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ABSTRACT

This paper describes the consumer program, "Helpful People in Touch," a self-help treatment program for people with the multiple disorders of mental illness, drug addiction, and/or alcoholism. First, the terms, "Mentally Ill Chemical Abusers and Addicted" (MICAA) and "Chemical Abusing Mentally Ill" (CAMI) are defined and differentiated, with typical characteristics listed. Next, traditional 12-step self-help recovery programs are described and modifications for people with mental illness are discussed. Initial establishment of the new self-help group specifically for this population is then described; and discussion and activities of the first few meetings are summarized, including determination of the group's purpose, sharing of group work, identification of tasks to achieve goals, and development of ground rules. The role of professionals is examined, which involved attending planning meetings only, while ongoing meetings were led by group members. Reactions of four long-time participants in the group are cited. The program model is currently being implemented in other communities. (DB)

"HELPFUL PEOPLE IN TOUCH" CONSUMER LED SELF HELP PROGRAMS FOR PEOPLE WITH MULTIPLE DISORDERS, MENTAL ILLNESS, DRUG ADDICTION, AND ALCOHOLISM (MIDAA)

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"Helpful People in Touch" Consumer Led Self Help Programs for People with Multiple Disorders Mental Illness, Drug Addiction and Alcoholism

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People with multiple disorders of mental illness, drug addiction and alcoholism are often suffering with the same serious degree of alcoholism and drug addiction as are people who have severe alcohol and drug addiction who are not severely mentally ill. The seriousness of these relapsing addictions frequently require daily support groups and networks at particular stages of recovery, and on-going support may continue to be necessary for years. Self help support programs for people with multiple disorders are very effective adjuncts in helping people with mental illness and substance abuse to attain and maintain recovery from the addictions.

Since my early work in the development of treatment models and treatment programs for people with multiple disorders (Sciacca, 1987), it has been clear to me that new and special program models are necessary. Rectifying the lack of treatment resources for people with multiple diagnoses required a comprehensive approach, integrating mental health and addiction treatment into a single program design. In recognition that traditional twelve-step self help programs often do not place enough emphasis on severe mental illness, and that people with severe mental illness who attend such programs often do not discuss their mental illness at these meetings, I facilitated the development of a self-help model that included all aspects of a person's needs. This program "Helpful People in Touch", was developed by the participants, thereby the format and content express what is important to these individuals within the realm of self-help.

In describing this program, I will begin by clarifying the terminology ascribed to define people who participate in these programs, in contrast to the terminology used to describe people who participate in traditional addiction treatment. Next I will review some aspects of traditional twelve-step programs, followed by an in-depth discussion of the consumer program "Helpful People in Touch." The latter will include the context of an overview of treatment program development throughout the county where the consumer group takes place.

Description of the Population:

The term "dual diagnosis" is ambiguous (for example: mental illness and mental retardation are dual diagnoses). The term "Mentally Ill Chemical Abusers" or MICA was introduced by the New York State Commission on Quality of Care in 1986 (1986) and has since had an additional "A" added for "and Addicted" hence, MICAA. The Commission's report made it clear that the term denoted people who had severe, persistent mental illness, accompanied by chemical abuse and/or addiction.

Some Characteristics of People who have MICAA:

1. Symptoms of a severe mental illness exist independently of substance abuse; These symptoms would meet the diagnostic criteria of a major mental illness even if there were not a substance abuse problem present.
2. People with MICAA are diagnosed on Axis I, by DSM III, R (1987) criteria, to have a major psychiatric disorder, such as schizophrenia or major affective disorder.
3. People with MICAA usually require medication to control their mental illness; if medication is stopped, specific symptoms are likely to emerge or worsen.
4. Substance abuse may exacerbate acute psychiatric symptoms, but these symptoms generally persist beyond the withdrawal of the precipitating substances.
5. People with MICAA, even when acute symptoms are in remission, frequently display the residual effects of major mental illness (schizophrenia, for example), such as marked social isolation or withdrawal, blunted or inappropriate affect, and marked lack of initiative, interest, or energy. Evidence of these residual effects often differentiates people with MICAA from populations of substance abusers who do not have severe mental illness.

