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Action Research in the Voluntary Sector:
A Case Study of Scholar-Activist Roles
In Self-Help Groups

by Mark Chesler

The Program on Conflict Management Alternatives
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ACTION RESEARCH IN THE VOLUNTARY
SECTOR: A CASE STUDY OF SCHOLAR-
ACTIVIST ROLES IN SELF-HELP GROUPS

Mark Chesler

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Action Research in the Voluntary Sector: A Case Study of Scholar-Activist Roles in Self-help Groups.

Mark A. Chesler
Professor of Sociology, University of Michigan
Co-Director, Program in Conflict Management Alternatives,
University of Michigan
President, Candlelighters Childhood Cancer Foundation

This conference on action research represents a rare arena within which we can provide each other with social and intellectual support. Whether we come from the academic setting or the field setting, most of us who practice action research do so with few full colleagues; we often have collaborators, but few colleagues. Thus, this opportunity to share ideas and feelings, to give and gain support from one another, is most welcome. Appropriately enough, the substantive focus of this presentation is also on social support. It discusses my role and tactics as an action researcher with mutual support and self-help groups of families with children with cancer.

The literature makes it quite clear that despite some common assumptions there are widely differing definitions of action research. As Chein and his colleagues noted several decades ago (1948), there are varying preferences regarding the research component of action research, including applied research, diagnosis, evaluation, and experimental studies, using either mainstream or innovative modes of scientific data collection and analysis. The more contemporary writings of Elden (1981); French

& Bell (1973) and Tichy & Freedman (1983) reflect these continuing differences. Likewise, there are various preferences regarding the action component of action research. Sanford (1970) argued early that much action research was research-oriented rather than action-oriented. Among the action options writers have suggested are organizational consultation, problem solving, data feedback, community organizing, consciousness raising and societal transformation (Fals-Borda, 1984; Kieffer, 1984; Tichy & Freedman, 1983). Underlying many alternative conceptions of appropriate action are disagreements over whether one's work can or should be impartial or of primary benefit to either societal/organizational power holders or representatives of low power and oppressed groups (Brown & Tandon, 1983; Carr & Kemnis, 1983). Different ones of us also select a different balance of action and research in our work. While we may be committed to both activities, and seek their integration, the appropriate or preferred mix of action and research is a matter of considerable debate. Even in this conference we see a marked division between people operating from an academic base and tradition, often seeking to put their findings and theories into practice, and people operating from a field and community setting, often seeking conceptual frameworks to expand understanding of their world and work.

One result of these varying definitions of action, of research, and of action research is that we select and become committed to different roles in various projects. Having championed action roles, research roles, and some that mixed

these priorities at different points in my career, I herein
describe one extended project which sought to fully integrate
these roles and their associated activities. In so doing, I will
try to emphasize the unique opportunities and problems I
encounter, and the general meaning they may have for all of us.
This is, then, a case study with, I hope, instructive power for
others.

The project involves work with self-help groups for families
with children with cancer. These groups are examples of
voluntary organizations formed by indigeneous citizen-leaders
(and sometimes professionals) in various arenas of health care
and throughout our society more broadly. They are part of a
burgeoning social movement, a growing phenomenon that is part of
the broad concern for voluntary action, consumers' rights and
informal systems of help (Gottlieb, 1981; Katz, 1981; Killilea,
1976; Lieberman & Borman, 1979; Powell, 1987). Debate often
occurs over the proper definition of self-help and self-help
groups in the context of voluntarism and social support. The
most important issues are whether groups should be led by
professionals or by consumers of professional services (Mellor,
et al, 1984; Powell, 1985; Rosenberg, 1984), and whether the
actions groups engage in should be focussed primarily on
education and emotional support or on political and social
advocacy (Katz & Bender, 1976; Riessman, 1985).

My role in these groups has been that of member and actor,
and member-leader with a special role of generating and sharing
information and concepts about group operations and activities.

