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## ABSTRACT

This document contains 18 papers presented at a conference designed to increase practitioners' understanding of disability issues and peer support strategies, with emphasis on peer support in such practice settings as independent living centers, community-based employment programs, medical programs, and secondary and higher education. The papers are: "Research on Peer Support" (Robert L. Akridge); "The Scientist and the Frog: A Tale of Two Creatures in the Form of an Experimental Fable" (Steven E. Brown); "Self-Help: Key to Empowerment" (Dale S. Brown); "A Case History of a Peer Counseling Program" (Jan Lilly); "A Movement towards Independence: One Perspective on the Disability Rights Movement" (John Chappell); "Peer Services and the VR System: A Parable of Peers" (Theodore W. Haworth); "Peer Support Counseling" (David G. Kay); "Minilab on Peer Counseling Skills" (Dale S. Brown); "Peer Support Services" (Kathleen M. Anderson); "The Kentucky Peer Support Program for Persons with Disabilities" (Dolores E. Reddinger); "Peer Counseling as It Relates to Persons Who Make a Transition from a Long-Term Care Facility into the Community" (Rick McWilliams); "A Personal Journey to Freedom" (Patricia Cudahy); "The Peer Mentoring Aspect of Enclaves in Supported Employment" (Debra A. Harley); "Return to Productivity: Innovative Vocational Programming for Persons with Spinal Cord Injury" (Ann Temkin); "ICAN, Increasing Capabilities Access Network Friends of Technology Network (A Peer Support Network)" (Karen Bays); "Jobs Rally: Community Development Rehabilitation Using Peer Support Strategies" (Robert L. Akridge); "Using the 'Jobs Rally' Approach to Community Development" (Dan Kessler and Marsha Mitchell); and "From Information Overload to Effective Access Skills: Equipping Consumer and Providers for the Information Age" (R. Brantley Cagle, Jr.). Ten general recommendations conclude the document. (Most papers include references.) (DB)

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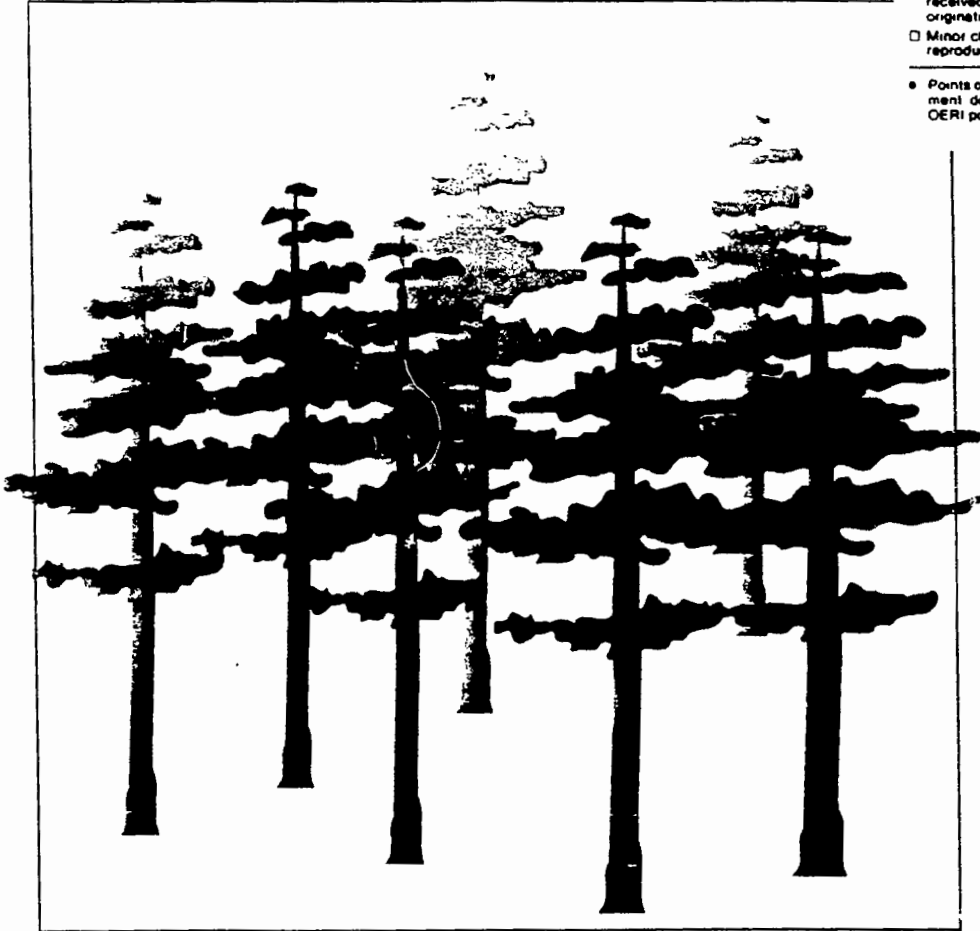
Proceedings of the First National Forum

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# Peer Support Programs

To Promote Independent Living and  
Career Development of People with Disabilities

Louisville, Kentucky • November 14, 1991

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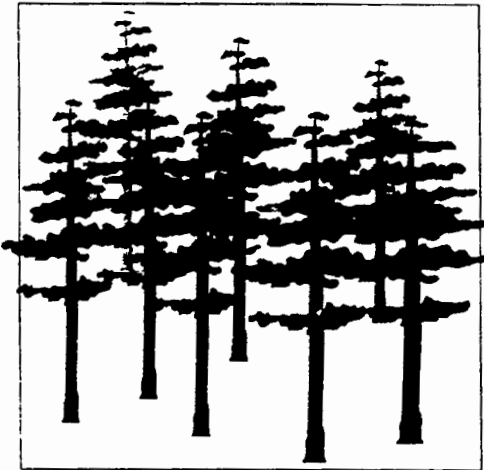
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Louisville, Kentucky • November 14, 1991

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## Introduction to the Forum

Robert L. Akridge

As we utilize this forum to expand our understanding of disability issues and peer support strategies we will be confronted with some presenters that challenge us to systematize our knowledge and build a database for doing needed research. There will be other presenters who will help us stay close to our experiential base that provides the uniqueness of peer support. This is, in my opinion, fitting and desirable. The accumulation of shared personal experiences with disabilities issues and concerns provides this group a tremendous resource to draw upon. It is hoped that the publication of the proceedings of this forum will provide much raw material for the construction of researchable hypotheses about peer support, and stimulate many projects to bolster peer support. Before going on to share some of my observations of research relative to peer support, and to disability concerns, allow me to briefly review the items emphasized in the call for papers.

The forum proposed to examine the broad range of peer support activities that have evolved in the disability service delivery system including the following modalities:

- peer counseling
- peer training
- peer consultation
- support groups
- mentoring
- networking
- advocacy
- general social support

Coverage of the following practice settings was emphasized: (a) independent living centers, (b) community-based employment programs, (c) medical programs, and (d) secondary and higher education.

## Research on Peer Support

Robert L. Akridge

There is a body of social and behavioral science literature evolving which validates the generic concept of social support. This literature documents social support's relationship to human development, both in terms of a direct contribution to the individual's coping ability and as a buffer against the adverse effects of stress. I reviewed this literature as part of a comprehensive review of peer-provided services in rehabilitation in the Annual Review of Rehabilitation (Akridge, 1986). This work was abstracted in Rehab Brief, Volume VII(2), 1984.

Other significant trends covered in the review on peer support included competency-based training in basic helping skills for both professionals and para-professionals and systematic training in coping skills sometimes referred to as Social Skills Training as a primary mode of professional treatment. These developments, along with the rapid expansion of the disability rights movement and passage of disability legislation, facilitated peer support programming in community-based disability service delivery systems, especially independent living centers.

It was shown that rehabilitation research was beginning to focus on ways to facilitate family and peer interventions to complement and extend professional interventions. It was suggested that an effective technology for developing and utilizing peer service programs may offer one of the better strategies for improving and extending rehabilitation services to presently underserved groups.

The individuals who are most underserved by the traditional disability service delivery system are likely to be those with the most difficulty in establishing a rapport with professional helpers. A well-managed program of peer services may provide the best strategy for extending help to such persons.

On the other hand, the content of peer support is often very personal and not easily manageable nor researchable by professionals. Herein lies the major challenge facing this forum and other similar attempts to improve peer support services. How can the rehabilitation professional incorporate peer support approaches without changing their essential nature?

Projects conducted at the Arkansas Research and Training Center in Vocational Rehabilitation in the early eighties resulted in two training packages designed to promote peer support at the community level. One focuses on Program Development and Management of Peer Counseling Services (Rice & Farley, 1987). The other utilizes a small group systematic



training format to train peer counselors in basic helping skills (Akridge, Farley, & Rice, 1986).

The purpose of support and the outcome of successful support--whether peer or professional--is to facilitate the individual's ongoing short- and long-term adaptation. Adapting is a function of the interaction of the individual's coping skills and resources and how responsive the community is to the needs of the individual. Adaptation integrates the two basic human trends of socialization and self-actualization.

### Conceptual Models of Rehabilitation

Traditional conceptual models of rehabilitation are being reconstrued to represent a community perspective. The full integration of individuals with disabilities into the community requires an aroused and proactive response from the community with all components integrated with all other components. The role of peer support is not derived from the role of professional support. Equal elements of a system are defined in terms of their relation to the whole, not to each other. Each program component is an equally valued element of the whole community support system.

In the present context, the term community model is synonymous with systems model or ecological model. The traditional or psychomedical model is synonymous to what Stubbins (1982) and others call the "clinical attitude" in rehabilitation where the rehabilitation process is said to be centered in the individual client, but may be more centered in the agency hierarchy. A community model of rehabilitation centers the rehabilitation process in the community. Integrating services at the community level is critical for integrating the individual with a disability into the community.

The community perspective is empowering in that it grants the consumer an equal status role in the rehabilitation process along with service providers, family and peer support persons, employers, or other stakeholders.

A community model focuses attention on how deep and how wide is the cultural mainstream (i.e., promotes cultural pluralism in the community and diversity in the workplace). Price (1990), after reviewing Wright's (1983) basic philosophical tenets for rehabilitation, argued that the focus in an integrated environment should not be directed toward elimination of all deviance, but rather on increased tolerance and support for those who may exhibit atypical appearances or behavior. The community model also addresses the perception of many consumers that rehabilitation professionals tend to look only within the person for disability-related problems or solutions. The community must sometimes be seen as the "patient" rather than the individual with a disability.

Responsive communities provide proactive networks of professional service providers, and independent networks of peer support, both of which are integrated into the community's political, business, human services, recreational, housing, and other basic systems.

The process of human adaptation, whether the individual has a disability or not is an ongoing process. Within an independent living perspective, adjusting to disabilities or coping with disabilities is a part of the developmental process and does not necessarily imply pathology. Both the profession of rehabilitation and community-based peer support programs must reject the traditional medical model and embrace a human resources development or wellness model.

### Conclusion

Every community needs programs to improve the individual's coping skills and access to resources and programs to improve community responsiveness to the independent living and career development needs of people with disabilities. Developing peer support programs is community development when such programs are integrated with other community support systems. What goes on in peer support programs is a very personal experience for all involved. The challenge from this group is to systematize the experience to manage and research the activity more effectively and still hold on to the strictly personal dimension.

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The Scientist and the Frog: A Tale of Two Creatures  
in the Form of an Experimental Fable

Steven E. Brown

Once upon a time in a land where all ideas were considered worthy there lived a scientist fascinated by frogs. He like little frogs and big frogs, spotted frogs and solid-colored frogs, baby frogs and older frogs, male frogs and female frogs. He just really liked frogs.

The scientist sat around in his laboratory all day long and daydreamed about frogs. He wondered if they talked to one another. He wondered if they knew how lyrical they sounded when they croaked in unison. He wondered what he would feel like if he were a frog. The more he thought about frogs the more determined he became to report something new and useful about these creatures he so admired.

Eventually he formed a plan. He wished for nothing more than to test the jumping ability of frogs. How far could they jump? How high? What would they do if something happened and they were injured? What could report about frogs and their jumping capacity?

He would not be content to watch frogs in the water and the swamp. He wanted instead to bring one special frog into the laboratory. Then he could experiment with how far the frog could jump under lots of different conditions.

After days of searching he found his special frog. He was so excited that the very same day he took his notebook, pencil, and his tape measure, and brought them and the frog to a long table. He took the frog, chattered with him, fondled him, and then sat him down and pushed, giving the command "jump" as he did so. The frog jumped almost the entire length of the table.

The scientist then measured the length of the jump and charted it carefully in his notebook. Being a scientist, he wanted to test the frog in other ways besides this. He decided he wanted to see the frog jump as if the animal had done battle. So he amputated one of the frog's rear legs. He then took the frog, talked to him, petted him, and gave the same command, "jump." Naturally, the frog's jump was not quite as long, and, just as naturally, the scientist dutifully recorded the jump in his notebook.

Over the next several days, a pattern developed. The scientist amputated the frog's remaining rear leg and issued the command: "jump." The jump was shorter, and its length was recorded in the growing notebook.

The next step was to amputate one of the frog's front legs. This was done; the routine steps of conversing and touching the frog followed; and then the "jump" command was delivered, and the frog jumped a little ways. The scientist recorded the jump in his notebook of observations.

Finally, the frog had no legs left, but the scientist was determined to pursue the experiment. He set the frog down, gave him his greetings and hug and issued the command, "jump." The frog did not move.

The scientist dutifully recorded in his book: "Upon amputation of all legs, frog appears to become deaf."

Do you recognize the frog. Perhaps it reminds you of someone you know or even of yourself? That poor frog, singled out as special, taken to a laboratory, and then pushed around and torn apart could easily be a metaphor for many a person with a disability caught in the cogs of an often abrasive social and human services system.

The scientist—the presumed expert—unfortunately represents the malfunctioning system. His intentions may not be noble, but they are not malicious. He is simply doing what scientists do—taking an interesting idea and testing it to find results which he hopes will be of use to someone else and of interest to him.

The story of the frog and the scientist is not an exaggeration. Just ask any person whose disability is a result of or has become worse because of a doctor's, or social worker's, care.

Over the years people with disabilities have devised a number of ways to try and stop that scientist (or the experts) from maiming the frog (us). One way is to get a bunch of frogs (people with disabilities) together. If we assemble in a group, we invariably learn that we are the experts and the appropriate ones to tell the scientists just how far we can jump or do anything else.

This group of people banding together does so to support one another. And because they are peers, we call this kind of interaction peer support.

My own primary interest in the past few years has been how this group of people coming together to provide one another with mutual support have developed their own special commonalties—or culture. The story of the scientist and the frog presented here is written in the style of a fairy tale. The scientist could easily be considered a villain. The frog is a victim. But what if the last paragraph of the tale were changed to read in the following way:

Finally, the frog had no legs left, but the scientist was determined to pursue the experiment. He set the frog down, gave him his greetings and hug and issued the command, "jump." The frog did not move. But, he was not still either. Instead the frog's head expanded like it was about to explode—his eyes bulged, foam formed in his mouth, his body tensed, and his tongue grew to a length and a strength that the scientist could not have imagined possible. The tongue grew and grew relentlessly inching toward the scientist. When the frog's tongue reached his tormenter it wrapped around the scientist until he was choking the bewildered man of science like a boa constrictor suffocating its dinner. Still the frog did not loosen his grip. Air wheezed out of

the scientist as surely as if a bloated tire had been punctured with an enormous nail. Finally, the deflated scientist slumped to the ground and expired. The frog retrieved his tongue, crooned a lullaby, and then magically wrapped his tongue around the pencil. He found the notebook and dutifully recorded, "When huggled, the scientist appears to lose interest in his experiment."

The entire fabric of the story has changed. The frog is no longer a victim. He is now a hero. Why? Because he has done something that no one would have expected from a frog. He has done something extraordinary. No longer a victim, he is now, in fact, a hero.

People with disabilities are performing heroic activities, like the fabled frog, everyday of our lives. In every community, someone with a disability is routinely doing something heroic, something out-of-the-ordinary. And, because there are so many people who intersect in our lives like the ill-fated scientist, where there are heroes there are also villains.

If in our magical story the frog sucked the life out of the scientist and left, someone would ponder the mysterious death for awhile and then go on with the rest of their lives. Because he left a message there is more to ponder, but little else has changed. But what if the frog escaped the laboratory and went back to the swamp? What if he found a group of frogs and relayed his story? What if they too had similar stories? They would be a peer support group sharing stories of defiance and heroism.

I believe that every person with a disability has hundreds of stories. I believe that every person with a disability has at some time or another been a hero. I believe that those stories are ones worth sharing with each other. I believe that the stories of how we have survived, grown, and overthrown our oppressors is at the very heart of our lives and our movement. I believe that peer support must recognize the validity of the stories and bring them into the vanguard of our movement.

I believe that the stories of our lives are the stuff that myths are made of. We have a tradition of powerlessness, oppression, and savage treatment. But, we also have a tradition of heroism, successful resistance, and survival. We have stories to tell that would fill newspapers, magazines, and books. But we have too often been timid in their telling—assuming that no one would care or that we would damage our already fragile existence by showing off our accomplishments.

In recent times, there has been a discovery of a group in New York City in the 1930s called the League of the Physically Handicapped. They took their disgruntlement, with a system which believed they could not work, to the streets. They established picket lines and sit-ins. But who remembers them? Virtually no one. Because they did not consider their story one that ought to be told. I vehemently disagree.

Telling our stories is the only way we will build our own traditions. It is the only way that we will recognize the oppression that we have been forced to

suffer. It is the only way we will acknowledge the heroism which is delivering us from our enemies.

Peer support groups are perfect instruments for the passage of these stories. Peer support groups are designed to provide role modeling. What better place to instruct ourselves in our history, our culture, our stories than peer support.

Let's take our fables, our stories, and make them into the kinds of myths that future generations will convey with pride when they discuss their ancestors—early heroes of the disability rights movement. Let's take our fables, our stories, and weave them into a cloth that enhances the very idea of peer support—using each other as role models for one another, because I am convinced that each and every one of us at some time in our lives has been and continues to be that role model that is the foundation of peer support.

## Self-help: Key to Empowerment

Dale S. Brown

It is a real honor to speak at the First National Forum on Peer Support Programs to Promote Independent Living and Career Development of People with Disabilities. This is a historic conference. I want to take a moment to thank Robert Akridge and the staff of the Arkansas Research and Training Center in Vocational Rehabilitation, the major entity that brought this conference to fruition. My speech today addresses the self-help movement. The self-help movement is the pool from which the cup of peer support programs is drawn. Sometimes the two terms are used interchangeably.

Self-help is the key to empowerment. Self-help brings help without teaching helplessness. Before a person can take political action to help others, s/he often must resolve personal issues through self-help. This presentation will describe three stages of empowerment which occur among individuals and the groups to which these individuals join. These stages are personal empowerment, educational empowerment, and political empowerment.

Self-help is a movement with roots deep in the heart of America--which is bearing many sweet fruits today. The voluntary ethos on which this national movement was founded holds that the best path towards getting help for oneself is often helping others. Citizens of the United States are known for using groups and organizations to help each other.

My speech will draw from two experiences. I have been a leader in the self-help movement for people with learning disabilities for over a decade and have helped at least 80 local groups form. And, my job as a Program Manager at the President's Committee on Employment of People with Disabilities has given me the privilege of frequent contact with national leaders in the self-help movements. However, my remarks should not be construed as the "official" position of the President's Committee. They are my own beliefs and experiences as a national self-help leader and a Program Manager at the agency.