More recently, the acronym CAMI has emerged. CAMI denotes people who have severe alcohol and/or drug addiction with associated symptoms of mental illness, but who do not have severe mental illness, or "Chemical Abusing Mentally Ill."

Some Characteristics of People who are characterized as CAMI:

1. People who are CAMI have severe substance dependence (alcoholism; heroin, cocaine, amphetamine or other addictions), and frequently have multiple substance abuse and/or poly-substance abuse or addiction.
2. People who are CAMI usually require treatment in alcohol of drug treatment programs.
3. People who are CAMI often have coexistent personality of character disorders (Axis II, DSM-III, R) (Solomon, 1982).
4. People who are CAMI may utilize the mental health system due to "toxic" or "substance induced" acute psychotic symptoms which resemble the acute symptoms of a major mental illness. In this instance, the acute symptoms are always precipitated by substance abuse, and the person does not have symptoms that meet the criteria for an Axis I major psychiatric disorder.
5. CAMI client's acute symptoms remit completely after a period of abstinence or detoxification. This period usually lasts a few days or weeks, but occasionally may require months.
6. CAMI clients do not exhibit the residual effects of a major mental illness when acute symptoms are in remission.

The program describe in this article is designed specifically for people with MICAA, not for people who are CAMI. People who are Cami are most often compatible to participation in traditional twelve-step self-help programs.

Traditional Twelve-step Self-help recovery programs:

Traditional self-help programs for alcoholism, Alcoholics Anonymous (A.A.), are guided by twelve-steps suggested as a program of recovery, and by twelve-traditions believed to be the best

answers to the questions, "How can A.A. best function?" and "How can A.A. best stay whole and so survive?" (A.A.,1977). Subsequent programs for drug addiction (Narcotics Anonymous, N.A., Cocaine Anonymous, C.A., Pills Anonymous, P.A., etc.) have also been developed around these steps and traditions. The first step toward recovery deals with denial, and participants come to admit, "We admitted we were powerless over alcohol--that our lives had become unmanageable." Other steps include areas such as step two, "Came to believe in a power greater than ourselves could restore us to sanity", the belief in a higher power; step four, "Made a fearless and searching moral inventory of ourselves," a review of one's value system, and step six, "Were entirely ready to have God remove all these defects of character," the willingness to let go of perceived faulty behaviors and beliefs. The concept of God or a higher power is conceptualized by each participant and is not taught as any specific concept of God (A.A. 1977). The program of steps is "worked" participants refer to one another as either "working the program" or "not working the program." People who are not working the program are considered likely to fail at recovery or relapse from sobriety. The development of a relationship with an A.A. member who works the program and has a degree of sobriety is recommended as a sponsor relationship. It is the sponsor's role to guide the participant through the steps and to assist them in understanding and working the program. It is often recommended that a new comer to A.A. attend ninety meetings within ninety days to assure initial sobriety. This may also serve as a consistent initiation into A.A. that helps a person engage in the fellowship and establish connections with a particular group.

One of the twelve traditions that guide A.A., number four, espouses that "Each group should be autonomous except in matters affecting other groups or A.A. as a whole." For this reason composition of different groups take on different characteristics and may be more or less compatible to people with severe mental illness. For example, although there is literature in A.A. that clearly states that prescribed medication is strictly a matter that involves the participant and his/her physician, some A.A. groups include members who believe that all chemicals, prescribed or not, are addictive substances and should be abstained from. It is frequently reported by people with severe mental illness who have attended A.A. meetings that they have been advised to discontinue medication. When recommending A.A. meetings to people who take prescribed medication, it is important to advise them that some A.A. members may have such beliefs, and to try to find groups that do not have members that hold such beliefs if possible.