My role as a member of the social science community has been to conduct empirical research and to generate theory about group organization, processes, programs, etc. As an action researcher in this context there has been minimal distance between these aspects of my work, and minimal anxiety or internal role conflict. The demands of the action world and of the research world are different, of course, and these two external constituencies often pose challenges to my ability to mix styles and maintain personal integrity and psychological balance. Since I am based in an academic social science department (Sociology), my primary academic rewards are based on publications in "mainstream" academic journals or trade books, only minimally on writing in professional or practitioner publications, and not at all on actions, speeches, workshops (translated as incidental service) or materials directed at parent stakeholders. On the other hand, as far as parent and self-help group constituencies are concerned, my academic writings are irrelevant except as they help legitimize the larger group movement. Writings or talks directed to professional practitioners who work with self-help groups (physicians, nurses and social workers) and to parents and self-help group members themselves, as well as action with and on behalf of these groups, are most highly valued.

I make no claim that the strategy described below is most appropriate for everyone; particular circumstances make it ideal for me and for the constituencies with which I work. I do claim that it is an action research option for each of us, in certain

settings; in the context of most reports presented at this conference it is a quite unusual approach.

Self-help groups for families of children with cancer.

Childhood cancer is a serious and chronic illness; it is diagnosed in over 6,000 youngsters under the age of 15 each year (Sutow, 1984). Even after several decades of major technological advance only about 50% of those children diagnosed with the disease will live five years beyond their diagnosis (National Cancer Institute--Office of Cancer Communications, 1986), and some who do survive will show the effects of serious complications from treatment; some others will succumb to the disease later. Childhood cancer also is a chronic illness. Treatment, which may include surgery, chemotherapy and radiologic therapy, generally occurs over at least a two-year period -- if everything goes well; some children may be in treatment for five or more years.

This illness creates substantial trauma and stress for all family members -- patients, siblings, parents -- and for other relatives and close friends. In addition to the terror and pain of the illness and treatment, fear and uncertainty about the outcome of treatment continues for several years. Despite advances in diagnosis and treatment, no one knows at the onset, or even soon after, which children will survive and which won't. Since cancer is a microscopic illness, even an apparently recovering child may covertly harbor the returning disease. There is no way to relax in the face of cancer until several

years have passed. Even then, long-term survivors and their parents report that anxiety about the return of the disease lingers (Koocher & O'Malley, 1981). Time and energy drains are common, due to the need to travel to treatment centers, the stigma of a dreaded illness, lost friendships, strained family relations, and major medical bills. Even young people who survive the illness report discrimination in educational services and difficulties in gaining employment and life or medical insurance (Feldman, 1980; Teta et al., 1986).

As families deal with these and other stresses they utilize a wide variety of coping mechanisms. Some family members talk a lot about the illness and others deny or avoid it; some remain optimistic in the face of these threats and others become pessimistic; some rely upon and strengthen their religious faith and others lose or change their views of God and fate. Many utilize social support as an aid to any and all other coping strategies. Support may come from varied sources, including family members, friends, community agencies, church leaders and fellow congregants, and medical staff members. One special source of support is other parents of children with cancer; people who have "been there", who are "in the same boat", represent a unique form of mutual support. Self-help groups offer the organizational framework and setting within which peers can find and provide mutual support to one another. Figure 1 suggests some of the ways in which self-help group programs and activities may be responsive to the stresses of childhood cancer.

