DRAFT REPORT

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MEETING ON CONSUMER/SURVIVOR-RUN PROGRAMS

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Note on terminology: Participants at the meeting did not reach consensus about one term that could be used to refer to themselves. Some preferred the term "consumers", while others saw themselves as "survivors". The authors of this report decided to use both terms side by side in this report, unless when quoting verbatim. To avoid excessive repetition in the report the term is frequently abbreviated as "c/s", especially when used in conjunction with other terms, i.e. "c/s-run program." Such abbreviation should not be translated into the spoken language, it should simply facilitate the reading of this report.

I. Introduction

A. Significance of the Issues

Self-help groups have been expanding at an unprecedented rate during the past decades in all areas of human need. These groups address a wide range of social, medical, and physical problems and conditions and are attractive because they are generally free, they help people develop their own resources and self-respect, and they provide a community of caring people. More recently, these developments have begun to impact on the field of mental health, as many former patients and their relatives have begun to form smaller and larger organizations designated to promote their common interests and provide mutual support.

Federal, state and local government initiatives have all taken notice of these development, and have begun to provide relatively modest support for such "consumer-run initiatives". These can take the form of free-standing self-help groups that meet regularly in someone else's space, on the one hand, or more complex organizations that provide services in the area of housing, advocacy, self-help, skills development, vocational training, outreach and peer counseling. Drop-in centers have been the most consistently replicated type of such programs, providing leisure time socialization as well as a host of other concrete services to persons that often are not finding their needs met by the mental health system.

In 1988, the National Institute of Mental Health (NIMH) Community Support Program (CSP) has funded 14 modest projects to demonstrate and evaluate consumer-operated self-help approaches. The learnings of these projects are yet to emerge, but they have obviously contributed in many ways to the development of this innovative area in mental health. At this point in time, a number of self-help programs, be they free-standing or funded from government sources, have been operating for several years, so that there

is a growing body of information on how to fund, plan, operate, and evaluate consumer-run drop-in centers and alternative programs and how to overcome common problems and obstacles they may encounter.

B. NIMH's contract

Aimed at furthering the goals of CSP in promoting self-help approaches, NIMH has issued a procurement to conduct a meeting of consumers/survivors, program administrators, and self-help researchers to discuss issues around operating and evaluating self-help programs including drop-in centers and consumer-run alternative programs. The mission outlined by NIMH was as follows:

Convene a meeting to include the suggested participants aiming to discuss, but not be limited to the issues listed below:

- Financing self-help programs
- Relating to funding agencies
- Meeting training needs
- Dealing with apathy among the members
- Dealing with substance abuse
- Handling psychiatric emergencies
- Conflict resolution
- Working with a board of directors
- Working with professionals while avoiding cooptation
- Becoming an independent entity
- For purposes of evaluation and research, identifying the essence of self-help programs (the common elements and characteristics), the expected outcomes, how to involve the members in evaluating or conducting research on the program, and how to conduct the research in a sensitive, empowering, non-intrusive manner.

C. Process of selecting participants and organizing the meeting

Subsequent to the successful funding of the proposal, the four members of the organizing committee (Ed Knight, Anne Lovell, Ike Powell and Peter Stastny) met to discuss the location, time, place and selection of participants for the meeting. Newark, New Jersey, was chosen as the location due to it's easy access to air transportation and it's reasonable hotel rates.

Given our budget limitations we were aiming to include a total of approximately 24 individuals, composed primarily of consumer/survivors with considerable experience in the running of programs and consumer-run initiatives. These were to be complemented by a small number of self-help researchers and state mental health administrators. In order to achieve geographic spread we decided to identify at least one representative consumer/survivor from each of the 13 Mental Health Regions designated by the National Institute of Mental Health. Using lists made available by CSP staff as well as recommendations obtained from local and national self-help clearinghouses, we developed an initial list of 20 persons, with each region represented by at least one individual. For some regions, certain persons clearly stood out as having the most experience in the actual running of programs. In regions, where there were numerous people with such experience, we discussed the issue with representatives from clearinghouses as well as individuals from those regions, to help decide whom to invite. It was obvious that there were many more people with considerable experience and expertise than we could accommodate in a small working meeting. Therefor all choices made were in some way arbitrary, inviting persons who we knew would be able to contribute, but excluding others who would have been just as valuable to the effort.

Initially about 20 consumer/survivors from across the country were contacted and asked if they would be interested in participating in this meeting. In addition three researchers and three state officials known to be committed to the implementation and

evaluation of self-help programs were invited. The letter sent to these persons included the following statement:

> "We have been asked by the National Institute of Mental Health Community Support Program office to convene a small group of consumers, state mental health officials, and researchers to a working meeting on consumer self-help programs. The purpose is to discuss and work through the salient issues and problems currently arising in the areas of funding, planning, implementing, and evaluation consumer-run programs. ....Because of budget limitations, only a small number of individuals can be invited to participate. Names were selected not only on the basis of expertise, experience, involvement in and committment to consumer self-help; but also to assure the greatest geographical, gender and ethnic diversity."

The vast majority of those who received this letter agreed to participate, and most were indeed present at the meeting. The final group included 16 consumer/survivors, three researchers, two state CSP directors, and three non-consumers involved in advocacy and self-help implementation, representing 13 states. (List of participants included in the Appendix.)

II. Overview of the meeting

A. Dates, place, mandate or mission to participants

The meeting took place on Saturday and Sunday December 8th and 9th, 1991, at the Newark Airport Comfort Inn. In spite of its proximity to the busy Newark Airport, the meeting site was basically comfortable without excessive noise pollution. Each participant, who chose to stay at the hotel, had a room to themselves and the meeting rooms were more than adequate for our purposes. We had arranged for audiotaping of the meeting, which was done quite professionally by two technicians.

B. List of participants, their background

The sixteen consumers/survivors from 12 states had a variety of backgrounds. Most

had experience in running drop-in centers or other self-directed programs. A number were active in developing state-wide self-help networks as well as in the national movement. Some participants had professional degrees and worked in the mental health system, while others had established themselves in alternate settings. At least two participants worked closely with state mental health agencies, heading consumer bureaus or state-wide organizing efforts financed by these agencies. A few attendees are clearly perceived as "national leaders", with many years of activism and visibility. Others have become involved relatively recently and are more known locally, where they are active in running self-help programs. A considerable proportion of the consumer/survivors who attended were interested in research and evaluation issues, and many have experience in fund raising and fiscal management.

The three researchers who participated in the meeting (including one member of the organizing committee) had extensive backgrounds in self-help research, from an anthropological and social psychology perspective. Some of the other non-consumer participants had multiple interests, which include research, program administration, funding and state-wide implementation.