The self-help movement of people with disabilities is part of a major national movement. For example, many of you have seen this issue of "Newsweek" which is titled, "Afflicted? Addicted? Support Groups Are the Answer for 15 Million Americans." The first paragraph reads:

All of a sudden, people are pouring back into churches and synagogues with a fervor that hasn't been seen since the 50's. It appears that a great religious revival is sweeping the land--until you examine the situation a little more closely. Then you'll notice the biggest crowds today often arrive in midweek. And instead of filing into the pews, these people head for the basement, where they immediately sit down and begin talking about their deepest secrets, darkest fears and strangest cravings.



In 1987, the Surgeon General of the United States brought together over 100 people from various health-related self-help movements to discuss how public health can be improved through partnership between self-helpers and the health care delivery system and how these partnerships can be achieved without compromising the essential nature of self-help. This conference, today, is facing similar questions in the field of independent living.

Two major reasons are given in the Newsweek article for the expansion of the self-help movement. One is the lack of other resources. Indeed, early in the movement of people with learning disabilities, I often said, "If we do not help ourselves, there is no other help." Today, that has changed. There are resources available for many of us. But, in many parts of the nation, self-help is, indeed, the best help available. The second reason, which I will not belabor, is the loss of family structure. Peer Support groups are replacing the extended family of yesterday.

The rest of this speech will detail the three stages of individual and group empowerment: personal, educational, and political. This theoretical framework is designed to assist independent living workers to assess individual needs and group dynamics.

Personal empowerment is usually the first stage. Groups working on personal empowerment usually emphasize emotional expression, catharsis, and support of each other. Usually the chairs are arranged in a circle.

These groups are members with a common experience of discrimination or a particular condition or functional limitation. The more similar the experiences of the people in the group, the safer they will feel in expressing themselves. This is why one sometimes finds groups that have "X" nationality with "X" disability who are female or male. Until people have told the stories of their struggles several times and feel they have been heard well, they are often not ready for the information that they need to move forward.

Sometimes, these groups are closed to people who do not share that similarity. This can become a divisive issue. People without disabilities need to understand the need for safety which comes through those who are guaranteed to understand through the similarity of experience. Most professional groups such as American Medical Association, National Association of Social Workers, and even National Rehabilitation Association exclude non-members of their profession from certain meetings and from voting.

Often, coping skills and strategies are exchanged. Frequently, these coping skills are more practical than the ones put forward by the professionals. For example, in the learning disabilities movement, people with auditory perception problems have always been encouraged to repeat back instructions to assure accuracy. Workers with learning disabilities, however, found that supervisors sometimes did not listen as they played the assignment back, so the self-help movement stressed the importance of assuring that the boss listened.

Some challenges faced by groups in the personal empowerment stage are:

1. Assuring that everyone gets equal attention and time. One individual can dominate a group by his or her particular dramatic story. Sometimes people play "more disabled than thou." Skilled leadership can encourage the group to include all members.
2. Assuring the personal empowerment of leaders. Leaders can burn out. Some leaders end up doing it all, helping others to the exclusion of helping themselves, or at the worst, denying their own need of help by being helpful. Some groups are designed to be leaderless, but there is usually some form of leadership that needs nurturance as much as the group members. Independent living centers often provide professional assistance to lay leaders to combat this stress.
3. Effectively assisting members to move from the need to tell their story to the decision to move forward in their lives and to learn more about their condition.

The second stage is educational empowerment. Experts often speak to these groups. Chairs are usually arranged theatre style--rows of chairs facing one person at a podium. This type of group provides resource lists and speakers. Often, the expert is also a member of the oppressed group who shares coping skills and strategies. Gaining knowledge and resources is a crucial step in coping with a disability.

Some challenges faced by groups in the educational empowerment stage are:

1. Assisting those members who need catharsis. Without sufficient personal empowerment, members may not have the attention necessary to learn or move forward. This is why people telephone requesting advice and interrupt with their stories or feelings when advice is offered. That person may not be ready for advice until they have a chance to sufficiently express themselves. The article entitled "Minilab on Peer Counseling Skills" shows some ways of helping catharsis.
2. Keeping group members involved. Too often, people come and learn from one lecture, but never return. To counteract this, the work of group maintenance should be shared.
3. Encouraging independence of group members. These groups can get stuck in an "expert model," reinforcing an underlying belief the member with a disability needs a professional to handle their lives.
4. Assuring the accuracy of the information given to the groups by the "experts." Some groups have professional advisory boards to weed out the quacks. People with disabilities need to maintain strict controls to assure that the expertise available is truly expert. On the other hand, self-

help groups often bring innovation to the professions because of their openness to new ideas.

In general, after becoming personally and educationally empowered, individual group members realize, often in a sudden flash of insight, that most of their problems are caused by discrimination. They stop blaming themselves and no longer feel the need to take responsibility alone. They choose to challenge oppressive practices.

Clearly, the disability community has had tremendous success through political empowerment. All of you are from cities and states that have taken tremendous steps forward. The Americans With Disabilities Act was passed because of grass roots advocacy. Last September, a national conference of personal assistance users began an effort towards consumer control of attendant care. The independent living concept itself is a monument to a movement which insisted that people with disabilities control their own service provision. And, many independent living centers began because a group of people with disabilities wrote a grant for the money to start a center, after they personally, educationally, and politically empowered themselves.

Some challenges of groups in the political empowerment stage are:

1. Developing effective structure. Many groups die because of fights over bylaws. Infighting often occurs at this stage.
2. Assuring effective education of all disabilities represented in the group. Most disabilities have tremendous variations. Conflicts occur between members with different types of the same disability if certain members believe that their disability symbolizes the entire disability group. Examples of conflicts that have occurred include difficulties between blind and partially sighted people; people who acquire deafness at birth; culturally deaf and people who become deaf later in life; and dyslexics and people with perceptual problems.
3. Assuring that group members continue the process of personal empowerment. People who are still angry over how they were treated may express those feelings against other group members. A person who has not told the story of his or her struggles enough times may tell it in a way that turns off others. If the listeners are legislators at a hearing, the results can be damaging. When individuals in a group effectively empower themselves educationally and personally, the group is more likely to stay united--a crucial need in today's political climate.

These three stages; personal empowerment, educational empowerment and political empowerment do not necessarily occur in order for individuals or groups. Nobody moves from one step to another in lock-step order. It is typical that groups in the political empowerment stage attract new members who have not yet experienced sufficient personal and/or educational empowerment. Many people who are extremely knowledgeable need to become more personally empowered. The best organizations give its members opportunities for all three types of empowerment: personal, educational, and political.

Self-help through peer support is the key to empowerment. Each person deserves opportunities for all three types of empowerment: personal, educational, and political. And, by keeping all three needs in mind, leaders can strengthen their groups and independent living centers can better assist self-help groups.

Self-help is the first step towards an oppressed group gaining political power. The disability community as a whole is beyond the first step, but we must assure that the new members of our community have the opportunities to personally, politically, and educationally empower themselves.

## A Case History of a Peer Counseling Program

Jan Lilly

The Mountain State Center in Huntington was the first center to open in West Virginia. It has been in operation since October 1, 1981, and I have been with the center for the entire decade. We started our peer counseling program nine years ago, and I served as the peer counseling coordinator for seven years. After being on the job for only a few months, I attended a training program developed and conducted by staff of the Arkansas Research and Training Center in Vocational Rehabilitation where I obtained basic information on managing a peer counseling program and training people to be effective peer support counselors.

In our program we recruit and train persons with disabilities to become peer support counselors. These peer supporters work on a volunteer basis and are expected to attend a 40-hour program to learn basic communication skills, independent living philosophy, center policies, and the role and importance of peer support.

The center has ten to 15 volunteer peer support counselors, some of whom attend the local university, some are former participants, and some are people with disabilities who are employed. The peer support counselors are utilized in the following ways.

1. teaching specific independent living skills training courses;
2. providing support to leaders of the small group peer counseling sessions;
3. serving as mentors on a one-to-one basis to assist with persons and social support;
4. helping center staff in conducting outreach activities;
5. assisting consumers obtain appropriate services from various federal, state, and municipal human service programs; and
6. providing sexuality counseling.

Once a year the center conducts peer counseling training in order to assure a variety of people with disabilities are available from the pool of volunteer peer support counselors.

In addition, I have developed a system for tracking progress made by persons needing peer support. We have had to develop our own forms to support our peer counseling program, such as time sheets, applications, and referral. The peer support counselors meet with the peer counseling coordinator on an as-needed basis, and all peer support counselors meet on a quarterly basis to discuss issues.

I have developed the peer counseling training materials that are used to conduct the 40-hour program.

It is our belief that peer support is vital to participants and we see four significant results. Three of these pertain to the individual consumers who experience increased self-confidence, improved self-image, and becomes an effective self-advocate-becoming empowered. A fourth result benefits the center; many persons who receive peer counseling services recognize its benefits and become peer supporters.

In addition, these four results not only benefit the person receiving peer counseling services, but the person providing the services gains these benefits as well.

Thank you for being here, and I would like to thank Robert Akridge for inviting me to participate in this program.

## A Movement Towards Independence: One Perspective on the Disability Rights Movement

John Chappell

### The Disability Movement: A Drive for Independence

In the current era, America is experiencing the coming-of-age of the disability movement. Employment of people with disabilities has become widely accepted, and those employed have proved that they can be productive and participating members of society. A substantial consensus has now been achieved that people with disabilities, regardless of their employment status, should have opportunities for full participation in all aspects of society. This consensus, and the long-building disability movement, have come to fusion in the landmark civil rights legislation of the Americans with Disabilities Act. Any discussion of the role of independent living services in vocational rehabilitation must be undertaken within the context of this disability movement.

### The Past of Persons with Disabilities: Punishment and Pity

The earliest days of persons with disabilities were filled with oppression and discrimination. In earliest recorded history, people who were disabled were often put to death. Those who had leprosy were destined to live a life of complete isolation. Those who were disabled and lived after some severe injury or who survived the early years of infancy with a congenital disability were relegated to begging.

All too often persons with disabilities were considered to be objects of pity and did not receive assistance towards independence. In fact, disability was considered by many as just reward for injustice or sin. The practice of allowing persons with disabilities to die at birth or at the time of accident still happens today in some cultures. History demonstrates that with all this abuse, the desires and needs of those with the disabilities were not included in the decision-making process. The individuals were reactive participants in the process. They were not given any say at all in what was to happen to their lives.

Not until the late 19th century and the early 20th century did the attitudes of the general public begin to change slightly. Most persons who had a severe disability spent their lives in an institutional setting, but a few of the most affluent were able to live with control over their own lives. Some notable examples were Renoir, who strapped a paint brush to his hand and painted from his wheelchair because of his severe arthritis; Thomas Edison, who though deaf became the most renowned inventor of the 19th and 20th centuries; Franklin D. Roosevelt, who was paralyzed due to polio and used a wheelchair, yet became the only president in U.S. history to serve four terms in the White House.

## Evolution of the National Rehabilitation System

### 1920 Establishments of the National Vocational Rehabilitation System

The Vocational Rehabilitation program began in 1920 with the passage of the Smith-Fess Act, and it traditionally has been the provider of services for persons with disabilities with vocational potential.

### 1954 Expansion Grants Program

The Innovation and Expansion program originated with the 1954 Amendments.

### 1965 Extended Evaluation of Persons with Severe Disabilities

The need to serve individuals with severe disabilities was recognized in the Vocational Rehabilitation Act amendments of 1965 which provided for "extended evaluation" of persons with disabilities applying for vocational rehabilitation services. The governing concept behind this provision was that the process of extended evaluation could do much to help the individual who is severely disabled to improve to the stage of employment.

### 1973 Protection of Certain Civil Rights of People with Disabilities

The Rehabilitation Act of 1973 established several important breakthroughs for persons with severe disabilities. Priority in the delivery of vocational rehabilitation services to clients with severe disabilities was mandated in the basic program. Section 305 of the Act established the Helen Keller National Center for Deaf Blind Youths and Adults.

Title V, the "civil rights title for the handicapped," contained important provisions regarding the welfare of individuals with disabilities. Sections 501, 502, 503, and 504 of Title V provided for affirmative action programs for the employment of the handicapped within the Federal government; for barrier-free work areas in such places; for the creation of Architectural and Transportation Barriers Compliance Board; and for nondiscrimination on the basis of handicap for programs and activities receiving or benefiting from Federal financial assistance.

### 1978 Establishment of the National Independent Living Program

Passage in 1978 of Title VII of the Rehabilitation Act providing for independent living services followed many years of unsuccessful attempts to add this service capacity to the Act. Though the independent living movement (ILM) and its programmatic efforts are regarded by many as a new phenomenon in rehabilitation, interest in providing these services dates back several decades. In the early 1950s many states introduced the concept of "mainstreaming" for mentally retarded individuals and were providing half-way houses for the mentally ill. During the period from 1959 to 1971, there were several attempts in Congress to enact legislation for special comprehensive rehabilitation services to improve the independent living of individuals with disabilities without regard



to their ultimate employability. Emphasis in these early bills was on increasing the ability for independent living of persons with severe disabilities, thereby reducing their dependence on public programs financed by public taxes.

In 1959, a bill (H.R. 361) was introduced (and reintroduced later in the year as H.R. 5416) that proposed an extension of rehabilitation benefits to persons with severe disabilities, even when no vocational objective was obvious.

In 1961, bills were introduced calling for a cooperative arrangement among state agencies administering public assistance, health services, social security, and other programs to provide independent living and ancillary services. To assure that attention given to this new program would not detract from traditional emphasis on vocational rehabilitation, it was recommended that the two concepts be segregated into separate programs.

The legislation contained a title on independent living rehabilitation (ILR) services, and included an authorized appropriation amount of \$15 million for the first year and \$25 million for the second year.

These bills were opposed by the Administration because the Department of Health, Education, and Welfare could not decide who might administer the provisions (Comprehensive Service Needs Study, Urban Institute, 1975). Meanwhile, persons with severe disabilities were initiating a variety of private attempts to solve their own problems. Community-based programs began to emerge and have continued to do so throughout the country. They utilized imaginative combinations of funds from sources such as state and Federal governments, vocational rehabilitation innovation and expansion grants, research and demonstration grants, and private and local funding.

In 1972 a new bill intended to replace expiring vocational rehabilitation legislation was passed by Congress (H.R. 8395). This bill included comprehensive rehabilitation services and any other goods (including aids and devices) or services provided with funds under titles of the Act that would "make a substantial contribution to helping a handicapped individual to improve his ability to live independently or function normally with his family and community."

The bill included the following definitions:

A "handicapped individual" means any individual who has a physical or mental disability which constitutes or results in a substantial handicap to employment and can reasonably be expected to benefit from vocational rehabilitation services or comprehensive rehabilitation services.

"Rehabilitation" means the goal of achieving, through the provision of community rehabilitation services, substantial improvement in the ability to live independently or function normally within the family or community on the part of achieving a vocational goal at the present time.

This legislation was pocket vetoed by President Jimmy Carter, who indicated the independent living measure would divert the vocational rehabilitation program from its basic vocational objectives, dilute the resources of the vocational program, and impair its potential for continued achievement.

A legislative breakthrough was accomplished with a compromise between Congress and the Administration which resulted in passage of the Rehabilitation Act of 1973.

#### Comprehensive Service Needs Study

The Rehabilitation Act of 1973 directed the Secretary of Health, Education, and Welfare to conduct a comprehensive needs study including research and demonstration projects of various methods of providing rehabilitation and related services to the most severely handicapped individuals.

The study investigated such key questions as the national population of people with severe disabilities, their characteristics, what their needs are, how their needs are being met, and their implications for policy if these needs were to be met more effectively.

The findings suggested that the specific needs of persons with severe disabilities are such that simple expansion of existing vocational rehabilitation services in the states was not enough, and that the development of an ILR program was a most crucial need.

Subsequently, on the basis of the authority of Section 130 and the CNS, Rehabilitation Services Administration (RSA) funded five demonstration projects to investigate (in summary) the following issues:

1. What organizational structure will be most efficient and effective for administering an ILR program?
2. What programs and services are needed for an independent living program, and who should provide them?
3. What manpower will be required and at what level can case loads be handled?
4. What are the expected outcomes that will result from given levels of expenditures?
5. What would be the relative costs of supporting various ILR goals?
6. What limits should be placed on who is served?
7. Are there persons too severely handicapped to benefit from ILR?
8. What are the objectives of an ILR program for which reasonable accountability can be maintained?

## 1974 Present

The Rehabilitation Act of 1973 was amended to include a broader definition of the term "handicapped individual." This was done in part to augment the implementation of Title V. It focused on major life activities rather than vocational objectives. It also authorized the White House Conference on Handicapped Individuals, which for the first time provided a national forum for people with disabilities to express their views and make recommendations for public policy to address their concerns.

## 1984 From "Vocational Rehabilitation" to "Rehabilitation"

In 1984 Congress made some technical changes to the Rehabilitation Act. One of the additions was a requirement to conduct a comprehensive evaluation of the centers for independent living program. The evaluation section of the Act mandated the development of and approval by the National Council on the Handicapped a set of standards for evaluation. The following was extracted from "Comprehensive Evaluation of Title VII, Part B, of the Rehabilitation Act of 1973, as Amended, Centers for Independent Living Program, Final Report; Published by the Department of Education, Contract #300-84-0209; Conducted by Berkeley Planning Associates in conjunction with the Center for Resource Management and the Research and Training Center for Independent Living at the University of Kansas.

These "standards" were to reflect the 11 specific areas of interest to Congress. The process for developing the evaluation standards ensured broad input from centers for independent living, consumer advocacy organizations, researchers, and policy makers. The evaluation standards then were approved by the National Council on the Handicapped for use in the evaluation. In addition, to their role in the national evaluation, the standards were also designed to serve as a self-evaluation tool for the centers.

The study was commissioned by the U.S. Department of Education and conducted by Berkeley Planning Associates in conjunction with the Center for Resource Management and The Research and Training Center for Independent Living at the University of Kansas.

## Standards Area Results

The results of the study showed that the outcomes of the meager resources provided for independent living centers is significant. It is clear that additional resources are needed to address more adequately the needs of the many hundreds of thousands of persons with disabilities and the need to empower those individuals toward greater independence. Evaluation of the various independent living efforts continues, and many unanswered questions remain. However, it is obvious that the need for these programs exists, and ILR should not be viewed as a futuristic concept but rather as an idea whose time has come.

In 1986 the Rehabilitation Act was amended to recognize explicitly the broadened purpose of the national system, the 1986 amendments to the Rehabilitation Act formally changed its name to the "Rehabilitation Act."

Correspondingly, the statement of purpose was revised to include independent living now reading as follows:

The purpose of this Act (29 USCS ss701 et seq.) is to develop and implement, through research, training, services, and the guarantee of equal opportunity, comprehensive and coordinated programs of vocational rehabilitation and independent living, for individuals with handicaps in order to maximize their employability, independence, and integration into workplace and the community.

The Amendments also more precisely defined persons with severe handicaps. The Congress took this action so that vocational rehabilitation agencies might have more uniformity in the definition of "severe handicap."