Traditional A.A. and N.A. self-help programs are used effectively by some people who have a severe mental illness. The third tradition, "The only requirement for A.A. membership is the desire to stop drinking," is an appropriate stage of readiness for participation. People who are in denial about the adverse effects of their addictions, will generally resist attending an A.A. meeting. Frequently, a person who has a severe mental illness will modify their participation in A.A. in a way that allows them to

benefit from the meetings without undue stress. For example, people who find ninety consecutive meetings too stressful to accomplish may forego that suggestion and attend meetings as needed. People who are not comfortable speaking in large groups may simply listen at meetings and gain the needed support and information. For people receiving mental health treatment, who acquire an A.A. sponsor, permission for the therapist to communicate with the sponsor will often foster the development of a modified program that will work in the client's best interest. When a client tends to keep their mental illness a secret from others in the A.A. group, educating the sponsor with the permission of the client opens up communication about mental illness that fosters communication between the sponsor and the client, and leads to an appropriate plan of participation.

Traditional self-help programs frequently emphasize the concept of "hitting bottom" as a necessary prerequisite to sobriety (that is, participants must experience severe losses or deterioration in order to perceive that they need help for addiction). For people who have a severe psychotic symptoms, and regression in all areas of functioning. This is not recommended. Sciacca has advocated that clients with severe mental illness be maintained at a stable level, and that progress in substance abuse treatment should proceed from that level (Sciacca, 1987).

Some people who have a severe mental illness have uncomfortable experiences within twelve-step programs, or they simply may not want to attend such programs. Alternatives to attending meetings that consist mainly of members who have CAMI characteristics include the develop of "institutional meetings" within a given mental health or other treatment program. Institutional meetings are led by A.A. members and are either attended exclusively by people who have a severe mental illness, or may include other members from the community in addition to the clients. The success of these programs depends upon the qualities and flexibility of the leader to modify A.A. steps and traditions in the best interest of the participants. In some treatment program models for MICAA, the inclusion of A.A. guest speakers (Sciacca, 1987) who attend groups and tell their story and answer questions about the program, serve as an introduction to A.A. as well as a way for people who do not want to attend A.A. to benefit from identifying with various aspects of these candid stories.

In attempting to develop important support networks for recovery from the addictions, A.A. and other twelve-step programs are important inclusions for people who are willing to try to participate in them. Twelve-step meetings are wide spread and one can have access to a daily meeting in most communities. For people who have a severe mental illness it is important that their positive and negative experiences of twelve-step programs are discussed in a setting where all of their symptoms are accepted, such as programs specifically developed for MICAA, or with their therapist, doctor or case manager. Frequently, adjustments in one's participation will facilitate a fruitful involvement in a twelve-step program once the issues are clarified. "Helpful People

in Touch" a Self-help Program for People Who Have a Severe Mental Illness.

Mental Illness

In recognition that traditional twelve-step programs are not always compatible to people who have a severe mental illness, the development of a self-help program that met the needs of the participants was facilitated by the author (Sciacca, 1991).

The program was conceptualized to include participants community wide versus institutional, therefore it was open to all who wanted to attend.

The author's work in program development for multiple disorders yielded a community, Westchester county, in New York State, where various hospitals, agencies, and programs are addressing and/or providing treatment services for people with MICAA profiles. Through the concept of inter-agency education and training for "the advancement of treatment for people with mental illness, chemical abuse and addiction," numerous agencies appointed staff to participate and to develop program initiatives (Sciacca, 1987a). These included residences, clinics, day treatment programs, addiction programs, shelters, hospital wards and units, continuing care programs, and others. After some discussion with the client's at some of these programs as to the usefulness of a new self-led, self-help model, the consensus was overwhelming, and the plan to proceed to develop the program took shape. This was in the latter part of 1988.

An announcement of the intention to begin this program was sent to consumers, families and service providers. The notice clearly stated that the format, content and philosophies of this program would be developed by the participants in attendance. The meeting place was the MICAA Training Site, which was directed and developed by the author as a resource center for consumers and providers, other consumer groups such as MICAA-NON (Sciacca, 1989) were also held there. The training site sufficed as a nontreatment-oriented milieu.

After a review of the literature on self-help programs the author adapted the role of the professional as evolving from one of greater to lesser participation, and the planning strategies for brainstorming the group's goals and related tasks from Rogers (Rogers, date unknown). Therefore, a professional was in attendance throughout the planning stages, and then ceased to attend once the format was developed. The first meeting was held in January, 1989.

