



Consumers Hold the Keys: A Manual for Consumer-Run Drop-in Centers

For more information about this manual, contact:
Dr. Carol T. Mowbray
University of Michigan, School of Social Work
1080 S. University
Ann Arbor, MI 48109-1106

Table of Contents

Page

Why Fidelity? Why a Manual?	4
Assessing Consumer-Centered Services Research Project (ACCS)	5
Fidelity Criteria for Consumer-Run Drop-in Centers	6
Part 1—Values and Principles	7
Leadership	11
Social Support	13
Recovery	14
Group Empowerment	15
Respect	17
Sense of Community	18
Outreach to the Community	19
Part 2—Putting it all into Practice	20
Starting a New CDI	20
Structure and Leadership	22
Outreach to Newcomers at the Center	27
Outreach to the Community.	28
Activities, Services and Referrals	29
Funding	31
Internal and External Environment	33
Rules	34
Resources for more Information	36

Consumer-run drop-in centers (CDIs) provide critically important social support for people with significant psychiatric disabilities (consumers). A CDI is run *by consumers for consumers* as a place where consumers can relax, be themselves, feel accepted and safe, and find the support and encouragement they need to rebuild meaningful lives. Generally, a CDI has comfortable furniture, coffee and maybe even snacks or a meal. It includes people who've experienced discrimination, loss of dignity, and prejudice, in addition to the extreme challenges their illness presents. People find friends at drop-ins who help each other solve daily living problems, like finding housing or transportation, or getting and keeping a job. At drop-ins, people can practice getting along with others and regaining social and communication skills. CDIs provide a sense of belonging and family that consumers are often sorely missing. Many consumers are poor, isolated in society, not participating in community mental health programs, and at-risk for psychiatric hospitalization; they often find work-related activities too stressful, and some are homeless. These consumers can particularly benefit from a CDI—there's no “treatment,” everyone is a consumer (no professionals); they find friends who accept, support and encourage one another toward independence and growth. Consumers share information and experience at CDIs and learn from each other. They can also get information from the center about other services in the community to meet their needs. Consumers also have the opportunity to get involved in running their center, helping with everything from cleaning to bookkeeping to organizing camping trips. This involvement is another way for consumers to gain and practice skills. These accomplishments and services to the group help consumers to feel competent and raise self-esteem. CDIs offer consumers the opportunity to gain a greater sense of their power as a group—they can join together to claim their rights, dignity, and self-respect.

Why Fidelity? Why a Manual?

The main purpose of this manual is to share information gathered through research to help consumers plan and operate effective consumer-run drop-in centers. This manual will lay out the values, principles and operating guidelines for CDIs, from consumer experts nationwide, as well as from site visits to 31 CDIs in Michigan—all part of the Assessing Consumer-Centered Services Research Project (ACCS)¹. Having criteria for a successful CDI model established by consumer experts and substantiated by research can help to maintain the quality of CDIs.

Consumers can use this manual when opening new drop-ins, to start off on the right track, and to improve the quality of existing centers. It can also be very useful as a tool to monitor centers, to make sure they don't drift away from the model over time—to help insure that they continue to be faithful to their established mission. In order to initially develop fidelity criteria for consumer-run drop-in centers (the most important things a consumer-run drop-in should be and do), we reviewed published and unpublished literature produced by consumer-run organizations and advocacy groups on the activities, values, and goals of consumer drop-ins and surveyed 67 national consumerism experts. These experts were identified through an extensive search of consumer newsletters (e.g. *The Key*), professional journal articles, and book chapters. Experts included consumers, advocates, service providers, and researchers, as well as individuals involved in a multi-site study of consumer operated services, funded by the Center for Mental Health Services. Respondents were from 21 states, representing all regions of the country. The experts endorsed the importance of having criteria which cover *structure* (for example, CDIs

¹ This research was supported NIMH grant #R24-MH51363-06, to the University of Michigan's School of Social Work, Center for Research on Poverty, Risk and Mental Health.

should be operated and controlled by consumers) as well as *process* (for example, empowerment and social support) aspects of CDI operations.

A program manual like this one can play an important part in effectiveness research. Without evidence of the effectiveness of CDIs, they are unlikely to move beyond the very limited funding they now receive. This manual outlines the criteria for a model consumer-run drop-in center and can be used to train staff and then to evaluate how well the program fits the criteria for a consumer-run drop-in center. Once criteria for the model CDI have been established, evaluators can then study how effective model CDIs are at achieving the desired outcomes—for example, helping consumers to achieve greater independence in housing and jobs; improving social and communication skills; and reducing psychiatric hospitalizations. Manuals like this one help to further research that may demonstrate that CDIs are effective ways to help consumers and therefore enable CDIs to receive more funding to continue their mission.

Assessing Consumer-Centered Services Research Project (ACCS)

Researchers in the School of Social Work at the University of Michigan worked with a consumer-run organization, Justice in Mental Health Organization (JIMHO), on a federally-funded (NIMH) study of consumer-run drop-in centers (CDIs) in Michigan. Beginning in June 2001, a 3-person field research team started collecting data at 31 CDIs across the state of Michigan. Two-day site visits were completed at each center in just over one year. At each drop-in, interested consumers were given the opportunity to complete a questionnaire about their thoughts and opinions of the center and how their lives were going. Center staff who worked at least 20 hours per week were asked to complete a staff survey and we interviewed the director of each program. We also collected documents like the annual budget, staff job descriptions,

brochure, certificate of incorporation, bylaws, written policies, rules, calendar of activities, newsletter, and mission statement. Consumers were each paid \$5.00 for their participation in the survey, and each center was given \$100.00.

During two-day site visits to each center, each researcher made structured and unstructured observations informed by the list of fidelity criteria. We observed consumers interacting with one another as well as staff interacting with consumers; opportunities for decision-making, advocacy and social support; cleanliness and general repair of the facility; layout of rooms and furniture; bulletin boards; available activities; safety of the surrounding neighborhood; available transportation; and photo albums. We also had conversations directly with consumers about their center. We observed the interior physical space, including activities in each area of the facility and postings on the walls. When the centers had meetings or discussion groups during our visit, we observed these, paying particular attention to group processes and dynamics. The research team collected 878 consumer surveys, 31 director surveys, 30 staff surveys, 9 group observations, 99 quantitative observations of the physical site locations, and 99 qualitative site observations.