In the context of a self-help or mutual support group, parents can identify with a community of persons who are "like oneself". They can test what it feels like to cry, to hope, to say in public "I am the parent of a child with cancer". They can discover that they are not alone, and that for most people life goes on in the midst of this trauma. On the basis of shared experiences parents can gather information and skills that are the product of a special kind of wisdom -- experiential expertise (Borkman, 1976; Reinharz, 1981). Such expertise, as distinguished from the credentialed expertise of professionals, comes from different bases, is relevant to different issues, and speaks with a different voice. For instance, medical staff members may be experts in the nature of the illness and treatment, but they may know little about how to manage a child whose bowel habits have regressed due to chemotherapeutically-induced constipation, how to feed a child whose appetite has been ravaged by drugs and radiation treatments, how to care for a sibling who feels left out, or how to get along with distressed friends and overworked and irritable physicians. Parents who have met and solved (or failed to solve but have learned about) such problems can contribute unique wisdom to one another. With time and energy available, they may help transport parents of newly diagnosed children to the hospital, absorb minor but non-insurable food and childcare costs and find housing for a family far from home. These "veterans" also may educate new parents with regard to the illness and its treatment. Perhaps even more important, they may inform parents of newly diagnosed children

regarding the talents and characteristics of various staff members, helping parents ascertain how to relate to the staff most effectively. In a self-help group parents can provide one another with important information and with tangible support, as well as with emotional succor, companionship and a sense of community.

In addition to these direct activities and benefits of self-help groups, parents who are able to contribute to the growth of others often overcome their own sense of futility and powerlessness with regard to their child's situation. While gaining information is a route to competence in a new situation, giving information and advice to others verifies that competence. Providing help to others announces that one is at least treading water instead of drowning, and that one has some spare or extra resources available for others. Being able to help other people is a vital part of the American tradition, and has been reported to be "therapeutic" for the giver of help, as well as for the receiver (Riessman, 1965; Dory & Riessman, 1984). Self-help groups thus represent an example of the tradition of voluntary and democratic action in our nation. Here people are acting on their own behalf, and on behalf of vulnerable loved ones, to connect and care for others by taking collective action. That action involves building social linkages to others, engaging in intimate forms of emotional support, educating peers in the nature of a new and difficult medical and social reality, raising money, and exerting collective influence on medical and community institutions. It is, often, a personally and collectively

empowering activity (Haggstrom, 1976; Rappaport, 1983-84; Suler, 1984; Withorn, 1980).

My role as an action-researcher with self-help groups.

My role as an insider to the life of self-help groups for families of children with cancer began in late 1976. At that time my eldest daughter, aged 11, was diagnosed with acute lymphoblastic leukemia - a life-threatening form of childhood cancer that attacks the bone marrow and blood system. As part of my own coping style, I began to read current medical and psychological literature on childhood cancer. The methods and findings of this research were appalling, oriented as they were to the problems of death and dying, on small samples, using primarily psychoanalytic methods, and focusing on the necessity of child and family adaptation to paradigms current in the medical treatment system. My wife and I took two further steps: (1) We began conversations with other families of children with cancer, and eventually undertook a program of systematic research into the psychosocial aspects of childhood cancer (Chesler & Barbarin, 1987); (2) We sought social support, first with our close friends, with the staff of the hospital and later with other families of children with cancer. In time, we helped form a local support group for families experiencing this childhood disease.

As the years passed, our daughter continued to be in remission, eventually to cease treatment and to enter the growing ranks of "survivors of childhood cancer". My activities in this

area also expanded. As a leader of a local family support group I became involved in informal peer counselling of other parents and families, learning to be an empathic and sympathetic listener and helper. In these settings I gained as much as I gave and was helped as much as I was able to help others (the principle of "helper therapy"). I also discovered that there were many other local support groups for families of children with cancer, and that many of these groups were linked with the Candlelighters Childhood Cancer Foundation. I then became involved with the Candlelighters Foundation, first as a visitor to its national office, then as a member of its National Advisory Board, and for the past several years as its President. In this role I serve as an organizer of and consultant to local groups, a designer of the Foundation's long-term strategy, and a spokesperson for the 300+ local groups and 22,000+ parents, young people and professionals involved in its activities.