Structuring the Planning Meetings, Developing a Format.

The meetings were scheduled in the evenings for one and one-half hours. It was assessed that the need for support programs were needed outside of treatment program hours. Meetings were held every other week, once a week. The first meeting had five consumers in attendance. One of the decisions made was that the size of the group would be limited to twelve participants.

The planning agenda, which took several meetings to cover, included the following:

1. Statement of purpose: How should a MICAA self-help group

differ from traditional A.A., N.A.?

How should a MICAA self-help group be similar to traditional self-help groups?

2. List one goal, activity: What would you like to get out of this group?

What are the common goals among participants?

3. How will group members share the responsibility for work?

4. List of tasks that will help to achieve goals...

5. Develop ground rules for groups and participation.

6. What shall the group be called or known as?

A black board was set up, and a participant volunteered to write the responses on the board, while a professional in attendance took minutes of the meeting. The group accomplished the statement of purpose, and began to work on goals in the first meeting. Minutes were typed by the training site staff and sent to the participants before the next meeting. They were also handed out to the seven new participants at the second meeting.

The following are some excerpts from the summary of the first planning meeting. Summary statement: Everyone present felt that the issues and areas that they wanted to address were not limited to substance abuse issues. Each member felt that they had other concerns and issues they wanted addressed. Therefore, this group would be open to any issue. Statement of Purpose: This group is being established to meet the needs of people who have a mental illness and some type of issue with the use of alcohol/drugs. This group is meant to help people who have been unable to get help from the more traditional self-help groups such as A.A. or N.A.. In many ways this group will discuss topics and issues that are not related to other self-help groups and substance abuse treatments. However, the group felt that there are certain aspects of the traditional self-help groups that they wanted to see in this group. These things are: refreshments, education, fellowship/support, willingness to actively participate, rotating leadership and other roles, a nice way of ending meetings, the use of speakers, films and literature, learning about the twelve-steps. The group also felt that there were certain aspects of the A.A. program that they did not want to include, which are: rigid requirements about medications, rigid requirements about doing ninety meetings in ninety days, and having to follow the twelve-steps.

The exploration of goals in the first meeting were summarized as follows: The group decided that this group would be open to anyone expressing an interest in learning about alcohol/drugs. Specific goals that were outlined by the group are: To help one another, to better communicate within oneself and to overcome

inhibitions, learn about other people's experiences so one can learn more about themselves, participation in a group situation.

The next planning meeting was scheduled and participants were asked to come prepared with topics they wanted to discuss at future meetings. The second meeting opened with the review of the minutes from the first meeting where the statement of purpose and initial goals were written. These ideas were explored and adapted by the seven new members, and the group proceeded with discussing one goal or activity they personally would like to achieve in this group. These included: Improved sobriety, quit smoking, achieve improved mental health, gain clearer insight into drug cravings, learn coping mechanisms for illnesses, transition into the community, dealing with stigma, improved self-confidence and support of self, and more independence. The group then proceeded to outline the tasks that would be necessary to achieve their goals. The fact that tasks would be shared responsibilities was stressed. Tasks included: Attendance-"make sure you get there," cleaning up after the meeting,setting up refreshments, acquiring materials for learning, someone to take notes, being supportive and responsive to others, facilitating discussion, leading topic groups, responsibility for sign-in sheet, prepare materials for MICAA staff to type and distribute, bring in speakers, develop a telephone list or address list for support, develop other supports among members, share information about leisure activities, form committees, commitment to being there and carrying out jobs, rotate jobs in some type of order.

Before the meeting ended, jobs were delegated for the next meeting. In the third meeting members discussed number three on the agenda, sharing the responsibilities for work. Members pared down the tasks to nine, and considered factors such as how long a person would hold the position. The majority vote decided that two meetings would be the length of time for each position to be held. The next consideration, "How can we set up a rotating list that would automatically identify the next person to perform the job?" resulted in the decision that leaders would choose among the volunteers at the time jobs were reassigned. It was also agreed that a "buddy system would be put in place in situation where a member did not feel comfortable in performing a particular job. Volunteers for each job were to sign their name on a sing-up sheet that was established for each job. A volunteer could sign their name to as many jobs as they wanted to do, and they would be selected in sequence for that particular job.