The following is the list of fidelity criteria that came from our consumer experts and our research at the 31 CDIs in Michigan. This manual is based on these criteria as the most important things a consumer-run drop-in center should be and do. The first part of this manual discusses the principles and values of a successful drop-in, the second part looks at the “nuts and bolts” of putting these principles and values into practice, and at the end you’ll find a list of resources you can contact for more information.

Fidelity Criteria for Consumer-Run Drop-in Centers

Consumer-operated—employees and Board members are consumers

Voluntary—attendance and participation not required or coerced, consumers come and go without permission

Consumer Determination of Policy, Operations, and Planning—consumers make these decisions

Availability—stable and predictable hours and location

Accessibility—transportation is accessible, affordable, dependable and safe

Exterior Physical Environment—pleasant, safe neighborhood, entrance wheelchair accessible

Interior Physical Environment—large enough, not too smoky, clean, comfortable furniture, wheelchair accessible interior

Social Environment—inclusive and respectful, no racist, sexist, anti-gay or demeaning speech or behavior

No Threat of Commitment—no mental health treatment at center; no clinical diagnosis, or other sanctions

Facilitating Referrals—information about where to get other needs met in the community

Member Retention—friendly atmosphere, orientation for newcomers

Outreach to Recruit New Members—reach new members & increase visibility in the community

Activities and Services Available—provides for some basic needs

Housing, Transportation, Education, and Job Assistance—provided by the CDI

Social Recreational Activities—opportunities for consumers to have fun

Group Empowerment—opportunities, e.g. groups, activities, conversations, posted information, conferences, to learn about social and political issues affecting consumers

Recovery Orientation, Personal Growth and Development—focus on strengths, skill-building, independence

Consumer Involvement—consumers involved in a wide variety of tasks to operate the center

Membership Participation—attendance

Consumer Choice/Decision Making—consumers choose how to spend their time at the center

Practice/Improve Social and Work-related Skills—opportunities to practice skills

Nonhierarchical Structure—everyone's equal at the CDI

Social Network Benefits and Social Support—friendship and support

Sense of Community—CDI creates a sense of family

Self Help and Reciprocity—sharing information, problem solving, role modeling

Part 1—Values and Principles

- *Consumers are in control of the drop-in*
- *Everyone is equal at the drop-in*
- *Consumers are free to make their own choices and decisions*
- *CDIs are democratic—everyone’s input is valued!*

The values and principles described in this section represent the core of an effective consumer-run drop-in center. These are the basics, the bottom line of what a CDI needs to be. The ways each of these values and principles are implemented, however, may vary depending on the needs and desires of consumers in particular communities, size of the CDI, the center’s resources, and other resources in the community. To begin, a central principle of consumer-run drop-in centers is *consumers in control*. Non-consumers do not operate these centers for the benefit of consumers; consumers themselves are in charge. For the most part, all employees² (staff) of the center should be consumers and no hierarchy should exist between consumers acting as staff and consumer-members. Rules apply equally to everyone. Equal access to resources and opportunities to participate should be openly shared with all members. A democratic culture, with wide participation in operations and decision-making at all levels, should be consistently demonstrated and encouraged.

Consumers should always be free to come and go from the center, and free to choose how to spend their time while there—attendance and participation are entirely voluntary. Often consumers, particularly those who live in group settings, have many aspects of their lives decided by others—when to wake up, when to go to bed, what to eat, and where they can go, etc.

² There may be exception for contractual services like legal or accounting, or positions that are difficult to fill.

If group homes or other outside agencies/individuals are requiring or coercing consumers to attend the CDI, the center needs to make it clear that making consumers attend or participate is entirely counter to the center's mission and will not be tolerated. By design, CDIs are places where consumers are in control of themselves. They can choose whether to attend the center, and while there, they choose their own level of participation and interaction with others. They may participate fully, or do nothing at all if they prefer. This is an empowering opportunity for those consumers who have previously had very little power to make choices for themselves.

Consumers should determine program operations, how decisions are made and what policies are in place. Centers need to have ways for consumers to express both dissatisfaction with aspects of their center, as well as new ideas, and feel that they are heard. For all of these to happen, centers need to have both democratic processes and a democratic culture. To make processes democratic, centers need to have open meetings and discussions to which all consumers are encouraged to attend and vote on decisions. All consumers at the center should be encouraged to give input regarding large and small decisions that involve both the short and long range. These include decisions about what goes on at the center; what is served for snacks or holiday dinners; what supplies will be purchased; whether (and how much) consumers will pay for food, activities, or used clothing at the center; determining the rules of the center; what the away-from-center activities will be and how often they will occur; and longer range decisions such as fundraising, grant proposals, whether to add/cut services or programs, changes to the hours/days of operation, and hiring/firing of staff. These decisions will usually be made by the Board of Directors, but it is most important that the Board be interested in gaining the input of consumers. Open meetings can be a good way to hear what consumers have to say—criticisms as well as applause, and ideas for the future. Often the best ideas come from brainstorming as a

group. Board members need to understand that the *best* Board members are those that listen well to the larger group of consumers and work hard to implement the desires of consumers as long as they are in line with the mission of the drop-in. If consumers, even a majority of consumers, want to see decisions implemented that go against important values of the drop-in (for example, wanting to exclude a particular consumer because she smells bad) the Board needs to uphold the values and mission of the CDI—keeping it open to all mental health consumers who abide by the rules and spirit of the drop-in. The more open the Board is about all the decisions they make, how money is spent, etc., the fewer complaints they’ll get from the larger group. The group that’s informed has less reason to be suspicious about decisions made “behind closed doors” and the larger membership will be more appreciative of the work the Board does on their behalf.