Many participants had been involved with NIMH through CSP either as project directors or on various ad hoc and grant review committees. Others had little, if any exposure to federal agencies.

C. List of facilitators and organizers, their background

The organizing committee included the following members:

Edward Knight, Ph.D., is the Facilitator of the New York State Self-Help Organizing Project and a recipient of psychiatric services including the experience of institutionalization. He was recently given the Clifford Beers Award from the National Mental Health Association. Dr. Knight has more than 10 years experience in advocacy and

community organizing and has facilitated the development of more than 150 self-help groups across New York State. He is also involved in research on self-help through an NIMH grant on Peer Specialists as Members of Intensive Case Management Teams, and in a study with the New York State Office of Mental Health on the characteristics of self-help groups in the state. The New York State Self-Help Organizing Project, directed by Dr. Knight, was begun in 1988 and has convened three annual conferences and has developed a set of curricula for self-help and advocacy. Over 500 individuals are involved in the Mental health Recipient Empowerment Project; mental health associations from several states have requested and received technical assistance on consumer self-help from the organization.

Anne Lovell, Ph.D., is an anthropologist and researcher with an interest in homelessness, self-help and coping strategies. She conducted the evaluation of Share Your Bounty, Inc., one of the 14 NIMH-funded consumer-operated projects. She is also the Research Director of a McKinney Research Demonstration Project to investigate the effects of residential placement and skills development on homeless persons with mental illness. She has participated in national meetings to discuss evaluation issues on consumer-operated projects.

Ike Powell is a private consultant with twenty-three years of experience in community organizing, group facilitation and strategic planning. The past four years, he has been working full time in mental health. He is currently contracted by the New York State Office of Mental Health and the Research Foundation for Mental Hygiene to implement the Local Collaboration in Self-Help Project funded by NIMH. He is also contracted by the Mental Health Association in New York State to assist in organizing consumers through the Mental Health Recipient Empowerment Project.

Peter Stastny, M.D., is a researcher, program developer and Associate Professor of Psychiatry at Albert Einstein College of Medicine, Bronx Psychiatric Center, and New York State Psychiatric Institute. He served as the Coordinator for the Organizing Committee. Dr. Stastny has worked extensively on peer support, transitional programs, rehabilitation

and empowerment. Currently he is the Project Director of an NIMH CSP Research Demonstration Project investigating the effects of peer counseling on Intensive Case Management clients and practices. In the past, Dr. Stastny has served as Program Director of the Rehabilitation Research and Training Center for Persons with Psychiatric Disabilities at Albert Einstein College of Medicine and has developed extensive contacts to the consumer/survivor, research and provider communities across the country.

For the purpose of facilitating the meeting, the original organizing committee of four was augmented by another person, Bonnie Cohen, the Executive Director of the Mental Health Association in New York State.

D. Process of meeting

The proposed agenda called for a "structured, but highly participatory, workshop process." This involved several steps 1) the participants would discern the issues to be discussed and establish the conference workgroups in the opening session. Individuals would select which group they wanted to be in for the duration of the conference. 2) The small groups would then meet to refine the issue and to give examples of how the issue is manifested in the consumer-survivor run programs. 3) Each small group would meet in plenary with the other groups to report back to and receive comments from the larger group. 4) Back in small groups the would further refine their work and move to the next step, recommendations to deal with the issue. They would prepare their report for the next plenary. This movement from small group work to large plenary reporting and feedback was to be the primary process of the meeting.

In the opening session, the group decided that everyone wanted to be in on the discussion of every issue. After much discussion, the participants decided to break into three smaller groups to discuss 1) External relations, which included cooptation, staying viable, credibility and visibility; 2) Internal relations, which included the broad area of how c/s-run programs operated. and 3) Criteria for c/s-run programs. The groups reconvened

for another extended plenary, then broke out again, with rotating membership, addressing permutations of the earlier themes, i.e. support and tension experienced by c/s running programs; minimal criteria for c/s programs; mission and content of programs. This occurred three times, resulting in three plenary sessions and three breakout segments. All sessions were audio-taped and written notes were taken for later use by the facilitators to prepare this report.

E. Process for writing the report

Transcripts from audiotapes of each session of the meeting were distributed to three of the facilitators, Edward Knight, Anne Lovell and Peter Stastny. Ike Powell was not available during this initial process. Each facilitator read the entire transcript and coded it for themes. The facilitators then met and related their lists of themes to each other. We found that the three lists overlapped considerably with each other and developed the final lists of themes found in this document. Initially, the themes were organized based on their quantitative representation in the transcripts, i.e. the amount of discussion and statements made relating to each of the identified themes. At the next meeting, the facilitators agreed on a way of organizing the themes under the following headings: A. Idealogies and Themes of the Consumer/Survivor Movement; B. Consumer/Survivor-run initiatives; C. Organizing the Consumer/Survivor Movement; D. Class and Ethnicity; E. Employment Issues; F. Professional View of the Consumer/Survivor Movement, and G. Research Issues. Under these heading, subthemes were again organized according to quantitative representation. Each facilitator, including Mr. Powell, was then assigned a set of themes to write up based on notes from the transcripts. The facilitators met a final time and reviewed each others write-ups and consensus was reached on this draft report.

III. Issues in Consumer-Run Programs

A. Ideologies and Themes of the Consumer/Survivor Movement

1. Ideologies

a. Major Tendencies in the Movement

Various ideologies that underlie the many segments of the consumer/ survivor movement were expressed at the meeting. These differences created core tensions that in turn stimulated further exchange of ideas. Several core tensions emerged. One such tensions was between consumers/survivors who prefer to work outside the mental health system and those who support selective use of components of that system, based on individual need, or "what feels useful" to someone. A second tension was between support for involuntary treatment in selected instances--such as grave danger to oneself or others--and adamant opposition to any involuntary commitment or treatment. Still another was the belief in the necessity for non-hierarchical or egalitarian structure within consumer-run initiatives versus the belief that such a structure was unrealistic or impossible.

These tensions were also expressed in critiques participants made of various movement tendencies. First, the "watering down" tendency in the movement was questioned. This tendency was defined as the reluctance to totally oppose the medical model and involuntary treatment.

A second critique targeted idealistic ideologies, such as anti-psychiatry, that are substituted for pragmatics, such as working to help consumers/survivors move out of the mental health system. Still other participants pointed out the importance of developing alternatives to involuntary treatment and commitment.

A related tension was that between "self-helpers" and "service providers". Some participants emphasized the importance of working and running programs that respond to very basic needs of consumers/survivors, such as those for food, a place to sleep, a job, and relationships. On the other hand, others countered that many consumers/survivors have become so involved in service delivery that they themselves use the objectifying jargon of

service providers and mental health professionals.

