The Metropolitan SchizophreniaAssociation: A Self-Help Health Group as a Formal Organization

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This shortened version of a *Master's thesis in social-cultural anthropology considers a local affiliate of the American Schizophrenia Association and its relationship to the national organization. Problems of goal maintenance, leadership, membership, and organizational structure are examined. Sustained personal leadership by founders of the Association is found to be a more important factor in the maintenance of original goals than is the structure of the organization. The possibility of actually attaining the goal of biochemical control of the disease(s) of schizophrenia is seen as being lessened by the opposition of organizations favoring the status quo in the social and cultural environment.*

The Director of Public Affairs of the American Psychiatric Association (APA) in 1973 directed public attention to a report soon to be published by the professional journal of that association. The report stated that "megavitamin therapy" pioneered by Abram Hoffer and Humphry Osmond had been proved worthless in the treatment of schizophrenia by a task force of the APA, it was said. The APA spokesman was quoted as saying that "Orthomolecular psychiatry," a term coined by Linus Pauling, included more than treatment based upon proven vitamin deficiencies and was too highly individualized for studies of its effectiveness to be replicated. "The promoters" of the treatment (presumably the psychiatrists and scientists just mentioned) were said to be "seeking insurance coverage for their treatment and financial support through their own American Schizophrenia Foundation" by the APA spokesman (Dietz, 1973).

It would appear from the above statement that the American Schizophrenia Association (the correct title) was an organization used by a group of doctors and scientists for their own benefit. On the other hand, at the same time (1973) Gussow and Tracy, who were making a comprehensive sociological

1 2403 Carey Lane, Vienna, Virginia 22180. The organization is called the "Metropolitan" Schizophrenia Association for the purpose of publication. The actual name of the Association was used for the anthropological thesis. The title of the thesis will be supplied upon request.

analysis of voluntary self-help health organizations, considered it but one of nearly 100 self-help health groups they were studying in the United States. Such organizations are devoted to a particular illness or disease condition, are initiated and conducted by patients, ex-patients, or relatives to provide needed support and benefits to the afflicted, and develop outside the aegis of both the medical and health organization establishments (Gussow and Tracy, 1972b:1). Gussow and Tracy ask the question: "Is there any relationship between a steadily declining public confidence in medicine and psychiatry and the growth and proliferation of self-help health groups?" (1973:3).

The Metropolitan Schizophrenia Association (MSA) was a local affiliate of the American Schizophrenia Association (ASA), the major division of the Huxley Institute for Biosocial Research (HIBR) with headquarters in New York City. The MSA had 260 dues-paying members during the period of the study (1973-1974) and an additional mailing list of 2,000 names of individuals who had contacted the Association. Although the local Association—started in 1968 by former patients and families of patients—fits the criteria for self-help health groups, the national Association — started in 1964 by both laymen and professionals—fits them less well. The organization, on both the national and local levels, was studied as a type of formal organization, a mutual-benefit association with elements of a service organization.

The problem of a few leaders using the Association for their own ends was raised by the spokesman for the APA. This problem of oligarchical control has been found to be characteristic of mutual-benefit associations—which include professional associations (such as the American Medical Association, AMA, and the APA), labor unions, clubs, and fraternities as well as many self-help health groups and other voluntary organizations. In addition to oligarchical control, major problems in similar organizations have been found to include membership apathy and goal displacement. These problems are the focus of the study.

The Mental Health Association in its grassroots days is considered to be the prototype for many self-help health associations by Gussow and Tracy. Started, by an ex-mental patient to improve the lot and treatment of mental patients, it still remains an independent organization, although co-opted to a certain extent by organized psychiatry (Gussow, 1972a:1-2). The highly successful National Foundation for Infantile Paralysis studied by Sills (1957) has been the model for other successful voluntary health organizations. Sills considered the primary problem of voluntary organizations to be the maintenance of original goals. He considered its corporate structure (with authority delegated downward) to be an important factor in the success of the National Foundation for Infantile Paralysis in attaining its goal of preventing polio and in then turning to an orderly succession of goals. The American Schizophrenia Association was founded on the corporate model and was first announced publicly in 1965 as the American Schizophrenia Foundation. (Initially it had financial backing which was later withdrawn.) The later name change to "Association" on the national level met with full approval of the local group as better expressing the actual nature of the organization—an association of people with common concerns rather than a foundation with money to dispense to other worthy causes. The corporate structure of the initial foundation remained, however. Sills stated that the ultimate character of an organization is determined by its formal structure, its membership, its activities, and the environment in which these activities are carried out (1957:203).