Democratic process should be usual and expected—something everyone can count on. In this way, the process of decision-making contributes to an atmosphere or culture at the center where consumers can see and believe that their opinions are valued. Consumers need to have the freedom and encouragement to initiate new activities at the center. Staff and/or a core of regular consumers should work to make the implementation of new ideas possible. This concretely demonstrates to consumers that their ideas are welcome, that others do take their ideas seriously at the center. Taking care to value *all* ideas that are put forward, and to encourage everyone to contribute their ideas, is key to supporting a democratic culture. If only the input of a few talkative, powerful or well-spoken people at the center is valued, many others may feel discouraged and less inclined to share their ideas. CDIs need to be places where all are welcome and all are valued.

Part of the democratic process and culture of the drop-in is evidenced by the wide array of opportunities all consumers have to take part in running the center. If one person does all the

work at the center, others may appreciate it, but they don't get the chance to feel that *they* are needed at the center. Being responsible for meaningful tasks helps people, in a concrete way, to feel important, needed and connected to their center. It is certainly important for consumers to tell one another how much they appreciate each other's contribution. It can be even *more* meaningful for people to demonstrate their value to themselves and to others by helping to run the center. Staff and other leaders need to pay particular attention to structuring the work of operating the center such that there are many meaningful tasks at various skill levels for consumers to do. Staff should not take care of the "important" or interesting work and leave the drudgery for others. CDIs provide invaluable opportunities that consumers don't find often enough—ways to make valuable contributions to their community. Consumers can be proud of the work they do at the center.

Leadership

- ***Leaders are fair and respectful—no tyrants at the drop-in!***
- ***Leaders encourage everyone to participate***
- ***Good leaders aren't born that way, they need training***

Perhaps the most important aspect of democratic process and culture is the nature of the leadership. Beyond the formal structure, good leaders pay attention to the ways they *act* that dramatically affect the culture of the drop-in and, consequently, how other consumers think about the center and even about themselves. To promote an atmosphere of equality, fairness, and general respect, leaders of the center, whether paid or not, should not be exempt from the rules—for example, they should not be allowed to smoke inside if others cannot. And they should not

have access to better resources than other consumers (no “staff only” bathrooms or better quality meals or snacks for some and not others). Effective leadership is shown by the ability to encourage others to participate, gain skills, effectively involve others in decision-making, and take on responsibility. Good leaders consistently demonstrate respect for *all* consumers who come to the center—they don’t show favoritism. The best leaders demonstrate their belief in the abilities of others, rather than seeking to have others see them as “in charge.”

It’s much more important to involve consumers in the work of the center than it is to have each task completed perfectly. When people learn something new, they rarely do it right the first time; it takes practice. Drop-ins ought to be places where consumers can get support and encouragement to try new things, take on new tasks, and get experience doing things they haven’t tried before. This experience is much more valuable to consumers than having every task completed perfectly. Most things that need doing at drop-ins aren’t so terribly important that beginners can’t try their hands at them. The real work of a CDI is providing opportunities for consumers to come together in an environment that helps people feel stronger, feel more competent, and strengthen their belief in themselves—this is the work that needs to be done well. The best leaders look for ways to involve others in as many ways as possible.

These leaders are also good role models; they work hard and are devoted to the center, and they take care of themselves too. They know their limits and boundaries; they don’t work for the center 24 hours per day 7 days per week. These leaders gently encourage others to share the load and receive appreciation from the group. At the same time that they encourage others to participate at the level they feel comfortable, they don’t expect that everyone will always want to be active—consumers at the center need to know they will be accepted even if they do very little to help run the center. There may be times when some will be under too much stress to take on

any more than getting through each day. People need to be able to come to the center and just sit, by themselves or with friends, when they need to. When there are many who are interested in and able to contribute to center operations, the center won't fall apart if a few people need to take a break from participating or even attending the center.

Leaders of CDIs can benefit greatly from training. Most consumers have not been involved in running an organization before and can't be expected to be experts merely because they are consumers. Often they have no experience in encouraging the democratic participation of a wide group of people—maybe they haven't received such encouragement themselves. In order for consumers to become adept at running an organization that can provide the self-enhancing atmosphere that makes a successful CDI they need training. Some specific training in the following areas may be useful: Board development, effective leadership, communication skills, group processes, how to involve members without pressuring, peer counseling, crisis prevention and intervention etc. Mental health agencies can often provide this kind of training, or help locate other sources in the community.

Social Support

- *Everyone needs a chance to have a friend and be a friend*
- *Consumers learn from each other at drop-ins*

We must use peer support and comfort one another. We are each other's friend. Sometimes we are best friends, even family to each other. We have enough enemies. We are avoided, stigmatized, and isolated from society. We need each other. We must be good to each other. That is the only way we shall overcome our disabilities and difficulties.
Chain of Hope Resource Guide, page 7

Consumers, like everyone else, need safe, relaxed places where they can be accepted just as they are, and find real friendship. We all need people to listen to our troubles and to trust us to listen to theirs. We need people to recognize our uniqueness and to champion our cause. We need encouragement to strive, and understanding when we make mistakes. We need people who genuinely like us and enjoy our company. And we need to belong, to believe we're an important part of the whole. These basic human needs can be very difficult for consumers to meet in the wider community given the stigma and damaged personal relationships that too often accompany serious mental illness. At CDIs, consumers can both find the support they need, and be supportive to others. Having friends and *being a friend* are key to feeling good about oneself. Supporting someone else, just by listening and being a friend, can help people feel better about themselves. To have people depend on *you* for friendship is self-affirming—being a “giver,” and not just a “taker.” This is something that even the kindest and most supportive therapist cannot offer—a chance to be needed in a reciprocal relationship.