There were many other substantive changes to the Rehabilitation Act. Perhaps however, the most important outcome of the significant changes was the shift in the way Congress saw persons with disabilities. For in just a few short years, the broadened purpose of the Rehabilitation Act set the tone for the ultimate passage of the Americans With Disabilities Act which was signed into law on July 26, 1990.

The Rehabilitation Act, as amended, has seven titles and addresses the many aspects of the lives of persons with disabilities.

#### Current Legislative and Statutory Bases of the National Rehabilitation System

The national rehabilitation system, including both VR and IL, operate directly under the authority of the Rehabilitation Act, and are strongly impacted by several other federal laws. These are briefly identified and outlined below.

#### The Rehabilitation Act of 1973, as Amended

##### *Title I Vocational Rehabilitation Services*

This title addresses the various aspects of providing funding for vocational rehabilitation services.

##### *Title II Research and Training*

This title addresses the priority Congress places on the need for research and training concerning the provision of services to persons with disabilities.

### *Title III Special Federal Responsibilities*

This title sets out the authorization of grants for the construction of rehabilitation facilities and the provision of funds for staffing and planning assistance of same.

### *Title IV National Council on Disability*

This title renames the National Council on the Handicapped to the National Council on Disability.

### *Title V Miscellaneous Provisions*

Although Title V is entitled, "Miscellaneous Provisions," it is one of the most far-reaching of all the titles in the original Rehabilitation Act of 1973. The various sections address a broad range of issues regarding the lives of persons with disabilities including the issues of employment in the Federal government and establishes a Federal Coordinating Committee regarding employment of persons with disabilities. It establishes the Architectural and Transportation Barriers Compliance Board and mandates the Board to report to Congress on how states are expending funds to address full access to programs and activities for persons with disabilities. It addresses equal employment opportunity and discriminatory practices.

Various other sections under Title V establish the requirement for an interagency coordinating committee and the requirement for annual reports to Congress, and the need to address electronic equipment accessibility by establishing guidelines that must be promulgated by 1988.

### *Title VI Employment Opportunities for Individuals with Handicaps*

This title establishes new areas entitled, "Community Service Employment Programs for Individuals with Handicaps," "Projects With Industry and Business Opportunities for Individuals with Handicaps," and "Supported Employment Services for Individuals with Severe Handicaps."

### *Title VII Comprehensive Services for Independent Living*

This sets out Congressional statement of purpose and eligibility.

## Other Legislation Affecting the Rehabilitation System

Some of the other major laws have or will have positive implications for persons with severe disabilities as follows:

- Education For All Handicapped Children Act of 1975 (P.L. 94-142), which calls for a sharply increased federal commitment to insure that all handicapped children receive full and appropriate educational services.
- Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103).
- Titles XVIII and XIX of the Social Security Act (Medicare and Medicaid)
- Title XX of the Social Security Act (Social Services Block Grant)
- Supplemental Security Income (SSI) Amendments (among them, P.L. 94-566, P.L. 94-569, and P.L. 94-585) extending SSI benefits to aged, blind, and disabled recipients in publicly operated community residences and a new assistance program for SSI eligible children.
- Architectural Barriers Act of 1968 (P.L. 90-480) as amended by P.L. 94-541, pertaining to barrier-free design in Federal buildings and facilities.
- Federal-Aid Highway Act of 1973 (P.L. 93-87) as amended by P.L. 93-643, requiring access to public mass transportation facilities, equipment, and services for the elderly and persons with disabilities.
- Department of Transportation Appropriations Act of 1975 (P.L. 93-391) directing that none of the funds under the Act be available for purchase of mass transit equipment or construction of facilities unless they meet the requirements of the elderly and persons with disabilities.
- Americans With Disabilities Act of 1990.

The concept of rehabilitation services has changed over the years. Medical and rehabilitation technology has made such advances in the past two decades that many of those who would have been targets for ILR services in the 1960s are now rehabilitated by the vocational rehabilitation programs. Advances in prosthetics, orthotics, communication and other technologies, medical science, and in the provision of services have vastly expanded the number of persons who can be vocationally rehabilitated as well as the range of life options available to people with severe disabilities.

The Independent Living (IL) Philosophy As A  
Movement And A Service Delivery System

### The Evolution of the IL Philosophy

The progress society has made in recognizing its real oppression of many of its minorities has only recently included those persons who have a disability. Until the early 1970s persons with disabilities were relegated to lives of control

by others in the belief that it was better to "protect" the individual from experiencing failure. It was the system that knew better; the system which determined who would succeed and in what vocational goals the person would excel; it was this system which perpetuated the philosophy of the individual with the disability being the problem.

Then, a few individuals across the country began to recognize that the right of self-determination was a right that all persons should have. The right to choose one's own destiny was as important for persons with disabilities as it was for any other minority. The individual was the solution not the problem. Failure was another way of learning that was experienced by all and so should be an option for people with disabilities. This new feeling about the right of an individual to self-direct (to the level of individual) became known as the independent living philosophy. IL became the backbone of the civil rights movement for people with disabilities. It recognized that access to the community, jobs, transportation, housing, and all the other things that others took for granted was and should be the right of a person who was disabled. This movement has had many phases. It has taken many giant leaps and yet still is just beginning to profoundly change the lives of people with disabilities.

#### Roots of the IL Movement

In the middle 1950s some rehabilitation professionals including E. B. Whitten, the President of the National Rehabilitation Association, proposed a comprehensive services system as an alternative to the vocational system. Whitten and others felt that those whose disability was "too severe for vocational potential" should have an alternative to an existence of living in an institution or being completely dependent on the family.

This alternative to the vocational rehabilitation model (independent living rehabilitation) never materialized as proposed by the rehabilitation community. There are many reasons why this alternative system did not make it. Certainly cost was raised as a major factor, but just as importantly, persons with disabilities were not speaking on behalf of themselves and their needs. It would take nearly two decades before people with disabilities would realize that not providing for equal access to a building or alternative living situations for mentally retarded adults was as much a civil rights issue as denying women equality in hiring. It would take people with disabilities nearly twenty years before they realized that they must speak for themselves before change would finally begin to take place. They would finally realize that it was as much as a civil rights issue for them to be denied access to the bus as requiring b!acks to ride the back of the bus in Selma or not providing a quality education for all people.

In the late 1960s a few people began to speak out about the inhumane treatment and the lack of control persons with severe disabilities had over their own lives. Ed Roberts and Judy Heumann in Berkeley, California, are considered by many to be the two persons who have had the most influence on the development of the independent living philosophy. Roberts and Heumann felt that people with the most severe disability should have the right to decide where they lived, ate, worked, or traveled--in essence that people with the most

severe disability should have the same options as others. Remember, most persons with severe disabilities were relegated to living in an institution, so this philosophy based on the right of an individual with a disability to the same options as others was a revolutionary approach.

It is certain that the civil rights movement begun by Dr. Martin Luther King and others for black people had a profound affect on the consciousness of others in this country. Women began to speak out for their civil rights. Other minorities also began to advocate for change to positively effect their own constituencies. The ILM then must have been influenced by this new awareness that people should not be judged solely because of their skin color or their sex or any other factor that may appear to make them "different."

Thus, the civil rights movement for persons with disabilities was born. After nearly 5000 years of oppression, people with disabilities began to recognize that they should not be treated differently simply because they happen to have a disability.

#### Independent Living as a Philosophy

The evolution of the civil rights movement for persons with disabilities into a practical philosophy has many different roots. At the same time that Ed Roberts and Judy Heumann were working on the first Center for Independent Living in Berkeley, California, many other groups of persons with disabilities were beginning to meet in small groups across the country. There was no national organization or any particular structure for the groups. In many places the groups were simply social clubs. In other locations they took on a more activist roll. In addition, disabled veterans who were returning from the Vietnam war were finding themselves excluded from participation in the community simply because of their disability.

The survival rate of those injured in the war approached 95% of those making it back to the field hospital. The helicopter had become the aircraft of the Vietnam war, especially for transporting troops and for field evacuation of those injured. Thus, getting to the field hospital was extremely efficient. This large number of persons with severe physical disabilities who had lived in the community all their lives and came home with a disability and no accessibility soon became a political force through the Paralyzed Veterans of America and the Disabled American Veterans. These two groups were a major force behind the passage in 1968 of the Architectural Barriers Act. This Act required that all new buildings built in part or whole with federal funds must be physically accessible. The law had no teeth, but it was the beginning of a political statement for persons with disabilities.

This visible force of persons with disabilities began to gather momentum in the early seventies, and the passage of the 1973 Rehabilitation Act is a testimony to this new political entity. Yet, except for the previously mentioned organizations there were only a few hundred persons with disabilities involved in this new ILM. The original network was an informal group of persons who usually met in their homes and had made it in spite of the rehabilitation system



because most of these individuals had been classified as too severely disabled for services.

One common thread throughout this movement, however, was the issue of who was making the decisions and who was developing the issues. Persons with disabilities were, for the first time in history, actively involved in determining their own destiny. The corner stone of the ILM had been laid! For unlike the early attempts by persons from the rehabilitation field attempting unsuccessfully to fund community-based services, this time those who would benefit from those services were in control.

This concept of consumer control and self-determination was certainly not a new concept. It was articulated in history when the French revolution occurred. It happened when much of the Roman Empire crumbled under the weight of the need for political identity. It was demonstrated in the 1950s when Dr. King and others from the civil rights movement spoke out about the injustice of discrimination against black persons. And now it was happening for and by persons with disabilities. They were saying that being excluded from participation in the community because of a disability was wrong. Discrimination was occurring against persons with disabilities because there were no community services; because there was no access to education; because there was no accessible housing and transportation.

The philosophy of independent living was born. The right to community access; the right to live in an accessible community; equal treatment under the law; use of accessible transportation; the availability of affordable, accessible housing; all of these issues coupled with the cornerstone of consumer direction and involvement laid the foundation for the development of a movement which would fundamentally alter the rights of persons with disabilities.

A very important aspect of the emerging independent living philosophy was the idea of risk taking and the right to fail. This issue of the right to fail and, therefore, the right to take risks has its origins in who was most qualified to make decisions for persons with disabilities. The traditional rehabilitation system had, for years, mandated the minimizing of failure of the clients of the vocational rehabilitation system. The root of this programmatic mandate was simple; the problem was with the individual, thus, s/he must be "changed" or fixed. The independent living philosophy reversed that practice and stated that the individual with the disability was the locus of the solution and not the problem.

#### The Development of the Independent Living Philosophy as a Service Model

The earliest days of the ILM were based on the concept that with the need to look at access as a civil rights issue, there must also be the understanding that community-based services were equally important. This coupling of equality of access (both programmatically and physically) with the necessary services to assist one to live in the community was a practical aspect of disability. For independent living does not necessarily mean that a person

must or should live independently; it means that a person must have control over his/her life.

Thus, a community-based, consumer-controlled resource center needed to be available to assist the individual to access the necessary services, to act as a political force for community change, and when necessary, provide certain services that were not available anywhere else. In the very early days of independent living centers the primary services were assistance in finding a personal care assistant (now called more appropriate personal assistance services), housing referral, and transportation assistance.

As more resources became available through Title VII of the Rehabilitation Act (amended in 1978) a more organized definition of what services constituted an independent living center developed. Certain core services began to evolve through a national conscientiousness and through looking at the basic services described in the original and later amendments of Title VII. The core services that evolved are advocacy (individual and systems), peer counseling, independent living skills training, information and referral.

These core services became the reference for new funding when, in 1986, the National Council on the Handicapped (NCH) adopted its standards for independent living centers. These standards, which were required to be developed and approved by NCH in the 1986 Amendments to Title VII, also set out formally the need for consumer control in both the staff and boards of independent living centers.

The following are some questions and answers that best describe the independent living centers model today.

#### What Are Independent Living Centers?

Independent living centers (ILCs) help people with disabilities achieve or maintain more self-sufficient and productive lives in their families and communities. People with disabilities are assisted in exploring alternatives to institutionalization and are encouraged to make their own decisions about how and where they will live. ILCs directly provide or coordinate through referral those services which assist people in increasing their abilities to exercise control over their lives. Control over one's life is defined as having a choice of acceptable options that minimize reliance on others in making decisions and performing every day activities. This includes managing or directing one's own affairs, participating in day-to-day community life, and fulfilling a range of social roles.

#### How are ILCs Unique?

Within the ILM there is a strong belief that peer conducted services are essential to assisting a person with a disability. Therefore, in ILCs, 51% or more of the staff and board of directors are people with disabilities who have personally experienced attitudinal, physical, and communication barriers. Their experiences have resulted in unique commitments to assist others with disabilities achieve lives of dignity. Staff serve as role models, demonstrating

that it is possible and desirable for people with disabilities to be productive and independent. The understanding, guidance, and support provided through ILCs give others the confidence to take the first steps toward their own independence.

ILCs provide community advocacy as well as direct services to individuals with disabilities. ILCs advocate for the improvement of the quality of life for all people with disabilities, seeking to eliminate society's attitudinal, environmental, social, psychological, and economic barriers to equal opportunities. ILCs offer a broad range of community-based services for people with a variety of disabilities regardless of age. ILCs are also unique in that they do not restrict or limit services to vocational or job-related goals.

#### What Impact Have the ILCs Had?

The efficacy of the ILM and its concepts are being proven daily by more and more people with severe disabilities as they choose to assume the responsibilities of directing their own lives and as they become active, contributing participants in their families and communities. As the movement has gained momentum, the public is becoming more aware of the abilities of people with disabilities and more supportive of the services needed to maximize those abilities.

#### Implications

The disability movement has traveled far, from an early belief that disability was a punishment to the current drive for self-determination and independence. The national rehabilitation system began with a narrow focus upon employment, but has gradually broadened to include a wide range of rights and services for people with disabilities. Within this context, the ILM developed as part of the civil rights movement out of a concern for people with disabilities to have the right to control their own lives and have access to the same options as others. The movement seeks to empower people with disabilities to participate fully in the affairs and benefits of our society through provision of a broad range of information, advocacy, community development, and skills training services. Independent living services and their holistic, empowerment emphases have been included as integral parts of the nation's Rehabilitation Act. It is now incumbent upon rehabilitation systems to take necessary steps to assure that vocational rehabilitation services are provided in ways that incorporate and make full use of the independent living programs and services which have been developed. The results will include increased consumer success in obtaining and (most importantly) maintaining employment and in taking control and responsibility for their own lives.

#### Summary

The disability movement has traveled far from an early belief that disability was a punishment to the current broad-based drive for self-determination, independence, and community integration. The national rehabilitation system began with a narrow focus upon employment, which has gradually broadened to include a wide range of rights and services for people with disabilities.

Rehabilitation agencies since the initial Rehabilitation Act of 1973 (Smith-Fess Act, P.L. 66-236) have provided independent living services of varying degrees to persons with severe disabilities. The civil rights movement helped launch the Independent Living Movement (ILM) as a recognized social initiative during the early 1970s. It developed as part of the civil rights movement out of a concern for people with disabilities. The philosophy upon which it is based holds that people with disabilities have the right to control their own lives and have access to the same options as others. The ILM seeks to empower people with disabilities to participate fully in the affairs and benefits of society through provision of a broad range of information, advocacy, community development, and skills training services.

The disabilities and independent living movements helped bring about passage of Title VII, which added ILR services and ILCs to the Rehabilitation Act and broadened the statutory purpose (1978 amendments). Independent living services and their holistic, empowerment emphases have thus been included as integral parts of the nation's rehabilitation system.

The historical and legislative perspective of the disability movement provides important insight to the lives of all people, demonstrating the ability of dedicated persons both professionals and consumers to alter the perceptions of the public about disability. This historical perspective also shows the need for a more direct connection between the vocational rehabilitation system and the evolving ILC service delivery system.

It is clear that the ILM and the disabilities rights movement both have their roots in the change in social consciousness that occurred in the U.S. during the fifties and the sixties. It must also be recognized, however, that the disabilities movement has been around for over a hundred years; organizing within the blind and the deaf communities began in the 1800s. Thus, the above brief description of the evolution of the independent living and disabilities movements by no means covers this rich and very broad movement.

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## Peer Services and the VR System: A Parable of Peers

Theodore W. Haworth

There once was a king who took a tumble from his throne--literally. As he leaned over to snatch his scepter from the floor to emphasize a weighty pronouncement, his crown began to slip. Grabbing for it, he twisted from the throne and crashed unceremoniously down the royal staircase. Later, awakening, he found he could not longer move his legs or arms. Days passed, but his condition did not change. He still had the will to be king, and to exercise the royal authority, but how could he do so? He had the will, but not the way.

Summoning his royal advisers, he entreated, "Help me. Tell me how to regain control over my subjects and my kingdom. Tell me what to do!" They conferred busily, and there began a long tale of frustration and pain, all to no avail. "Summon the physicians," they advised. He did, and forthwith was poked, pried, and bled. Finally, the physicians pronounced him improved and departed, but he still could not walk or grasp. "What shall I do?" he cried.

Again the advisers conferred, this time advising, "Summon your personal coaches." He did, and was exercised, stretched, and sweat. Finally, the coaches proclaimed him fit and departed, but he still could not walk or grasp. "What now shall I do?" he cried.

Once again the advisers huddled in conference, this time emerging to advise, "Summon you entertainers." He did, and was entertained, cajoled, and flattered, but he still could not walk or grasp. "What, O what..." he cried, failing this time even to make his point.

About then, an aging king from a neighboring state came by to give his regards. Finding his friend severely confused and distraught, he said, "Please, my friend, look to what it is you yet can do, not to what others say you cannot." Thereupon the neighboring king confided his learning from a lifetime of tribulation and trial.

Soon our king was once more upon his throne, hearing cases, giving judgements, and wisely controlling his subjects and kingdom. "What all the experts could not do," he said, "my neighboring colleague could. It was only he who truly heard what I said, because he too had been there. What the physicians, the coaches, and the entertainers did, I needed. But, they could not do what I must do--and, what only I can do. They could not make my decisions, set my visions, and honor my values. It took a peer to share with me what he had learned--that is, that a king must make decisions to rule, and must take charge to be in control. Advice is but opinion, but decisions are control. Only I can take charge of my own life and determine what it is I choose to do!"

What is the place of peer services in vocational rehabilitation? Those of us who are professionals know that we can not have all the answers for people

with disabilities--and that people with disabilities are themselves a powerful, yet often untapped resource to help one another.

People with disabilities can help each other by providing a bridge between the specialized areas of professional advice that we represent and the day-to-day experience of the individual. What we say is, of necessity, heavily weighted with the "baggage" of our professional perspectives, standards, training, and structure. By contrast, one person with a disability can talk to another simply as a fellow human being, who has himself or herself trod the same ground.

The involvement of a peer can empower both the professional and the consumer. The professional, because the peer can help translate professional structure and perspectives into the framework of the consumer's own life. The consumer, because the peer can help connect the responses of the consumer to the realities of treatment and rehabilitative regimens. In this way, the peer can serve as an interactive participant in the rehabilitation process, providing consultation to the professional and personal support to the consumer. This can facilitate effective delivery of services by the practitioner and beneficial use of those services by the consumer.

Working as a partner in a collaborative rehabilitation profession, the peer can help bridge the difference between the traditional independent living (IL) and vocational rehabilitation (VR) paradigms. As conceived by Gerben deJong (deJong, 1978) and others, the traditional rehabilitation paradigm has been characterized by professionals directing treatment of a patient or client, including: a focus on the environment, with the medical model and the rehabilitation process as the locus of the problem; identification of dependencies, inadequate support services, architectural and economic barriers; problem resolution through peer counseling, advocacy, self-help, consumer control, and removal of barriers and disincentives; control of services by the consumer; and achievement of self-direction, least restrictive environment, and social and economic productivity.