In addition, several years ago I began a program of action research with self-help groups for families of children with cancer. In the conduct of this project I visited 50 groups throughout the nation.1 Some of these groups are large and well-organized, others are small and quite informal. Some are located in or near major population centers, other are located in rural areas or small towns. Some are located nearby a specialty center

1. I collected most of the data personally, since my special status as a parent of a child with cancer, a network leader and a scientific professional usually guaranteed a special depth of access to group life. Later in the development of the project, however, four colleagues visited and gathered data from 11 of the 50 groups. Visits by colleagues generally were preceded by my personal mail and telephone introduction to group leaders.

for the treatment of childhood cancer, others are hundreds of miles from such a center.

The methods used to gather data are described in detail elsewhere (Chesler & Yoak, 1983; Yoak & Chesler, 1985). Basically, we utilized a grounded theory approach to collect comparative organizational data on a theoretically saturated sample of 50 groups (Glazer & Strauss, 1967). We utilized group interviews, personal interviews, analysis of materials, and paper and pencil questionnaires to gather data on group history, organizational structures, programs, leadership patterns, membership patterns, relationships with the medical staff and community environments. Wherever possible, we also interviewed medical professionals (physicians, social workers, nurses) who worked closely with the local self-help group. My personal credentials as a parent of a child with cancer permitted me to enter deeply into the lives of individual parents and local groups; I was part of their community. I was often invited to stay at the home of a group member rather than in a motel, often invited to eat dinner with a local family, and often served a "gemultlich" family dinner of lasagna. Casual conversations often became intimate and deeply moving exchanges of life histories, feelings about the illness, hopes for our children and "stories" about the medical system. Since I knew this research would rather immediately, not merely eventually, benefit parents and local groups, I freely and deeply entered into these shared confidences. Both the role I played, and the grounded methods used in research, helped avoid feelings of exploitation of

"subjects" typical in the examination of intimate issues in scientific research.2 My status as a scholar and a mental health professional also provided access to members of the medical and social work staffs of hospitals dealing with families and local self-help groups.

Preliminary findings were compared in several settings, and generally "tested" in action. First, I often shared what I had learned from a group with a group, asking them to verify and react to my understanding of or explanation of their local reality. This strategem has been recommended by several grounded theorists and participatory or action researchers (Douglas, 1976). Moreover, I often addressed or consulted on solutions to group problems, helping to diagnose local issues, encouraging the expression of local needs and insights, and sharing tactics or programs I had seen while visiting other groups. The kinds of issues group members primarily wanted to have information about included programs that might really meet parents' needs, ways of recruiting parents of newly diagnosed children, ways of counselling or helping parents who were having a "hard time", ways of running effective meetings, ways of electing officers and avoiding leader burn-out, and ways of working cooperatively with medical staff members. I sometimes carried names and addresses from one group to another, suggesting, for instance, that several

2 When my colleagues, who were not parents of children with cancer, visited with these groups they often expressed concern about entering too deeply into these intimacies, and wondered whether they were imposing on parents. One colleague, herself a young adult who had had cancer as a child, reacted much as I did, freely entering into parents' and families' lives. She was often welcomed as an example of the positive future that might be in store for all ill children and all struggling families.

groups located in southern California contact and visit one another. As the representative of a national network, such message-carrying and linking were important elements in extending this network.

Second, I presented the results of my visits to staff and National Board members of the Candlelighters Foundation. Just because I conducted "research" on these groups did not mean I was the wisest, or only wise, person with regard to group realities and experiences. Board members with their own experiences in local groups often corrected or expanded my understanding. In return, I often verified or expanded others' understanding, leading to better ways the national Foundation might serve local groups. When one board member said, "Mark's research validates what we all know about our groups from our common sense", I took this as a compliment.

Third, as other scholars, I shared results of this research with scientists and professionals working with self-help groups. In scientific meetings and as a representative to professional organizations and community agencies; I presented the findings of this research, trying to advance the state of knowledge about support systems and small voluntary agencies, and to examine the implications of these findings for the more effective operation of local self-help groups and professional or community services (Chesler, 1984; Yoak & Chesler, 1985).