Another way that friendships can be reciprocal is through sharing information and learning from one another. Often consumers have insight, experience and concrete information that can benefit others—for example, about medication, housing, education, jobs, getting along with family and care providers. The CDIs offers a place and a relaxed atmosphere conducive to sharing this information. Obtaining information from a peer, an equal, at a CDI may be more palatable *and* more helpful than receiving it from a professional. Unfortunately, in many traditional mental health programs, consumers are not in a position to give useful information to others—they are consistently in less powerful, less prestigious subordinate roles. Every consumer has had experiences that may be valuable to others. In this way, everyone at a CDI has a chance to help someone else.

Recovery

- *Drop-ins focus on people’s strengths, what they CAN do*

Recovery does not imply curing the mental illness, but learning to work within and beyond the limits of the disability so that individuals' personal rights of friendships, homes, families, satisfying jobs, access to education, and decent pay can become realities.

Center for Psychiatric Rehabilitation, Boston University, website

A good drop-in center provides not only acceptance, friendship, and supports, it also promotes recovery for people with serious mental illnesses. There is a focus on strengths and abilities rather than disabilities, disorders or dysfunction. A center can promote an atmosphere of problem-solving and moving forward toward renewed meaning and purpose in life. When a recovery orientation is present, hope is a pervasive theme—staff and consumers encourage one another toward independence in housing, education, and jobs. Seeing other consumers who have achieved greater independence is heartening and gives hope to those just beginning or struggling in their recovery. The Justice in Mental Health Organization (JIMHO) has this to say about the ways drop-ins assist consumers in their recovery,

Through consistent submission to “caretakers,” individuals suffering emotional and mental health problems are discouraged. Individuals are taught that they are not capable, that others know what is best for them and that they can’t trust their own thoughts and feelings. At the center, personal motivation and strength return. Individuals learn that they can be capable of taking care of themselves, their lives, and most importantly that they can think for themselves. Individuals learn to do for themselves, find hope in their future and encouragement in their struggle.

Group Empowerment

- *Consumers often run into similar roadblocks*
- *Consumers can make a difference when they work together*

CDIs provide an environment in which consumers can see themselves as members of a group, “people with mental illnesses,” who are similarly affected by social and political forces. When consumers come together and share their individual experiences, they see more and more that laws, bureaucracies and individuals discriminate against people with mental illnesses in similar ways. They see that the troubles they’ve had are often similar to troubles others with mental illnesses have had, irrespective of their specific illness, character or individual circumstances. Many difficulties are due to being part of a group that has been thrown to the edges of society and increasingly told to stay there. Leaders at CDIs can promote a sense among consumers at their centers that they can work to change this; they don’t have to accept the status quo. They can gain information about the variety of ways they are impacted by, for example, prescription drug laws, eligibility for entitlements, housing laws, etc. They can attend consumer conferences where they can share information and learn with other groups of consumers how to advocate for their rights and the rights of others. They can pool their efforts, joining together to participate in political struggles to gain more respect, fair treatment, and equal access to resources—by going to local, state, and national demonstrations, voter registration drives, anti-stigma activities, letter-writing campaigns, trips to visit government officials, etc., and continuing to reach out to inform and involve other consumers.

A sense of empowerment is a result of standing up for one's rights and beliefs. Consumers lose many of their rights in the chaos of the mental health system. . . . Empowerment is learning to take control of one's life. Empowerment is pride in ourselves and where we have been. Empowerment is doing for yourself and allowing others to do for themselves.

Justice in Mental Health Organization (JIMHO)

Respect

- ***Everyone's differences need to be respected: no matter their race, gender, sexual orientation, or mental illness***

Consumers often have much in common given their experiences with mental illnesses, mistreatment, and discrimination. They may also differ from one another in these experiences as well as many others. Leaders at the center need to promote tolerance of differences and acceptance of others. Individuals want to be accepted just as they are, and so too they need to reach out with respect and acceptance to others. Therefore, center leaders need to openly engage their members in informal discussions about race, gender, sexual orientation, etc., in order to establish norms for respectful behavior and inclusion. Formal meetings or debates are not usually a good way to talk about these issues—people get defensive, others get their feelings hurt, and meetings about sensitive topics can easily get out of control. Leaders of CDIs, however, may not know how to effectively have these informal conversations and could benefit from training—the local mental health agency, or other nonprofit organizations may have training resources available. Some consumers may have personal racist, sexist, anti-gay, or other intolerant beliefs. Individuals should not be made to feel that they need to change their deeply held beliefs in order

to be a part of the center. People can *believe* any way they wish, they just need to *behave* respectfully at the center. Everyone needs to understand that every person deserves respect and that the center is a place where respect and inclusion are taken seriously. Leaders need to speak up when anyone at the center is being intolerant or hateful and they need to invoke these norms when needed, standing up for “the kind of place this is.” This helps everyone, not just those experiencing discrimination, to genuinely trust that the center is a safe place where disrespect will not go unaddressed.

Sense of Community

- *A drop-in center can be like a family*
- *The group cares about each member*

A CDI can be a community that not only values each consumer as an individual, but also prioritizes maintaining a sense of community within the group—where consumers feel some similarity to others at the center and feel connected to the place and the people there. A sense of community is partly built upon the ways people act toward one another, and it’s larger than that—more of a feeling or atmosphere that permeates the center. A sense that this is a group that cares about each member and is happy to welcome newcomers. There aren’t so many “special” cliques that other people feel left out. When a sense of community is absent, a drop-in center feels more like a place that provides services—coffee, snacks, maybe a place to play pool—but it isn’t a place where people feel ownership, or like they’re really *part* of things at the center. It’s this sense of belonging and ownership—“This is *our* place”—that can be a uniquely valuable experience at a drop-in center.

Outreach to the Community

- *Reach out to tell new consumers about the drop-in*
- *Create a positive relationship with the community*

CDIs need to reach out to their neighborhood and community for at least two reasons. First, to meet the needs of consumers and to ensure the survival of the center, new consumers need to be invited to the center. The center needs to publicize itself so that consumers in the area find out about the drop-in and that they're welcome. A drop-in can't exist with the same few people forever. Attendance will dwindle as consumers move to other communities, change their daily activities, or take a break from center participation. To keep the community at the center alive, new consumers need to be encouraged to come and try it out. Second, CDIs need to develop a positive relationship with the larger community. Getting off to a positive start can help to reduce the anxiety that communities often have about groups of people with mental illnesses gathering in their area. As a CDI makes itself more and more visible in the community in positive ways, negative attitudes about people with mental illnesses may lessen.