These points of disagreement incorporated another major tension: that between seasoned activists who have been involved in self-help and/or the consumer/survivor movement for many years, on the one hand, and those with more recent involvement, on the other. The newer members sometimes believe that the older ones attempt to impose their ideology, a "movement mentality", on them. They feel that the long-term members tend to be more clearly anti-psychiatric, emphasizing the social control aspect of the mental health system, as well as the importance of being politicized. The earlier generation also insists on bringing an historical understanding of the movement to their work. Within the consumer/survivor movement, according to some participants, tenure, or length of time in the movement, even becomes an issue of legitimacy. More seasoned members at the meeting expressed the view that, without having gone through the process of becoming politicized, someone cannot truly represent other consumers/survivors.

By contrast, still other participants suggested that different ways of becoming politicized exist. They asked whether some consumers/survivors have the right to try to shape the political understanding of others. Any ideology or vision driving the movement, it was felt, must incorporate a diversity of opinions and views, because the thousands of consumers/survivors in the United States themselves make up a very diverse group. The self-help movement needs to find a way to communicate with representatives of the mental health system with some unity, in spite of these differences.

b. Legitimacy Among Consumers/Survivors

Several questions arose as to what constitutes "consumer-driven" or "consumer-run" social movements or programs. In some states mental health agencies continue to define "consumers", in practice as families of persons diagnosed mentally ill. Family organizations are therefore considered to be "consumer groups." Family members receive funding to attend "consumer" conferences, and in some places they even receive funding for "consumer" programs. Because family members may express views and concerns contrary

to those of actual consumer/survivors--for example, support for psychiatric hospitalization and involuntary medication--it is important for consumers/survivors to maintain their own separate interest groups. In some situations, consumers/survivors have actually been accused by family members of not representing all of the "mentally ill". This need to separate "primary" consumers from family members is becoming more crucial as more money becomes available across the United States for "consumer" programs. Without defining who qualifies as a "consumer", such money may be used to run programs that work against consumers/survivors' interests.

Overall, most participants thought it important to begin to define what is meant by "consumer-driven". Some suggested that this term is defined by the extent to which decisions in a program or organization are made by consumers/survivors only. Other indices of the degree to which a program is "consumer-run" include who controls the funds and who does the hiring and firing. Still other criteria might be who has access to a "consumer-run" program and where it is located (e.g., a free-standing building versus part of a mental health facility). Finally, some participants tied this question of legitimacy to that of old and new members. Concern was expressed about who would receive state and federal mental health money earmarked for "consumers." Some participants had reservations about such funds going to individuals who, have experienced psychiatric hospitalization, have no experience developing and working with consumer/survivor groups. (Some of the reasons are explained in the section on Cooptation).

c. The Need for a Mission or Ideology

Despite the differences in ideology expressed at the meeting, several participants said that it was important to develop a mission and a set of basic principles that all members of the consumer/survivor movement could support. While agreement as to what these principles might be was not reached at the meeting, several criteria were suggested. These include: (1) consumer/survivor programs and activities must be truly consumer-driven, that is they must lead to consumers/survivors assuming control over their own lives;

(2) consumers/survivors' must define their own priorities themselves, rather than allowing the mental health system to define them; (3) consumer/survivor programs must be adequately funded.

Other principles that were suggested included a focus on power and politics, instead of treatment and care; and an emphasis on advocacy as the major component of the c/s movement. One participant suggested that the test of a c/s program might be its willingness to risk its funding for its principles. Such situations arise, for example, when a state-funded advocacy organization becomes a plaintiff in a "patients' rights" lawsuit against the very same state department of mental health.

d. The Importance of Language

The language used to describe experiences and concepts common to consumers/survivors has an effect on the actions and perceptions of others. Some participants pointed out that terminology such as "recovery" and "remission" imply a whole set of standards and outcomes that may run counter to those of consumers/survivors themselves. For example, "recovery" implies a certain concept of illness, if not a medical model. Other participants, however, stated that concepts such as "recovery" have broader meanings, such as "becoming part of society and feeling whole again".

2. Spirituality in the Consumer/Survivor Movement

There was quite a bit of interest in the topic of spirituality, but it was not felt that this was the focus of the meeting. The topic was brought up several times, without adequate follow-up.

A brief discussion took place regarding the issue of researching spirituality. Some felt that this issue was not researchable, while others felt that it could be. For example, research on meditation has so far not paid adequate attention to the vast number of meditation methods available. Different methods have different results and the scientific community is very unsophisticated about this area of interest.

There was also a discussion on the "self" and the "higher self". Some felt that the "self" was a Western ethnocentric concept given too much attention. Others suggested that this concept was used by psychology in a very limiting way. It was felt that the concept, as used, is a "regional sort of mentalist approach to self...an individual self." Some participants felt that the concept of a "higher self" was needed as a reference. Obviously, many people had much more to say, but the topics set out by the group did not include spirituality and much more time than available at the meeting was needed to do it justice.

3. Solidarity in the Consumer/Survivor Movement

Throughout the meeting, participants brought up the necessity of maintaining the sense of commonality they share with other consumers, as they all struggle against the mental health system. The sense of solidarity with the pain other persons feel seemed to run like a thread through much of what consumers/survivors described as their practice with one another. What emerged as central to c/s-run initiatives was, in the words of one participant, "just being with other people with the same problems [as you] and discussing their problems". Alternate c/s practices are based on this type of empathy.

Another form of solidarity mentioned is cultivated by networks of persons who understand what someone experiences as well as how he or she handles that experience. Several first-person accounts were given of how network members stepped in when someone was undergoing distressing experiences. The understanding of network members, and their suggestions for how to handle the experience often prevented hospitalization.

Still another type of solidarity mentioned concerns the acknowledgement and validation of perceptions that may not be shared by society at large. One example concerned feeling isolated. Agreeing that a sense of isolation comes from living in a society that is unsupportive and individualistic, rather than from an illness, creates a sense of solidarity with the isolated person.

The sense of solidarity also seemed to characterize definitions participants gave of

the self-help movement. One participant explained:

> "the movement is not an agency where people come in , get treated, and go out. It is more of a family. You are always a part of the family, even if you [move] elsewhere..."

B. Consumer/Survivor-Run Initiatives

1. Programmatic Issues/Drop-In Centers

a. Positive Functions of drop-in centers

A great deal of attention was given during the meeting to the positive and unique features common to c/s-run programs, in particular drop-in centers. Although discussion revolved around what might be essential elements of such programs, no agreement was reached on a "laundry-list" of minimal criteria. In fact the group agreed that this task should be tabled for a future meeting in which only consumers/survivors would be present. Other attendees pointed to the problem with publicizing such a set of criteria, even if the participants could come to an agreement about them. Given that heterogeneity and the breadth of alternative approaches may indeed be a hallmark of c/s-run efforts, a set of uniform criteria would contradict this.

i. Salient features

Several aspects and functions of c/s-run programs were mentioned by various members of the group. There was no rank order among them.