At the fourth meeting, members began discussing how they would reimburse the two members who paid for coffee and cookies at the previous meeting. This discussion resulted in the decision to implement dues, and a treasurer to collect and account for the dues. The treasurer's job was to last for three months versus two meetings and an assistant treasurer would work with the treasurer and replace him or her at the end of the appointment. It was decided that one dollar per month, per participant would cover refreshments, and a notice to this effect was sent with the minutes.

The members then went on to discuss number five on the agenda, ground rules. Some rules for participation included: One person should talk at a time and others should not interrupt, everyone must try to stay on the topic, members must be in such a condition that they are able to maintain touch with reality, the members must be able to exhibit self-control, members must be able to exhibit self control, members must be able to share in job responsibilities, no physical violence, if anyone is to become violent for any reason, thy will no longer be allowed to attend the group.

This was followed by the matter of establishing rules for membership. Decisions were made around attendance and dues. It was established that if a member missed three meetings, the group would evaluate the person's membership and explore whether or not the person is serious about his/her participation. Members were required to call the training site if the were unable to attend. Members who did not pay their dues (unless they were in a financial crisis) were not to share in the refreshments.

The last item on the agenda, giving the group a name, was also accomplished at this meeting. Individual ideas included: Beginning of Eve, Helpfulness, Beginners, Two-Way Street, Keeping in Touch, and People in Touch."

At the fifth meeting co-facilitator were designated for the next two meetings. the sixth meeting was consumer led without a professional in attendance. The professional continues to remain on the premises where the groups are held, and is available to assist members with requests for materials, or to handle difficult situations such as occasional attendance by an intoxicated individual.

The author developed written "Basic Guidelines for Facilitator" that complimented the purposes, goals, content and format of the meetings. Leaders rely upon these guidelines when conducting groups. The role of the peer leader includes structuring participation of all members in discussions and decision-making, and ensuring completion of group tasks such as shopping for refreshments, preparing coffee, collecting dues, taking minutes, and so on. Near the close of each meeting, the members decide the format and content of the next meeting. This may include selecting reading materials, films or videos, choosing a topic for discussion, or deciding to have an open discussion. In keeping with the groups decision to adapt "a nice way to end meetings" from the A.A. tradition (the serenity prayer), members read aloud the text for the specific date of the meeting from "The Promise of a New Day: A Book of Daily Meditations" (Casey, 1983), at the end of each meeting. A copy of that page is sent along with the minutes of each member.

Most recently (February 1991) the author spoke to four of the core members about their experiences in this program. They discussed the following: Don (pseudonym) stated, "I think being a facilitator or co-facilitator or even being called on as a member of the group can help more inhibited types perhaps even function at a higher level." "I found the group helped me along because I had

alot of trouble with public speaking and at one point I was leading the group with maybe eight or nine members." "I found it was helpful the way it was structured and it got me over some of my shyness. I didn't feel at ease to talk to large groups." "I led it for two or three months I think, and I think I found that the subjects we'd talk about, and the films we see, it was a good group to go to, I wish that it was run more often and with more people and more films." Joe (pseudonym) stated, "I came in when the planning was going on, I felt there were too many rules, too much business, I know most people liked that." "I had the job of writing on the blackboard, I didn't want to do it. After a while, I dropped out because it wasn't fun." "I came back for something to do, I liked meeting new people." "I find it difficult to lead the group when the people don't know me." I really like staff run groups, I don't know why I'm that way." "I like shopping, I did shopping for at least two or three months." "As long as this group is here, I'll still come." Bob (pseudonym) stated, "When I was facilitator and went to buy cookies it gave me something to look forward to, these people are depending on me for cookies, leading. If I'm not here the group ain't going to go." "I got something out of the group, I've seen what I'm doing to myself in the long run, but I'm still doing it." "I was brought here for a D.W.I. (driving while intoxicated) referred by New York Hospital (case manager)." "I came here by myself, I also have a mental problem where I'm taking medication." "I'm still drinking, I haven't changed my ways, I didn't know I was an alcoholic, now I know I'm an alcoholic." "I was very relaxed with the group, even though I was drinking, I was comfortable because they understood my problem." "I like leading, not for no self esteem or anything like that, I wanted to try to conduct...if I could help somebody out, I would help somebody out." Mark (pseudonym) "There were alot of people when I first came in, then I left and went into the hospital." "I realized that when you're on medication and you drink, it's alot more serious." "I take a drink it exaggerates everything, alcohol exaggerates everything." "Before this group I didn't have any treatment. I got medication from the pharmacy. This is the only place I come to, it's fun." "Before I came here I didn't realize it was that much of a problem." "Because I have this group, I have something to think about during the week."