Findings were disseminated in various ways to various audiences. As noted above, the audiences included: parents of children with cancer, local self-help groups and leaders of local

groups, staff and board members of the national networking
organization - Candlelighters Foundation, professionals working
with local groups, professionals working within agencies such as
the American Cancer Society concerned with national policy
regarding psychosocial issues surrounding childhood cancer,
social scientists, physicians, educators of medical staffs, the
public at large, and now action researchers. Reaching different
audiences often required speaking different languages. Obviously
articles written for scholarly journals would not be well
received by parents; their concerns and needs for information,
let alone their criteria for evaluating written work, are very
different. Indeed, even this article, written for a primarily
scholarly and professional audience, would never find its way
into a mainstream academic journal nor into parents' hands.
Often information was shared with parents to verify their sense
that groups were useful devices, and to suggest ways to improve
their functioning. Information shared with professionals often
was designed to persuade them of the value of such groups and to
diminish their fears of what parents might do if they ever got
together. Thus, a given finding often was written in several
ways and shared with different audiences in different kinds of
publications (academic journals, book chapters, technical
reports, columns in parent newsletters, informal memoranda).3
Public speeches and workshops were additional forums for the
presentation of results, and for influencing scientists,

3 Compare, for instance, Chesler & Barbarin (1984) with Chesler &
Barbarin (1985).

professionals, group members and various publics with regard to
self-help groups.

This work calls for a range of psychological skills in
dealing with people who hurt, intellectual skills in research
methods and social analysis, political skills in working with
constituencies who often are in conflict, and skills in
organizational and community development and change. I am
learning as I go, and immediately using what I am learning.

Generalizing from my role in this project.

There are some unique aspects to the action-research roles I
adopted in this project. Whether experienced as conflict or
creative exchange, there always is a dualism or dialectic among
the activities reflected in the term action-research. In
addition, however, I encountered another dialectic because of my
joint roles as a parent and a professional. As a parent of a
child with cancer and an organizer of support groups, I was an
insider to the experience of parents and to the reality of self-
help groups. As a professional (both mental health professional
and scientist) I could, on occasion, stand outside the parental
experience. Similarly, this duality permitted me to stand inside
and outside the professional experience. For instance, in
contrast to how I exploited my insider parent role in interviews
with parents, I certainly jettisoned part of my parent role in
interviews with medical staffs; only my professional insider
status promoted access and openness in professional settings.
This "double dualism" is reflected in the chart below:

	Parent	Professional
Activist	Advocate of groups Counsellor to parents Comrade in "situation"	Presentor of scientific evidence. Teacher of professionals working with groups.
Researcher	Student of parental reactions.	Student of medical structures and professional attitudes.

It is not always easy to keep these roles clear, to exploit the dialectic among roles, or to manage relations among various identities or constituencies, especially in specific settings where there is open conflict. More than once I found myself predisposed to dislike or disagree with a professional (or a group member) because of what I had heard in a prior interview with a group member (or a professional). Most of the time I discovered this predisposition, after the interview if not in its midst, and tried to use my own reaction as a means for gaining insight into this phenomenon. These are among the epistemological and political advantages of an "insider" as well as "outsider" base for intellectual inquiry and social action. As Merton has argued, those of us who claim the gains of "insider" knowledge must also attend to its potential costs (Merton, 1972).

Such a role construction, while uniquely displayed here, is not unique in our experience as action researchers. Many of us, when we study issues "close to home", are part of the issue as well as apart from the issue. Scientists who are peace activists, and who study the mobilization of peace movements in

scientific ways, are doing the same thing. Feminist scholars who utilize both their academic backgrounds and their personal insights, and who share their findings with feminist activists as well as with other scholars, are doing the same thing. Rather than eschewing such work in the interest of objectivity and distance, we may embrace the opportunity to fully integrate these diverse aspects of our lives. In so doing we may, in Keller's terms (1985), substitute "dynamic objectivity" for "objectivism", the result of struggling to disentangle self from other, subject from object, rather than attempting to sever the relation between the two. Keller's effort to overcome processes of disinterest, autonomy and alienation in modern science calls for enough trust to dare the "blurring of the boundary between subject and object" (1985, p. 87). In such empathic science lies the potential for great insight. The exploration of such new methods and roles also would help reduce the gap and encourage dialogue between "action-researchers" and "participatory-researchers" (Brown & Tandon, 1983; Peters & Robinson, 1984).