Consumer/survivor-run programs were seen as existing outside the mental health system, possibly as a (more effective) addition to other forms of intervention ("treatment"). In such programs support is provided simply by "being with other people" and they offer opportunities to "discuss problems with people who have similar problems". In so doing they constitute an environment for "healing" or "recovery" (the latter term was favored by some participants, but rejected by others). The elements that were deemed to make this

healing process possible included "not being judged" and being able to choose among the strategies that the program uses. Interestingly, c/s-run programs were also seen as "replacing the family", presumably by offering a supportive, family-like atmosphere.

Some saw c/s-run programs as fostering a positive process "to get accepted into the community".

ii. Motivation to attend

Many participants pointed out that c/s-run programs appear to provide environments that inherently motivate people to attend. In fact, many of these persons have not felt motivated to attend traditional programs offered by the mental health system. This attractiveness extends even to people who have resisted all types of mental health interventions. Simply asking the question, "Why do people get up in the morning and come to something that offers them nothing but people" might provide an answer as to the attractiveness of these programs. Reasons are often quite personal and differ from person to person.

iii. Individual benefits

For the individual participant, programs were seen as providing a range of functions. On the one hand, programs "protect" from noxious influences, "buffer" against stressful environments and experiences, and help "defend" the person against hostile forces (in society and the mental health system). On the other hand they can "sustain" people in the community and "help them live in spite of [serious problems]". Some thought that consumer-run programs could go much further than that by "building a new person -- something better than before".

iv. Membership participation

A key element of programmatic features was the ability of program participants to determine the nature and direction of the program. This is exemplified by the following

statement: "in a professionally run program, if the people aren't doing what the program says they're supposed to be doing, the people have to change. In our program, the program changes." What this implies here is a participatory rather than a purely hierarchical process.

The degree of participation varies from program to program

Some programs do not separate the "staff" from the program participants. Some even reject the idea of having a Board of Directors separate from the membership. In other words, the organization functions completely on the basis of a participatory democratic process.

According to one participant, a formula that might best encapsulate the most salient elements of consumer-run programs is the "combination of control (over the program), self-help and mutual support". This triad allows maximum autonomy, while being broad enough to encompass a host of distinct approaches.

b. Problematic areas in program functioning: some questions

Many issues different groups were struggling with were raised in the course of the meeting. Since no ready made solutions appear to exist at this time for many of these issues, we present them here as problems to be addressed. Opinions about solutions varied widely; much further discussion and practical experience will be necessary to arrive at more definitive answers. In fact, the point was made that participants at the meeting are continuously grappling with difficult issues precisely because "there is no book to look things up on page 43."

i. Should consumer-survivor run programs be in a separate category ?

The question, whether consumer-run programs should be considered as a separate category within the panoply of mental health programs, concerned many participants. The

answer to this question has primarily fiscal implications (i.e. whether there should be a separate funding stream - see below). But it also impinges upon the issue of performance standards used to evaluate the activities and effectiveness of such programs.

ii. How important is documentation ?

Documentation of program efforts was another hotly debated area, with many unanswered questions. Most agreed that "paperwork" was a suitable "means of accountability", but little agreement was reached on "what to document and what not." Much of the controversy around this question boiled down to who defines the method and extent of records kept (for example, which forms are used, what kind of information goes into them).

iii. Management issues

Some of the thorniest problems concerned the area of program management. One example was the question how a good balance between level of personal responsibility and decision-making power is achieved. Board members who never participate in program activities, but who make decisions for constituents, were brought up as a problem by some participants. Others thought that "the most effective boards are the ones that have least to do with day to day operations." As was mentioned above, some programs in fact function entirely without boards and all decisions are made by the membership.

A second management concern raised was that c/s-run programs may be "reinventing the wheel" and thereby "recreating the mental health system". A variety of strategies were suggested to prevent this, primarily "maintaining a bottoms-up perspective" wherein "everything stays very close to the pain and the people". Participants seemed to agree that top-down organizing is disadvantageous. It was compared to a tenants' organization set up by a landlord. (This is discussed further below under Cooptation).

Another management problem lies in external requirements for program organization and structure. As one participant explained, "we create bureaucratic layers that we don't really need because we're scared; we think that somebody else is going to come in and say 'you're not doing it right'." Involving the membership in all program aspects including funding was suggested as a remedy against this tension. However, some questioned whether this "base democracy" approach was applicable to all situations at all times They advocated instead for a flexible model of management, which can shift from a democratic to a hierarchical approach whenever necessary for optimal operations.

iv. Should programs be placed inside or outside the system ?

While all agreed that it was important to achieve credibility and visibility, no one method of doing so was favored over others. Some thought programs should "prove their worth to local decision makers" while others favored open competition with local mental health programs. One participant put the mission of his program quite succinctly: "I want protection for the consumers from these vultures [the local mental health providers]". This led to a debate about where c/s-run programs should be positioned. Should they establish themselves and remain outside the mental health system, thereby constituting true alternatives ? Or should they should become part of the "mental health continuum [of services] ?" Both perspectives found support among the participants. Some thought that programs should be both, which may be difficult to accomplish (see below under "Cooptation"). In either case, c/s-run programs were seen as "the new kids on the block in the mental health system", a role which obviously has effects on program practice.

v. Can coercive elements be completely avoided ?

The dangers of "becoming a controlling agent" were pointed out quite clearly and repeatedly. This could occur for example because a c/s-run program became a payee for

a client. Or, program staff might see themselves forced to use involuntary committment procedures for clients who they see as dangerous, thus "working hand in hand with the mental health system". The importance of "distinguishing between acceptable and not-acceptable program components" was emphasized in the context of this discussion. Considerable debate focused on the element of control in the practice of consumer-run programs. Some thought that exerting any kind of control over constituents was completely antithetical to consumer-run programs. Others felt that "not helping [certain people in certain situations] is just as bad as control."