Problems considered paramount by Blau and Scott for mutual-benefit associations were oligarchical control and membership apathy. According to their criterion of cui bono (who benefits), members of mutual-benefit associations

are expected to be the prime beneficiaries and to govern themselves, but the development of a bureaucratic apparatus centralizes power in the hands of administrative officials. As experience gained by leaders makes them virtually indispensable for the successful implementation of the organization's objectives, their dominant position is strengthened (Blau and Scott, 1962:227-228). The majority of the general membership is content to leave the running of mutual-benefit associations to a corps of active members (Blau and Scott, 1962:46).

Although the local MSA was primarily a mutual-benefit association of families of those who had been diagnosed as schizophrenic and victims so diagnosed who were seeking effective medical treatment, the organization was seen as a service organization by many who called the new office of the local Association. The office was listed in the local telephone book "Yellow Pages" under "Social Service Organizations."

A service organization is defined as one whose prime beneficiary is the part of the public in direct contact with the organization with whom and on whom its members work—such as social work agencies. The welfare of their clients is presumed to be the chief concern of service organizations, but the client is not expected to know what will best serve his own interests. Professional services require that the clients' wishes, as distinguished from their interests, not influence the decisions of the professional (Blau and Scott, 1962:52).

In a mutual-benefit association, the member is presumed to know what is in his own best interest. In the office of the MSA which was staffed by volunteers, professional decisions were not made. The two major functions of the Association were education and service with education emphasized so that members and others calling for help could make their own enlightened decisions in regard to various doctors or clinics.

The question of goal maintenance which Sills stated was the primary problem for voluntary organizations was also of concern to members of the local MSA when the national organization changed its name to the "Huxley Institute for Biosocial Research" with "American Schizophrenia Association" secondary. It was found in the present study (based upon published material, public lectures given by doctors, local records, recorded conversations, and questionnaires) that from the inception of the national organization in 1964 to the close of the study a decade later, the original goal of finding and making available effective treatment for schizophrenia (by whatever name or no name) had not changed. It appeared that this was due, in great part, to the determined leadership on both national and local levels which had not changed. Some of the initiators on both levels had remained in control: through two name changes, two moves, and the attracting of other scientists already working in allied fields and with broad backgrounds in Biochemistry and nutrition on the national level, and one name change, the recruitment of a variety of referral doctors, and the opening of an office on the local level.

Three of the original five officers of the national Association remained officers of that organization, and three of the founding group of the local Association were still on the board or were officers of the local group.

Chester Barnard, one of the originators of the formal organization approach, said that probably the most frequent origin of enduring organization lies in the deliberate intention of a single person who conceives and formulates a purpose, transmits it to others, and induces them to cooperate with him (1966:102). A formal organization can begin with the coordinated actions of four or five individuals with a common purpose. This being true, there is no reason why the originators of an organization should not continue to lead a mutual-benefit association as long as others are still convinced that the goals of the association and its leaders coincide with their own best interests. In the organization studied, they did coincide according to

members.

Members of MSA were questioned about what they considered to be the goals of the organization and their own incentives for belonging. The major goal as seen by members was "to find a cure" (or "best treatment") for schizophrenia. Another goal was to make biochemical treatment more readily available. (A short-term local goal was to have a diagnostic and treatment clinic within financial reach of those needing help in the area since no local psychiatric facility allowed "megavitamin therapy" and laboratory tests were beyond the means of many members.) Members' incentives for belonging were to help themselves and/or their family members and to help others in the same situation with regard to schizophrenia (i.e., "mutual-benefit").

"Moral support" was also listed as an incentive for belonging to the MSA by families who were found to have had the following common problems: confusion as to what had gone wrong with the victim; problems in getting a diagnosis; confusion and fear when the diagnosis of schizophrenia had been given; feelings of guilt, particularly in mothers; confusion engendered by various psycho-dynamic treatment modalities; financial problems. (The affirmation of the value of the family as the basic supportive and decision-making unit of society was found to be an implicit function of the MSA.)

