

Excerpt from Chapter 1, On Our Own, Together
About Us: What We Have in Common

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Defining the Common Ingredients

Program Structure

The most important ingredient of any consumer-run program is that its administration and primary activities are independent of provider organizations and that consumers control its board of directors, its staff, and its budget. This is the definition of *consumer operated* that SAMHSA used to determine whether a program qualified to participate in its 1998–2002 COSP study. Consumer operated is also the first common ingredient, labeled as core, in the [Consumer Advisory Panel List], and it follows one of the most honored principles of the disability rights movement: “Nothing About Us without Us.”

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Environment

The core ingredient in the Environment category is *safety*, which for mental health consumers means a noncoercive milieu that soothes fears resulting from past trauma, including trauma induced by the mental health system. There is no threat of commitment, clinical diagnosis, or unwanted treatment except in cases of suicide attempt or physical danger to other participants. Participants draw up their own rules and norms of behavior in order to protect the well-being of themselves and others.

Even peer programs such as educational trainings that meet in classrooms endeavor to provide an *informal setting*. According to this characteristic, a peer-run program should provide an environment that is people-friendly and comfortable. Rigid distinctions between staff and client do not exist, and there is a sense of freedom, fellowship, and belonging. Participants feel supported and free to express themselves. They care about each other and create community together. Most participants readily identify their sense of belonging as the first and perhaps most important benefit of joining a peer-run program.

Other elements of a peer environment borrow terms from the disability movement, such as accessibility and reasonable accommodation. For mental health consumers, *accessibility* refers to transportation and meeting times, which should be convenient to consumers, as well as wheelchair accommodation. *Reasonable accommodation* applies to mental as well as to physical disabilities.

Belief Systems

The largest number of common ingredients falls under the section Values, which heads the single category of Belief Systems. This is not surprising, for consumers are an idealistic lot—we have experienced disruptions in our lives that put our identities and all of our relationships in question. Most of us, after going through such experiences, come out philosophizing. The core ingredients under “Belief Systems” are the peer principle, the helper’s principle, and empowerment, concepts

that emphasize the equality and mutuality of relationships among all consumers in a program, and the strength derived from these values.

According to the *peer principle*, relationships are based on shared experiences and values and are characterized by reciprocity and mutuality. *Peer* is defined in the dictionary as “a person who has equal standing with another in rank or class.” Within the consumer/survivor movement, a peer is not just someone with equal standing but also someone who has shared similar experiences and challenges. A peer relationship implies equality, along with mutual acceptance and unconditional respect. Any group of self-identified peers, whether it is within a twelve-step meeting, cancer support group, or a mental health group, creates a palpable feeling of hope and belonging.

The *helper’s principle* is a corollary of the peer principle. It means acting for the benefit of both oneself and others. Consumer/survivors believe that working for the recovery of others, especially one’s peers, facilitates personal recovery for both. Help or advice is friendly rather than professional and does not demand compliance the way that much formal treatment does. All peer-run services are based on peer-to-peer relationships, as part of the peer principle and the helper’s principle. Most successful peer-run programs in mental health have been started by persons who were themselves still on the road to recovery. In the process of creating a program to help others, they find that that they themselves achieve wisdom and satisfaction in their lives.

Empowerment is honored as an important basis of recovery. Personal empowerment is defined as a sense of personal strength and efficacy, with self-direction and control over one’s life. It produces hope, an element indispensable to independent living and recovery. Consumers believe that recovery and well-being are not possible unless we begin with a strong sense of hope. The sense of ownership felt by participants in a peer-run program is an important source of empowerment as well.

Empowerment is a two-way street—participants in a peer-run program are expected, but not forced, to be accountable for their actions and to act responsibly. Self-reliance is encouraged. Group empowerment comes from belonging to an organized group that is recognized by the larger community. The legitimacy of any group contributes both to the personal empowerment of the individuals within it and to improvements in social systems. Consumers participate in systems-level activities at their own pace.

All of our belief systems operate from a strong sense of personal ethics and an unconditional respect for each person as an individual with the right to make decisions for himself or herself. Thus, our values include not just the philosophies of peer principle, helper’s principle, and empowerment but also creativity and humor, choice, recovery, acceptance and respect for diversity, and spiritual growth. Many of us have found that *creativity* comes naturally to those who experience madness, and pursuing artistic endeavors such as writing and painting can be healing. Likewise, *humor* is healing. Joking with our peers deepens friendships, and barriers of stigma dissolve when we can laugh together with so-called normal persons.

Mental health clients believe in the element of *choice* largely because we know from experience that involuntary treatment has failed to heal and may even damage us. Thus, participation in a peer-run program is completely voluntary, and all activities are elective and noncoercive. Choice of services includes the right to choose none. Consumers are regarded as experts in defining their own experiences and choosing the peer-run or professional services that best suit them. Problems to be

addressed are those identified by the consumer, not by professionals or other external persons. For example, a client in a community mental health clinic may be required to participate in assigned appointments and activities and to reach certain goals and self-improvement within a set period of time.

