

# A Program of Support for Consumer Participation in Systems Change

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## *The West Virginia Leadership Academy*

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*Systems in support of services to persons with psychiatric disabilities are recognizing the benefit of developing a significant place for mental health consumers in shaping policy and services. This is an opportunity to enhance self-determination, but specific consumer attributes are required for success. The West Virginia Leadership Academy is a collective advocacy training program operating, since 1995, under the administration of grassroots consumer groups with the support of the West Virginia Office of Behavioral Health Services/Bureau for Behavioral Health and Health Facilities and, at the federal level, by the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration. The program is intended to meet the human resource requirements of a consumer-participatory system. The Leadership Academy has produced more than 375 graduates in West Virginia and, as a service of the Consumer Organization Networking Technical Assistance Center, it has evolved into a nationwide vehicle for the organization and training of mental health consumers.*

Self-determination is particularly integral as an issue in psychiatric disabilities. Barriers to self-determination for persons with psychiatric disabilities are multiplied by negative professional and general societal assumptions regarding the capacity of such persons to make rational choices for themselves. For the individual, this results in a cycle of disempowerment as debilitating as mental illness itself (Deegan, 1994). For mental health systems, the result often is the development of erroneous service policies that fail to advance the persons they serve (W. A. Anthony, Cohen, & Kennard, 1990).

Recent emphasis on the concept of recovery from major mental illnesses is drawing widespread attention to the centrality of self-determination and personal empowerment as predictors of favorable outcomes in these disorders (Anthony, 1994; Young & Ensing, 1999). Concomitantly, scrutiny is focusing upon the impact on the process of recovery by the degree of self-determination that services promote through practitioners' willingness to work in an empowering partnership with the persons they serve (Ridgway, 2001).

These conditions of self-determination and partnership for individuals with psychiatric disabilities are paralleled at the

systems level by the results of collective efforts of groups of mental health service consumers to influence policy (Trainor, Shepherd, Boydell, Leff, & Crawford, 1997). The public sector mental health system is recognizing the benefit of developing a significant place for consumers of mental health services and their family members in the planning, decision-making, implementation, and evaluation processes of state mental health agencies. The recruitment of consumers by managed care organizations to include the consumer voice in their policy development is increasing as well (Emery, Glover, & Mazade, 1998).

These developments have created an unprecedented opportunity for grassroots advocates concerned with psychiatric disability issues to make their voices heard in the shaping of policies and services. Taking advantage of these opportunities, however, requires monitoring events, identifying issues, reporting issues, organizing, and conducting strategic planning (Seekins, Balcazar, & Fawcett, 1984). These complex skills are underdeveloped among many consumers of mental health services and their family members. *Collective advocacy training* for consumers and families in Connecticut (Advocacy Unlimited, Inc., 1998), Georgia (L. Fricks, personal communication,

February 3, 2000), Idaho (Hess, Clapper, & Gibson, 2001), Maryland (Kadis, 1996; Kadis & Holmes, 1996), and West Virginia (NAMI West Virginia, 1998; Stringfellow, 2000) has arisen to (a) meet this human resource need and (b) provide a structure for ensuring that the principles of self-determination are further embedded within policy-making and service delivery processes.

Collective advocacy is *systems advocacy* in that it is oriented toward system-wide changes on behalf of a class of people rather than for a particular individual (Freddolino, 1983; Cohen, Nemec, Farkas, & Forbess, 1988). In collective advocacy training, the intended outcome is that participants will be more self-determined in the role of participatory citizen, with the capacity for democratic contribution to their community.

Social technology has been developed to facilitate participatory empowerment of people who are politically disadvantaged (Fawcett, Seekins, Whang, Muiu, & Balcazar, 1984). One such technology was developed by Seekins et al. (1984) and first implemented with mental health services consumers and their families in an Idaho training program called The Leadership Academy (Hess et al., 2001). As a result of initial reports of successful outcomes in Idaho, this technology was adopted and implemented in 1995 in West Virginia as a program to develop human resources for collective advocacy.

The West Virginia Leadership Academy for Consumers and Families initially operated with a federal grant from the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration. The academy was jointly administered by the National Alliance for the Mentally Ill, West Virginia (NAMI West Virginia), the West Virginia Mental Health Consumer Association, and what was then the West Virginia Office of Behavioral Health Services, now reorganized as a part of the West Virginia Bureau of Behavioral Health and Health Facilities.

## Leadership Academy Description

The two target populations of the West Virginia Leadership Academy program are direct recipients of mental health services and persons with family members who receive such services. West Virginia's advocacy training experience has two fundamental elements: formal Leadership Academy training events and subsequent engagement in the West Virginia mental health advocacy network.

