

EMPOWERMENT EFFECTS OF
TEACHING LEADERSHIP SKILLS
TO ADULTS WITH
A SEVERE MENTAL ILLNESS
AND THEIR FAMILIES

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As consumers become proficient with advocacy skills, they are better able to impact the planning and provision of mental health and support services at the state and local levels. A Leadership Academy was conducted in Idaho to teach the basic skills necessary for adults with a mental illness and family members to become effective leaders in grassroots advocacy organizations. Participants learned to identify issues and develop and implement action plans to address those issues within the context of their local communities. While the first three sessions of the Academy were facilitated by professional instructors, the last two were led by consumers and family members who had graduated from the Academy. In the course of five sessions in three years, 160 consumers and family members graduated from the Leadership Academy. In a 27 months period, graduates took 1,345 action steps to address issues of concern, with 400 outcomes, ranging, from the establishment of a speakers bureau to starting a respite facility.

Significantly involving people who use mental health services in system planning and evaluation is essential to the development of an effective and responsive system of services. Strong input from consumers is required to determine what services they find useful and appropriate, what alternatives or modifications are needed, and what processes need to be improved. There is a need to determine what services might be run by professionals and what services are better run by consumers, family members, or others. Finally, there is a need for consumers to become more empowered in their own recovery, by

A major problem is that many consumers and family members do not have the skills to identify their needs and express their opinions in a clear, positive and assertive manner. Most do not have the experience or training to allow them to effectively influence political systems. Consumers who have lived in group residences or institutions or participated in day treatment programs for long periods of time, often have difficulty identifying personal issues and making choices, as many, if not most, decisions have been made for them by professional staff. To make an impact on their environments, they need assistance in empowering

According to Kieffer (1984), empowerment is a process of development that takes place over time, as a result of active and emotional struggling through conflict within a context of peer support. He suggests that people who become empowered, progress through four stages of developmental competence similar to the developmental life stages of infancy, childhood, adolescence, and adulthood as they develop skills, confidence, self-esteem, and maturity through continued long-term involvement with grassroots advocacy organizations. Knowledge of both the system that is being addressed, and the tools that may be effective in addressing that system are important components of this process.

Hess (1984) and Fawcett, Seekins, Whang, Muii, and Suarez de Balcazar (1984) suggest that power can only be understood within the context of a system. Fawcett and his colleagues hypothesize that empowerment may be affected by (a) increasing knowledge and skills, (b) increasing effects on both positive and negative consequences, and (c) increasing environmental opportunities. They suggest that human service professionals can facilitate community empowerment through the development of social technologies (e.g., training, educating, and providing information). This has been supported by Balcazar, Seekins, Fawcett, and Hopkins (1990) and by Balcazar, Mathews, Fawcett and Seekins (1992), who found that training members of disabilities advocacy organizations in issue identification and reporting skills, resulted in increased reports of disability issues, increased activities and outcomes, and improved chairperson performance.

The first three authors, together with the Idaho Consumer Advocacy Coalition, the Idaho Alliance for the Mentally Ill, and the Shoshone Bannock Tribal Health and Human Services, start

ed the Idaho Leadership Academy to provide consumers and family members with the skills needed to assume a position of strong leadership in changing the system of mental health services and supports in the state of Idaho. The Academy was also designed to provide a support system for graduates and opportunities to use their skills in their home communities. Finally, the Academy was intended to provide them with the ability to collect data to assess the impact of their leadership on the local, state, and national levels.

METHODS

Participants

Five Leadership Academy sessions were offered over a two-year period. Each was open to a maximum enrollment of 45 participants consisting of adults with a severe mental illness and family members. The goal was to balance enrollment to include three consumers from each of seven geographical service regions in Idaho, two family members from each region, and up to ten Native American consumers or family members from the five reservations and six major tribes in Idaho. Each regional consumer group, Alliance for the Mentally Ill affiliate, and tribe selected its own representatives to attend the Academy.