The rehabilitation system is driven by a broadly encompassing mission. The purpose, as stated in the Rehabilitation Act, is:

...to develop and implement, through research, training, services, and the guarantee of equal opportunity, comprehensive and coordinated programs of vocational rehabilitation and independent living, for individuals with handicaps in order to maximize their employability, independence, and integration into the workplace and the community. (The Rehabilitation Act of 1973, as amended, Section 2.)

The current era is of particular importance for rehabilitation agencies. A unique set of forces is shaping our profession and changing the rehabilitation process. Medical technology is sustaining life for many who would previously have died. Assistive technology is creating dramatic new possibilities for persons with disabilities to control their own lives and to be productive. Stubborn recessionary trends are reducing job opportunities and also

constraining local, state, and national service agencies. The national societal-political sense is encouraging individual self-reliance and employability. The Americans With Disabilities Act has formalized the national commitment to remove barriers in employment, public services and transportation, public accommodations, and telecommunications.

These forces are moving rehabilitation agencies into new levels of collaboration with other human service agencies, greater reliance upon a wide array of other community resources, and a greatly enhanced sense of partnership with those who are seeking rehabilitation services. Any belief that public and private rehabilitation agencies and facilities can form a self-contained rehabilitation industry has proved to be a myth. The complexity and interdependencies of our economic and service institutions require a multi-disciplinary and collaborative approach. There is no other way of achieving the statutory promise of employability, independence, and integration into the workplace and the community of people with disabilities!

Under these circumstances, I suggest there are three imperatives that mandate the use of peer services as an integral part of the rehabilitation process:

1. A person's readiness to enter employment is dependent upon stable personal and environmental supports. One of these supports is found among people with disabilities who have succeeded, or can act as mentors.
2. Unresolved needs for personal and environmental supports severely constrain a person's capacity for learning skills and behaviors required for employment. It is clear from studies that family and environmental supports lead to more successful and stable community integration.
3. Lack of supports to deal with newly emerging personal and environmental problems will result in decreased job performance, frequently leading to loss of employment. The importance of such supports has been confirmed by a variety of studies and evaluations.

Following these imperatives and involving peers in the provision of services will, I believe, contribute to the development of a new disability services paradigm. Such a paradigm will focus on the consumer as the driving force for services, and promote partnership among the agencies in responding to that force. It will be characterized by collaboration, integration and networking among the various service delivery systems--all in mutual support of the individual's own cultural and lifestyle choices. The new paradigm will be applicable to all persons with disabilities, regardless of age, sex, type of disability, or other factors. It will join all participants and service providers in expecting and encouraging the maximum level of participation possible by the individual consumer, with a comprehensive and holistic view of services across all stages of life.

In closing, I offer my thanks to Dr. Robert Akridge and the forum sponsors for providing this opportunity. Since the mid 1970s, the disability movement has been stressing the value of peer support as a definite part of the



IL movement. It is my hope that what we do here today will help emphasize the importance of this value, not only for the IL movement, but also for the entire field of rehabilitation.

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#### Acknowledgement

These remarks reflect and summarize many of the themes which are presented in the Institute on Rehabilitation Issues publication cited (Rice, 1991).

## Peer Support Counseling

David G. Kay

The peer support model is the foundation and backbone of the services provided by centers for independent living. The peer model was born out of the basic human desire "to help one's self and one another" and traditionally has been used by various groups within American society to teach and reinforce those values deemed intrinsic to that particular group. Peer Support and peer counseling is the catalyst for individual change and group development within society. Examples and variations of peer models can be found in movements representative of women, minorities, older persons, teens, and more currently, for people with disabilities. In fact, elements of peer counseling were present at the beginning of the disability rights and independent living movements of the late 60's, 70's and early 80's.

Within our society, there are few positive role models for persons with disabilities. Peer support counseling fills that need for role models within each of us. A key reason peer support is so validating for persons with disabilities is because it is not based on a format of "hero" worship as are many other role models. On the contrary, peer support counseling takes place at a very real human level: people with disabilities to people with disabilities. The peer support counseling process helps to eradicate negative stereotypical images of persons with disabilities, emphasizing the person, not disability, thus creating opportunities for real change to occur.

Statements such as "you are such a wonderful person because of your disability," change to, "you are really something because you are a person." Peer support offers to people with disabilities the opportunity to interact without the "hoopla." The peer is often the first honest communicator to a person with a disability. Honesty is refreshing at any time. The open communication of the process provides an opportunity for an exchange of information between peers. Once the peer relationship begins to develop a mutual rapport, a level of positive acceptance is created, essential to an effective peer process.

Formalized peer support relationships, unlike friendships offer those seeking help the assurance that they will receive services from an individual who has been trained in basic peer counseling skills. Additionally, it offers a support system to the counselee as well as the opportunity to establish goals and objectives, supported by confidentiality.

The matching process involves carefully considering personalities, disabilities and lifestyles. It is important to note that linkage of a peer support counselor to a prospective counselee requires a flexible decision making style that integrates various kinds of information including specific disabilities.

The working phase of the peer process is critical because it assists persons with disabilities in establishing goals and demonstrates how to accomplish those goals. Emphasis is placed upon mutual determination with

concurrent encouragement from the peer counselor to the counselee to self-direct the process at a pace and level comfortable for that particular person. This value maintains support in the peer counseling relationship while preventing dependency. The working phase of the peer support counseling process might be more appropriately labeled the "Trial and Error of real life" phase. Everyone, regardless of presence of disability, needs the hard work of learning by trial and error to develop those experiences that teach self-esteem and confidence in one's own ability to function. These functional experiences are much more real to a person with a disability when supported by a peer who has experienced similar problems and developed positive coping strategies.

Coping and compensating are necessary skills for a person with a disability to achieve his/her desired level of independence. For example, the person who has a recent disability may be in rehabilitation thinking "my life is over;" conversely, a peer support counselor provides the message there are options for quality of life after disability! This positive message is provided in words as well as in action by the peer support counselor rolling into the hospital room of a counselee, which immediately begins to dispel the "life is over" line of thinking. Another example of modified thinking is "use of a wheelchair will make me helpless" to "use of a wheelchair provides the mobility that I need." This change in self perception is a much more functional view point and can lead to a much more productive dynamic.

The following are benefits of the working phase of the peer support counseling process. The development of decision making skills comes from the opportunity for trial and error. Persons with disabilities have not always had the opportunity to develop decision making skills because of the lack of accessibility to education, socialization events, and other experiences often available to non-disabled peers. Peer support counseling processes develop active ownership within the person with a disability, to achieve those personal goals he or she set. An example of the positive impact of the peer support processes includes persons with disabilities who have long been institutionalized who have shared how peer support counseling has added personal value to their lives. The following excerpt illustrates this intrinsic value, shared in a peer support counsel between two individuals who reside in nursing homes. "Just because you live in a nursing home doesn't give you permission to give up on yourself. I've lived in one for 20 years, let's remember it's where you live. Let's talk about what your doing at Independent Living Options away from the nursing home." The value of focus on ability and perspective coupled with a shared understanding of common situations brought by peer to peer creates effective dynamics.

The termination/closure phase of the peer support process serves as an opportunity to reinforce the learned and innate abilities of the person with the disability. In my work, I consider the termination phase to be the place independence begins in for the person with a disability. Closure on a specific independent living issue actually means beginning of opportunity as the individual moves forward in self-determination. Frequently, at some later date the same person may select to participate in a peer counseling role to pass along what he/she may have learned.

Peer support counseling occurs in the following formats at Independent Living Options, Inc.: individual, one on one; over the phone; or in face to face small group sessions facilitated by a staff member who has a disability. No one format is more effective than the other. The imperative factor is that peer support counseling occurs between people with disabilities regardless of issue or type of disability. The importance of quality in the peer support counseling is critical and is sponsored through a systematic peer training process. The training process enables prospective peer support counselors to formalize their informal but important knowledge of developing and managing effective strategies, and of people with disabilities.

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#### Acknowledgements

I would like to additionally acknowledge Dr. Nancy Opie, as well as all the many peer support volunteers, and others who over 6 years have contributed to the perfecting of our current peer support programs.

## Minilab on Peer Counseling Skills

Dale S. Brown

### Introduction to Dyadic Listening

This paper is based on a workshop given at the First National Forum on Peer Support Programs to Promote Independent Living and Career Development of People with Disabilities. The workshop instructed participants in "dyadic listening," a peer counseling technique used in the past decade in the self-help movement for people with learning disabilities. This article has two purposes; to describe the workshop as closely as possible, since it is part of a Proceedings; and to give the reader sufficient knowledge that they can try the technique themselves and teach it to a group.

The dyadic listening technique developed from my experience as a leader in the movement of people with learning disabilities. After speaking publicly about my own experience with learning disabilities, I would generally be flooded with people who called and wrote me because they wanted to talk about themselves. With my encouragement, people told me about their difficulties. But gradually, I burned out. The solution was to train people to listen to each other.

In the dyadic listening procedure, people are asked to get into pairs and take turns listening with instructions from a facilitator. Group members are given clear instructions on how to listen well. The success of the technique in the movement of people with learning disabilities has caused it to spread to other oppressed groups—both inside and outside the field of disability. My work on dyadic listening has taken place mostly as a volunteer. This information is not considered the official policy of my agency.

### Suggested Instructions from Facilitator

The next section of this article includes my instruction to the group in quotes and information regarding how the reader can adapt it to future groups in italic type.

1. "Get yourselves into pairs, preferably with someone you do not yet know. Friends may work together, but it is my recommendation that you take this opportunity to meet someone new."
2. "Figure out which one of you has a last name first in the alphabet. That person should raise their hand." *Use any technique of randomly choosing one person.*
3. "People with their hands up are the talkers. Talkers raise your hands. Listeners raise your hands." *Scan the group to assure that each person knows their assigned role.*

4. "First, I would like to instruct the talkers. Steve Brown inspired us by telling us about the many stories that we tell each other in the disability community about people who have made powerful contributions to our advancement in both great and small ways. For this reason, I would like each of you to think of a story to tell your listener. This should be any story in which you have overcome something deep within yourself. It does not have to be disability related." *Instructions to talkers should include any open-ended question that relates to what the group has in common.*

Other examples include:

- *What is it like to have "X" disability?*
- *What are the hardest challenges about being a rehabilitation counselor and how do you handle it?*
- *What was it like growing up as a woman who is blind?*

5. "Next I would like to instruct the listeners. Your major job is to look fascinated by what the talker says. Look at them in the eye. Give good non-verbal cues that show that you are listening. If there is a pause in their conversation, wait. They may start talking again after being given time to think. If they remain silent, ask an open-ended question. Examples of open-ended questions are:

- *What happened next?*
- *What did that mean to you?*
- *What were you thinking at that time?*

"Remember, your major job is to listen and look interested. Both of you have five minutes. Please begin now."

*When giving these instructions to a group of people that share the same oppression, state, "When you hear your talker's story, it is normal to want to interrupt and tell your own story. Please avoid that temptation. Your job as listener is to listen. You'll have a turn later."*

6. *Five minutes later, stand up and say several sentences to give everyone the time to wind up their stories. After that ask the following questions and elicit responses from the group.*

"What was it like to talk?"

"How did your listener let you know that you were being listened to?"

"What was it like to listen?"

7. Ask people to switch roles. Review the role of speaker and listener. (Instructions 3-6 above.)

### Teaching the Technique to a Self-help Group

The exercise went very smoothly with high quality listening and talking, probably because many delegates of the First National Forum on Peer Support Programs to Promote Independent Living and Career Development of People with Disabilities, were trained as counselors. The goal of the workshop, however, was to show how they could teach it to a self-help group of less experienced people with disabilities. Some points made by group members and me during discussion included:

- Most people find it pleasant to talk for five minutes at a time without interruption. Consciously listening rather than responding is an addition to our conversational repertoire. It is a gift that we can all give each other at times.
- Most people find it challenging to listen for five minutes without interruption. The facilitator needs to reinforce all examples of good listening behavior bought up by the group. Listening well deserves encouragement.
- Many people find it pleasant to listen and learn a lot about the person they are listening to.
- Several group members reported that they were going to continue their stories after the workshop.

### Other Peer Counseling Skills

The short time of the workshop allowed demonstration of only one exercise. Here are other dyadic listening skills.

Encourage expression of emotion. This can be done in many ways. Here are some:

- Ask the person to tell the story again. Children tend to tell the same story over and over again until they have it out of their system. Encourage your talker to give in to the ordinary human urge to repeat himself.
- Encourage expression of anger, by having the person talk in an angry tone of voice, stamp their foot, or pound a pillow.
- Encourage expression of grief by allowing tears. In my moments of intense closeness with people with learning disabilities and parents of people with learning disabilities, I have found that many people need to cry. It's hard for many people to watch others cry. They have been taught that crying means that a person is in pain, so they think if they stop the tears, they also stop the pain. Untrue! In fact, tears are part of the healing process. In the movie, "Country," Jessica Lang and her

husband are about to lose their farm. Lang saw her children sleeping, realized how unfair this was, and burst into tears. After a good cry, she started organizing her neighbors to save their farms. You may have noticed that emotion expressed through excited talk, laughter, and tears often leads to constructive action.

If the person is discussing a current experience, ask questions that connect it to the past. Examples of such questions include:

- When was the first time this happened?
- What memories does this bring up?
- What was (name the person's topic) like when you were young?

Show the positive reality. Often the most healing moments are when we realize our good points. If someone is telling you everything she thinks she has ever done wrong, ask her to talk about what a good (parent, person surviving a disability, housing coordinator) she is. Or tell her yourself. Point out that she is doing the best she can.

#### My First Experience with Peer Counseling

The first time I used these techniques publicly was ten years ago, when I was giving a small workshop on transition from school to work. A woman with a learning disability was trying to tell us about the intense struggle of her life. I was tempted to stick to my lecture, but instead, I decided to help her through listening techniques.

"I'd like to give her a chance to feel her feelings," I told the group. "If you agree to this use of our time, please listen to her with love and respect. It might not be easy, because, as you watch her, you'll feel all sorts of things. She shouldn't be interrupted and I need your agreement to that before we go on."

The others looked interested in what was going to happen. They each nodded. I moved closer to the woman.

"Keep telling us," I said.

She continued her story, pausing occasionally as tears came to her eyes and shakes went through her body. I encouraged the tears and shakes, knowing that this was a sign of her recovering from her hurts.

"What was it like for you when you were young?" I asked. She told us about school...of being unable to complete her homework...of being teased...of teachers telling her she was bad...of friends rejecting her. Her tears were falling faster. But her head was downcast and her eyes were almost closed. Clearly, she was too wrapped up in emotion and needed to be in better touch with the group.

"Keeping looking at us as you talk to us," I suggested gently. "Be aware that all of us care about you."



This helped. She cried harder. She told us how people thought she'd never amount to anything. How nobody thought she could make it to college. How she had failed several college semesters.

"Okay," I said. "What I need you to do next is to appreciate yourself, to tell us the good things about yourself with full pride in your voice, eyes, and posture."

"I can't," she shouted. "You don't understand. What you are telling me to do is hard. I can't."

"I know it's hard," I said. "You've been told a lot of times how bad you are, and you have to fight off those old false voices. But those old recordings are untrue. You know the truth about yourself. So tell us."

She cried for a few minutes, then said softly, "I am intelligent." She looked at me nervously.

"Say it with pride," I said. Holding my head high and in a proud tone of voice, I modeled, "I am intelligent."

She sobbed again and suddenly looked up and said with a joyous ring in her voice, "I am intelligent."

"What else?" I asked.

"I will make it through college," she sang out. "I am intelligent."

She sobbed again. Her self praise alternated with intense shaking and sobbing. She was realizing the reality, recognizing her innate goodness which had taken her so far through so much. It was inspiring to watch. Her eyes shined brightly.

Soon the time came to draw her attention away from herself and her feelings to the world around her. I asked her to describe the room, to say what she saw and felt. I asked her to describe a lamp in the corner, to tell us the background noise she heard, and to describe people in the group. Finally, she succeeded in bringing her attention to those of us in the group.

This example shows the steps which can be used when listening to someone describe a difficult experience or series of experiences. They are:

- listening well,
- encouraging the expression of emotion,
- connecting current experiences to experiences in the past, and
- bringing out the positive reality.

at the end of the session, bringing the person's attention away from emotion to the environment.

### Find a Listener for Yourself

Often, people who are good at listening well are overwhelmed by people who want to talk to them. Listening is hard work, particularly when someone else's problem reminds you of one of your own. Listening without getting equal interest and concern from someone else can lead to burnout.

Therefore, service providers and self-help leaders need to talk to someone who listens well. Many service providers find a listening partner and split time formally, each taking fifteen minutes to review the high and low points of the day. They take turns expressing themselves.

### A Proposed Format for Support Groups

This type of listening can also be done in a group. People who are not professionals can lead support groups when the format is well structured. One particular format requires very little planning time on the part of the leader. Keep the group small (eight or less) and follow these steps:

1. Ask everyone to take turns briefly sharing good news. Sometimes this is called "Good News."
2. Divide the amount of time left by the number of people and subtract two minutes. Give each person that amount of time to answer a question such as:
  - What makes you proud to be a member of the disability community?
  - What was it like growing up with (your particular disability)?
  - What gets in the way of complete success in \_\_\_\_\_?

Planning the question is the major job of the leader. The question needs to:

- relate to the common interest of the support group,
- be open-ended, and
- bring out emotions.

Each person should select a chief listener (usually, but not necessarily the leader) whose job it is to let them speak, encourage expression of emotion and state present reality. The others should listen quietly and respectfully.

At the end of the person's turn, the chief listener should carefully turn the speaker's attention from his problems to paying attention to the environment as described earlier in this article.

3. At the end of the group, each person should say something they like about the person on their right and one thing they are looking forward to doing each week.

These groups can get quite intense and once trust develops, people share deeply. Feelings of safety are encouraged if everyone agrees to leave what was said in the room. What has been said should not be mentioned to anyone outside the group or even to the person who has shared of themselves.

Good listening is crucial to the entire peer counseling movement. Having peers counsel each other is an important addition to the model of having selected people with disabilities serve as paraprofessional counselors. The dyadic listening exercise can be helpful to many groups. Please try it!

## Peer Support Services

Kathleen M. Anderson

Since January of 1990, the Grand Rapids Center for Independent Living, in cooperation with the local office of Michigan Rehabilitation Services, has offered a Peer Support Services program. Initial targeted service recipients were individuals receiving SSI or SSDI who had been placed in regular competitive employment for supported work. The program goal was to provide a support system to help cope with the changes in life-style brought about by their employment. Through the group process, newly employed consumers gain access to peer support and other community resources to maintain employment and address other independent living issues.

Since its beginning, the program's service perimeters have expanded. Peer Support Services has proven to be a viable and cost effective means to meet a variety of consumer needs. Listed below is a description of each of the needs now being addressed by Peer Support Services.

