

**Appendix 6**

**Suggested Readings for**

**Chapter 6: Skills and Strategies for**

**Effective Self-Advocacy**

## A WORKING DEFINITION OF EMPOWERMENT\*

"Empowerment" has become a popular term in mental health programs, yet it has lacked a clear definition. In a research project designed to measure empowerment in programs funded by and for mental health services users, we first undertook to come up with a working definition. Key elements of empowerment were identified, including access to information, ability to make choices, assertiveness, and self-esteem. Empowerment has both an individual and a group dimension. Details of the definition are provided, along with a discussion of the implications of empowerment for psychiatric rehabilitation programs.

### Introduction

"Empowerment" is a term that has become very popular in mental health services (at least in the United States). Nearly every kind of mental health program claims to "empower" its clients, yet in practice there have been few operational definitions of the term, and it is far from clear that programs that use the term are in any measurable way different from those that do not. Still lacking a definition, the word has become common political rhetoric, with a flexibility of meaning so broad that it seems to be in danger of losing any inherent meaning at all. Some conservative U.S. politicians have promoted welfare "reform," for example, by claiming that cutting off benefits will "empower" recipients (who would thus, presumably, become self-sufficient)! Such usages make it difficult to claim that "empowerment" is a meaningful concept. The problem of using the term meaningfully becomes even more problematic in other countries and other languages. When I have spoken abroad, I find that the word is usually not translated; the translator merely repeats "empowerment," in English, perhaps hoping that the listeners will be able to draw some meaning from the context. Nonetheless, I believe that the term can have real meaning, and that the first step in making it meaningful is to define it.

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\* Judi Chamberlin © 1999. National Empowerment Center, Inc. All rights reserved. Available at [http://www.power2u.org/empower/working\\_def.html](http://www.power2u.org/empower/working_def.html). Judi Chamberlin is a psychiatric survivor and a long-time activist for patients' rights. She is the author of On Our Own: Patient Controlled Alternatives to the Mental Health System, as well as numerous articles on the topics of self-help and alternatives. She is affiliated with the Center for Psychiatric Rehabilitation, Boston University, and with the National Empowerment Center, Lawrence, Massachusetts. For information contact the author at the Center for Psychiatric Rehabilitation, 930 Commonwealth Avenue, Boston, MA 02215, USA.

## A Working Definition of Empowerment

At the Center for Psychiatric Rehabilitation, I directed a research project that studied participants in user-run self-help programs for people with psychiatric disabilities.<sup>1</sup> At the beginning of the study, we found that many of these groups included the term "empowerment" in their program definitions. It was clearly a key concept, making it necessary to define empowerment as part of the project. We therefore brought together a group of a dozen leading U.S. consumer/survivor self-help practitioners,<sup>2</sup> who formed the Advisory Board of our project, and we made our first task the formulation of a definition. Although we recognized that empowerment had elements in common with such concepts as self-esteem and self-efficacy, we also felt that these concepts did not fully capture what we saw as distinctive about empowerment. After much discussion, we defined empowerment as having a number of qualities, as follows:

1. Having decision-making power.
2. Having access to information and resources.
3. Having a range of options from which to make choices (not just yes/no, either/or.)
4. Assertiveness.
5. A feeling that the individual can make a difference (being hopeful).
6. Learning to think critically; learning the conditioning; seeing things differently; e.g.,
  - a. Learning to redefine who we are (speaking in our own voice).
  - b. Learning to redefine what we can do.
  - c. Learning to redefine our relationships to institutionalized power.
7. Learning about and expressing anger.
8. Not feeling alone; feeling part of a group.
9. Understanding that people have rights.
10. Effecting change in one's life and one's community.
11. Learning skills (e.g., communication) that the individual defines as important.
12. Changing others' perceptions of one's competency and capacity to act.
13. Coming out of the closet.
14. Growth and change that is never ending and self-initiated.

## 15. Increasing one's positive self-image and overcoming stigma.

We decided early in our discussions that empowerment was complex, multidimensional concept, and that it described a process rather than an event. Therefore, we did not believe that an individual had to display every quality on the list in order to be considered "empowered." This definition is not necessarily a global one, but is linked specifically to the research project, and is offered as a working definition for the purpose of opening discussion as to whether "empowerment" is a meaningful term that describes a discrete mechanism used by members of the self-help groups in our study. In fact, I have found that in presenting the definition to various groups, it often does begin such a useful discussion, and I have been told by non-English speakers that the definition has been useful in their attempts to translate the word.

### **Empowerment: The Elements**

Returning to the definition, let us now look at each of the elements:

**Having decision-making power.** Clients of mental health programs are often assumed by professionals to lack the ability to make decisions, or to make "correct" decisions. Therefore, many programs assume the paternalistic stance of limiting the number or quality of decisions their clients may make. Clients may be able to decide on the dinner menu, for example, but not on the overall course of their treatment. Yet, without practice in making decisions, clients are maintained in long-term dependency relationships. No one can become independent unless he or she is given the opportunity to make important decisions about his or her life.

**Having access to information and resources.** Decision making shouldn't happen in a vacuum. Decisions are best made when the individual has sufficient information to weigh the possible consequences of various choices. Again, out of paternalism, many mental health professionals restrict such information, believing restriction to be in the client's "best interest." This can become a self-fulfilling prophecy, since, lacking adequate information, clients may make impulsive choices that confirm professionals' beliefs in their inadequacy.

**Having a range of options from which to make choices.** Meaningful choice is not merely a matter of "hamburgers of hot dogs" or "bowling or swimming." If you prefer salad, or the library, you're out of luck!