The Leadership Academy training events are structured skill-development experiences for advocacy initiates. The advocacy network has coalesced from a variety of activities embraced and supported by the Office of Behavioral Health Services/Bureau for Behavioral Health and Health Facilities and the major West Virginia mental health consumer organizations. Although some of these activities are linked only casually to the formal Leadership Academy program, the relationship has clearly been symbiotic. Their growth and success, which have

provided enhanced system access for Leadership Academy graduates, stem largely from the human resources made available by the Leadership Academy.

### *Leadership Academy Training*

To date, the West Virginia Leadership Academy has provided 17 formal training events, and more than 375 people have successfully completed the training. Leadership Academy training is a formal event lasting 3 to 4 days. Critical behavioral variables of advocacy identified by Fawcett et al. (1984) provide much of the structure for the class content:

- *Knowledge of problems:* Participants receive instruction in monitoring organizational and community environments for important events.
- *Skill in presenting issues:* Concise and comprehensive reporting of events is taught.
- *Skill in forming and leading groups:* Instruction in organizational structure and meeting process is provided. Rules of order and organizational officer roles are outlined and practiced.
- *Strategic planning:* Participants learn how to choose projects and generate alternative solutions to community problems using cost-benefit analyses of resources and outcomes.
- *Controlling consequences for critical actors in the system:* Emphasis is placed on techniques for controlling consequences experienced by decision makers, both positive (e.g., votes for elected officials) and negative (e.g., unfavorable media attention).
- *Structural variables:* Participants learn how to access the power inherent in critical information sources such as minutes for boards of directors' meetings or meeting agendas of elected officials.

Instructors for the first few academies were clinical professionals. Thereafter, however, trainer-training sessions have been offered concurrent with the training events. Volunteer Leadership Academy graduates are prepared to be providers of advocacy education and with subsequent training events, these consumer-trainers have taken on an ever-increasing role. Since 1997, consumer-trainers have provided nearly all instruction at the Leadership Academy.

Teaching within the Leadership Academy is congruent with the principles of adult education. There is a focus on experiential learning that is oriented to trainees' building upon their individual levels of prior knowledge and experience of advocacy in an equalitarian learning environment (Knowles, Holton, Swanson, & Holton, 1998). The Academy uses a modified Direct Skills Teaching (Nemec, McNamara, & Walsh, 1992) approach that emphasizes the acquisition of discrete critical skills. Sessions run from 2 to 3 hours, combined into approximately 7-hour workshop days.

Along with skill development and support of empowering attitudes, a primary goal of the Leadership Academy is to socialize participants in the behavioral expectations of everyday workgroups and classrooms. An observation frequently made is that many members of the consumer advocacy community have been conditioned, through years of participation in support and/or therapy groups, to automatically use group settings as venues for self-revelation and seeking personal support, behaviors not necessarily congruent with effective advocacy. The Leadership Academy strives for a normalized academic ambiance that is free of traditional mental health roles. This is supported by peripheral aspects of the training events:

- Discussion of personal pathology and problems is not encouraged. Instruction emphasizes the importance of objective verbal reporting of issues relevant to the group.
- Discussion of personal dissatisfactions with systems and services is channeled into experiential lessons that focus on systems change rather than an exploration of personal meaning.
- Staff professionals do not function as clinical practitioners. Professional instructors, who may themselves be consumers, maintain a stance of supportive educational partnership. Likewise, trainees who are professionals in mental health or related fields are offered the opportunity to shed their roles. Opportunities exist for casual social contact between trainees and staff members at breaks and in evening social gatherings.
- The management team currently consists of one representative each from the West Virginia Mental Health Consumers Association and NAMI West Virginia. They work closely with the Leadership Academy coordinator, who is a consumer, and two Leadership Academy outreach workers, one from each organization. As noted previously, currently the majority of instructors are consumers.

For some participants, transition into the role of student or instructor from that of client or patient has been a key rehabilitative effect of the Leadership Academy. This rehabilitative effect also extends to the attitudes of many professionals observing the Academy in that their expectations regarding consumer performance have been expanded.

### *The Advocacy Network*

Skill-teaching success is ensured by maintaining skills at the needed level in specific real-world circumstances (Nemec et al., 1992). Although the formal Leadership Academy training events encourage the germination of politically empowered attitudes and provide for the acquisition of the knowledge and

skills required for advocacy, it is in the network of advocacy activities made available through the Leadership Academy, the West Virginia Bureau for Behavioral Health and Health Facilities, and the state's mental health advocacy community that Leadership Academy graduates experience a supportive venue in which to implement the knowledge and skills they have acquired. This network of activities includes the following:

- *Periodic conference calls.* Every 6 to 8 weeks, the Leadership Academy coordinator conducts conference calls for all graduates who wish to participate. Agendas typically include a report from each geographic area represented, information about current issues and activities, current success stories, and any questions participants may have.
- *Annual Leadership Academy conference.* All graduates are encouraged to attend an annual Leadership Academy conference. The conferences consist of organizational and system updates, motivational presentations, and advocacy skills workshops with practice opportunities. Leadership Academy graduates sharpen their presentation skills by providing workshops.
- *Mental Health Planning Council-Plus.* The West Virginia Mental Health Planning Council, charged by federal law with advocacy, planning, and monitoring of the state mental health system, meets at least twice annually in a Council-Plus format. All interested persons are invited to attend these Council-Plus meetings, with special encouragement extended through the advocacy organizations to Leadership Academy graduates. These meetings provide an opportunity for Leadership Academy graduates to observe and participate in the parliamentary procedure of a statewide policy development process.
- *Participation in consumer organizations.* Graduates are encouraged to participate in the ongoing activities (advocacy, administration, peer-support services) of the West Virginia Mental Health Consumers Association and/or those of NAMI West Virginia.
- *Other advocacy network activities.* Graduates receive frequent mailings of issue alerts and legislative updates. Some individuals have created informal correspondence networks with other graduates. Many graduates participated in the Behavioral Health Town Meetings operated by the West Virginia Office of Behavioral Health Services. These meetings consisted of focus groups to discuss behavioral health service delivery issues. Some individuals have taken on volunteer roles that have led to employment throughout the state mental health system.

Graduates serve on the boards of directors of both of West Virginia's state hospitals, as well as on Regional Comprehensive Behavioral Health Center boards of directors. In addition, many graduates of the Leadership Academy serve as full members or officers of the West Virginia Mental Health Planning Council and are thereby empowered to participate in official state governmental monitoring of services (Ingholia, 2001). They have attended state, regional, and national conferences where they have been elected to offices and chosen to serve on committees.

Most of the above activities are available at minimal cost to graduates of the Academy. Arrangements for transportation and lodging are provided for any individuals who wish to participate.

### **Choosing Leadership Academy Participants**

Screening applicants for the statewide Leadership Academy training events has proven necessary. Some early Leadership Academies were disrupted by the presence of persons preoccupied with personal needs not related to training that precluded their benefiting from the experience. In addition, many individuals enrolled with the erroneous expectation of learning about mental illness.

The West Virginia Leadership Academy management team uses a formal application process for participant selection. The general criteria for selecting applicants evolved out of experience and include degree of commitment to advocacy, possession of the personal resources needed to complete instruction and apply learning, and the readiness to move beyond personal difficulties to addressing the needs of a group. These criteria are applied liberally. Many people who only marginally met all these requirements have been successful participants and have provided valuable contributions to the West Virginia mental health advocacy community. A primary intention for the statewide leadership academies, however, is to develop leaders who may carry the information to their local groups where persons not so ready, according to the above criteria, may be exposed to the training contents at a more gradual pace.

### **Nationwide Dissemination**

The West Virginia Leadership Academy has evolved into a nationwide vehicle for the organization and training in advocacy of mental health consumers. In 1998, the West Virginia Mental Health Consumers Association received a federal grant from the Center for Mental Health Services of the Substance

Abuse and Mental Health Services Administration to establish the Consumer Organization and Networking Technical Assistance Center (CONTAC) project. As a national consumer-operated technical assistance center, CONTAC is a resource for consumers and consumer-run organizations across the United States, promoting self-help, recovery, and empowerment for individuals with psychiatric disabilities.

The Leadership Academy is acknowledged by the Substance Abuse and Mental Health Services Administration as an exemplary program. Part of CONTAC's mission is to provide programming oriented to consumer self-determination (such as the Leadership Academy) to consumer groups across the United States and its territories. Today, as a result of the CONTAC initiative, there are more than 400 Leadership Academy graduates in 15 states and the Virgin Islands. Some of these Leadership Academies have had a specific cultural emphasis, including the African American Women's Leadership Academy, which was held in Pennsylvania in 2001. The Fifty-Five Plus Leadership Academy for senior citizens was held in West Virginia in 2001.

The CONTAC Leadership Academy has strived to maintain fidelity to the original concept. Funding from the CONTAC project has allowed improvements to be made to the basic Leadership Academy, however. For example, in 2000, Jaime Delgado of the University of Illinois in Chicago contributed a lesson on "Working with Culturally Diverse Populations." Currently in development is a Spanish version of the participant's manual so as to bring this much-needed program to consumers in Spanish-speaking communities.

The CONTAC Leadership Academy is a 3-day event lead by two or three consumer instructors who have undergone a train-the-trainers program. For consumers who want more, CONTAC provides an optional 4th-day workshop: "Train the Trainers & Statewide Networks." This 1-day workshop is held for individuals who have shown interest and ability in becoming Leadership Academy trainers and planners, and it provides opportunities for leaders to develop a common vision and network their skills and resources. Tips are given to assist in managing and conducting the group's future activities.