Part 2—Putting it all into Practice

- *Each drop-in is a little different*
- *Yet they all have the same values and principles*

There isn't a rigid formula for putting into practice the values and principles for an effective consumer-run drop-in center outlined in the previous section. In this section we present examples of different ways that drop-ins can respond to the needs and desires of consumers in various communities. For example, some drop-ins focus more on activities inside the center, while others are more interested in organizing outings into the community, or even trips to places further away. Food may be a priority for some centers, so they spend much of their time, energy, and money on providing meals at the center for consumers; other centers just serve coffee. This section is designed to spark ideas about how to put into practice the criteria for an effective consumer-run drop-in center. At the same time, in order to carry out the critical values and principles for a consumer-run drop-in center, centers need to have certain structures and processes in place.

Starting a New CDI

- *The drop-in needs to “belong” to consumers from the beginning*
- *Professionals can help, but consumers need to be in control*
- *Learn from other drop-ins*

A small group of consumers interested in starting a CDI is the necessary place to begin. Consumers who have heard about or been a part of a CDI in another area may be the ones to

begin talking with others about wanting to open a CDI in their area. A mental health agency charged with the mandate to open a CDI is not enough. Agency staff should talk with consumers to see if there are those who want to put their energy behind building such a center. A group of consumers committed to the effort is an essential feature of a CDI. Democratic, consumer-run principles need to be in place from the beginning. If mental health professionals set up the program and then “give” it to consumers, consumers won’t have the ownership necessary for a true CDI. A more effective process is one where professionals act as facilitators and resource people who assist consumers in decision-making by providing information and consulting, promoting wide democratic participation of all consumers at each stage of planning. MH professionals have much information that they can use to help CDIs become stronger, more independent, and able to make decisions for themselves. Alternatively, professionals can act as “gatekeepers” of this information and guard it in order to keep consumers continually dependent upon them. Some consumers may be anxious about being in control of their own organization; they may not have had this level of responsibility before and may not believe they are capable. It is up to professionals to act responsibly in this regard and support consumers in their ability to make their own decisions, given the necessary information to do so. For example, mental health professionals have the information to assist consumers in making informed decisions about the structure and functioning of their organization—e.g. one director vs. a more collective model. Mental health professionals can be valuable consultants to a consumer-run program and can contribute greatly to its success, if their role, responsibilities and authority are specifically described, straight-forward and transparent.

We suggest that CDI directors and Board members talk often to drop-in centers in other communities, and even in other states—there’s much to learn from their experiences and ideas.

Get on their mailing lists, and put them on yours. Relationships with other centers can provide important feedback and support—you can learn from their mistakes and their successes.

Consumer conferences are one good way to meet consumers from all over the country. IAPSR (International Association of Psychosocial Rehabilitation Services) is one organization that holds annual conferences which many consumers attend; another annual conference is called “Alternatives” and is organized by the National Mental Health Consumers’ Self-Help Clearinghouse. See the section on Resources for contact information.

Structure and Leadership

- *Consumers elect a Board of Directors*
- *The Board hires a consumer to be Director of the drop-in*
- *All consumers need to be encouraged to help in running the drop-in*
- *Set a timeframe for becoming independent of the mental health agency*
- *Get help to figure out how to file the necessary paperwork to become independent*

The leadership and decision-making structure of a center is determined by the consumers founding the center and by the resources available: the number of leaders, how they will be chosen, specific duties/responsibilities, and the process for decision-making. These are fundamental questions consumers confront when starting a CDI, and they are often confronted again and again.

Most CDIs have an elected Board of Directors. The purpose of a Board is to govern operations of the organization, maintaining its mission. The Board will be responsible for

making plans to carry out the mission of the drop-in with much input from all the consumers at the center. Many final decisions are made only by Board members. All meetings, including Board meetings, should be open to all consumers—it's helpful for the consumers to have an open view of the work of the Board. Often the Board hires one consumer to act as director of the drop-in. Sometimes two or three consumers can share the position of director, each working part-time. Some drop-ins are run as more of a collective with a group of leaders who each work part-time at the drop-in. Many different leadership and decision-making structures are possible. The three most important aspects of any structure for a drop-in are: (1) the structure must both allow for and encourage the wide democratic participation of all the members of the drop-in, (2) the structure needs to include ways for consumers to be accountable to one another for designated responsibilities, and (3) responsibilities and authority of each position (staff, Board, volunteer, etc.) are agreed upon in advance—this helps to avoid arbitrary actions, power struggles, and conflicts.

Within a structure where there is a director (or more than one) of the drop-in, the director(s) carry out decisions made by the elected Board or by consumers of the drop-in. For example, if consumers vote to make a “no smoking inside the drop-in” rule, it can be the responsibility of the director(s) to enforce the rule, if no other consumer does. It's best if all consumers at the drop-in feel enough ownership of the center to help operate it; the director(s) is there to make sure that what needs to be done, gets done. This includes everything from welcoming newcomers, to picking up cigarette butts outside, to compiling reports—it's best to involve a wide group of consumers in these activities, and for the director(s) to make sure that all necessary tasks are accomplished. Tasks which need to be done can be scheduled and structured in advance—laid out so consumers can pick the ways in which they want to contribute to the

center's operations. Consumers should be asked, not ordered, to do things by the staff or Board members.

Excerpts from JIMHO's June 2003, *Drop-In Director's Responsibilities—Training Manual*

The director is the host of the drop-in and therefore it is important to open the center on time, make sure that the coffee is made, and that the building is clean and presentable. It is also important that the director treats the drop-in as a business and must carry out its activities in a professional manner.

The director is responsible for the daily operations of the center and sets the tone for the atmosphere at the drop-in. Greeting consumers with a smile and making them feel comfortable and like part of the family is very important.