The rationale for enrolling multiple individuals from regions or tribes was to foster the development of local teams. This was designed to address a problem common throughout Idaho in which individual leaders would emerge in a region, be identified as such, and quickly become overburdened with the responsibilities and tasks that accompany a leadership role. Without major support and assistance, these individuals often became highly stressed, with some being hospitalized as a result. The team approach emphasized by the Academy was meant to develop cadres of leaders

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in regions or reservations in which members could actively support one another and share the responsibilities and tasks of leadership.

It is important to note that a special effort was made by the Academy to involve Native Americans. There are six major tribes on five reservations in Idaho. When the Academy was established, the Native American tribes recognized issues such as substance abuse and depression, but were reluctant to recognize other types of mental illness.

Native American adults with a serious mental illness and their family members did not have access to consumer or family support groups or sufficient professional services. Suicides and suicide attempts were disproportionately high on some reservations. To help facilitate the involvement of Native American consumers and family members, a full-time Native American coordinator was hired.

A total of 160 consumers and family members graduated from the five Academy sessions. Table 1 provides demographic information about the participants. Of special note, is that while only 1% of Idaho's population is Native American, 20% of participants were Native American. The 42 % of unreported diagnoses reflects participants who were family members.

Description of Academy Sessions

Each of the five Leadership Academy sessions lasted two and one-half days. Leadership and advocacy skills were taught through discussion, the use of four workbooks, small group exercises, and role-playing. Participants actively practiced these skills by leading mock meetings, writing action plans, writing letters, and making presentations to the group. Each Academy session had a social event during the evening of the first day. During this time, participants, instructors, and support staff gathered for

Table I-Demographic Characteristics of Leadership Academy Participants

CHARACTERISTIC	N	%
Group		
Consumers	92	58
Family members	68	42
Mental Illness		
Bipolar	38	24
Depression	12	8
Schizophrenia	27	17
Other	15	9
Not reported	68	42
Race		
Black	2	1
Hispanic	4	3
Native American	32	20
White	122	76
Gender		
Female	103	64
Male	57	36
Age		
18-29	31	19
30-39	49	31
40-49	45	28
50-59	25	16
60-69	9	6
70+	1	0

evening snacks and entertainment. Entertainment consisted of individuals volunteering to sing songs, tell jokes or stories, sponsor skits, and organize impromptu games. Two of the more moving moments were one consumer playing a Lakota flute the first time in public, and another consumer describing how she attempted to relieve the pain of hospital seclusion through "101 things to do in a seclusion room."

University faculty taught the first three Academy sessions. During the third session of the Academy, graduates were invited to apply for additional training, so that they could serve as trainers at the fourth and fifth sessions. Ten consumers and family members, including one Native American, were chosen to receive additional instruction on how to use the

materials to train others. These consumers and family members taught the fourth and fifth Academy sessions using a team teaching format.

Since one of the goals of the Academy was to network all graduates so they could support one another, share their knowledge, and acquire new skills, graduates were invited to attend subsequent sessions of the Academy. Graduate consumers and family members began new Academy sessions by providing an orientation to new participants. They reported on the actions that they had taken after graduating from the Leadership Academy, and they provided information about local advocacy groups and concerns. They served as positive role models for new participants.

Following the orientation, graduates were given the opportunity to participate in advanced training tracks. These tracks included practice in giving legislative testimony and courses in how to work with the media, public speaking, local advocacy group development, fundraising techniques, and on-line computer networking. National mental health advocacy leaders and local community experts were recruited to teach these workshops. Of those attending advanced training, 60% were consumers and 40% were family members, with an average of 28 participants attending each graduate Academy track.

To provide further support and networking opportunities for graduates, statewide telephone conference calls involving all interested graduates were held approximately every 6 to 8 weeks. During these calls, graduates discussed their accomplishments, exchanged advocacy information, assisted each other in solving problems, and provided mutual support. It was not unusual to have 30 individuals from throughout the state participating in a single conference call.

Materials

Leadership Academy training materials consisted of four workbooks based on workbooks previously used by people with physical disabilities. To make them relevant for Academy participants, a team consisting of mental health professionals, a consumer, a family member, and a Native American modified their contents before the first Academy session was held. Workbooks were designed to teach participants to become advocates by learning to monitor events, report issues, conduct effective meetings, identify issues of concern, avoid nonissues, plan projects and action plans to address identified issues, and learn to teach advocacy and leadership skills to others. Instructors used additional materials with written examples to teach participants how to write effective letters and give testimony to public officials.