In looking at the problem of "membership apathy," Sills found that people are influenced by the general social structure as well as the structural characteristics of the associations to which they belong. Of first importance are obligations to job and family, and secondly, in America, individuals are apt to have memberships in several associations. Prior obligations vie for their time. If the objectives of two or more organizations are at cross-purposes, the usual solution is to withdraw from a voluntary organization (Sills, 1957:36).

In a truly voluntary association, members do not have to join and they may leave the association at any time if it does not fulfill their needs or wishes. This can hardly be said of some mutual-benefit associations like labor unions and some professional organizations. The union man who leaves the union may have a hard time finding another job in a unionized field, and the doctor who flouts the current policies of the AMA may find that financial difficulties as well as the disapproval of his peers will follow. Clients of some service organizations—for instance, welfare agencies-may have no alternative to being clients of that agency if they are to get any help at all.

Leadership of voluntary organizations is time-consuming. Five of the 13 board members or officers of MSA were retired or semi-retired. One of the reasons for not being more active cited by other members was that they were already too busy. In addition to the general reasons that Sills found for so-called "membership apathy" in voluntary associations, the MSA had to cope with the additional problem of the stigma attached to the term "schizophrenia." This was frequently mentioned by leaders as a reason for lack of active participation by other members or prospective members.

While Sills considered that the corporate structure of the National Foundation for Infantile Paralysis was of major importance in the success of that organization both in attaining its goals and in turning to an orderly succession of goals, he also considered other reasons for the success of the organization. These can be compared for the association whose goal it was to control polio and the one whose goal it was to control schizophrenia.

There had been no charismatic national leader of the new American Schizophrenia Foundation to start its fund-raising effort; the hoped-for broad base of fund-raising volunteers similar to the March of Dimes organization did not materialize. The original money was withdrawn, and there was nothing to replace it.

The membership of the American Schizophrenia Association, like that of

A SELF-HELP HEALTH GROUP AS A FORMAL ORGANIZATION

National Foundation	American Schizophrenia Association
1) Charismatic leader, a president who had been the victim of polio.	1) No national charismatic leader.
2) Over one million dollars raised by birthday balls in 1934 to start foundation.	2) Benefactor withdrew financial support soon after foundation was incorporated.
3) Corporate structure, National Board of Trustees, local chapters small.	3) Corporate structure, National Board of Trustees, local chapters small.
4) March of Dimes fund-raising organization.	4) No separate fund-raising organization.
5) 18 percent of members connected with polio as victims or families.	5) Almost all members connected with schizophrenia at the time they joined.
6) Polio identifiable disease with predictable course.	6) "Schizophrenia" umbrella term. Course erratic.
7) Polio crippling, struck young children.	7) Schizophrenia does not necessarily show, strikes mainly young adults.
8) Incidence of polio low, even in epidemic years. Chapters could help with high patient care expenses.	8) Incidence of schizophrenia remains 1 percent of population or more. Cost of private treatment high.
9) Service organization staffed by volunteers.	9) Mutual-benefit association.
10) Young middle-class parents members.	10) Older middle-class parents members.
11) Members of chapters civic leaders.	11) Members of chapters civic leaders.
12) Polio hit prosperous communities.	12) Schizophrenia probably highest in lower-class communities.
13) No stigma. Patients and families both considered victims.	13) Stigma for both victim and family. (Family-as-cause theory widely held. Victim considered to have lost "mind.")
14) Education and research programs.	14) Education sustained. Research short of funds.
15) Noncontroversial; stamp of community approval. Much publicity.	15) Highly controversial. Some TV and radio coverage.

the National Foundation for Infantile Paralysis, was generally white and middle-class. Like Sills' volunteers, leaders of local chapters were community leaders, knowledgeable about voluntary organizations. They were, however, parents of "antisocial" young adults rather than parents of appealing small children. Rather than joining together to work for the long-term goal of stamping out a disease that for most was only a potential threat, they joined or contacted the Association already in need of help, requesting treatment already outlined. They were the same as the patients and families for whom and upon whom Sills's service organization and its volunteers worked as well as the volunteers themselves.