The director is the supervisor. Interviewing and recruitment of prospective staff and volunteers, and annual evaluations of all staff is the director's responsibility.

The director is the administrator. The director is responsible for maintaining inventory and purchasing supplies for the drop-in. Other duties include correspondence/networking with other community agencies and assisting our consumers in accessing those services.

...

The director is responsible for finances. The director is responsible for paying bills, receipts, and keeping check ledgers accurate as well as developing and monitoring the budget. The director can also solicit donations for the center.

The director is the reporter. The director is responsible for monthly financial reports to the Board and funding sources . . . The director is also required to fulfill all requests of the Board, as they are the employer. The director will notify the Board of any issues requiring immediate attention. The director will receive annual performance reviews from the Board.

Centers may want to decentralize these tasks more than is described above, or have the focus be on the director(s)' responsibility to make certain these tasks are accomplished, but not necessarily responsible for doing it all themselves—in fact, it's best if others are involved in this work and responsibility is shared.

When consumers come together to start a new drop-in center, they'll need to make decisions about the legal structure of their organization. Will the drop-in start off as part of another non-profit agency—e.g. the local mental health service provider or association—or

become it's own independent, tax exempt, corporation from the beginning. Each of these choices has it's own benefits and potential drawbacks.

Many CDIs start out as part of their local mental health agency and become independent later on. Starting and growing a CDI is a lot of work in the beginning and an existing agency can provide much-needed assistance and funding to help get the CDI up and running. A potential drawback may be that being a part of the mental health agency may mean reduced independence at the beginning. The mental health agency would be responsible for how the CDI spends its money and may see this responsibility as giving them the right to be more involved in decision-making than the consumers feel is appropriate. Consumers may benefit from the specialized knowledge and skills the agency can provide, all parties just need to be clear about their roles. Most CDIs decide to become independent at some point, so that they can be truly consumer-run, either in the beginning or after they've gotten some experience operating the drop-in. It may be a good idea to set a specific date (for example, one year after opening) independence. Without a target date for independence, agency professionals may put off independence indefinitely thinking that the consumers just aren't ready yet, and consumers can come to think they're just not able to function independently. With this target date in mind, both the consumers and the mental health agency can prepare.

When a CDI becomes an organization entirely independent of the mental health system, they can still receive funding from the local (or state) mental health agency as a contractor. The agency and the CDI can sign a contract that says the agency will pay a specific amount of money to the CDI to provide drop-in services. As part of the contract, CDIs are often required to file reports with the funding agency to show how the money was spent—according to the budget or agreement that was made with the agency. This kind of reporting can be a good practice, whether

required by an agency or not. These reports of how the center's money is spent can be used to show all the consumers of the drop-in where the money is going. This demonstrates that the leadership is being accountable to all the consumers of the drop-in and can be part of a discussion where consumers have an opportunity to give their input on expenditures, share money-saving ideas, and discuss the priorities and future direction of the center. Having these kinds of meetings not only provides consumers with information about the workings of the center, it increases the democracy and participation of consumers at the center, and helps the leadership to be sure that planned projects are really those that consumers want most.

As an independent nonprofit organization, CDIs can incorporate (become a corporation) and apply for tax exempt status, called 501(c)3 status because Section 501(c)3 of the tax code spells out the rules for non-profits being tax exempt. To obtain 501(c)3 status, the CDI must first become incorporated and then file the 501(c)3 application within the next 15 months. The process of incorporating and obtaining the 501(c)3 status involve filing legal documents and forms with the IRS ; an attorney can be useful, though often expensive. Attorneys experienced with this process know all the steps to follow and can be an enormous help. You may be able to find help through Legal Aid or a local law school. You can also call your local bar association to find out if free legal help is available. Also talk to other CDIs in your state about the process and find out where they obtained help. The National Mental Health Consumers' Self-Help Clearinghouse has an excellent Technical Assistance Guide for Consumer-Run Businesses and Services that goes into more detail about the process of incorporating and obtaining 501(c)3 status. JIMHO also provides much useful information about this process, specifically for the state of Michigan, including sample by-laws and articles of incorporation. See the Resources section at the end of this manual for contact information.

Outreach to Newcomers at the Center

- *Welcome newcomers, give them a tour, and make printed info available*
- *Be friendly, but let new people settle in at their own pace*

Help new members feel accepted as people by other people. As mental health consumers we have a hard time meeting new people, mostly because of our damaged self-images and the stigma attached to mental illness. We often build a wall around ourselves so that we are protected from further hurt. We are defensive and on guard. This stands in the way of making new friends. We don't know what to say or do. We are afraid to reveal too much of ourselves and our illnesses because to do that is to risk rejection.

Chain of Hope Resource Guide, page 10

Since newcomers may be nervous when they first come to the center, it can help for a consumer to give new people a tour, tell them briefly what the center's all about, and introduce them to a few others. It's also nice to have some material available for them to take home, just a page or two about the drop-in that they can read later. This brochure or flyer should include the center's name, address, phone number, hours etc. in case they forget. Some people may be too shy at first to ask many questions and printed information can let them know them know important information like the center is *run by and for* consumers, and doesn't involve any treatment by professionals. Some people may feel overwhelmed by being given a lot of papers, so letting new consumers know this information is available is enough. This can be a colorful brochure produced on a computer, or it can be as simple as a page or two of information with copies made on a copy machine or at a copy store. This can be a good project for those starting the drop-in to come together to decide what should go into this brochure or flyer—what's most

important about this drop-in that you want newcomers to know or remember? These can also be put in treatment locations to attract new members to the drop-in.

Outreach to the Community

- *Educate the community about the drop-in*
- *Spread your brochures or flyers throughout the community*
- *Participate as a group in the life of the community*

CDIs use many creative ways to let the community know what their center is all about. Some have talked to leaders at places consumers often frequent (churches, homeless shelters, dollar stores, food pantries, etc.) and posted flyers with their permission. The mental health agencies that serve people with serious mental illnesses can be important liaisons between consumers and CDIs. Case managers can tell their clients about the drop-in and give them your flyer or brochure with information about the center's hours and location. The staff at these agencies need to be sure to communicate to consumers that the drop-in is separate from their agency and run by consumers.