In contrast, in a consumer-run drop-in center, a member can follow his or her own schedule and goals. If she is not yet ready to move forward, for example, she can just sit and drink coffee until she is ready to go on to something else. Often drop-in centers are criticized for the number of people who seem to just sit around and do nothing. But often it is precisely because we are allowed to “take our time” that we can find the feeling of safety and freedom necessary to pursue true healing.

Often members of our Consumer Advisory Panel expressed the belief that *acceptance* and *respect for diversity* were essential components of peer support. As peers, we are able to tolerate people whose actions and beliefs in a professional setting might be labeled “symptomatic” or considered “inappropriate.” Since we have been crazy ourselves, we feel compassion for the confusion of others rather than fear of their madness, and we strive to offer unconditional respect to those who are “in the same boat” as we are.

It was surprising to some of us that we could not come up with satisfactory definitions for recovery and spirituality. We all agreed that *recovery* is an important component of peer-run programs, but we could not pin down exactly what it is. In the end, we agreed that recovery is a process, not an outcome, and that each individual defines recovery in his or her own terms. There was similar uncertainty over the role of *spiritual growth* in peer-run programs. Although we could not arrive at a way to identify true spirituality, we did agree that the subjective beliefs and experiences of each person should be respected, and not labeled as symptoms of illness.

Peer Support

The idea of peer-facilitated recovery really began with Alcoholics Anonymous and has been adopted by other peer groups of every kind. In mental health, *peer support* is the core and the mainstay of any consumer-run program. Individual participants are available to each other to listen with empathy and compassion based on common experience. Similar support may be provided in formal support groups, such as those that meet at scheduled times or are conducted with a peer facilitator.

Small support or conversation groups allow participants to share common experiences. These groups may be formal peer support groups or casual, ad hoc conversations. *Telling our stories* is a common way for mental health consumers to share personal feelings and information with each other. We also use the technique of telling our stories to take our message to the larger community and to raise the consciousness of other people and agencies, as well as ourselves. Personal accounts of life experiences are embedded in all forms of peer support and education. Sharing life experiences is a powerful tool for public education and an effective means of eliminating stigma. An excellent example of personal story-telling may be found in Chapter 10, in a story entitled “A Voice from the Region” by Sam Viar.

The same skills used in peer support allow peer-run programs to provide formal or informal *crisis prevention* and inspire persons in recovery to act as role models for their peers, and even mentors

or teachers. Through *peer mentoring and teaching* participants receive information about the consumer movement, and new participants discover commonality with others. This peer support often produces the first dramatic change in a consumer's perspective, helping him or her move from despair to hope and empowerment. Consumers often report that joining a peer-run program gave them a sense of belonging that replaced their previous loneliness and isolation.

Education and Advocacy

The core ingredients in this category are *self-management and problem-solving strategies* as well as *self-advocacy*, and these ingredients apply, for the most part, to all of the programs in our study. Most peer-run programs provide some way of learning self-management skills, and most encourage participants to identify their own needs and to advocate for themselves when there are gaps in services. In one way or another, all peer-run programs allow participants to develop and improve social skills in a natural environment in which they feel comfortable. This is often a first step toward creating or re-establishing valued roles in the community and reintegrating into community life. The focus is on practical solutions to human concerns.

The cluster of programs under Education/advocacy also contains elements that are sometimes particular to education classes or advocacy training and not as prominent in drop-in centers and peer support programs. Educational programs, various kinds of advocacy, and community education are projects that may or may not be present in a drop-in center or a mentoring program. For example, training models of peer-run programs such as BRIDGES in Tennessee are more likely to offer formal instruction in daily living skills, such as job readiness, communication skills, and assertiveness skills.

Most programs encourage consumers to practice self-advocacy by becoming active partners in developing their service plans with traditional agencies or mental health professionals. However, some peer-run agencies also feature well-defined programs in which individual advocates work on behalf of their peers to assist them in resolving problems encountered with entitlement programs, medical institutions, community agencies, residences, and even their own families. In our study, for example, educational programs such as Advocacy Unlimited and drop-ins such as MHCAN both teach and practice self-advocacy and individual peer advocacy. These peer-run advocacy programs also use a number of tools to carry out *systems advocacy*, to bring changes at the societal and legislative levels. Such tools may include testifying before the legislature; participating on boards, committees, and task forces; and communicating directly with policy and lawmakers.

Finally, *community education* is practiced by all programs to some degree through newsletters and other methods of outreach to the public. Some programs, however, such as the four drop-in centers in our group, go a step further by creating a bureau that provides speakers to make formal presentations before local community groups or nationally held conferences for consumers, families, and mental health professionals. Speakers such as these, or such as individual consumers who tell their stories, are probably the single best stigma-destroying tool available to us. Remarkable changes can occur when we just make the point that we are human beings with the same needs and aspirations as everyone else.