### Pre-vocational Peer Support for Physically or Otherwise Health Impaired (POHI)

In January of 1991, a Peer Support Group was assembled to address individuals with physical disabilities who have not yet been the recipients of any vocational services or job placement assistance. Some of the members of the group were still enrolled at the local POHI program with the Grand Rapids Public Schools. The remaining members were graduates of that educational program. The group met for six months. During that time a curriculum was followed. Topics covered included: identifying individual capabilities, developing a functional resume, practice interviewing, and arranging transportation. Additionally, the curriculum requires each group member to seek and obtain a community-based volunteer position for a minimum of four hours per week. This work experience enables each person to have a work environment with which they can identify throughout the group process.

The end result for this group was the referral of each member to job placement service through the cooperative efforts of the local Michigan Rehabilitation Services and Hope Network Vocational Resource Center.

### Transportation

One of the key elements in terms of resources needed for independent living is transportation. A large majority of consumers face not only the lack of services but also an affordable means of transportation. Many who are employed have difficulty finding affordable transportation for work. In the past, some individuals do not earn enough to justify the cost of transportation.

Through Peer Support Services, consumers have support in finding alternative transportation options. These options include training in the use of public transit, specialized public transportation ("Go Bus"), taking the SSI deduction available, the PASS program, or seeking funding for driver's education and the purchase of an automobile.

### Pre-vocational Peer Support for General Assistance (GA) and Aid Dependent Children (ADC) Recipients

This group is made up of persons involved in job seeking through Vocational Services. Many of the group members have never worked or have been absent from the work force for an extended period of time.

The issues for this group are unique from other consumer needs. Budget cuts and lack of public money is threatening the livelihood of this group. Through Peer Support they are able to make decisions that will change the course of their lives. Many of these group members have been rejected and isolated due to the stigma given them because of their dependent economic status.

### Peer Consultants

Peer consultants are screened through the process of application once an individual is selected to work as a Peer Consultant. They are put under contract with the Grand Rapids Center for Independent Living. Each consultant is paid an hourly wage for delivering Peer Support Services. One of the key elements of the Peer approach is that the individual consultant is paid for using his/her expertise. Since we believe that the Peer Consultant role is a viable and valued resource, payment is made for the service rendered just like other traditional "professional services" (i.e., social work, therapist, placement counselor, etc.).

Training for Peer Consultant is an ongoing process and is required through the contract agreement between the consultant and the Center. The training often uses community resources. In addition to training and information, the monthly meetings provides a natural support for all who are engaged in the effort of peer support services.

In determining eligibility as a Peer Consultant several factors are considered. For some groups it is essential that the consultant have a successful history of employment. Gainful volunteer work experience is also considered. For other Peer needs some group leaders are considered for the experience in independent living and the surrounding issues.

### Conclusion

As the Peer Support Services program evolves it is clear to us that this service has a variety of ways to deliver services to consumers in the community. The Peer Support Services' major asset is the fact that it is cost effective, which enables long-term services delivery. For those with disabilities, long-term services can contribute to the success of an individual's independent living endeavors.

## The Kentucky Peer Support Program for Persons With Disabilities

Dolores E. Reddinger

The Center for Accessible Living, a private, non-profit organization governed by a consumer-controlled board of directors and staffed by both disabled and non-disabled persons, offers services and programs to individuals with disabilities. Since its founding in 1981, the Center's mission has been to assist in creating an environment which supports the disabled individual in choosing, achieving, and maintaining his or her personal level of independence. Because it is the only cross-disability related independent living center in Kentucky, through the years it has received numerous requests for assistance from communities across the state. Many such requests, particularly those for ongoing emotional support, could not be answered due to constraints of time and funding. However, early in 1991, the opportunity to address the needs of disabled Kentuckians who live beyond the reach of Center programs came in the form of a grant from the Department of Vocational Rehabilitation. In keeping with Vocational Rehabilitation's growing emphasis on independent living services for persons presently considered too severely disabled to be employed, the Center for Accessible Living received funding to create and administer the Kentucky Peer Support Program.

### Goal of the Kentucky Peer Support Program

The program was designed to provide access to the information, education, and support necessary for independent living to all Kentuckians, in or near their own communities. To achieve its goal, the program employs Peer Support Coordinators who work from their homes to: (a) organize local support groups, (b) provide referrals to services and programs in their area, (c) offer information on accessible housing and adaptive equipment, (d) promote advocacy for disability-related issues, (e) speak to community organizations, (f) provide information on the Americans with Disabilities Act (ADA), and (g) work with other service providers to most effectively assist consumers.

The program began with four coordinators: two in eastern Kentucky and two in the western portion of the state, areas which are predominantly rural and have long been underserved. Expansion into the central part of the state is currently in progress. Making the position of coordinators a full-time job and/or adding more coordinators in each area are other possibilities for expanding the program, if and when funding permits.

### Qualifications for Coordinators

The Kentucky Peer Support Program's Coordinators are persons who have some type of disability, have demonstrated their ability to live independently, and have the desire to help other disabled individuals reach their chosen level of independence. Qualifications for the position are: (a) high

school diploma or equivalent, (b) in-depth knowledge of and commitment to the Independent Living Philosophy, and (c) superior interpersonal and communication skills. Relevant life experience may be considered as an additional qualifying factor.

The job description for the position requires Coordinators to be able to work 20 hours per week, do much of their work by telephone, travel throughout their area, keep records, make reports, and commit to working in the program for one year. A salary of \$6.00 per hour was selected so that persons with disabilities could work as Coordinators without losing their benefits.

#### Selection Process for Coordinators

Referrals for candidates for the coordinator positions were requested from Vocational Rehabilitation field offices, the Kentucky Coalition for People with Handicaps (KCPH), the Kentucky Assistive Technology Service (KATS) Network, and other disability-related organizations across the state. For the original four positions, 51 persons made inquiries, 21 sent applications, and 13 were interviewed.

The two men and two women eventually chosen as Coordinators had college experience; two had degrees and two were still attending classes. One Coordinator's disability was of adult onset; the others were developmentally disabled. All four had previous working experience, and all were already doing work similar to that required by the program, though on a smaller scale and on a voluntary basis.

#### Training of Coordinators

Training for the Coordinators was conducted at the Center for Accessible Living over a three-day period. It was based on the Center's own peer support training program and also drew on the knowledge and experience of Center staff members. All staff participated in the sessions.

Topics covered included: the independent living movement, the Center's programs and services, language focusing on dignity, advocacy, the ADA, developing a community resources network, conducting interviews, confidentiality, and counseling skills. Particular attention was given to the similarities and differences between visible and invisible disabilities and between adult onset and developmental disabilities. The many possible areas of concern with which consumers might need assistance were also discussed.

The trainees attended one of the Center's peer support group meetings, and then discussed facilitating groups with the leader. A visit to the Disabled Citizens' Computer Center located at the Louisville Free Public Library helped familiarize them with some of the assistive technology available to disabled persons.

Learning to use the Facsimile Machine (one is supplied to each Coordinator) and how to keep the records and make the reports required by the program were important parts of training. Coordinators are reimbursed for

mileage, toll calls, FAX transmissions, postage, and supplies; therefore, documentation procedures for claiming these reimbursements required explanation.

### Importance of Peer Support Groups

While the Center for Accessible Living employs a professional counselor to work with individual consumers on personal issues, it recognizes that peer counseling is the most effective method for fostering independence and for teaching independent living skills. It recognizes, too, that only a person with a disability can help another disabled person work through certain problems. Therefore, from the time that the Kentucky Peer Support Program was only an idea, peer support groups and peer counseling were considered to be the heart of the program.

All four Coordinator trainees had some knowledge of support groups, but membership in such a group, even for a limited time, was important to their training. Being together for the three days of training gave them an opportunity to share their own experiences with disability and to develop a feeling of community and a sense of common purpose. When they returned to their homes and began their work, they continued to share problems and to encourage one another by phone, thus forming the program's first peer support group.

Peer support groups in this program, like any other support groups, are formed when people who share an experience come together to help one another. There are, however, three additional elements in the Kentucky Peer Support Program: (a) peers are persons with disabilities, (b) support groups teach and promote advocacy, and (c) members learn independent living skills.

Leading group sessions allows the Coordinators to use their time most efficiently by teaching decision-making skills and modeling ways of dealing with everyday problems to more than one person. However, in the more isolated rural areas served by the program, bringing people together in groups is often impossible. To help these consumers feel less isolated, Coordinators are linking them with one another for support via telephone. For those without phones, home visits by the Coordinators may be their only opportunity to speak with another disabled person or to feel understood and accepted.

### Services for People Without Disabilities

Membership in the program's support groups is not limited to disabled persons; several Coordinators lead groups for parents of disabled children. The Coordinators also offer their services to groups and to individuals who have concerns as relatives or close friends of persons with disabilities or as advocates for disabled individuals.

### Supervision and Ongoing Training

Supervision for the Coordinators is conducted by the Center's Counseling Program Manager via phone, FAX, mail, and, when necessary, in person. Phone logs and consumer contact logs are submitted monthly as is a



report of number of contacts made, number of referrals from and to Vocational Rehabilitation, and participation in community activities. The Coordinators are always able to call the program supervisor or other staff persons at the Center for assistance with problems. All staff members send the Coordinators helpful information on a regular basis.

From time to time, the Coordinators are brought in for a special training session. For example, the month after they began working, they returned to Louisville for a one-day training session on the ADA sponsored by the Center and conducted by Liz Savage of the Disability Rights Education and Defense Fund in Washington, DC.

They also participate in training sessions at which they speak about the Kentucky Peer Support Program. The two eastern Kentucky Coordinators and their supervisor spoke to publicize the program at a recent meeting of the Kentucky Independent Living Council. All the Coordinators, the supervisor, and an associate director of the Center gave a presentation at The Buck Starts Here Conference sponsored jointly by the KATS Network and KCPH.

### Problems

The two most outstanding problems encountered so far have been lack of transportation and the need for more referrals to the program. The transportation difficulties were anticipated because the program operates mainly in rural areas which have no public transportation. The Coordinators frequently go to consumers' homes. However, bringing some of these consumers together for support groups is simply too difficult. Even when consumers have transportation available, they may live at such great distances from one another that weekly meetings are not possible. Linking isolated consumers with one another by phone and visits from the Coordinator are the methods being used to alleviate this problem.

Because the program is new and yet unproven, referrals have been slow to come. The Coordinators do all they can to publicize their program, making effective use of local media, church bulletins, and public bulletin boards in their area. They offer to speak to social, service, and business groups; at schools; and to health service and other community agencies. They network with other disability-related groups and participate in as many community activities as possible. Recently referrals have increased and, as word of the program is spread, more are anticipated.

A third problem concerns funding. Though the original six-month grant has recently been renewed for one year, funds allow for adding only one new Coordinator; the Center had hoped to add two. Making the Coordinators full-time employees was another hope that cannot yet be achieved. Coordinators are paid only for 20 hours per week, but actually average 35 hours weekly. The Center would like to pay them for all their working hours.

A fourth problem, the sudden death of one Coordinator, occurred four months after the program began. Robert Seals was a tireless and dedicated worker and advocate for persons with disabilities. He had become a reliable

source of assistance, encouragement, and support for the other Coordinators, and his presence is missed by all who worked with him.

The Kentucky Peer Support Program is entering its sixth month of operation, extending its coverage into a new area, and adding another Coordinator. It is good to be growing at a time when implementation of the ADA is focusing attention on the rights of disabled persons. It is good to be able to bring awareness of these rights to disabled Kentuckians who may never have heard of the ADA, or who never thought it would make a difference in their lives. And it is good to take on the challenge of empowering persons with disabilities. The program has made a small, but significant, beginning toward meeting this challenge by serving approximately 400 persons. Given adequate funding, it will continue enabling Kentuckians with disabilities to live as independently as they choose, and creating an environment which supports their independence.

Peer Counseling as it Relates to  
Persons Who Make a Transition from a  
Long-term Care Facility into the Community

Rick McWilliams

Empowerment is a core issue when talking about helping individuals with disabilities to set and achieve goals. Historically, society did not think much of the capabilities or contributions of people with disabilities. In fact, at one point, the accepted way of thinking was that we should be "put away" in facilities to be cared for and an air of "dependence" was formed. It was thought that we were not able to function in society, let alone make a contribution to it. More recently, however, people with disabilities began asking the same question posed by people in other minority groups. We began asking questions like where is the integrity of the people who control our lives? But, as with individuals who are part of other minority groups, only a few, secure members felt confident enough in the challenge. The people who were "put away," never had an opportunity to develop the skills necessary to be empowered. Peer counseling is a means by which empowerment begins for these individuals. Transitioning is a "process" and the peer counselor supports the consumer, emotionally, through the entire process...before, during and after the move.

Peer counseling is an important part of the transition process because people who have spent time in nursing homes have lost or never gained many of the skills, emotional and otherwise, necessary to successfully live in the community. Some of the issues addressed through our peer counseling programs are disability adjustment, learning how to explore options, developing decision making skills, self advocacy instruction, empowerment, attendant management and housing acquisition assistance. Each person who receives services has an individualized goal plan which is tailored to that person's needs and desires and it is mutually agreed upon as well as determined to be realistic by s/he and the peer counselor.

Disability adjustment deals with the emotional aspects of accepting the fact that you must live your life as a person with certain limitations. When a person has been living in a nursing home, chances are that person has not had an opportunity to learn to deal with having a disability. Most of their energy has been spent learning to cope with the loss of control over their body in particular and life in general, including being away from their family and adjusting to a different atmosphere. The peer counselor is someone who has gone through this coping process and can relate his/her experiences. This sharing of experiences not only shows the consumer that s/he is not the only one who feels these feelings, but enables that consumer to work toward finding his/her abilities and expand upon them.

When living in an institutional setting, the freedom of choice is greatly diminished or absent. The entire time a person lives in such a setting, decisions

are made for them (i.e., what time to get up in the morning is dictated by how many staff are available, how many other people need assistance in getting up and the extent of each person's need for assistance etc.). Therefore, an initial objective for the peer counselor is to help the individual learn that s/he has alternatives and how to find them. The process of learning to find their options also enables these persons to learn decision making skills. When working with consumers, we not only help them to discover their options but also assist them in determining the possible consequences of choosing each prior to making a decision.

Self advocacy and self empowerment go hand in hand. I think the key to success in these areas is self esteem. The way you see yourself is commensurate with the way others perceive you. It is very difficult to feel good about yourself when you have little to no say in how your life is maintained. Many people who participate in our transitioning programs have not learned what their needs are, much less how to manage those needs. A peer counselor is someone who can provide a role model, show how s/he learned self advocacy skills, what they are and assist that consumer in finding the most appropriate method of learning said skills, given his/her strengths.

As we all know, Attendant Care can play a significant role in one's ability to successfully live in the community. Peer counseling gives the person who is considering a more independent lifestyle a chance to talk directly with someone who is living in the community and has personal experience with an attendant who assists with ADL's. Through my experiences managing an attendant, I can guide another through the process of learning the principles of hiring, managing and if necessary, firing an attendant.

Another area where peer counseling has been effective in assisting people relocate into the community is helping them to find an appropriate residence in the community. The Center for Independent Living of Southwestern Pennsylvania (CILSWPA) has a computer database of housing information in a five (5) county region. The available information includes accessibility features as well as location and application information. Through this and other resources such as an established relationship with the local housing authorities, we are able to locate the appropriate housing. However, one of the most important features of this system is almost impossible to include. That is the ability to know whether or not an appropriate housing setting is available. Unfortunately, there is a tremendous need for accessible housing and few resources. Much of the housing that is accessible, is not available.

After consumers have relocated into the community, peer counseling is continued. It can then become a vehicle for the consumer to explore and utilize community resources and to assist them in becoming vital members of their community.

Peer counseling at CILSWPA is offered to our consumers in two (2) types of settings, one-to-one and in a group setting, according to the individual's needs and wishes. The one-to-one is provided by direct service staff

and consultants. The group sessions are provided in the nursing homes as well as at CILSWPA.

For over 5 years, "Transitioning" has been an important part of the services provided at the CILSWPA. Our initial program was conceived of an Allegheny County (where Pittsburgh is located). It was brought to the attention of the County Commissioners that there were many young people residing in nursing homes, who were capable of leading more productive lives. Therefore, they contacted local agencies who provide services for individuals with disabilities to meet and come up with other alternatives for the people who were identified. The two agencies who met with the Commissioners were United Cerebral Palsy of Pittsburgh (UCP) and CILSWPA. The result of this meeting was a contract between the Allegheny County Department of Aging and CILSWPA. It was also the beginning of a program called the Supported Housing Demonstration Project (SHDP).

During the beginning phase of this program, two levels of need were identified. There were consumers who had never had an opportunity to live independently or have not done so for a long time, and there were those who had lived in the community and acquired a disability. This distinction was the basis for where each consumer would be referred.

The individuals who had little experience in making their own decisions had never had true control of their lives. Therefore, their opportunity was provided through UCP, where they live in a group home setting, receive 24 hour attendant care services and attend day classes geared toward helping them to learn independent living skills.

The consumers who had lived independently and acquired a disability, were referred to CILSWPA and received assistance in locating housing, purchasing furniture, and attendant care on an "as needed" basis. Attendant care, for both programs, was/is sponsored by Pennsylvania Department of Public Welfare and Case Management is provided through the Allegheny County Department of Aging.

As the program developed, it became apparent that there were two pieces missing: (1) There was a need for someone to provide psychological and emotional support to enable individuals to prepare for a move, and (2) There was a need for someone who could identify the specific needs of the consumer when s/he was in the community. Through an RFP, we then applied for Federal money through our State VR system. This resulted in our receiving a grant to provide transitioning services. Among other services, this contract enabled us to provide peer counseling and skills training specifically to the consumers who are involved in the transitioning process.

In addition to the SHDP and transitioning, CILSWPA administers a program called the Community Services Program for People with Physical Disabilities (CSPPPD). The CSPPPD is Pennsylvania reaction to the Omnibus Reconciliation Act of 1987 (OBRA-87). OBRA-87 specifically targets persons with mental illness, mental retardation or other related conditions. In October of 1988, the Office of Social Programs, within Pennsylvania Department of Public

Welfare, was designated the Office responsible for providing services to persons with other related conditions who are affected by OBRA-87.<sup>1</sup> CILSWPA is responsible for administering this program in 23 counties in Western Pennsylvania.

A vital component of the CSPPPD is "specialized services." Specialized services are made up of generic services, support services and service coordination activities that are arranged into a continuous program that is directed toward the consumer's acquiring the behaviors necessary to function with as much independence as possible and to prevent the loss of the consumer's current functional abilities. It is through specialized services that we provide peer counseling and supports to consumers in this program.

Not so long ago it was generally accepted that people with disabilities did not have much to contribute to society. Rather, the community would be better off to hide us away. Peer counseling has proven to be an effective means of assisting consumers become knowledgeable of their options, develop decision making skills, develop a sense of self-confidence and become productive members of society. It has also provided a vehicle for information dissemination to the general public regarding the contributions that we can make.

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<sup>1</sup> Persons with other related conditions are persons who have a severe, chronic disability whose onset was before age 22.

## A Personal Journey to Freedom

Patricia Cudahy

The efforts of disability rights activists and the impact of the independent living movement have brought about an awareness of those barriers, both attitudinal and physical faced by persons with disabilities. The Americans with Disabilities Act and other civil rights legislation has laid the groundwork for significant change. Communities are becoming more accessible but improvement is too often too slow in coming.