Meeting with other non-profit community groups, and nearby businesses, to educate them about the center can help. CDIs can organize activities where consumers from the center contribute to the community—highway cleanup, working in community gardens, etc. One drop-in center in Pennsylvania made it a point to be on good terms with their neighbors—helping elderly people in their neighborhood by doing their yard work and bringing them a meal when they were ill. These contributions to the community promote goodwill, as well as an opportunity

for consumers to feel good about themselves. Consumers can take pride in being contributing members of society.

Activities, Services, and Referrals

- *Drop-ins can provide some of the services that consumers need*
- *Staff should share information about other services available in the community*
- *Consumers can organize fun activities inside and outside the drop-in*

Depending on their financial and organizational resources and the needs and desires of consumers in their community, centers provide a wide variety of activities and services. Some centers provide transportation to and from the center, to appointments, for shopping or errands. Some offer computer classes, help studying for a G.E.D., and supported housing services. Some of these services require financial resources that are hard for many CDIs to come by, and staff to run them. They are certainly possible, particularly if a CDI has a group of consumers who are committed to a project and have energy to devote to seeing it through. When people are creative and begin to interact more in their community, they can often find individuals or businesses who may be interested in donating goods or services to the drop-in. For example, one drop-in came across a volunteer who offers \$1.00 haircuts at the CDI every month.

The more staff and Board members are aware of the agencies in the community that offer services to people with low income, the more consumers at the center will benefit. Staff should become knowledgeable about agencies like the FIA and social security offices that handle SSI and SSDI, in order to help consumers know where to go when they need help applying for these

entitlements. It's a great service to consumers to have staff at the drop-in who know about food banks, soup kitchens, homeless shelters, churches who offer help to people in need, and any other resource in the community that could be helpful to consumers. It helps to make and put up posters at the drop-in to let consumers know about these resources and that they can ask staff for more information. Sometimes consumers have needs and have no idea that someone at the drop-in has information that could help.

Consumers also need to have fun and socialize at the drop-in. Most centers have televisions, VCRs, and stereos. Often there are board games, cards, crafts, and sometimes pool or ping pong tables. Activities inside the center rarely cost much, and it's a way for consumers to have fun together. Having choices beyond the television give consumers more ways to interact with each other, make new friends, have fun and do something different. Some drop-ins have weekly exercise classes, tournaments (cards, board games, pool or ping pong), craft night, holiday celebrations, birthday dinners each month, and women's night (particularly if most of the drop-in's consumers are men). A cooking night where consumers cook and eat a meal together is a popular way to learn cooking skills from one another, share recipes, and enjoy a nice meal with friends. Giving cards or having small celebrations for birthdays, weddings, new babies etc., can help to reinforce the sense of a caring community at the center.

CDIs often have self-help groups meeting at the center, to support consumers' recovery from mental health problems—Schizophrenics Anonymous, Recovery, Alcoholics and/or Narcotics Anonymous, Manic Depressive / Depressive Anonymous (MDDA), among others. Other ideas include inviting speakers to give a short talk on any topic consumers at the drop-in are particularly interested in—for example: how to apply for SSDI or food stamps, how to make healthier food choices, or current events (e.g. what's happening with prescription drug laws).

Centers can also invite visitors from other drop-ins to come and share ideas about how they do things at their drop-ins.

Activities carried on outside the center also vary depending on consumers' interests and available funding. Many centers go shopping, to movies, plays, or roller skating; often they hold picnics, attend community festivals, and enjoy sports events together (if you call ahead, you may be able to get free tickets). Some plan overnight trips for camping and fishing, attend consumer conferences in other states, or visit other drop-in centers. These outings are a lot of fun and they also enable consumers to interact in the community in the company of friends. Activities outside the center are also ways for consumers to bond with one another in new ways, and stockpile happy memories to remember later—particularly if they take pictures to put in an album or display at the center.

Projects that consumers decide as a group that they want to undertake—such as, some improvement to the property or appearance of the center, a letter-writing campaign to a political representative, or a demonstration they want to attend and make signs for—provide opportunities for consumers to work together toward a common goal. Not everyone has to participate in every activity, project, or trip to make this sort of undertaking a net positive for the group—these experiences enhance group solidarity that is available for everyone to draw upon and be a part of.

Funding

- ***Where to find the money to run a drop-in***

Running a drop-in center requires funding. Some have started so small that all they really needed was a place to meet. One group's local mental health agency let them use an old

previously unused building; they didn't have any paid staff in the beginning, and they sold pop to earn enough money to buy coffee and a few snacks. Despite humble beginnings, many drop-ins have grown to be quite large and have acquired funding to own vehicles, and their own buildings. Available funding for drop-in centers varies from community to community and state to state. One place to start gathering information is the local mental health agency. If they don't know, they should know where to go to find out more. Some states require local mental health agencies to provide at least one "consumer-delivered or -operated" service. Local and state departments of community health or mental health will have this information.

Often CDIs start out as part of their local mental health agency—they aren't entirely independent. There are often "strings" attached and the CDI is dependent on the agency. This could be a good arrangement for a CDI in the beginning, to have some professionals helping in this sort of close advisory role for some period of time. Eventually, however, the CDI will have enough experience that they will have outgrown their need for this oversight, and want to be independent. A CDI can be independent and still receive funding through the agency—they will essentially be contracted by the agency to provide the drop-in for the community, just like the agency contracts others to provide services they can't provide themselves. Any professionals involved with the CDI need to support the CDI's eventual move toward complete independence. These professionals need to work with consumers at the beginning to construct a plan for how and when independence will happen—this process needs to be transparent to consumers from the start, not a murky process where consumers are left in the dark.