This issue was particularly relevant to the handling of personal crises and other emergencies. "Encroaching professionalism" was diagnosed as a seeping problem in programs that provide direct services. For example, some consumers/survivors working in these programs accept that one must have the "necessary detachment when talking someone through a suicidal crisis." This is antithetical to practices based on solidarity and empathy (discussed above).

vi. Heterogeneity of programs

As mentioned earlier, heterogeneity of programs was emphasized over specific essential program elements. Some felt that it may be unwise to restrict programs to self-help approaches and thus limit the use of other interventions. Even the overall program mission was debated. For example, as discussed elsewhere, some participants felt that "recovery implies a whole set of standards that may not be the standards of the consumer-run organization." It was suggested that c/s groups just starting out review different models of c/s-run initiatives. "Franchising" was not encouraged because every situation is unique. What works in one context may not work in another. Nevertheless, participants underscored the need to expand the knowledge base about different models.

c. Criteria for consumer/survivor-run programs

While no consensus was reached about a universal definition of a "consumer-run program" (see also earlier under "Ideology"), participants did discuss a set of minimal criteria, again without coming to full agreement. One purpose of such a set of minimal criteria could be to "fence out things that masquerade as self-help, without putting a straightjacket on what a program has to be."

All agreed that programs had to be fully "client-run" as well as "client-developed" in order to qualify. It was felt that many programs did not meet the second criterion and that these were qualitatively different from ones that were truly client-developed.

The following questions were introduced as a kind of litmus test for c/s-run programs:
(1) Who has control over the funding ? (2) Was the program, developed by consumers/survivors ? (3) Do program participants define what they want? (4) Does it contain elements of self-help ? (5) Who controls the hiring and firing ?

2. Funding issues

While not receiving a great deal of attention, the area of funding and fiscal management nevertheless appeared particularly troublesome to the meeting participants. Major questions were raised, requiring further consideration.

a. Should consumer/survivor-run programs be funded separately?

It became apparent that many programs are funded under "a different category than what the program actually does". In fact, the funding mechanisms do not recognize the nature of these services. This led to a discussion of the pros and cons of a separate funding stream for c/s-run programs. This could take the form of separate and completely non-

clinical cost centers to be established by state mental health agencies. It also had a quantitative dimension: "if they were funding 10 programs they would have a category, which would make things easier", postulating that once a separate category were established, more programs were likely to receive steady funding. Some went further, suggesting that funding should be designated outside of mental health funding, i.e. as legislative set-asides. One participant pointed out that such set-asides are quite vulnerable to budget cuts, while there may be a certain leeway in protecting program dollars from within the mental health system.

One state (Michigan) has established "consumer line items", an approach that effectively earmarks funds for consumer run programs. The value of obtaining initial funding under the umbrella of a mental health agency was debated. Another valuable, but contrasting strategy favored bypassing the mental health system by seeking "community development" funding.

Vocational rehabilitation and social security disability funds were also mentioned as examples of non-mental health sources that people felt more comfortable about tapping. Participants pointed out that in all cases, "consumer run organizations are just as legitimate a primary source of funding as psychiatrist-run organizations."

b. Does money create problems ?

Some participants were concerned that "money can hurt", particularly by "giving too much money too soon to the wrong group [i.e a group that was not ready to administer large amounts of money]." On the other hand, funds given to c/s-run programs was seen as "less hurtful than other money that NIMH is giving out [i.e. money supporting coercive interventions]." An inverse relationship was observed between the "radical" nature of groups and the amounts of funding they received. In other words, the more freedom and organization has in the work it carries out, the less money seems available for it. Some participants felt that "handpicked consumers get [more] funding." However, it was also

noted that "newcomers get bashed by the grant-writing process", that is, they may not receive funding because they do not yet know the rules of the grant-writing "game".

Quantification and reimbursement of services was brought up as another problem. Any reimbursement system that uses billable units of services was considered difficult to apply to c/s-run programs. Still another issue concerned the extent of changes in goals and objectives organizations are willing to make in order to obtain funds. It was generally felt that organizations could only go so far to accommodate the demands of a particular funding source.

c. Conclusions

Irrespective of all the pitfalls of funding, everyone agreed that consumer-run programs are in fact "competing for a pittance."
In other words, a minuscule proportion of state and federal mental health funding is actually being allocated to these initiatives. Clearly, the participants stated that "all kinds of programs should have adequate resources to do what they do. We want a lot of resources and money to do all the different things we can think of doing."

3. Impact of Consumer-Run Initiatives

While this issue was not explicitly addressed at the meeting, either in research of other objective terms, the general sense was that c/s-operated initiatives have introduced a positive tension into the mental health system. The impact on the consumer/survivors they attract seems difficult to discount, given the broad confirmation that thousands of consumers/survivors in most states choose and keep attending these programs on their own free will. Whether or not the mental health system will actually reorient itself based on the experiences of self-help programs remains to be seen.

D. Organizing the Consumer Movement

1. Organizing Strategies for Consumers/Survivors

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When looked at within the broader framework of the whole of American society, self-help is a part of "the need for new structures in the community." As one participant put it, "there are no block organizations, no community, no cultural organizations, no citizen committees, all of these things are dead ... Now, people are talking about them again." Self-help and the consumer/survivor movement may be reversing this trend. But the question still remains: How to make it happen ?

Participants asked if state offices of mental health are able to make this possible for people diagnosed with a mental or emotional problem. Some felt we need to begin to think about those kinds of structures. However, doubt was expressed, whether the mental health system can support those ideas.

What is the process to make these kinds of things happen among consumer/survivors ? All agreed that consumers/survivors must first be "very clear about the initial vision and very strong in talking about it." If funding from a mental health system source is to be involved, then the question arises "...how do we attain...our purpose and our service, our philosophy without jeopardizing the funding source?" Is it possible to hold a self-help vision and be funded by "the system"? Conversely, is an impact on the system possible?

Another problem involves convincing others that the consumer/survivor movement is viable. One way is to achieve this is to document what is being done. Such documentation serves a couple of purposes, as one participants explained:

> "...we'll document reimbursement for the miles and all that other good stuff. Because to me, the needs of the people have to be documented and disseminated, not just for the purpose of the funding source but the person [to] be educated. That's the idea of consumerism: not only to help your peers, but to educate society [as to] what they really need by the peers themselves telling them, ..., the money should go down so the consumers themselves will be developing their own program and their own agenda."

In organizing decisions should be "made by the community as a whole, the state legislators, the local community, our organization..." After a common vision has been created, consumers/survivors have to establish credibility. Participants gave examples of how c/s groups start with support groups and with helping each other." After that

> "they will be in the courts, and they will be in the Department of Social Services, and... when you start interacting with the judges, the Department of Mental Health, legislators, testifying, they know you're doing a great job, they know that you're helping their clients..."

Visibility also means networking. This can mean "visibility amongst your community, sheriffs and people there who knew you as individuals." Visibility does not simply happen within NIMH or at the state capitol, rather consumer/survivors "created a network of people who ... saw how important you were from different perspectives." Funding is the next step.