Materials used to enable consumers and family members to identify local and state issues of concern, were developed according to the concerns report method. The concerns report method is a systematic, data-based process for citizens to identify issues of concern in their communities, such as housing, employment, and stigma. This method has been used to identify issues, and ideas for improvement, from the perspective of a variety of groups, including people with disabilities (Fawcett, et al., 1988) and people with low incomes (Seekins & Fawcett, 1987). The concerns report method uses a survey to allow respondents to rate both the importance of an issue and their satisfaction with the community's efforts to address the issue. Each is rated on a five-point numerical scale. A score is determined for each issue by multiplying the level of satisfaction by the level of importance; items with the lowest level of satisfaction and the highest level of importance are identified as having the highest priority. The concerns report

method was chosen because it involves consumers and family members in selecting issues and interpreting results, because it describes problems and strengths to system decision makers in the form of data, and it serves as a catalyst for the development of concrete proposals to solve problems and preserve strengths.

In order to develop a concerns report survey that accurately reflected items of importance to adults with a severe mental illness and their family members, a list of over 100 potential issues of concern was presented for revision to a representative group of consumers and family members, including Native Americans. Prioritized topics included housing, employment, health care, stigma, service access, and other areas. The revised list was then presented to consumer and family member participants at the first Leadership Academy session for further revision and reduction of the items to a manageable number. This resulted in two 20-item concerns report surveys: one containing consumer concerns for use in surveys of consumers, and the other containing family member concerns for use in surveys of families.

Description of Concerns Report Process

The two concerns report surveys developed during the first Leadership Academy session were distributed to consumers and family members in each of the seven regions of the state and on two Native American reservations. Approximately 25% of the surveys were completed and returned. Of the 279 individuals who responded to surveys, 181 were consumers and 98 were family members. Of the 181 consumers, 12 were Native American. Of the 98 family members, 48 were Native American.

Survey results were analyzed to determine the top four issues and the top four strengths, identified by consumers and family members for each region and

reservation that responded. Town meetings, to which consumers, families, the media, state and local government staff, and the general public were invited, were held in the seven regions and one reservation to discuss the results.

A total of 375 people attended town meetings. Of these, 163 were consumers, 33 were family members, 10 were tribal agency representatives, 82 were from state government, 76 were representatives of other agencies, nine were from the media, and two were legislators.

Town meetings allowed for open discussion and clarification of local issues, strengths, obstacles, and resources. Participants spent time brainstorming possible ways to address concerns and developing action plans. In a number of cases, teams were formed during the meetings to immediately begin work on issues.

Assessment Procedures

Effectiveness of the Leadership Academy was measured according to the number of mental health advocacy actions and outcomes accomplished by Academy participants. The operational definition used to measure actions was "the work ing steps one takes on an issue, such as planning an event, researching a fund ing source, making significant telephone calls, assembling mailings, attending meetings, or preparing testimony" The operational definition used to measure outcomes was "a tangible product of one or more advocacy actions, such as a group presentation, a response from a legislator, a consumer receiving a new service, an event held, an article printed in the newspaper, or a grant received." Evaluating the resulting impact of the actions and outcomes, such as increased public understanding of mental illness or improved quality of life for individuals with a mental illness, was beyond the scope of the project.

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Data were collected on advocacy actions and outcomes through monthly telephone calls and quarterly interviews with Academy participants. Data were gathered for 27 months. Collected information was delineated by action and outcome under nine categories of advocacy work:

1. Recognition (e.g., thanking an individual or organization for their active support of a mental health issue);
2. Community education (e.g., raising the awareness of community members, businesses, schools, and other organizations about mental illness and mental health issues);
3. Policy/legislative changes (e.g., acting to influence local, state, or national policy on mental health issues);
4. Leadership appointments (e.g., accepting an appointment to a local, regional, state, or national board or council which has influence over mental health issues, or becoming an officer in a board or council);
5. Fundraising (e.g., identifying funding needs, researching funding sources, holding fundraising events, writing grant proposals, seeking donations of goods and services);
6. Improving services (e.g., identifying service preferences of consumers, making services more responsive to consumer needs, creating new services, and evaluating services);
7. Consumer rights (e.g., defining consumer rights, teaching consumers or providers about consumer rights, standing up for consumer rights);
8. Building networks (e.g., forming beneficial relationships with businesses, service providers, policy makers, other associations and advocacy groups);

9. Strengthening an advocacy group (e.g., improving membership, functioning, or focus of a local mental health advocacy group).