People with disabilities have come together to form a network of independent living centers, which help other disabled people recognize their own ability to take control of their lives and become more self-sufficient. Centers are managed and staffed by people with disabilities who have successfully made the journey to personal independence. They understand the "degree of difficulty" in such a journey, but they also know the triumph of success. They believe that every individual has the right to be all that they can be. Peer counseling (or as it is sometimes referred to--peer partnering) is a cornerstone of independent living.

For the person with a disability, there are many barriers and obstacles to independence. Such individuals must face their "different-ness," and the impact it has on those around them. Parents may struggle with feelings of anger, shame, guilt and loss, while siblings often are resentful of the special attention given the child with the disability. There may be an attitude of lowered expectation, in which the individual is not expected to achieve because of the disability and needs to be taken care of. Or an unrealistically high expectation may dictate that he overcompensate and become a "super cripple," thus "making up" for his inadequacies. Physical barriers may block access to the community, preventing the person from finding a job, participating in social activities, and developing relationships.

There is one paradigm yet to be explored and confronted: the barriers the disabled person erects himself. This may be the most challenging hurdle of all to overcome.

Personal barriers, those constructed and erected by the individual, are often more "crippling" than the disability. If not recognized and confronted, they can result in a life of isolation, frustration, and emotional emptiness. To be truly independent, persons with disabilities must see "personness" first. It is important that individuals not over-identify with one aspect of themselves whether the part is an ability or a disability, a goal or a problem.

Leo Busgalia, in his book, "The Disabled and Their Parents," addresses this very issue. "Individuals are handicapped to the extent they internalize their limitations as debilitating and undesirable." "The disabled person is largely responsible for determining his own status. He must value himself in the total sense, recognizing strength and abilities as well as accepting his real limits,

trusting his own feelings, and doing his own personal self-assessment." He goes on to say that adapting to a disability is an education for life; that living is a reciprocal process--to be loved, you must give love; to be cared for, you must care for; to be given to, you must give. There must be a recognition of the whole person by one's significant others, but even more important, one's self.

My own personal experience with disability has been a journey of 46 years. I have faced many hurdles, but the ones that have been the most challenging were the ones I erected myself.

I don't remember much of my early childhood. Flashes of recollection surface with images of grandparents, the family dog, skipping rope with my friends, and planting the garden with my dad. I remember being able to run. I had polio when I was six years old, and then the memories become sharp, vivid, and disturbing. Hot packs with their warm, moist, woolen smell; trips to the hospital where I stayed for months at a time; President Roosevelt, standing with the aid of braces, shaking my hand and asking me what my name was; alone in a big hospital bed pretending that the sounds coming from the kitchen were really my Mother washing the dishes, and I was at home and not alone and afraid in a rehab hospital.

Having spent so much of my life in a hospital, it was no surprise when I announced that I wanted to be a nurse. At least no surprise to my family who reinforced my belief that I could be whatever I chose. In 1956 I entered Vassar Brothers School in Poughkeepsie, New York on a six-month trial basis. I married, had a baby, completed my training, and graduated in 1960 as a Registered Nurse.

Life was wonderful. I had succeeded in overcoming those barriers in the way of my independence. I realize now that I was building my own personal barriers behind which I could hide. These walls soon became a fortress, keeping the world out, and me safe. I dealt with the loss of my physical strength, by pushing myself, being the "over-achiever." I resolved that I would never use crutches, and if I had to use a wheelchair, I would simply kill myself. I worked full-time, put my husband through school, and raised a family. To the world, I was a success, but I knew I was running, trying to out-distance the specter of reality.

My world came tumbling down in the spring of 1983. I traveled to the Rehab unit at Warm Springs, Georgia to be told that I had post-polio syndrome. I learned that I would become gradually weaker, and braces and wheelchairs were no longer a probability; they had become a certainty. I returned home to face the grim news that my marriage was crumbling, and that I would be facing my future and my worsening condition alone.

The next few years were a blur of depression, divorce, and hopelessness. The post-polio syndrome worsened, and with it came pain and muscle deterioration. I could see no reason to live, and seriously thought about suicide. Even my skills as a "super-achiever" no longer worked, and I began to give up.



I realize now that that time in my life was a turning point. I was going through a very painful process of "letting go" of all those barriers I had erected and was coming face-to-face with the real Pat Cudahy. I could no longer push myself and expect to maintain my stamina and vitality. I would have to accept the fact that I needed braces in order to walk, and at times would have to use a wheelchair. I also finally admitted that I did have a disability, and that it was going to get worse. I was facing my own mortality, and through that process was accepting the person I really was.

The last five years have been rich in self-discovery and understanding. While I still have days when I push myself, I am realizing that such behavior to excess, is self-destructive. I have accepted, and actually embraced a wheelchair, which allows me to be truly independent. I can now "power shop" in a mall at about 5 miles per hour. My husband and I visited Epcot Center and we were able to see all the attractions together. I was not exhausted and gray with fatigue at the end of the day, and was able to enjoy a romantic candle light dinner that evening. I now carry crutches, cane, and chair in my car so that I am ready to meet any challenge.

The single biggest discovery in my journey to freedom, is that my disability is only a small part of who I am. There are many other parts that have had a much bigger impact, yet I wouldn't acknowledge them. I have discovered that my disability often provided a shield behind which I could hide; that faced with the picture of a "poor crippled" girl, few people dared to challenge me. I shall always be grateful to those "courageous" few, who dared to expose those myths I had perpetuated, and helped me to grow and become me.

My new husband certainly deserves a Medal of Honor for continuing to insist that I use my cane, my crutches, and when necessary, my wheelchair. And, all the while, he lets me know that he loves me, even if I walk funny.

Neil Lamper, a dear friend who looks like Willy Nelson, confronted me with the fact that I was using my disability as an excuse to avoid the hurts and joys of life. I raged at his insensitivity and ignorance, but know now that he helped me not only find myself, but taught me how to love and nurture Pat.

Nancy Jachim, has been my own personal peer counselor. Nancy is a CIL Director, a gorgeous woman, a successful business person, mother of four, and a wonderful friend. She showed me that you can be all of these things and have a disability. She demonstrated to me that you can have a disability, but you don't have to be disabled.

My journey has resulted in a career change. I am now the Director of a Center for Independent Living. I have found that the independent living environment provides the support I need, while at the same time giving me the opportunity for professional growth. It also allows me to make good use of my experiences in helping others as they make their journeys.

Talking about my own personal adjustment to disability has been difficult. In the professional world, it's not acceptable to "personalize" situations. Even the task of "writing a paper" seemed to demand research,

footnotes, and documentation. I would like to say that independent living, and in particular peer counseling, is a powerful, living dynamic; we are experiencing everyday what others have to read about in textbooks.

Busgalia writes, "The disabled person is responsible for determining his own status. He must be given the freedom to be, to try, to fail, to grow, to succeed, to learn, to enjoy, to laugh, to cry, and even suffer."

We are responsible for painting our own life picture, and we can be there for others as they paint theirs.

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# The Peer Mentoring Aspect of Enclaves in Supported Employment

Debra A. Harley

## Introduction

Peer mentoring is a technique employed to maximize positive outcome. The technique of mentoring is rooted in the historical epic of Homer's The Odyssey (Anderson & Shannon, 1988). Throughout history, mentoring has been viewed as a relationship in which the more mature and experienced individual assumes the responsibility of guiding the less experienced individual or novice (McPartland, 1985; Merriam, 1983; Phillips-Jones, 1982). According to Gebrke (1988), in order to guide an individual, "the mentor must be more mature, advanced, or more experienced--not a peer" (p. 43).

The purpose of this paper is to present the peer mentoring aspect of enclaves in supported employment. Because the type of supported employment model selected is determined by the particular needs of the individual consumer, a specific approach focusing on enclaves will be taken. This will be accomplished through a discussion of the definition of supported employment, purpose of enclaves, the concept of mentoring, and the impact of peer mentoring on job performance and maintenance.

## Definition of Supported Employment

"Supported employment is paid employment that takes place in regular or normal work settings" (Wehman, 1988, p. 4). The concept of supported employment is characterized by three components: competitive employment, an integrated work setting, and the presence of on-going support services (Federal Register, 1987). Supported employment is based on a philosophy of integration and normalization (Wehman & Moon, 1988).

Supported employment is geared to provide services to individuals with the most severe handicap. Wehman (1988) pointed out that "failure to do so negates a major supposition of supported employment and, in fact, is a perversion of the entire concept" (p. 5). Supported employment's responsiveness to assist individuals with the greatest deficits is its major advantage.

Overall, seven critical attributes are necessary for a job situation to be considered supported employment: (a) placement first, (b) integration, (c) wages and benefits, (d) zero reject, (e) flexible support, (f) life-long support, and (g) choices (Powell et al., 1991). Typically, supported employment is developed in four phases occurring in the following order: (a) career planning, (b) job development, (c) instruction, and (d) on-going support (Wehman & Moon, 1988). The needs of the individual consumer will determine which of these phases will become the primary focus. Five major

models are typically used: (a) individual jobs, (b) apprenticeships, (c) small enterprise, (d) mobile work crews, and (e) enclaves (Powell et al., 1991; Rusch, 1987; Wehman & Moon, 1988). Each of these models is guided by specific goals, objectives, and structure.

Supported employment is designed to counteract the limitations imposed by the individuals with severe handicaps to be self-sufficient and productive and contributing members of society. One aspect of supported employment that adheres to this principle is enclaves. The following section will discuss the definition and purpose of enclaves.

### Definition and Purpose of Enclaves

An enclave is a group of individuals who work in a specific training unit within an integrated community-based setting (Moon & Griffin, 1988). An enclave usually consists of no more than six persons who receive continuous, systematic, and reliable support (Powell et al., 1991). Traditionally, enclaves pay workers a salary that is commensurate to that of their counterparts doing the same or similar work. An enclave has a supervisor who is usually an employee of the "host" company (Rhodes & Valenta, 1985).

The purpose of enclaves is to provide workers with severe handicaps an alternative to individual job placement. Additionally, enclaves can promote integration of persons with disabilities with other workers through interactions before and after work, break and lunch times, recreational time, and placement throughout the work setting (Powell et al., 1991). Workers obtain a longer-than-average amount of time to master job skills.

Overall, enclaves benefit employees with severe disabilities as well as employers. Employees experience paid employment, economic self-sufficiency, and autonomy. Employers get a labor pool of skilled employees who meet market labor demands and guaranteed production value (Parent, Hill, & Wehman, 1989).

An enclave lends itself to being applicable to the concept of peer mentoring. The characteristics of on-going support, flexible support, and locus on control allow peer mentoring to be a feasible aspect of enclaves. The following section will present the concept of mentoring.

### The Concept of Mentoring

Mentoring is a complex relationship of roles, tasks, commitment, and procedures. Daresh and Playko (1989) noted that mentoring is "a method designed to support the work of" individuals who are at the beginning learning stages of their career (p. 89). Mentoring is an on-going and reciprocal relationship which involves teaching, befriending, encouraging, supporting, and promoting (Daresh & Playko, 1989; Taibbi, 1988). According to Taibbi (1988), "as the novice is ready to learn, the mentor is ready to lead" (p. 60).

Mentorship has several underlying concepts. First, the relationship is a naturally occurring event which develops in a given environment. It does not

flourish based on assignment, but based on interaction (Taibbi, 1988). Second, a mentorship is ongoing. The mentor-mentee relationship may undergo change over time, but for the most part it is long lasting (Gebrke, 1988). After all, it is the intent of mentorship for the individuals to learn and grow. Third, a mentorship is based on rapport. It is easier to work with and learn from someone with whom openness and honesty exist. Mutual enhancement is at the core of the mentorship (Daresh & Playko, 1988). Fourth, a mentor serves as a role model (Anderson & Shannon, 1988) and, exhibits behaviors and aspirations which can be adopted by the mentee. The mentor serves as a mirror-image to the mentee by reflecting an example which promotes growth and stimulates development. Finally, a mentorship is a counseling process involving problem-solving through active dialogue, and "behaviors such as listening, probing, clarifying, and advising" (Anderson & Shannon, 1988, p. 41).

Mentoring involves a goal-directed relationship which focuses on certain perspectives that are sustained over time. It accentuates the positive aspects of an individual's behavior and performance and does not concentrate on the individual's inability to perform a task (Laabs, 1991). Mentorship is characterized by commitment and perseverance. Mentoring reflects a growth and development process, and a learning process. At a time when the mentee is no longer a novice, but not yet experienced, the mentor becomes the liaison during the transitional period. The next section will discuss the potential impact of peer mentoring on job performance and job maintenance.

#### The Impact of Peer Mentoring on Job Performance and Job Maintenance

In developing peer mentoring, it is appropriate to consider some elements of mentoring as related to both the mentee and mentor. The focus is on the functions of mentorship as a prelude relevant to learning as a holistic and individualized approach. Effective application of peer mentoring increases the probability of individuals with disabilities in supported work environments, employing desirable jobs skills and behaviors in enclaves as an aspect of supported employment. The techniques presented in this section provide a practical exploration into the advantages of peer mentoring.

Peer mentoring represents a new dimension for employees with severe handicaps. The operative term "peer" refers to the utilization of another individual with a handicap in the role as mentor. As with most jobs, there is an individual who acts as an immediate supervisor, a department supervisor, regional supervisor, and so forth. The same is true of the peer mentoring agent. Although the peer mentor serves as the immediate supervisor, she or he also has a supervisor.

The impact of peer mentoring includes several features. A comfort zone can be established. The mentee and mentor are of equal status and the role assumed by each one of them is non-judgmental. A comfort zone not only benefits the employee in terms of work atmosphere, but the employer in terms of increased production and quality of work.

Second, peer mentoring decreases isolation due to intimidation of the superior/subordinate roles of supervisor/worker. Workers may be more inclined to ask questions or seek assistance when they are not intimidated. A peer mentor serves as a supportive function and provides the mentee with reinforcement, feedback, instruction on new tasks, and socialization (Powell et al., 1991).

Third, the peer mentor is an advocate for the mentee. Aside from the traditional function of an advocate, the mentor provides guidance which facilitates problem solving on the part of the mentee. Unlike the supervisor who represents an evaluator of quality control, the peer mentor is less restrictive and more human. Figure 1 depicts this conceptual framework of the impact of the peer mentor versus the supervisor. The peer mentor yields an unlimited role model who is viewed as a friend or advocate in a facilitative manner. The supervisor is seen as a limited role model who is regarded as a task regulator and quality control monitor. Workers perform differently when they are being supervised than when they are working independently (Rusch et al., 1984).

Fourth, peer mentoring promotes autonomy. The peer mentor is non-paternalistic and allows the mentee to assume the locus of control. Gradually, as the mentee's experience and confidence increase, she or he needs less of the mentor's leadership. The gradual transference of control helps to eliminate feelings of being rejected or unappreciated as a mentor. Peer mentorship makes the acclimation to the job setting, tasks, and co-workers easier because the peer mentor has, more often than not, experienced the same or similar problems, frustrations, and circumstances.

Fifth, peer mentoring provides social validation of the mentee's performance (Shafer, Tait, Keen, & Jesiolowski, 1989). Social validation is "The process of collecting information on employer and co-worker impressions" (Powell et al., 1991, p. 123). Peer mentorship increases the potential of detecting covert performance standards within the work setting (Shafer et al., 1989).

Lagomarcino and Rusch (1989) reported that "poor individual adjustment on the job accounted for approximately 40% of all job separations for persons on individual and enclave placements" (p. 48). Since enclaves provide greater access to non-handicapped co-workers, social skills are important for individuals with severe disabilities in integrated work environments (Hanley-Maxwell, Rusch, Chadsey-Rusch, & Renzaglia, 1986). Enclaves allow workers with various disabilities and different functional levels and limitations to collectively produce work under the guidance of a supervisor.

Peer mentoring can be a viable tool in the acquisition of job skills, job maintenance, and job performance. However, care should be taken in the selection of peer mentors and in matching mentors and mentees. The privacy of all parties involved in the mentorship must be protected, and ethical implications must be considered. The impact of peer support on job performance and job maintenance is predicated on several factors: perceptions, ecological determinants, and generalization of work behavior.

## Perceptions

The perceptions of persons with disabilities about their abilities in relation to others around them have far-reaching effects on job performance. People have a tendency to believe what they have been told. If a person's capabilities and skills are underestimated by employers, family members, educators, and co-workers, the person's behavior will reflect that perception. Self-fulfilling prophecy comes into play.

Kierman and Brinkman (1988) asserted that negative perceptions can limit job opportunities and create "unrealistic demands upon the relationship of the person with disabilities to employment" (p. 223). The peer supporter or mentor as a role model can serve as an example to other persons with disabilities in that they provide evidence and hope that people with disabilities can do this job. The impact of peer support will become evident by factors such as quality of output, quantity of output, flexibility, rate of absenteeism, safety, tenure, job advancement, and training (Greenwood, Schriener, & Johnson, 1991).

## Ecological Determinants

Ecological determinants refer to environmental setting and auxiliary responses to the environment (Parker, Szymanski, & Hanley-Maxwell, 1989). While the work setting available to persons with disabilities have expanded to include various types of environments, access to certain work environments is still restricted. The majority of job openings for persons with severe disabilities are in the service or fast food industry. Likewise, the access to peer supporters with disabilities is also restricted in competitive work settings. Although it is the goal of supported employment to achieve integrated work through inclusion (Rogan & Murphy, 1991), peer support can make physical and social integration for persons with disabilities a smooth transition.

## Generalization of Work Behavior

Generalization refers to the occurrence of the desired behavior in "non-training conditions when no extra training manipulations are needed; or may be claimed when some extra manipulation are necessary, but the cost or extent is clearly less than that of direct intervention" (Stokes & Baer, 1977, p. 350). It is important to note that techniques that lead to the acquisition of skills are not necessarily the same as skills that enhance generalization (Gifford, Rusch, Martin, & White, 1984). Natural contingences are recognized as the most effective way to maintain skills over time.

Mentors, peer or otherwise, can facilitate generalization. Many jobs held by persons with severe disabilities require team work where members work as a unit in the production process. The interaction between team workers is when natural clues and maintenance skills are solidified.

## Summary

Peer mentoring has been introduced as a viable option to enhance job performance and job maintenance for persons with severe disabilities. The application of the peer mentor as a part of enclaves offers an explanation of the potential benefits of peers as effective facilitators in the supported employment process. The use of peers as mentors is suggested to supplement, not necessarily replace employment specialist or non-handicapped coworkers as role models.

Many features of mentoring programs are applicable for peer mentorship in enclaves. Throughout this paper, a number of specific features were presented that would make peer mentoring effective. Peer mentoring can work, but it must be planned and implemented based on an individualized approach. If peer mentoring is to succeed, it must be understood as a part of the disability service delivery system.

