution to those efforts.

### References

1. Council of Directors of Psychology in HHC Hospitals (1987) *Newsletter*, December.
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