A limited number of scholarships are made available annually to bring the Academy to individual states. In return for a scholarship, a state is expected to hold its own Leadership Academy within the following year. CONTAC will send a trainer to mentor that Leadership Academy at no cost to the organization.

This program of replication bears fruit as states are conducting their own Leadership Academies and follow-up conferences. For example, Maine had its first statewide Leadership Academy conference in 2001, with more than 100 graduates attending. This occurred only 1 year after the state's first Leadership Academy took place. Colorado has obtained federal funding to hire a director and conduct Leadership Academies throughout the state. This has occurred within 2 years of Colorado's initial Leadership Academy and train-the-trainers event conducted by CONTAC.

Exposure to parts of the training has been even wider as graduates of the Leadership Academy have presented excerpts as workshops at national conferences such as Alternatives, Clifford Beers, and the International Association of Psychosocial Rehabilitation Services.

To enhance the nationwide consumer networking emerging through the production of Leadership Academies, a database of graduates of all the academies has been developed so as to continue communication efforts, and Leadership Academy caucuses are being held at national events.

## Summary

The ongoing success of the Leadership Academy may be attributed to collective advocacy training that produces benefits, through self-determination and experience in new roles, on a range of levels. The person with a disability, the local community, and the mental health system are all enhanced by a policy that promotes service programming oriented to increasing these individuals' functioning as participatory citizens.

### *The Person*

The rehabilitative nature of collective advocacy training lies in its emphasis on role functioning in the real-world community. Some resulting role growth is peripheral to the political mission of the Leadership Academy. Numerous anecdotes have been given of Leadership Academy graduates who, having experienced in advocacy their first postdisability success in a role other than patient or client, have acquired the confidence to move on to successful employment or return to the education interrupted by their mental illness.

Along with the traditional rehabilitation emphases such as employment, living arrangements, and education, political functioning as a rehabilitative goal is legitimate and important. Living, learning, working, and socializing environments have been identified as areas of focus for increasing functioning within the psychiatric rehabilitation process (Anthony, Cohen, & Farkas, 1990). As persons with psychiatric disabilities develop and implement the knowledge, skills, and attitudes required for full involvement as citizens, a fifth environment of psychiatric rehabilitation—civic participation—emerges. Functioning in the environment of civic participation presents a new aspect of the value of community integration for persons with disabilities.

Although system support for services directly addressing personal change in the political dimension for persons with disabilities is a recent policy development, the efficacy of such services has already been demonstrated. A relationship between political attitudes and participation in collective advocacy training was supported in a study of participants in the West Virginia Leadership Academy (Stringfellow, 2000). Changes in political behavior are documented in the 2001 study by Hess

et al. that validated the impact of collective advocacy training in Idaho in terms of (a) action steps taken by graduates and (b) the resulting systemic outcomes.

The political orientation of collective advocacy training as an agent of rehabilitative personal change is particularly congruent with certain views of recovery from mental illness. Many persons who report on recovery from mental illness as a personal experience express it primarily as a politicization in which personal identification with issues of power and powerlessness emerge in action as political organization to bring about social change (Jacobson, 2001).

### *The Local Community*

Empowerment is both a community and an individual experience (Rappaport, 1984). System support of collective advocacy training, by enhancing individuals' abilities to respond to local problems through local organization, serves to strengthen local communities and avoids the destructiveness generated when policies usurp natural community functioning (McKnight, 1995). Persons with psychiatric disabilities have much to contribute to their communities, and the Leadership Academy has been facilitating this contribution.

### *The Mental Health System*

For a service system to be effective, system planners must perform their function with a clear understanding of the goals held by the individuals served by those systems (Anthony et al., 1990). Mental health system planners now listen to consumers more closely than ever (Emery et al., 1998), but without a clear articulation of what persons with disabilities want in services, the efficacy of policy remains in jeopardy. Collective advocacy training develops human resources prepared to provide the information required by systems planners.

The broadening of roles for persons with disabilities goes beyond developing the ability to articulate needs, however. The roles that consumers of services play in the mental health system are undergoing rapid expansion in other directions. For example, consumers are moving beyond the role of recipients of services to providers of services (Mowbray et al., 1996). So, too, through collective advocacy training and practice, consumers may move from recipients of policy to participants in policy development. This is significant to ensuring self-determination in policy, in that these consumer system participants do not just believe in self-determination for persons with disabilities—they are living it. To the degree that they proactively participate as an integral system element, the dichotomy between the service system and those served is diffused. Self-determination thereby infuses not only the products of policy but also the process.

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