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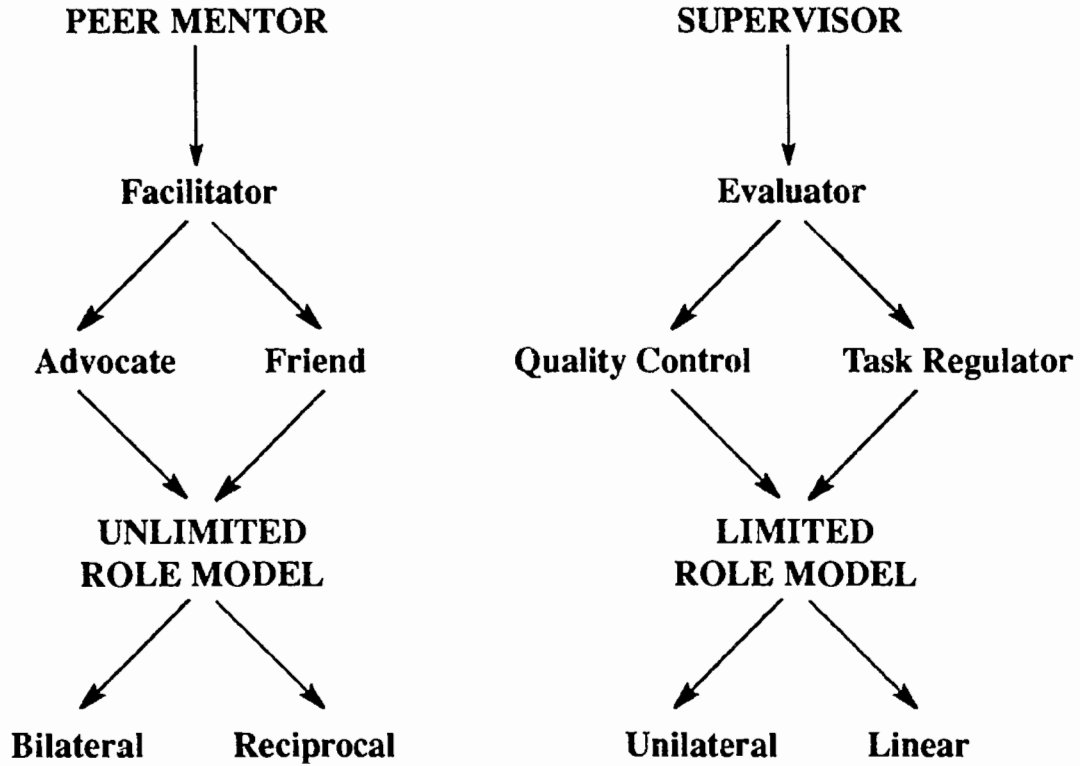


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**Figure 1**

**Impact of peer mentoring as compared to the supervisor**



## Return to Productivity: Innovative Vocational Programming for Persons with Spinal Cord Injury

Ann Temkin

None dispute the extent or gravity of the problem of underproductivity and unemployment among individuals with spinal cord injury (SCI). Most persons with SCI remain chronically unemployed. The National Spinal Cord Injury Statistical Center Annual Report No. 8 (1990) states that only 11.5% of persons with SCI were employed 1 year post injury, and as late as 5 years post injury only 23% were employed. These statistics become even more important in light of the research demonstrating that persons with SCI who are active and whose vocational adjustment is better not only lead fuller lives but actually live longer (Krause & Crewe, 1987).

Further, SCI obviously impairs physically, and is most often incurred by the physically active; this means that very often the individual planned to do a type of work which is no longer viable. Some will be both able and willing to make this adjustment. For some--a doctoral psychology student for example--the vocational adjustment may be minimal. But for others, it will be difficult to find a type of work which fits both their pre-injury abilities and their post-injury physical limitations. Others may be intellectually equipped for a variety of desk jobs, but find the work almost intolerable from the perspective of personality structure.

Living with a disability is also expensive--sometimes extremely expensive. This means that the individual needs to earn more money than before the injury. Economics further limits the range of choices and raises additional barriers for persons who have high level injuries (and higher expenses), or whose natural abilities tend to match jobs that pay less, or both. Because so many who incur SCI are young adults, they may also lack significant work histories. This means they are without confidence, work place habits, resumes, references, co-worker networks. Finally, there are, of course, the numerous barriers in the community: physical and attitudinal. In addition to major issues like transportation, monies for attendant services, and the attitude of some employers, there are benefit system disincentives which continue to exist, the inexperience (with SCI) of many health professionals, and the depressed job market.

It is not surprising that the road from injury to maximum productivity is often long and marked by numerous special problems. Traditional services--while essential--are insufficient to meet these needs. Barriers should not and often cannot be dealt with by the individual alone. Programming must match all phases of the journey; teams and networks must be developed so that the reduction of barriers becomes a project of the community as a whole.

*Return to Productivity* (RTP) is an umbrella term. What began in 1989 as a pilot project for inpatients has developed into a series of nontraditional inpatient and outpatient programs whose purpose is to increase productivity and employment among persons with SCI. RTP is intended to supplement the traditional vocational services offered patients so that a full continuum of programming is available throughout the journey from injury to employment. The original inpatient component included 100 subjects: 65 randomly assigned to the experimental and 35 randomly assigned to the control group. All subjects were between the ages of 18 and 60, had at least a sixth grade reading level, and demonstrated no signs of psychosis or active chemical dependency.

Persons in the experimental group were exposed to a structured educational intervention. Employed professionals with SCI were involved in all phases of the project. Small groups met for six classes and used the RTP Manual—a manual developed specifically for the project—which focuses on problem-solving and goal-setting/attainment skills. The workbook for the patient emphasizes visual images, active participation, group cohesiveness/feedback, and concrete problem-solving. The content of the six sessions may be summarized as follows:

1. *Productivity - What Is It?*

An exploration of productivity and its meaning for the individual.

2. *Control and Choices*

The focus is where the individual has choices to make. Each person develops his/her *control picture*—various aspects of life viewed from the perspective of how much control the individual has in this area, and the consequences for the possibility of change.

3. *Getting the Future in Focus*

Guided imagery and discussion leading to a visual representation (*Futurphoto*) by the patient of where s/he wants to be one year later.

4. *Futurphoto--My Collage*

The visual representation from session three is expanded into a collage.

5. *Journey to My Future*

Creation of a visual representation of a map from the rehabilitation center to the *Futurphoto*, with the landmarks, or goals, that mark stages of the journey.

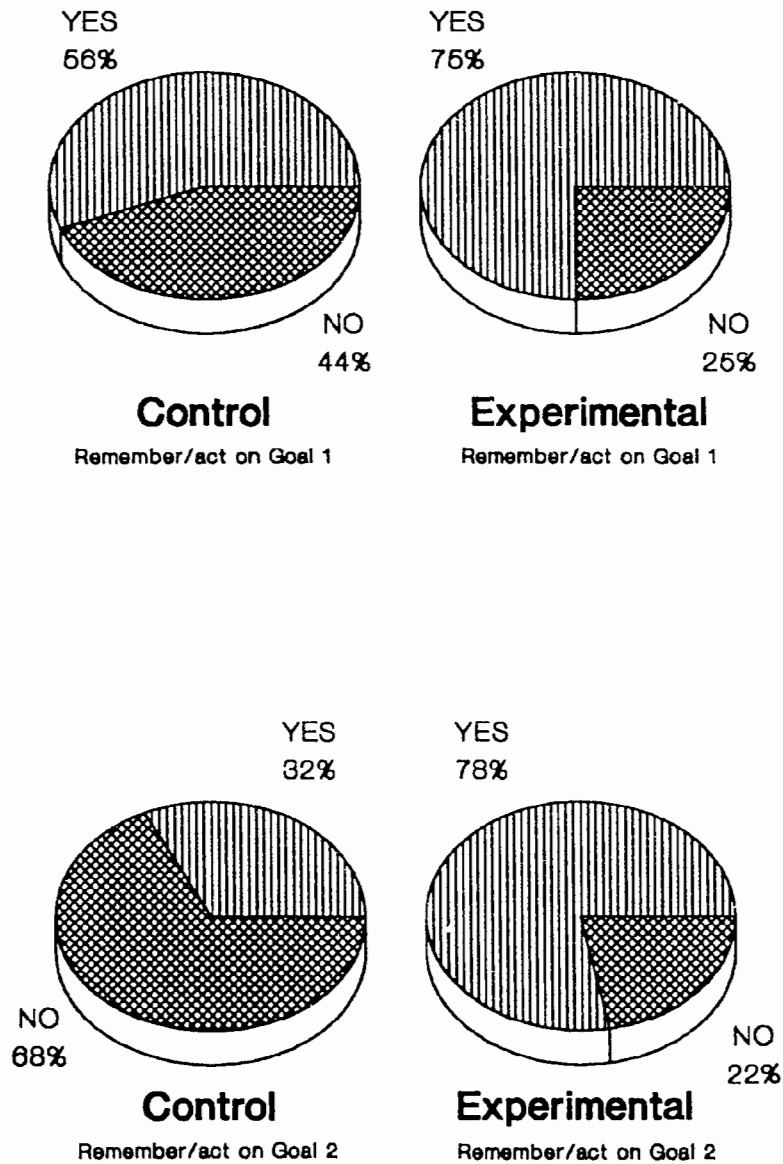
6. *My Contract with Myself*

Each person works toward selecting three very specific, measurable goals that will enable him/her to start out on the journey. Camera shots of the group are given each patient to symbolize companionship on the journey.

Approximately eight weeks after discharge from inpatient rehabilitation, a questionnaire was administered to 85 subjects—34 in the control group and 51 in the experimental group. Fifteen persons were not surveyed; one person could not be reached; 14 people dropped out of the study before receiving any services—in many cases because they were transferred to another rehabilitation facility. Family members were also surveyed separately to check the validity of the patient self report mechanism. No significant difference was observed between patient and family responses.

Persons surveyed were asked whether they had a goal when they left Shepherd Spinal Center. Those who answered affirmatively were then asked to name the goal and to describe any actions they had taken to pursue it. Those who again responded affirmatively were asked whether or not they had a second goal, and if so, what actions they had taken. The responses of the experimental group (who were exposed to inpatient RTP), and of the control group (who were not in the program) are summarized in Figure 1.

Figure 1



Logistical problems created particular challenges in the implementation of inpatient RTP. Busy patient schedules made it necessary to schedule the sessions in the evening--when patients also had visitors and outings. Of the 65 persons selected for the program, 31 were considered to have completed RTP--that is, they attended at least half the sessions and completed their contract; 20 patients attended less than half the sessions. If we look at the questionnaire responses of those who completed the program, we find nothing significant related to a first goal. When these persons were

asked about pursuit of a second goal however, 84% of the completers responded affirmatively, and only 16% negatively. The difference between those who attended RTP (for any number of sessions) and those who were not in the program is great. Those who completed RTP demonstrate the highest level of goal attainment.

RTP has now been adapted and used with persons living in the community with SCI. A condensed (three session) version of RTP will be offered four times a year. RTP will be open to inpatients as well as persons living in the community. Criteria for admission will be a stated interest in pursuing vocational goals and a need for skill development in problem solving and goal setting. We anticipate that this program will help persons meeting these criteria to benefit fully from other vocational services. In some instances, where motivation is an issue, RTP may serve as a job readiness assessment tool, demonstrating to both the client and the staff the extent of the individual's readiness to work on vocational goals. In each of these cases, RTP will have increased the efficiency and effectiveness of the delivery of vocational services.

"On Your Mark" was designed as an outpatient follow-up piece for RTP. Funded by the Dole Foundation, "On Your Mark" focuses on the development of informal mechanisms for bringing together unemployed persons with SCI, employers, and employed persons with SCI. Between January 1990 and June 1991 three workshops were offered and a Network exists which now has a life of its own and an impact beyond the population with SCI. The opportunity for employers and participants with SCI to learn together proved invaluable. Barriers like transportation problems and the related frustration became tangible when discussed by *real people*. We are aware of the direct and some of the indirect benefits from these workshops; we know, for example, that a local bank hired a deaf individual for a job that would have been closed to her prior to the workshop. We know that when a major corporation set plans a motion to open a new office in Atlanta, transportation issues were reviewed in relation to the hiring of persons with disabilities. The impact of On Your Mark continues to grow as persons are drawn into the network.

Fifty-two clients have been served by this project. The productivity status of these persons is shown in Table 1.

<u>Productivity Status</u>	<u>Number People</u>	<u>Percent</u>
Employed Full Time	10	19%
Employed Part Time	10	19%
Employed--Special Projects	5	10%
Pre-existing Employment Supported	3	6%
Actively Seeking Employment	6	12%
Students	10	19%
Active in Disability Advocacy Movement	5	10%
Not Productive	2	4%
Unknown	1	2%

The "On Your Mark" Network is strongly committed to continuing the project beyond the funding period. A Steering Committee has been formed consisting of employers, participants with SCI, and staff from the vocational services program. This committee is now planning the next "On Your Mark" workshop to be held in the spring of 1992. While members of the rehabilitation facility staff serve on this committee, their role is greatly reduced. The hope is that the community of employers

and participants will make this project totally their own, and that staff will serve only in a consultant role as requested.

"Return to Productivity" and "On Your Mark" are only beginnings. A project is being piloted to arrange creative workplace situations; plans are being made to develop new and very intensive systems of assistance during the actual process of the job search. All innovative programming will include involvement by employed persons with SCI, since this kind of peer support has clearly been one of the key success factors of RTP and "On Your Mark."

Much has been learned about what works and what does not. Some of the most important learning relates to issues of timing--when can the individual benefit most from a given opportunity or service? Originally it had seemed best to offer the initial RTP--training in goal setting and attainment--to inpatients, and then invite people to "On Your Mark" workshops and the Network immediately post discharge. We have learned that we are more successful when our timing is altered. RTP has helped many inpatients, but there are also logistical problems. Inpatients must learn an enormous amount of information and skills related to basic physical survival--how to care for their skin, bowel and bladder programs, etc. Also, the psychological trauma of SCI is massive. Many patients leave rehabilitation still in denial, convinced that they will have full neurologic recovery. Once at home, the adjustments--physical and emotional--are often overwhelming. Many patients say that it is not until one year post injury that they are ready to begin to think about the future.

This should not be interpreted to mean that no services should be offered until a year post injury except in the case of the unusual person. On the contrary, making the connection during inpatient rehabilitation with the "On Your Mark" Network and planting the idea of future employment seem essential. It is hoped that the Network will develop so that each newly discharged person will be contacted by a representative as soon as s/he returns home. Work can then begin.

The ultimate goal is to offer a full continuum of traditional and innovative programming, and to match clients and programs so as to maximize both use of resources and the chances of success. If such a continuum exists, and if it is offered within the context of communities working together to reduce barriers, the rate of employment among persons with SCI will increase. The ultimate goal is to have programming and bridges in the community which are so strong that everyone with SCI who wants a job can get one.

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ICAN, Increasing Capabilities Access Network  
Friends of Technology Network  
(A Peer Support Network)

Karen Bays

ICAN Overview

ICAN, the Increasing Capabilities Access Network, is a program of the Arkansas Department of Human Services, Division of Rehabilitation Services. The program was established in 1989 as the result of P.L. 100-407, the Technology Related Assistance For Individuals with Disabilities Act of 1988. ICAN is committed to the philosophy that with assistive technology individuals with disabilities can achieve their full potential, participate in and be productive members of their communities.

ICAN provides the following programs:

- Information and referral services regarding assistive technology and related services.
- A used-equipment exchange network.
- Training on issues related to assistive technology.
- Marketing and public awareness regarding the benefits and availability of assistive technology.
- Friends of Technology Network.
- Local resource consultants--a statewide network of volunteers designed to share information about assistive technology and related services and to identify local technology related resources.
- Five technology access centers designed to provide evaluations, information, and hands-on demonstrations of assistive technology. The disability areas the centers represent include: blind and visually impaired, communication and computer access, deaf and hard of hearing, independent living, and language and learning.
- A governor's interagency council on technology for persons with disabilities.

Program Overview

In January of 1989 an advisory committee was established to provide input into the development of the initial ICAN grant application. The committee was composed of individuals with disabilities, their family members, and professionals who serve in disability-related occupations. The committee played an active role in identifying the technology-related needs of Arkansans with disabilities. In addition, they proposed programs to meet these needs. It was through the efforts of the advisory committee that the need for an assistive technology peer support program was identified and written into the initial grant application. The committee felt that a peer support program would allow

individuals with disabilities and their families to access first-hand information regarding availability, benefits, and maintenance of assistive technology.

In the fall of 1990 ICAN developed a peer support network that enabled individuals with disabilities and their families to share information and experiences regarding assistive technology. The program had originally been called the "Peer Consultant Network." The program's concept was to enlist experienced technology users as peer consultants who should share their experiences and expertise with others who were interested in particular types of technology.

During the summer of 1991 ICAN reviewed the network and its utilization by consumers. ICAN found that utilization of the program was low. Changes needed to be made to increase its value and usefulness among individuals with disabilities and their families.

The first change that was identified involved restructuring the format of the program from that of a peer consultant-to-consultee relationship to more of a peer-to-peer relationship among the participants. ICAN lists the names of all individuals who are interested in assistive technology on the network. The network is represented by individuals with a wide range of interests and varying degrees of expertise in the use of assistive technology. Network participants are provided with information regarding their peers who have similar technology-related interests. This change was made on the belief that common interests frequently serve as the catalyst for the sharing of information.

Another change to the network involved making it less formal and more inviting to all individuals who have an interest in assistive technology. One method for doing this was to change the name and make it less intimidating. The original name, "Peer Consultant Network," implied a professional relationship or a helper/helpee relationship. In keeping with the above format change, ICAN wanted a name that would reflect the peer-to-peer relationship. It was also important that the new name imply that people participating in the network did not have to be trained in assistive technology before they could use the network. After much consideration, ICAN chose the name Friends of Technology Network.

All proposed changes were presented to the ICAN advisory council and to the ICAN local resource consultants, a statewide volunteer network composed primarily of individuals with disabilities and their families. Both groups approved of the proposed changes to the program. ICAN is currently in the process of implementing these changes.

The revised Friends of Technology Network is a statewide program designed to put people with disabilities and their family members in contact with each other to share information about assistive technology or, as ICAN calls it, "tools for living." By sharing information with others, consumers and their families can learn more about what is available and its effectiveness. Consumers may also benefit from each others experiences in purchasing, maintaining, and repairing the technology they use.

### Program Management

The Friends of Technology Network is available to all individuals who are interested in sharing or acquiring information about assistive technology. Persons interested in having their name listed on the network are asked to complete an information form. The form contains three different sections. The first section focuses on demographic information about the participants including age, disability, and whether they are a consumer or a family member. Section two gathers information about the specific types of assistive technology that the individuals are interested in discussing with others. And, the third section identifies general areas of interest such as personal care, job modification, home modification, food preparation, recreation, etc. that network participants can share. All of those on the network are asked to sign a release of information form to permit ICAN to share their information with others. Based on the information provided, consumers and their families are matched with people who have similar interests. Consumers seeking information are responsible for making all initial contacts.

ICAN is currently in the process of developing a database that will house information on each participant in the network. The database will contain a field for each of the areas listed on the participant information form. By using the database, ICAN staff will be able to make quick matches between participants based on interest and geographic locations within the state.

### Marketing the Friends of Technology

Through experience, ICAN has learned that marketing this program is crucial for its success. Several steps have been taken to promote the Friends of Technology Network. As in keeping with ICAN policy, information about this program and all other programs is available in alternate formats. This allows individuals who use braille, large print, or cassette tapes to have access to the material. Efforts have also been made to use basic terminology in the development of written materials to ensure easier reading and comprehension of the information. Information about the network is shared at all ICAN presentations and is incorporated into ICAN publications including the quarterly editions of the *ICAN Update*. The ICAN technology access centers and the local resource consultants also distribute information to recruit participants for the network. However, ICAN has found that the most effective methods for marketing the network is personal contact with consumers and their families.