Work with self-help groups, like work with other voluntary groups, poses problems (and opportunities) for action-researchers quite different from those encountered in work with industrial or governmental bureacracies. First, the audience is only minimally captive, and can not easily be coerced or regulated into participation in a project agreed to by nominal leaders. Thus, access may be more difficult, since gatekeepers have only partial control over member participation in studies or change projects. Of course, even in traditional bureaucracies, line workers may

sabotage a Vice-President's project, but they may have to do so
subtly, so as not to risk job loss or sanction. If voluntary
group members do not wish to participate they are more likely to
say so and to do so quite overtly (sometimes loudly). Because
coercion, and the strong resistance to coercion, seldom is
encountered in voluntary groups the incentives for participation
are both more subtle and immediate.

In voluntary groups action research may be conducted with
ultimate users of service, not just with higher level managers or
distant service providers. As a result, the action aspects of an
action-researcher's role is likely to be more concrete and
specific; more pressure to be placed on generating practical
implications, and more accountability applied to results.

If voluntary groups, or social movement groups, seek to
generate a "new reality", a vision or version of "what is" or
"what might be" that is counter to establishment values, they
will be very cautious about establishment-based action research
(or establishment-based action researchers). Several writers
have reported self-help group resistance to traditional forms of
social research (Lieberman & Borman, 1979; Powell, 1987) and even
to some forms of action research (Rappaport et al., 1985). Some
have mistakenly interpreted this resistance as a form of anti-
intellectualism, but there is good reason for caution. In a
highly politicized environment, research (even action research)
may be coopted by powerful organizational elements, explicitly
hired to justify elites' organizational priorities, or (even
inadvertently) employed to retaliate against people raising

criticism and advocating change. In the same context, if
empowerment is an issue for voluntary groups, as it surely is for
social movements, and generally is for self-help groups, dominant
elements that resist new empowerment dynamics for oppressed
groups or service recipients can be expected to resist the action
research efforts that accompany them.

Finally, work with voluntary groups is harder to generalize
and share broadly. Problems of differing life situations, of
local uniqueness, of language, of access, of risk of
disempowerment by revealing tactics, and of positive or negative
payoffs of publicity are quite different. So, too, are the
payoffs to the action researcher working with such groups. Work
with high-power groups, with system managers, governmental
elites, and medical professionals is more highly respected and
rewarded in the academic professions, as well as in the society
at large, than is work with low-power groups, oppressed people
and service recipients. It is, however, no less fulfilling or
meaningful for those of us trying it.

The excitement of this action research project is rooted in
three basic elements of its construction. First, I am working on
issues that are central to my own life and I operate as an
insider to the phenomena under study. This permits me to combine
standard strategies and orientations of objective scientific
study with the empathy and insight (and sense of struggle)
permeating the life of persons experiencing the issues directly.
Second, I have sought an integrative dialectic between action and
research that treats both goals/roles equally, and that moves

simultaneously from action efforts to knowledge generation and
from research to action. With initiative coming from both action
and research goals, and with accomplishment of both of equal
priority, both are concrete, immediate and constant. Third,
working with voluntary support organizations puts me in touch
with compassionate exchanges between people who hurt and care, as
well as with struggles for personal and collective influence.
The self-help agenda, implicitly or explicitly focused on
patient/parent/professional empowerment, is the lifeblood of a
concern for personal growth and democratic social change in our
society. Action research can contribute to that concern in
unique and important ways.

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