In addition, data were collected regarding participant opinions of the Leadership Academy. Participants in at least one of the first four Academy sessions were asked to respond to a written satisfaction survey. Of the 97 participants surveyed, 45 responded. Survey questions inducted assessment of the usefulness of the training, whether the training enabled the respondent to be a more effective advocate, what part of the training was most useful, and what was needed to continue to develop advocacy skills.

Advocacy Actions and Outcomes

Over a 27-months period, Leadership Academy participants initiated a total of 1,345 advocacy actions. Table 2 illustrates total actions by category. The greatest level of advocacy work occurred in the areas of community education and improving services.

As a result of these actions, Academy participants achieved 400 advocacy outcomes. Table 2 shows that the categories of advocacy outcomes align closely with the advocacy actions. Community education actions generated the most outcomes, with policy or legislation outcomes ranking second.

Table 3 illustrates the advocacy actions and outcomes by quarter for the 27 months that data were collected. Levels of advocacy activity peaked during the fifth and ninth (final) quarters. These peaks followed Leadership Academy sessions that offered advanced advocacy training. The third highest period of advocacy activity occurred during the seventh quarter, again immediately after an Academy session.

Examples of Advocacy Actions and Outcomes

Qualitative data were collected on advocacy actions and outcomes stemming from involvement in the Leadership Academy. The following sections provide some examples of the accomplishments of consumers and families.

Advocacy for housing and crisis respite care.

Consumers in several areas of the state identified the lack of housing options, including crisis and respite hous

ing, as a major area of concern. Following the town meeting to discuss results of the local concerns report survey, consumers in one region formed a coalition and created, by consensus, a model of how they wanted consumer respite services to look. With the support of the manager of the local mental health program, the coalition sought funding to support the model.

In another region, the local consumer self-help group opened a facility to ad

Table 2-Actions and lines Achieved by Leadership Academy Participants

AREA	Actions		OUTCOMES	
	N	%	N	%
Building networks	93	7	12	3
Community education	405	30	14	134
Consumer rights	18	17	2	2
Fundraising	91	7	18	5
Improved services	252	19	48	12
Leadership appointments	67	5	65	16
Policy and legislation	227	17	74	19
Recognition	45	3	5	1
Strengthening groups	147	11	30	8

Table 3--Actions and Outcomes Achieved by Leadership Academy Participants by Quarter

Quarter	ACTIONS		OUTCOMES	
	N	%	N	%
First	73	6	16	4
Second	111	8	27	7
Third	93	7	22	5
Fourth	110	8	30	8
Fifth	252	19	99	25
Sixth	140	10	46	11
Seventh	190	14	51	13
Eighth	104	8	23	6
Ninth	272	20	86	21

dress respite care and room and board needs for those with a severe mental illness. Plans for the facility grew out of a discussion at the town meeting in which results of the local concerns report survey were presented. Consumers, family members, staff, and other advocates worked together to create this new facility with funding from both the county and state.

Advocacy against stigma. Stigma attached to mental illness was another top concern identified in several regions of the state. A consumer self-help group in one region addressed this issue by developing and distributing educational brochures in the community. A second region's efforts included submitting a goal to the state plan to develop a speakers bureau to provide community education about mental illness. This goal was supported by the local mental health center, consumers, family members, and the local mental health advisory board. In that region, the local consumer self-help group formed a committee which applied for and received a small grant to develop a speakers bureau.

As a result of their town meeting, participants in a third region formed an ongoing coalition to address identified concerns, including stigma. The coalition applied for and received a seed grant to research and purchase an educational curriculum on mental illness that could be used in local schools. In addition to presentations in local schools, this group presented information on mental illness at a state conference of school counselors.