Centers are often creative about ways to make money and provide services for their members. One CDI in rural Michigan had a continuing problem with adequate transportation for consumers to get to the drop-in. The public transportation was extremely limited. They came up

with the idea of starting a dial-a-ride business that would serve the community, provide enough funding to support the service itself, and provide transportation for consumers of the drop-in at the same time. Other centers focus on networking to obtain donations of food, furniture, computers, tickets to sporting events, and anything else the center might need. Also, some centers have a large number of volunteers who help to make a variety of activities and services possible.

Internal and External Environment

- ***Make the drop-in clean, safe, welcoming, and comfortable***
- ***Locate the CDI in a safe, convenient neighborhood***

The physical environment of the drop-in needs to be safe and welcoming—both inside and out. Consumers need to feel comfortable coming to, and spending time at, the drop-in. Ideally, the center needs to be easily accessible by public transportation and located in a neighborhood where consumers will feel safe walking home, or to the bus stop. Drop-ins should be open for regular evening hours or have occasional activities in the evenings so consumers need to be safe coming and going in the evening as well as during the day and weekends.

The area inside the CDI is equally important. The space needs to be clean, comfortable and cheerful, with large spaces for the entire group to gather and smaller areas where people can be alone or have conversation with just a few. The furniture doesn't need to be new, but it should be clean and comfortable, with easy chairs and sofas—to encourage people to feel relaxed and at home. If the center is housed in a building that looks institutional or like office space, do use everyone's creativity to make the space feel more homey and welcoming. Often consumers feel

it's important to have ample kitchen facilities they can use for regular meals, parties and holiday celebrations. A CDI should have enough bathrooms, well stocked with necessary hygiene supplies, to handle the number of consumers who attend. The space should also be large enough to accommodate some growth in attendance. Many CDIs have bulletin boards to post helpful information about services available in the community, self-help groups, changes in laws or regulations that affect consumers, etc. These postings need to be easy to read and understand and eye-catching. You'll want to make these so appealing and useful that consumers get in the habit of looking at the bulletin board often.

Smoking is an issue centers often need to contend with. Many consumers like and want to smoke inside the drop-in; non-smoking consumers often don't want to be subjected to smoke-filled rooms. The drop-in needs to consider the desires, comfort and health of all consumers at the center, as well as newcomers the center would like to welcome. Some centers decide to make all indoor areas non-smoking. Some choose the opposite. While some drop-ins are large enough to have separate smoking and non-smoking areas with effective air filtration systems to clean the air. This is an opportunity for consumers at the center to democratically make decisions that accommodate differing opinions and needs.

Rules

- ***Decide on a few important ground rules***
- ***Make them fair and enforce them equally for everyone—no favoritism***

CDIs need to set some ground rules to for everyone who comes to the center to ensure that this will be a place of safety and respect. Rules are important to ensure fair and consistent

treatment of everyone; no favoritism. Rules need to be decided democratically and clearly posted so that everyone knows what they are. It's better if the rules are kept to a minimum—easier for everyone to remember. They need to be clear, fair, and prominently posted; no one has to fear that arbitrary rules will be declared on the spot and unfairly applied. The rules apply to everyone whether they are regular attendees, newcomers, staff, or mental health professionals. Centers need enough rules for people to feel safe, and few enough that people don't feel their every move is constrained by a long list of rules.

Often drop-in rules include prohibitions against physical violence; disrespectful, rude, threatening or obnoxious talk or behavior; drugs/alcohol in or on people while at the center; weapons; destruction of property; and “bumming” cigarettes or money. Centers also need to decide what happens when someone breaks a rule. Will there be verbal warnings? Will people be asked to leave the CDI for a specific amount of time? Is there a policy for individuals being allowed back at the CDI after repeated violations?

Resources for more Information

Bazelon Center for Mental Health Law
1101 15th Street NW, Suite 1212
Washington, DC 20005
(202) 467-5730
<http://www.bazelon.org>

Center for Psychiatric Rehabilitation
Boston University
940 Commonwealth Avenue West
Boston, MA 02215
(617) 353-3549
<http://www.bu.edu/sarpsych/>

Consumer Organization and Networking Technical Assistance Center (CONTAC)
910 Quarrier St.
Charleston, WV 25301
Toll-free number (1-888-825-8324)
Website: <http://www.contac.org>

Justice in Mental Health Organization (JIMHO)
421 Seymour
Lansing, MI 48933
(517) 371-2794
Email: jeanthepig@aol.com

National Alliance for the Mentally Ill (NAMI)
Colonial Place Three
2107 Wilson Blvd., Suite 300
Arlington, VA 22201-3042
Main: (703) 524-7600
Fax: (703) 524-9094
TDD: (703) 516-7227
Member Services: (800) 950-NAMI
Website: <http://www.nami.org>

National Mental Health Association (NMHA)
1021 Prince Street
Alexandria, VA 22314
(800) 969-NMHA
Website: <http://www.nmha.org>

National Mental Health Consumers' Self-Help Clearinghouse

1211 Chestnut Street, Suite 1207

Philadelphia, PA 19107

(800) 553-4KEY (4539)

(215) 636-6312 (FAX)

Website: <http://www.mhselfhelp.org>

E-mail: info@mhselfhelp.org

“COH Resource Guide to Starting a Self-Help Group
And a Consumer-Run Drop-in Center” written by Nancy Abel
and the Chain of Hope Consumer Group is just one of the
many valuable resources available from this organization.

United States Psychiatric Rehabilitation Association (USPRA)

601 North Hammonds Ferry Rd, Suite A

Linthicum, MD 21090

(410) 789-7054 phone

(410) 789-7675 fax

(410) 789-7682 TDD

Email: info@uspra.org

Website: <http://www.iasprs.org>

Also, this book is a great resource for developing and sustaining services run by consumers:

Carol T. Mowbray, David P. Moxley, Colleen A. Jasper, and Lisa L. Howell, eds. Consumers as Providers in Psychiatric Rehabilitation. Columbia, MD: International Association of Psychosocial Rehabilitation Services, 1997.