> "And then at some point you become visible to these people and they want you to keep doing what you're doing. And you ask for money. Or they ask you to do something for money."

Becoming established locally, it was felt, is very important to viability if money originally comes from the state or the national level. The NIMH representative at the meeting explained:

> "When groups come to us for funding, and we fund them, ... sooner or later [they must] be picked up locally. The localities don't want to pick [them] up because it is seen as [the responsibility of the state], they don't have any investment in it. The group may have proven to [NIMH] that they're wonderful, but [they] have not proven it to the local decision makers..."

Developing local visibility also creates problems, which several participants pointed to. For example, "liability, stigma, the whole gamut of things that get in the way...", and accountability may become paramount.

Technical assistance may be needed at this point. Several participants suggested that technical assistance organizations should exist. For example a c/s group in one city

might be able to help those in another city with legal problems, understanding a letter from the IRS, setting up an accountability mechanism, and so on. Some felt that such technical assistance should be provided by a public, non-mental health agency.

Accountability and technical assistance, however, can lead to cooptation.

> "...It seems to me that technical assistance of a business management type is totally different than technical assistance [provided by] a mental health professional [who] comes in and has expectations for how and what kind of service you would be providing to meet professional standards."

This was brought up as an example of "top down organizing" which will simply recreate the mental health system. Some states prefer this form of organization and tie drop-in centers to mental health clinics or give money to parents' groups to organize consumer/survivors. Office of mental health money can be limiting: "...the things that we're getting funded for are things the system has allowed us to do..."

Several participants warned against "organizing from a bureaucratic perspective", when mental health administrators come along and say "we'd like to start a consumer-operated program and ... here are some nice ideas that you might choose from." To start a new group it is important to avoid going from the top down. Organizing should involve facilitating that people get to know each other rather than imposing "nice" ideas on them.

One strategy of networking in the community and getting technical assistance at the same time is to create an Associates program. Representing one of the most successful organizing efforts in the country, a participant explained: " ...the Associates Program are people who believe in who you are and what you do ... and obviously can't be members because they're not consumers, or are ... closet consumers. These Associates are people who want to be part of you and can give you help." Examples of such assistance might be fund-raising, accounting, lobbying, legal services, and so forth.

2. Cooptation of the Consumer/Survivor Movement

By definition, cooptation is the act of being taken absorbed or taken over by something or someone else. The consumer/survivor movement within the mental health field largely works through and is funded by the national, state and local governmental mental health systems. Thus there is always a great danger that this movement will be defined or redefined by the very system that it is out to change.

Participants mentioned many ways that the mental health system, subtly or openly, attempts to impose its values on initiatives that arise from local, grassroots creativity. First, since most self-help funding is for "research", the research guidelines, terminology, and so forth, play a big role in defining what is self-help and what is not. Also, the research is most often conducted by professional researchers rather than being in the hands of the c/s movement. Second, accountability guidelines for funding are generally externally imposed by the mental health system. Consumers/survivors at times collude with their own cooptation by espousing a mind-set that forbids to "bite the hand that feeds them" or to "challenge your funding source." Third, because of the success and popularity of local c/s self-help initiatives, the mental health system frequently attempts to mandate their existence or organize them from the top down. When technical assistance is provided by professionals who are not consumers/survivors, a different set of values is brought to the task. The more all of these activities occur, the more there is the danger that c/s initiatives will begin to embody the values, qualities, language, jargon, and so forth, of the mental health system they are challenging.

Probably the most painful form of cooptation mentioned occurs when local initiatives become so strapped with the unnecessary complexities and obstacles of the funding bureaucracy and its guidelines that consumer/survivors become overwhelmed. At this point the mental health bureaucracy uses this crisis to justify "professionals" stepping in and taking over the management of the initiative. Oftentimes, this is done with a "we knew you would fail" attitude.

Participants suggested some ideas from their experiences about how to prevent cooptation. Consumers/survivors need to know how their vision of healing is different from that of the mental health system. It is important to be clear about priorities, allegiances and the core issues the initiative is trying to resolve and that these issues are those of the constituents and not the professionals or issues that the professionals think consumers/survivors want. Technical assistance needs to come from consumers/survivors whenever possible and it needs to be given on the receivers terms. Those running initiatives should be able to negotiate with the funders, researchers, and other "outsiders" on guidelines, definitions, personnel procedures, program standards, and so forth. They must be accountable to quality criteria generated from within their own initiative. C/s-run initiatives need to be recognized for what they are -- consumer/survivor-run initiatives, and not partial care or psychosocial rehabilitation -- in order to have separate program categories and separate cost centers. It is especially important to be clear about who is finally in control of finances, hiring, firing and other "administrative decisions." Decision making power needs to be kept as close to the people who are being served as possible.

3. Insider/outsider Roles for Consumers/Survivors Working as Mental Health Professionals

a. Insider/Outsider Role Strain

Consumers/survivors have succeeded in being hired and/or receiving funding from mental health systems. This has created a new series of problems, which participants at the meeting collectively called "insider/outsider" problems. The problem of cooptation is ever present. As one person put it, "I've seen a lot of advocates, consumer advocates, survivor advocates who try to go out and fix the system, only to become immersed in it." Some people deal with this tension by hiding their past experiences. However, many are hired

and/or funded at least partially because of their past as consumer/survivors. For them the insider/outsider problems become paramount.

Many consumer/survivors working in the mental health system feel the strain "of trying to be of help to somebody in a new way." Not only is there conflict between funding demands and self-help process. "Conflicts...developed", explained one advocate, "because we have different visions of healing from our service provider peers...We are not fully trusted by self-helpers because we're also "them", professionals..."

Consumer/survivors on the inside are relating to consumer/survivors on the outside. How are people with diagnoses working "on the inside" perceived by people with diagnoses "on the outside". Is the insider a sell-out or a liaison? Many outsiders undoubtedly see the insider as a sell-out. Sometimes the motivation is jealousy of the insider, sometimes not. "Well you're a professional" or "you're in the system and I can't trust you..." One person pointed at a parallel between this dynamic and the "Uncle Tom syndrome" in the African-American movement. She described it as follows: "An Uncle Tom in the black community is someone who sells out the black community to win points with the white community." However, as she also pointed out, the Uncle Tom role is not so simple. Historically, an Uncle Tom is also "someone who runs back and forth and communicates what's going on in both camps... The whole point ... was to act as a liaison between both camps." This was related to another view participants expressed concerning the insider/outsider role. It is a complex role. "There has to be a shared mission or goals that the inside party and the outside party [can] choreograph together or develop and implement together."