**Assertiveness.** Non-diagnosed people are rewarded for this quality; in mental health clients, on the other hand, it is often labeled "manipulativeness." This is an example of how a psychiatric label results in positive qualities being redefined

negatively. Assertiveness—being able to clearly state one's wishes and to stand up for oneself - helps an individual to get what he or she wants.

**A feeling that the individual can make a difference.** Hope is an essential element in our definition. A person who is hopeful believes in the possibility of future change and improvement; without hope, it can seem pointless to make an effort. Yet mental health professionals who label their clients "incurable" or "chronic" seem at the same time to expect them to be motivated to take action and make changes in their lives, despite the overall hopelessness such labels convey.

**Learning to think critically; unlearning the conditioning; seeing things differently.** This part of the definition created the most discussion within our group, and we were unable to come up with a single phrase that encapsulated it. We believed that as part of the process of psychiatric diagnosis and treatment, clients have had their lives, their personal stories, transformed into "case histories." Therefore, part of the empowerment process is a reclaiming process for these life stories. Similarly, the empowerment process includes a reclaiming of one's sense of competence, and a recognition of the often-hidden power relationships inherent in the treatment situation. In the early stages of participation in self-help groups, for example, it is very common for members to tell one another their stories; both the act of telling and that of being listened to are important events for group members.

**Learning about and expressing anger.** Clients who express anger are often considered by professionals to be "decompensating" or "out of control." This is true even when the anger is legitimate and would be considered so when expressed by a "normal" person, and is yet another example of the way in which a positive quality becomes a negative once a person is diagnosed. Because the expression of anger has often been so restricted, it is common for clients to fear their own anger and overestimate its destructive power. Clients need opportunities to learn about anger, to express it safely, and to recognize its limits.

**Not feeling alone; feeling part of a group.** An important element in our definition is its group dimension. We believe that it is necessary to recognize that empowerment does not occur to the individual alone, but has to do with experiencing a sense of connectedness with other people. As was brought up numerous times during our discussion, we did not want to leave the impression that we considered the image of "John Wayne coming into town, fixing everything, and riding off into the sunset" to be synonymous with our definition!

**Understanding that people have rights.** The self-help movement among psychiatric survivors is part of a broader movement to establish basic legal rights. We see powerful parallels between our movement and other movements of oppressed and

disadvantaged people, including racial and ethnic minorities, women, gays and lesbians, and people with disabilities. Part of all of these liberation movements has been the struggle for equal rights. Through understanding our rights, we increase our sense of strength and self-confidence.

**Effecting change in one's life and one's community.** Empowerment is about more than a "feeling" or a "sense," we see such feelings as precursors to action. When a person brings about actual change, he or she increases feelings of mastery and control. This, in turn, leads to further and more effective change. Again, we emphasized that this is not merely personal change, but has a group dimension.

**Learning skills that the individual defines as important.** Mental health professionals often complain that their clients have poor skills and cannot seem to learn new ones. At the same time, the skills that professionals define as important are often not the ones that clients themselves find interesting or important (e.g., daily bed making). When clients are given the opportunity to learn things that they want to learn, they often surprise professionals (and sometimes themselves) by being able to learn them well.

**Changing others' perceptions of one's competency and capacity to act.** If anything defines the public (and professional) perception of "mental patients," it is incompetency. People with psychiatric diagnoses are widely assumed to be unable to know their own needs or to act on them. As one becomes better able to take control of one's life, demonstrating one's essential similarity to so called "normal" people, this perception should begin to change. And the client who recognizes that he or she is earning the respect of others increases in self-confidence, thus further changing outsiders' perceptions.

**Coming out of the closet.** This is a term we have taken from the gay/lesbian movement. People with devalued social statuses who can hide that fact often (quite wisely) choose to do so. However, this decision takes its toll in the form of decreased self-esteem and fear of discovery. Individuals who reach the point where they can reveal their identity are displaying self-confidence.

**Growth and change that is never ending and self-initiated.** We wanted to emphasize in this element that empowerment is not a destination, but a journey; that no one reached a final stage in which further growth and change is unnecessary.

**Increasing one's positive self-image and overcoming stigma.** As a person becomes more empowered, he or she begins to feel more confident and capable. This, in turn, leads to increased ability to manage one's life, resulting in a still more improved self-image. The negative identity of "mental patient" that has been

internalized also begins to change; the individual may discard the label entirely, or may redefine it to convey positive qualities.

## **Empowerment and Rehabilitation**

Within the research project, the definition was the starting point for the development of a measurement instrument.<sup>3</sup> Although our study was limited in scope, we found that participants in the groups we studied displayed a fairly high level of empowerment.<sup>4</sup> It is hoped that both the definition and the research project will promote the further study of the concept of empowerment for people with psychiatric disabilities. This concept is particularly important within psychiatric rehabilitation programs, since these programs often claim that they are promoting independence, autonomy, and other ideas related to empowerment. It would be extremely useful to find out, for example, whether rehabilitation practitioners believed their programs were promoting empowerment in their clients, and whether clients of those programs agreed. An increase in empowerment scores following participation in a program would be a positive indicator about that program. If scores did not increase, practitioners (and program clients) should try to identify those program elements that interfere with clients becoming empowered.

Operating an empowerment-oriented program has risks, as does becoming empowered. The desire to protect (and to be protected) is a strong one; nonetheless, there are genuine benefits when clients begin to control their own lives, and when practitioners become guides and coaches in this process, rather than assuming the long-term, paternalistic role of supervisors. Such a shift of roles and practices would make rehabilitation services truly transformative in the lives of their clients.

<sup>1</sup> Copies of the project materials and results are available from the author.

<sup>2</sup> A list of the Advisory Board members is available from the author.

<sup>3</sup> Copies of the instrument, "Making Decisions," are available from the author.

<sup>4</sup> An article describing the instrument and the study result is currently in preparation.