In a fourth region, the local consumer self-help group applied for a seed grant to make an educational video on mental illness for community presentations. This video was written and produced by consumers.

After town meetings in another region, the You Erase Stigma task force was es

tablished, involving consumers, family members, mental health staff, and community members. Its speakers bureau developed a curriculum and arranged speaking engagements and press releases related to community education about mental illness.

Advocacy for consumer rights.

Consumers in one region identified lack of knowledge about their rights as citizens with a mental illness as their top concern. Staff from the regional mental health center and the local protection and advocacy group responded by providing education on the rights of consumers of mental health services.

Family members in another region identified the lack of information about the condition of their family member as a top concern. The local family self-help group chose to address this issue through initiation of a family education program at the nearby state hospital.

The hospital now maintains family and consumer involvement on its grievance review board.

At the state level, the lack of information about consumer rights was addressed by a task force that included representation from consumers and families. The task force helped secure adoption of a family involvement policy and a consumer rights policy in mental health services. An informational booklet written by consumers on this topic was distributed throughout the state.

Other areas of consumer advocacy. In response to identified consumer concerns, advocacy efforts addressed other areas, including strengthening relationships with law enforcement, supporting drop-in centers, and developing task forces for the prevention of suicides. For example, in response to family member concerns in one region, the mental health center assigned a staff member to

Table 7--Participant Ratings of Effects of the Leadership Academy

EFFECT	Rating (%)				
	5	4	3	2	1
Sense of empowerment Advocacy	41	34	18	5	2
Advocacy effectiveness	32	32	25	9	2
Advocacy activity level	34	36	14	9	7
Strength of own local advocacy group	19	36	24	5	16

Note. Ratings range from 5 (much more/greatly increased) to 1 (not/no more increased). n = 45.

Table 5—Participant Ratings of Aspects of the leadership Academy

Aspect	Rating (%)				
	5	4	3	2	1
Usefulness	66	25	5	2	2
Satisfaction in addressing state mental health issues	12	16	44	14	14
Satisfaction in addressing local mental health issues	9	21	35	19	16

Note. Ratings include four positive levels ranging from very (5) to little (2) and one negative level (not, which was scored as 1). N = 45.

educate law enforcement personnel, connect with city government, and clarify roles to improve crisis services and avert crises.

Participants reported improvements in local crisis services and improved relationships with the courts and law enforcement.

Similarly, as a result of strong collaborative efforts, a drop-in and activity center opened on a reservation.

In another region, following the town meeting in which it was identified as an issue, the local mental health center provided funding and support for a consumer-run drop-in center. Finally, motivated by identified concerns and several suicides among members of the Shoshone-Bannock tribe, advocates in that community began a suicide prevention task force.

Length of Advocacy Involvement

Leadership Academy participants were tracked 6 months and 1 year after they attended the Academy to determine if they were still active as advocates. Given the project time frame, it was not possible to follow up with the participants in the fifth Academy session, and those from the fourth session were only tracked at a 6-month interval. Of the 130 participants attending the first four Academy sessions, 88 (68%) were still involved in mental health advocacy activities 6 months after they attended the Academy, while 100 (43%) of those attending one of the first three sessions were still active after 1 year. Reasons individuals gave for discontinuing their advocacy activities included illness or personal or family crisis (28%), entering school or employment (26%), moving away (14%), death (4%) and other (28%).

Participant Rating of the Leadership Academy After the fourth Leadership Academy session, 45 participants from the first four sessions responded to a written survey on their opinions of the Academy

Table 6--Participant Ranking of Most Valuable Aspects of the Leadership Academy

ASPECT	RANKING	PERCENT
Networking with consumers and family members	1	34
Support and confidence budding	2	19
Skills in approaching advocacy issues	3	17
Leadership skills	4	16
Letter writing to legislators	5	9
Written materials	6	5

Note. N=45

Table 7-Participant Ranking of Types of Further Assistance Desired of the Leadership Academy

TYPE OF ASSISTANCE	RANKING	PERCENT
More advocacy training	1	34
Continued statewide networking	2	22
Information updates on issues	3	19
Support and development of local advocacy group	4	16
Practice in doing advocacy work	5	9