Those who spoke from the perspective of insiders felt that they need the outsiders to succeed in changing the system. As one put it:

> "the most important aspect of my job ... is how to get the consumer movement to work with me. They're outside. I'm inside... I'm looking for a technical way of how I can arrange for them to support me. Because I'm in there, wearing myself out. Fighting every day... its this constant bureaucracy pounding..."

Contact of those working in the system with grassroot movement activists is a way of renewing oneself from the strains and pressures imparted by the bureaucracy. Yet these

contacts are often filled with conflicts, exacerbated by what insiders feel is an unrealistic expectation. That is because of their insider position outsiders expect them to change the mental health system.

Consumer/survivors must also maintain relations with professionals and deal with the perceptions these professionals have of their role. On the one hand, mental health professionals avoid dealing with the "sickest", yet they often qualify the presence of consumer/survivors on the inside by saying: "They're not really sick" or "they were mis-diagnosed". This puts consumer/survivors in the unenviable position of having to prove that they are really disabled. "We find ourselves ironically insisting that we are really sick."

The mental health system also pushes toward professionalization of consumers/survivors by demanding degrees for people working in self-help. Among examples mentioned at the meeting was that a "director of a drop-in center [must] have a B.S.W. or a B.A., two years of experience plus twelve social science credits." Experience still does not seem to count.

Besides these strains their is the issue of hierarchies within bureaucratic systems and the "rough" internal politics that are typical for such agencies. "... peoples' participation [on the] inside [involves] a whole hierarchical system and if you don't learn... you'll be crushed." "You might say bureaucracies are very paranoid places to be in. Really terrible."

Consumers/survivors "have to function in two worlds." "...One paradox that is very painful is the one that either says consumer professional or professional consumer. You know that the roles itself ... cause an inner conflict." This tension is not always perceived as negative. "...I think tension is a very creative thing... I don't think tension is something to be escaped from into support." The question remains however, "When does tension feel productive...?" "...how do you facilitate the tension when it is not...[productive]?"

Part of the tension was perceived by participants as necessary to the role of insider/outsider:

> "...if I lose that uncomfortableness, if I lose being an outsider while I'm in the system, I think I've really lost the whole ball game." "... the mental health professionals that I associate with very often tell me that they're uncomfortable with

> me because they don't know exactly where I'm coming from, who I am, are you an advocate, [what are you]? ... and I take that as [a] sign that I'm doing o.k."

A number of ways were discussed for dealing with this tension. Tension must first be recognized for what it is. "I locate exactly in my body where I feel the stress... just to recognize your tension..." "...when I locate it in my body and really feel it, I find out it's not so frightening." A general problem mentioned was "...how to function but not overextend...[yourself]." Participants espoused various methods of dealing with burnout. Many of them focused on being a part of a movement, something larger than the isolated self. "I can raise my focus and my vision and recall the history and my own in the movement, ... that gives me a sense of being part of something that's much larger." According to one person, a primary ways to avoid burnout is "working together with someone." "Being a part of the whole... of belonging, and you're not out there alone..." A concrete way of collaborating is "to share demands" "... always work[ing] with other people... who [can] replace me..." "I am part of a peer-support group and ... when we get a request we [always] ask around among ourselves [which] two of us ... would like to go... and that's vital."

This sharing was seen as part of the leadership role. "...It is the leader's role to [support] other people ... and move them into position[s of responsibility]." Another way of coping was saying no to demands.

> "... if I didn't show up at a very important meeting, the world wasn't going to collapse." "...You change the nature of the expectations [and] you change the relationship. One of the hardest things I've ever had to do in my life in the movement was say no." "About a month ago, I was really stressed out and burned out, I took a weeks vacation and no one knew it."

Many insiders screen phonecalls. Various ways were used to "keep control over what comes in..." Many other ways of dealing with stress were mentioned briefly such as physical exercise, meditation, sex, T.V. and so on. All in all the most favored way of coping with stress was being part of the movement, a larger whole.

E. Class and Ethnicity in the Consumer/Survivor Movement

Several participants pointed out the lack of attention that has been paid within the movement to social class and ethnic differences among consumers/survivors. These differences have implications for organizing self-help, developing leadership, and implementing programs.

Some participants pointed out that middle-class consumers/survivors tend to be more concerned with issues of civil rights, self-esteem and stigma. Poorer consumers/survivors, on the other hand, are more interested in attaining housing and entitlements. Because of this, poorer consumers often "buy into the system", without seeing the implications. They may be less ideological than their middle-class peers, but they are more pragmatic. They may also resist very little as they have more to lose. Paradoxically, however, consumers/survivors may reap advantages over other poor, because the label of "mental illness" types them as being more deserving of entitlements and other privileges than are other poor.

It was also noted that certain subgroups, such as Hispanic consumers/survivors, are impeded by language barriers and discrimination. Some self-help groups run by minority representatives have been told they could not receive funding because they did not know how to run a program.

At the same time, both c/s groups and professional and governmental organizations have not always been sensitive to the needs of poorer consumers/survivors. For example, resources are not always provided so that members can attend meetings. When they are, they may be minimal, as organizers do not realize the difficulties someone may have in paying carfare or meals even at fast food places. Also, poor consumers/survivors cannot afford to put out money up front to attend conferences, and await later reimbursement.

Class and ethnicity create "insider-outsider" roles within the consumer/survivor movement. Some participants felt that the question of minorities in the movement is

almost as serious as it is in the mental health system. Several participants insisted that lack of attention to class and ethnicity issues has created gaps that must be bridged in the self-help movement. Furthermore, organizers need to be concerned with pragmatism in meeting very basic and pressing needs of consumers/survivors.

F. Employment Issues for Consumers

Many things are working against people who have been labelled mentally ill getting employment. Unlike in the field of substance abuse, credit for having had "the experience", of having lived with the stigma of mental illness or worked within the consumer/survivor movement is not given. This makes it difficult to meet the educational requirements for certain positions. There are many professionals within the mental health system, who feel they must wait on research results to prove the benefits of consumers/survivors in certain positions. The directors of c/s-run programs are not viewed with the same respect as directors of more mainstream agencies, and, therefore, are not compensated with commensurate salaries. This also goes along with the widespread attitude of "let's not pay the consumer too much."

All consumers/survivors struggle with the common barriers of stigma and confidentiality when they apply for work. As one person put it, neither employers nor the mental health system set standards as high as the ones used by survivors. "You are mentally ill, you better start at McDonalds" is the attitude that many people have towards persons labelled mentally ill.