Some previous members of Helpful People in Touch have moved on to more traditional self-help programs. Others have moved out of the community, or dropped out of the group for other reasons. This group has sustained itself for more than two years. A core group of seven members is the stable force, with other members remaining for various lengths of time. Since it is open to twelve participants it is always accepting of new participants.

Considerations for Implementing consumer led self-help Programs for MICAA.

The development of this program in a community where MICAA treatment programs had been implemented, in part, facilitated the participation of some members who had received some MICAA treatment, and therefore had begun to address some of their substance abuse issues. Announcements sent to the Alliance for Mentally Ill (AMI) local chapters also facilitated consistent announcements of upcoming meeting to a broad community of advocates. The group also attracts participants who have a history of adversity to treatment, and therefore have not attended any kind of programs at all. These participants may be addressing their

issues for the first time. Such referrals often come from case managers, or hospital discharge planners.

It is required that each participant be referred by a professional. Since we do not provide treatment, it is important that there be a professional contact person in the event of an emergency or a crisis. This does not necessitate that the participant be in a treatment program. Case management referrals are acceptable.

For participants who have received some MICAA treatment, the format provides new and advanced ways to address the issues, and opportunities for new roles in group participation. Many members are attracted to the leadership role and volunteer to co-facilitate meetings. Groups leading as well as other responsibilities involve members in new ways. Participants in treatment, remain in treatment, and this program provides another evening of support and networking in their over-all plan of recovery.

The program is an example of a consumer-led adjunct to treatment or traditional self-help programs, depending upon the situation of the individual. In some cases it is the only involvement in program. It does not provide the daily support and structure deemed necessary for recovery, but it does provide a positive working program model for people who have not had an opportunity such as this, and who prefer this program to other available programs.

Some of the deterrents to the growth and stability of this program were discussed by the members recently. These included the fact that the program space was changed from the Training Site (which was closed due to budgetary cuts) to a clinical setting. The clinical setting does not provide the privacy or exclusive use of the kitchen for preparing refreshments, and it was stated "is not as luxurious" as the previous meeting place. This has interfered with job responsibilities (refreshments) which are frequently taken on by the professional monitor to avoid conflicts. Members expressed their agreement that the structure for job responsibilities should not be broken down. The notices of each meeting which were mailed to numerous professionals, family groups, consumers and members, have been discontinued due to loss of funds for postage costs. This has been replaced by a limited telephone chain that only includes members in attendance, and therefore does not usually generate new members. The members were clear on the areas that they felt required rejuvenation and support. This has led to the consideration of changing to the space to a church room or other non-treatment oriented milieu. Ideas such as members doing personal outreach at existing MICAA programs by visiting and talking about the program were considered. This regrouping, and the opportunity to address the changes that have taken place pronounced the strength and commitment of the core members, and gave them an opportunity to explore the reasons why they are invested in the survival of this program.

The author is in the process of implementing this program model in several other communities where she has developed programs and provided education and training. Helpful people in touch have

provided us with a clear example of a consumer-led self help program for people with multiple disorders of severe mental illness, drug addiction and/or alcoholism. We are now in a position to foster the development of new and similar groups, and provide opportunities for growth and support to many people who may benefit.

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