Sills said (1957:55) that the fact that the objectives and programs of the National Foundation were non-controversial was an important factor in the success of the organization. That both schizophrenia and the treatment advocated were the subjects of controversy had an adverse affect upon the membership of the ASA, its activities, the relationship between the national Association and its local affiliates, and upon the ability of the organization to work toward its goal.

The American Schizophrenia Association was opposed by two powerful mutual-benefit associations, the American Medical Association and the American Psychiatric Association—although usually only the doctors who were leaders were taken to task. The AMA generally discounted the use of vitamins or pointed out the dangers of overuse (of vitamins generally, the B-complex vitamins principally used in "megavitamin therapy" were not mentioned specifically in the press.) The Task Force APA Report, previously cited, stated that "megavitamins" were worthless in the treatment of schizophrenia. This report was widely publicized. The local Metropolitan Schizophrenia Association, as an organization, was generally ignored by the psychiatric and medical

establishments.

Although the ASA—initially and by design—had a corporate structure similar to that of the National Foundation for Infantile Paralysis, this structure could not function well in the face of the massive professional opposition encountered on the national level and the many problems faced by local affiliates. It appeared that local leaders expected national leaders to give more direct organizational leadership than they could and that national leaders expected that local members would have more influence with "family doctors" than they actually had. (Lay members requested doctor referrals from the national organization after being unable to persuade local doctors to investigate and try the biochemical approach. At least partially in response to the expressed need for doctors, a professional association, the Academy of Orthomolecular Psychiatry, was formed in 1971.)

A major change in structure of the organization took place at a meeting of Chapter Representatives with the President, the Chairman of the Board, and the office staff of HIBR/ASA in New York in May of 1974. Prior to that meeting, ASA members could join either directly or through local affiliates. When they joined (or renewed membership) through local chapters, membership dues were split between the chapters and the national Association with local affiliates retaining the larger proportion. It was announced that the national Association could no longer afford this financially and that membership and dues would thereafter be separate. Chapter representatives, expressing a need for better communication, then selected a Chapter Coordinator. The move was from a corporate structure, with authority delegated downward, to a loosely federated structure, with authority delegated upward, as far as local associations were concerned.

Local leadership and suggestions were beginning to surface when this study was concluded in the summer of 1974. The national Association continued its education and service functions: supplying educational materials (books, reprints of articles, a newsletter, professional journal, cassette tapes, films, and the like) and making known doctors and clinics able to offer requested services. Local activities continued to be published in the national newsletter.

CONCLUSIONS

It is concluded that membership and activities were, as thought by Sills, important in determining the character of the organization both local and national, but that what Sills calls "forces" in the environment affected the membership, the activities, and the formal structure of the organization itself. The change in structure toward a federated association of local units would better represent what the organization was actually capable of being in the environment than had the corporate structure.

Although the structure of the national organization changed, and despite the potentially broad objective of the Huxley Institute for Biosocial Research, the major goal of the organization, its founding doctors, local leaders, and other members, had not changed. It remained to eradicate schizophrenia (by whatever name), to cure individuals, or to control their physical problems in much the same way that diabetes or some heart conditions can be said to be controlled. In maintaining this goal, sustained leadership was more important than formal structure.

Sills concluded that voluntary associations are limited in their usefulness as instruments for rationally planned change because they are also objects of change, molded by forces tangential to rationally ordered structure and stated goals (1959). There is a possibility that forces in the environment resisting change might make it impossible for the American Schizophrenia Association to continue to exist as an organization, although this seems unlikely.
Gussow and Tracy consider that

consumer-initiated groups of the medically underprivileged constitute a social movement. Such phenomena arise, they say, when a hiatus exists between felt need and the existence of available services adequate to meet such need (1973:3). Such a need was brought to light by the American Schizophrenia Association and could be seen clearly in the Metropolitan Schizophrenia Association. It is considered here that as a social movement, the schizophrenia association movement will undoubtedly continue.

Literature about schizophrenia has been made available to well-educated laymen and much of the mystery surrounding the term "schizophrenia" has been dispelled for them. Beyond that, there are patients who have found successful treatment, either for unnamed conditions which had been previously classified as "schizophrenia," or they were found to have other physical problems known to laymen as well as to doctors (inside or outside of the Association) which had not been previously diagnosed by either psychiatrists or other M.D.s. The lay referral system, to be found in all societies, will not allow the word of this to be silenced, and the direct human support system will continue.

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