The mental health system itself gives little incentive to leave current benefits. Most consumers/survivors are given just enough money to live on and experience tremendous pressure not to make it any further or try to improve themselves. The flexibility of working part-time would be a considerable benefit to persons desiring to transition from public subsidies to personal income; however such opportunities are far too rare to make a difference. In the midst of all these obstacles to finding employment, there are some things that seem to be working for persons labelled mentally ill. Participants pointed

out that more and more positions are opening up in c/s-run programs. Certain programs have structured themselves so that they are legally not able to hire non-consumers. There are more apprentice positions in c/s organizations for training and relieving the pressure of overworked regular staff. Some professionals are beginning to value the experience of having been a consumer.

Finally, one question raised during the meeting, but not discussed in detail was "Can a person not working in the mental health system stay related to the consumer-survivor movement ? Is the movement encouraging this ? This was seen as relevant, since some participants felt that working in self-help initiatives can be a transitory setting leading to meaningful jobs outside of mental health.

G. Professional view of C/S

1. Idealization

The main point brought out about professionals' viewing c/s-run programs was their unrealistic expectations. One participant stated that "professionals idealize the few things that are happening, as if it's a revolution." A reason given for this idealization was that "professionals think it's a big thing because they have no new things." This unrealistic assessment was expressed in one statement by a professional at the meeting: " The entire mental health system ought to be yours."

2. Pigeonholing

The professional view was also criticized for "setting things up for failure by using too stringent measurements." Proving themselves right, professionals "think that consumers

cannot be managers of programs, when their (the professionals') technical assistance process fails." Many agreed that technical assistance should be provided by consumers/survivors for each other. A selectivity and favoritism by professionals for certain kinds of programs (i.e. self-help groups) was also noted.

Interestingly it was felt that consumers/survivors who work inside the system were not immune to some of these attitudes ("encroaching professionalism").

H. Research Issues on Consumer Initiatives

1. Technical Problems with Existing Research on Consumer Programs

Participants stated that most researchers have yet to understand what alternative programs, consumer initiatives, or consumers' experiences actually are. Furthermore, existing documentation is inadequate or nonexistent. Several reasons were given for these shortcomings. First, appropriate research tools and methodologies have not yet been developed. When new or alternative techniques are studied, the methodology often is unsophisticated. For example, research on meditation has been limited to one form of meditation and whether or not it works. Yet grant proposals for studying new techniques are stymied by a scientific method that requires a review of the literature on the techniques themselves. The result is paradoxical: new interventions cannot be studied because nothing is known about them.

Secondly, the questions asked by such research are not always appropriate, and the interpretation of data is often incorrect. For example, research projects may not always identify important outcome variables. The toxic side-effects of supposedly therapeutic practices are not examined. Brief hospitalization is interpreted as a negative outcome, when it may be part of a process of getting better. Anger, criticism, and other responses to difficult or oppressive situations are often interpreted as symptoms of mental illness. "Self-

help" and " consumer" may be defined or operationalized in research according to the service provider's view, thus missing an important aspect of what is essential about consumer/survivor alternatives.

2. Political Problems with Existing Research on Consumer Initiatives

Several political problems were also identified. One concerns research that is carried out for purely political reasons, such as to justify funding. Consumers/survivors who receive such funding often find themselves in the double of bind of having to support the research, even if they do not ultimately believe in it. At the same time, having to carry out evaluation and research can conflict with a program or community organizing effort. Examples were provided of organizing meetings in which over half of the time was taken up in administering "academic-sounding" questionnaires that some consumers/survivors did not understand. This had the destructive effect of breaking the momentum of a self-help group that was evolving. In some cases, questionnaires imposed by and agency or research project have seemed so irrelevant or off target in relation to consumers/survivors' concerns that they had an alienating and disempowering effect.

Some participants also criticized the large amount of money that is allocated to research, as opposed to programs. One concern was with the formula for Research Demonstration Projects funded by NIMH's Community Support Programs. To meet the standards set by N.I.M.H., more than 40% percent of the grants almost necessarily go to research. The research enterprise channels large sums to universities.

Finally, research often conflicts with pragmatic concerns. Too much time is spent testing assumptions about what works, rather than actually trying out something new.

3. Positive Aspects of Research

Several positive aspects of current research on consumer/survivor self-help were

pointed out. These included research as a way of legitimating self-help and selling it to legislatures. Research findings can also be used as an educational tool. Administrators of c/s initiatives sometimes find research useful in learning what is actually going on in a program.

4. Suggestions Concerning Future Research

Several suggestions were made about alternatives to research as well as about ways of restructuring research on c/s-run initiatives. Participants voiced the opinion that more research should be "bottom-up" rather than "top-down". First, consensus should be arrived at as to defining certain concepts and positive outcomes. For example, agreement needs to be reached on the definition of "consumer", as well on what constitutes a positive outcome in self-help. Such definitions could be arrived at through collaboration between the researchers and the consumers/survivors whose programs are being studied.

Second, measures used should incorporate the consumers/survivors' viewpoints. Research designs should allow for understanding the diversity of experiences. Individual outcomes should be measured in relation to individual aspirations, rather than to some outside standard.

Third, consumers/survivors should be allowed to "vote with their feet". That is, the popularity of a program should be used as an indicator of its success.

Fourth, documentation is needed of the diverse modes of existence of c/s programs in different circumstances. Not only should the viability of these programs be understood, but the processes in the evolution of the programs explicated as well. Finally, some participants suggested that research standards already exist in the survey method. Others, however, felt that alternative ways of explaining program processes and initiatives should be developed. These might include qualitative methods.

IV. Recommendations and Conclusions

The organizers and facilitators of the meeting agreed that the report reflects to the extent possible what was discussed during the two days. As such, the report stands on its own. The reader can draw his or her conclusions from it.

During the course of the meeting , the participants considered the possibility of drawing up recommendations about c/s-run initiatives -- such as definitions of "consumer-run", funding priorities, etc. As the body of this report indicates, consensus was not reached to actually generate recommendations. Although the meeting represented a broad diversity within the consumer/survivor movement, some individuals felt they could not recommend guidelines that might then be used as standards to be imposed on all c/s-run programs that receive government funding. Participants also agreed that such recommendations could only be generated through a process which, at least in its first stage, involved solely consumers/survivors. This meeting, however, was attended by a few state administrators, as well as researchers and mental health professionals. Finally there was some concern about how such recommendations would be used. As a result, this issue was tabled for a future meeting.

V. APPENDIX

Names and addresses of all participants

Note on terminology: Participants at the meeting did not reach consensus about one term that could be used to refer to themselves. Some preferred the term "consumers", while others saw themselves as "survivors". The authors of this report decided to use both terms side by side in this report, unless when quoting verbatim. To avoid excessive repetition in the report the term is frequently abbreviated as "c/s", especially when used in conjunction with other terms, i.e. "c/s-run program." Such abbreviation should not be translated into the spoken language, it should simply facilitate the reading of this report.

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