Note. N= 45

project. Tables 4 through 7 display their responses to the survey questions. Table 4 shows that the majority, 79% to 93%, of the survey respondents indicated that the Leadership Academy had a positive impact on their advocacy efforts and their sense of empowerment. Table 5 shows that 66% rated the Leadership Academy as very useful. It also shows that there was slightly higher satisfaction among participants in addressing state issues than in addressing local issues. This is not surprising, given that the public mental health system in Idaho is primarily state-operated. Table 6 is of interest as it shows that the most valuable aspect of the Leadership Academy, as perceived by participants, was its networking and support. As

noted earlier, the Academy stressed this aspect through the use of regional teams, the structure of sessions, and the use of statewide conference calls. Table 7 adds support with the two most highly rated types of further assistance desired being more advocacy training and continued statewide networking.

DISCUSSION

This study focused on how teaching grassroots advocacy skills to adults with a severe mental illness and their family members changes the way they relate to their environment. The longitudinal data collection provides information on ways that trained individuals and advocacy groups became empowered and began to take action steps designed to

significantly *affect their* environment and the development of the mental health service system in Idaho. Results of this study corroborate those found in a previous study (Balcazar, Seekins, Fawcett, & Hopkins, 1990) in that consumer advocacy organizations were able to increase consumer empowerment, and bring about some changes in the community through similar training methods.

Participants reported that the most helpful aspects of the Leadership Academy were the opportunities to network with other consumers and family members from around the state, and the support and confidence building engendered by the process. Participant survey comments noted that the opportunity for consumers and family members to socialize, support, and learn from each other was extremely valuable; reinforcing the Academy's emphasis on the use of teams as agents of change. They also reported that they felt empowered, positive, and better equipped to stand up for themselves and others.

The next most important aspects of the training, as reported by participants, were the opportunities to learn advocacy skills, and to effectively lead groups or meetings.

Participants remarked that the structure and format of the workbooks, and the Academy in general, were extremely helpful in teaching them how to lead effective meetings, communicate with the legislature, and work with the media. One participant stated, "I have gained useable knowledge to go forth and make a difference in people's lives who deserve a chance."

The process of collecting data on Academy outcomes revealed barriers and challenges faced by individuals in their advocacy work. Burners included difficulty choosing issues, finding and balancing time and energy for a personal life as well as for advocacy activities, and deciding whether to focus advocacy

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efforts on the local, regional, state, or national level. Some individuals were highly motivated after training at the Academy and took on too much too fast, which caused them to burn out. Those who advocated for longer periods of time, seemed to be more likely to comfortably balance their personal lives with their advocacy activities, while those new to advocacy experimented to find the level of involvement that worked best for them. Many individuals worked well when they involved themselves in existing structures, such as regional mental health advisory boards, local coalitions and task forces, and the state mental health planning council.

Another obstacle to advocacy relates to the fact that either the consumer or a family member must cope either directly or indirectly with a severe mental illness on a daily basis. The consumer with a mental illness is challenged with keeping the illness under control while working on advocacy issues. The family member may be stressed by energy draining situations when the consumer in their family is ill or in crisis. These concerns emphasize the importance of the efforts of individuals to strike a balance between involvement in advocacy activities and taking care of themselves. Although advocacy work can be challenging, active participants appeared to function better and feel better about themselves. Advocates reported that they felt a sense of accomplishment and meaning through their interaction with others, and also began to feel more self-determined rather than dependent on others. Several participants became inactive as advocates because their functioning improved to the point that they either enrolled in college or began to work full time.

The categories of reported outcomes reflected strong interest in community education (34%), policy or legislation (19%), and leadership appointments (16%). The emphasis on community education reflected a statewide concern identified in the concerns report survey process about the negative effects of stigma. The percentages of policy or legislation and leadership appointment outcomes are indicative of strong advocacy interest around influencing the development of a mental health service system that is responsive to the needs and desires of consumers and their families. This project demonstrates several advantages of teaching grassroots advocacy skills to adults with a severe mental illness and their family members. A Leadership Academy designed to teach basic skills of issue identification, how