### Evaluation of the Friends of Technology

ICAN is currently in the process of developing an evaluation system for the Friends of Technology Network. This evaluation system will be incorporated into the overall program evaluation. Through evaluation of the network, ICAN hopes to receive information in the following areas.

- The number of people who are aware of the network.
- The number of participants listed on the network.
- The number of matches made between people on the network and those seeking information.

- The effectiveness of the network in providing useful information and meeting the needs of consumer and their families.

### Summary

The ICAN Friends of Technology Network has recently undergone changes to increase its utilization. With these changes, ICAN hopes to enhance its responsiveness to the needs of Arkansans with disabilities and their families. IT is still too early to predict the effectiveness of the peer-to-peer networking format. ICAN anticipates that information regarding the effectiveness of the program will be obtained through the evaluation system. Based on this data, ICAN will continue to make changes to improve the Friends of Technology Network.

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## Jobs Rally: Community Development Rehabilitation Using Peer Support Strategies

Robert L. Akridge, Ed.D.

How responsive are communities to the independent living and career development needs of persons with disabilities? The rehabilitation profession has come under increasing criticism for only looking within the person for the "problem" and for potential "solutions," without sufficient regard to the context within which people with disabilities exist. Even where the profession has expanded its perspective to include the concept of support systems, its practice has maintained a narrow focus on the individual. Peer counseling, for instance, has become an important adjunct to professional rehabilitation services but it too tends to locate the problem within the individual with a disability (Pittman & Mathews, 1984; Rehab Brief, 1984). Likewise, the "job coach model" of supported employment has emphasized individual services to the client at the job site with only minimal attention to improving natural support systems. A review by Hagner, Rogan, and Murphy (1992) concluded that:

Impressive demonstrations of the effectiveness of the job coach model as compared with previous employment services available to people with severe disabilities have, however been accompanied by a recognition that external intervention by human service personnel alone is insufficient as a source of community employment support. (p. 29)

There is a growing awareness among people with disabilities and their service providers and advocates, of the need for more interventions which directly address the community's responsiveness to the needs of its members with disabilities. Passage of the Americans With Disabilities Act for instance provides each community a set of criteria for determining how responsive the community is to the needs of people with disabilities in such areas as employment, transportation, communication, and public accommodations.

### Overview of the Jobs Rally Program

The Arkansas Research and Training Center in Vocational Rehabilitation, in recognition of the need for additional technology utilizing a community development approach, created the Jobs Rally package (Akridge, in press) which is outlined below.

The intervention may be used in any size community by any organization that wishes to improve independent living and employment opportunities for people with disabilities. The basic approach is to sponsor a community forum to bring together people with disabilities who are employed, people with

disabilities who are not employed, and a sampling of service providers and advocates to:

- Share information and support
- Strengthen the network or coalition of persons concerned about improving employment opportunities for people with disabilities in the local community
- Engage in mutual problem solving
- Provide leadership for rallying a community response

The purpose of the program is to rally the community's attention and resources to enhance the independent living and career development of its members with disabilities. The three-hour rally is preceded by extensive and detailed planning and followed by a comprehensive follow-up and evaluation.

Phase I of the forum is structured around a panel discussion of employed persons with disabilities. The panel moderator may also preside over the larger group of participating consumers, service providers and advocates present. After a 30-minute break, Phase II utilizes small groups facilitated by co-leaders consisting of one of the panel members and a service provider. Other service providers and advocates are distributed among the groups as resource persons. Thus the small work groups are composed of unemployed persons with disabilities with peer and professional resource people.

The Jobs Rally is the kind of community development activity that a disability related organization might conduct annually. Educating the community to become more responsive to the independent living and career development needs of people with disabilities is the primary goal. The strategy is to strengthen and make more visible the community peer support network and the network of professional service providers in the community, and to strengthen the communication linkage between these two networks.

During Phase I the major emphasis is on developing motivation by working through the following activities.

1. Provide an impactful event designed to develop group cohesiveness and to influence people with severe disabilities who may not be actively seeking employment to explore the following questions:

*How could I improve the way I am currently living my life?*

*Are there any jobs that I could do (or learn to do) which might add more to my life than they would take away?*

*How can I work together with others with disabilities to improve independent living and career development opportunities in the community?*

2. Provide people with disabilities who are employed an opportunity for active participation in community development leadership.

*Invite 12 people with disabilities who are employed to participate in a panel discussion.*

- Describe their jobs and work setting following structured outline provided (5 minutes each)
- Have each presenter select 5 points from a list of 10 employment issues to cover (e.g., effects on child rearing, social life, long-range financial security)
- Panel members establish a relationship with the audience and lay the ground work for serving as small group facilitators in Phase II.

*Recruit presenters who:*

- Represent a cross-section of the community in terms of type of work, status, pay, and integration into the community
  - Represent facilitative, supportive (non-exploitive), work settings where Employer-Rehabilitation Partnerships are likely to develop
3. The primary consumers of the program will consist of 20 to 40 people with disabilities who are not employed or who consider themselves under-employed whom will have been recruited from the following sources:

*Sponsoring organization's target population*

*Consumer organizations and other peer support networks*

*Rehabilitation agencies, organizations, and institutions*

*Self-referrals from public announcements and other outreach programs*

After a 30-minute break, continue through the assessment and intervention activities in Phase Two as outlined below:

1. Provide opportunity to explore following questions in small groups

*What knowledge and skills could I bring to the workplace?*

*What would supervisors and co-workers find attractive about me?*

*How can I use family, friends, rehabilitation services and other community resources*

- *to get an acceptable job,*
- *to perform it satisfactorily, and*



- *to fit the work role into my life?*

*What is my next career development step?*

2. Facilitate group discussion and peer feedback.
3. Pass out information resource packet to total group and discuss:
  - Directory of all community-based employment programs,
  - Information about independent living services, and
  - Other community resources.
4. While in small groups with peer facilitators and professional consultants:
  - Discuss information presented.
  - Help each other answer assessment questions presented above.
  - Identify ways the community needs to be more responsive.

#### Program Methodology

Market the Jobs Rally community development program to the disability service delivery system, consumers of rehabilitation services, employers, and the community-at-large. Sample releases for different kinds of media are included in the package. A method for forming peer support and professional networks is also described. Identify corporate sponsors to endorse, promote, and support the Jobs Rally. Employers such as super market chains will usually donate refreshments to serve during the break. Allow a 30 minute break for refreshments, socialization, and networking between phase one and phase two of the program that are oriented toward community development. Promote the integration of all community-based services as a way of serving employer needs as well as a more comprehensive response to the needs of individuals with disabilities.

#### Program Evaluation Procedure

Collect descriptive data on presenters and participants prior to conducting the Jobs Rally. Questionnaires covering the following areas are included in the package.

- Demographic information
- Independent living status indicators
- Employment history and current status indicators

Conduct a one-month follow-up by inviting the group back together for a bag lunch to share their perceptions of the benefits gained and to follow-up on

issues raised during the initial meeting. After 12 months readminister the base level questionnaire. Analyze and report results to all interested stake holders.

### Field Test of the Program

Informal feedback from participants in two field tests of the Jobs Rally program have been very positive. The program was conducted at Independent Living Centers in a small town and in a metropolitan area. Total attendance was around 35 and 45 respectively. About half of each group were people with disabilities who were unemployed and the remainder was split between people with disabilities who were employed, service providers and advocates such as family members. At the informal 30-day follow-up meetings, the groups' appraisal was primarily positive with some suggestions for improvement. In each instance an ad hoc group formed to pursue a common concern that evolved from the group discussion. One was dealing with transportation and the other was housing.

### Summary

The JOBS RALLY CHECKLIST on the next page is used in the Jobs Rally Package and provides a summary of all program activity.

### References

- Akridge, R. L. (in press). Jobs rally: Marketing a community development project using peer support strategies. Fayetteville: University of Arkansas, Research and Training Center in Vocational Rehabilitation.
- Hagner, David, Rogan, Pat, & Murphy, Stephen (1992). Facilitating natural supports in the workplace: Strategies for support consultants. Journal of Rehabilitation, 58(1), 29-34.
- Pittman, Janice L., & Mathews, Mark (1984). Peer counseling: Four exemplary programs. American Rehabilitation Literature, 10(4), 21-24.
- Author. (1984). Peer counseling: As a movement, as a rehabilitation service. Rehab Brief, Volume VII(2).

## JOBS RALLY CHECKLIST

DATE  
ACCOMPLISHED

ACTIVITY

- \_\_\_\_\_ 1. Review the information in the JOBS RALLY package from the Arkansas Research and Training Center in Vocational Rehabilitation.
- \_\_\_\_\_ 2. Conduct informal appraisal of how responsive your community is to the independent living and career development needs of people with severe disabilities (e.g., ask yourself, your colleagues, and clientele).
- \_\_\_\_\_ 3. Compile a local directory (including name of contact person and telephone number) of all individuals, programs, or agencies that promote independent living and career development outcomes for people with disabilities.
- \_\_\_\_\_ 4. Send early draft of Network directories to all listed and ask permission to include their names and request them to suggest additional names.
- \_\_\_\_\_ 5. Be sure to identify both professional and peer sources of support. Emphasize peer support and consumer control.
- \_\_\_\_\_ 6. Select a disability-related organization to sponsor a JOBS RALLY.
- \_\_\_\_\_ 7. Name a coordinator for the JOBS RALLY program.
- \_\_\_\_\_ 8. Market the JOBS RALLY program concept to the professional and peer networks identified in Step 3...(a) distribute JOBS RALLY concept paper, (b) make follow-up telephone call or personal visit.
- \_\_\_\_\_ 9. After consultation with professional and peer networks, set date, time and place for JOBS RALLY.
- \_\_\_\_\_ 10. Secure corporate sponsor to provide liaison with other employers and donate refreshments for the break.
- \_\_\_\_\_ 11. Order program brochures (see sample brochure in package).
- \_\_\_\_\_ 12. Distribute program brochure to potential participants through professional and peer networks.
- \_\_\_\_\_ 13. Collect material for information resource packet to be distributed to JOBS RALLY participants such as brochures from professional and peer service providers and other information relative to independent living and career development.
- \_\_\_\_\_ 14. Solicit media coverage of proposed JOBS RALLY (see sample news releases).
- \_\_\_\_\_ 15. Identify program panel of employed persons with disabilities.
- \_\_\_\_\_ 16. Provide panel members adequate information, orientation and support.
- \_\_\_\_\_ 17. Identify individual to manage participant registration and the collection of base-line and follow-up data.
- \_\_\_\_\_ 18. Identify individual to M.C. (general facilitator) the JOBS RALLY program.
- \_\_\_\_\_ 19. Identify individual to serve as moderator of panel discussion. NOTE: could be the same person as Step 17.
- \_\_\_\_\_ 20. Conduct JOBS RALLY program.
- \_\_\_\_\_ 21. Ascertain that base-line data questionnaires collected on all participants.
- \_\_\_\_\_ 22. Invite professional and peer support networks panel members, and program participants to a general follow-up meeting to critique the JOBS RALLY program and follow up on recommendations generated.
- \_\_\_\_\_ 23. Ascertain that 12-months follow-up questionnaires collected.
- \_\_\_\_\_ 24. Analyze questionnaire data and integrate into program evaluation report along with staff observations and group critique from Step 22.
- \_\_\_\_\_ 25. Submit summary of program evaluation report to funding sources, professional and peer support networks and other relevant publics.

Akridge, R. L. (1992, revision). Jobs Rally: Marketing a community development project using peer support strategies. Fayetteville: University of Arkansas Research and Training Center in Vocational Rehabilitation.

## Using the "Jobs Rally" Approach to Community Development

Dan Kessler and Marsha Mitchell

Birmingham (Alabama) Independent Living Center, in conjunction with the University of Arkansas Rehabilitation and Training Center in Vocational Rehabilitation, sponsored a "Jobs Rally" on Saturday, January 12, 1991. The objectives of this event were to:

- bring together people with disabilities who are successfully employed with those who are not to share information and support;
- to improve employment opportunities for people with disabilities in the local community; and
- to work toward the removal of barriers to employment through mutual problem-solving activities.

The three-hour event was based upon a model developed by Akridge (1992) of the University of Arkansas. The initial phase of the program was a panel discussion consisting of people with disabilities who are employed, moderated by an independent living center (ILC) staff member who maintained communication among panelists, consumers, and service providers. Next, panelists facilitated small group discussions. The purpose of these groups was to share ideas regarding the removal of barriers to employment and how to locate needed resources. Service providers were distributed among the participants to serve as resource personnel. Following small groups discussions, all the participants came back together to summarize their findings and make recommendations.

Participants included disabled consumers, panelists, agency representatives, and ILC staff members. Twenty-nine unemployed consumers representing various disability groups attended the rally, including people with epilepsy, cerebral palsy, rheumatoid arthritis, blindness, mental illness, sickle-cell anemia, traumatic brain injury, and heart disease. Panelists included a deaf graphic designer, a computer programmer with cerebral palsy, a store clerk with epilepsy, and a laundry worker with cerebral palsy.

Organizations represented at the JOBS RALLY included the Alliance for the Mentally Ill, Alabama Head Injury Foundation, Sickle Cell Anemia Foundation, Division of Rehabilitation Services, United Cerebral Palsy, Workshops, Inc., the Association for Retarded Citizens, and the Jefferson/Blount Mental Health Authority.

One criteria used to select panelists was the perceived degree of similarity to the consumer groups, i.e., that they were seen as peers. By and large, this occurred. It was believed that consumers would be better able to relate to panelists who were employed in positions that participants perceived as

being attainable. The result was that panelists varied in their degree of effectiveness in relating to various segments of the audience.

While panelists were effective in their jobs, not all were comfortable speaking before a large group or facilitating small group discussion. The success of the small group discussions was based heavily upon the ability of the panelist/facilitator to insure that no one consumer or service provider dominated the discussion and to encourage participants to engage in mutual problem solving. Not all facilitators were able to do that. Certain consumers deferred to the service providers as "experts." The role of the service provider, however, was to act as a resource and to support, not supplant the facilitator.

Based upon the experience of participants of this Job Rally, the following suggestions are offered:

1. Role definitions of all participants, particularly panelists, must be made clear from the onset. Insofar as certain panelists may not feel comfortable serving as facilitators, consideration should be given to separating these roles. Also, a good "mix" of disability groups and occupations represented will allow a wide range of consumers to benefit from the collective wisdom of the panel.
2. Panelists must be oriented to their role prior to the Jobs Rally, perhaps utilizing role playing and video technology to reinforce learning.
3. Regardless of how many panelists agree to serve on the program, sponsors may want to consider "overbooking" because, in all likelihood, some panelists will cancel at the last minute.
4. The structure of the agenda worked well. Ample time was devoted to each phase.
5. Climate control, and, therefore, location, is important with certain disability groups, including those with sickle cell anemia. The Rally at ILC was held on what turned out to be one of the coldest days of the year, which caused those consumers difficulty. Consequently, they had to leave the program early.
6. Many participants required assistance with completing the employment survey. Therefore, staff and/or volunteers should be available.

The Jobs Rally at ILC was considered a success by most participants. All expressed an interest in additional information about employment issues. One recommendation was that co-workers be included in future Job Rally programs.

As a result of the Job Rally hosted in January, ILC initiated additional programs. In May of 1991, ILC has initiated a series of job readiness classes. The Center also plans a housing seminar based upon the Jobs Rally model.

## References

Akridge, R. L. (1992). Jobs Rally: Community development rehabilitation using peer support strategies. Submitted for publication.

## From Information Overload to Effective Access Skills: Equipping Consumer and Providers for the Information Age

R. Brantley Cagle, Jr.

Identifying and accessing appropriate information resources on issues regarding disabilities is becoming a major service issue of the 1990s for people with disabilities and professional providers. Both groups are confronted and often overwhelmed by a voluminous explosion of information designed to maximize people with disabilities participation in the community. This paper will acquaint the participants with a number of information retrieval strategies which equip consumers and providers to retrieve the right information at the right time in the right format.

Historically a large portion of people with disabilities have been institutionalized or limited to restricted residential environments which significantly limited their access to information services. During the 1970s there was a surge of interest in the acquisition of internal and external information in public and private delivery systems concerned with the well-being of people with disabilities. In the 1980s there was not much awareness of the lack of knowledge people had in how to access the information they needed. Securing access to needed information services for developmentally disabled individuals living in the community will be a major goal of human service providers during the 1990s.

Introducing people with disabilities to a variety of specialized information networks, information and retrieval services, and specific key reference tools can be helpful in understanding important issues in our daily lives. (Here we will focus on materials relating to the Americans with Disabilities Act of 1990 (ADA) and the Fair Housing Act of 1988. ADA did not address housing due to the existence of the 1988 Act.) After working with several human service agencies as a documents specialist, I observed that rehabilitation professionals, social workers and other system personnel seeking information tend to overlook cost effective resources. Improving consumer and provider awareness of effective retrieval techniques can significantly equip the self advocate to retrieve the right knowledge from a reliable source. If knowledge is real power, equipping the consumer with effective information access skills is empowerment.

The ADA, signed into law on July 26, 1990, bans discrimination based on disability. Of necessity, many of the determinations may be made on a case-by-case basis. At this writing the ADA consists of 51 pages. The current regulations published on July 26, 1991, consist of 349 pages. Instead of equipping the consumer and professional provider with detailed knowledge of all 400 pages, it is more important to promote a skill which facilitates need oriented retrieval of information on specific topics which can be used for advocacy and other potential needs. The Fair Housing Act of 1988 has produced a significant volume of regulations, information pamphlets and court decisions

which require special retrieval skills. This presentation will reveal how consumers and providers can effectively retrieve needed information without being overwhelmed by complex retrieval tools and techniques.

One of the tragic consequences of poor access to information is the use of unofficial sources to accomplish advocacy goals. The fragmentation of disability law has placed the consumer at a disadvantage due to the fact he had no access to a comprehensive civil rights law designed to protect and facilitate his rights as an American citizen. ADA and the Fair Housing Amendments of 1988 represent a comprehensive resource of legal protections which afford equality of treatment. Developing access skills is imperative to the consumer's appropriate social use of these historic documents. Naturally most citizens can be overwhelmed by a voluminous reservoir of acts and regulations which are geared to meet his needs but are difficult to use and understand. The ADA has been termed one of the most complicated Acts ever written, yet most of the text is quite clear and straight forward. The first step to developing an understanding of how to access information requires a basic comprehension of the construction of the Act which is divided into five titles: Title I Employment, Title II Public Service, Title III Public Accommodation, Title IV Telecommunications, Title V Miscellaneous.

The next step to developing an access understanding is to know what agencies have the legal responsibility for overseeing the implementation of the Act through regulatory authority. Title I, for example, is enforced through the Equal Employment Opportunity Commission. Under a final rule issued on July 26, 1991, the EEOC issued substantive regulations which were published in the July 26, 1991 issue of the Federal Regulations (56 FR 35726). These regulations will reappear in the Code of Federal Regulations at a later date (29 CFR 1630). The consumer must understand that the Act itself (P.L. 101-336) and these regulations are the only official version of the ADA. When engaging in advocacy work pamphlets can be helpful but they should never be used in advocacy negotiations. Always use the official source. Next, after completing the first two steps, the advocate should carefully analyze the main issues which must be addressed and resolved. Effective advocacy communication never results from generalized arguments which do not address specific and relevant issues. ADA does facilitate employment opportunities which historically have been denied, yet some people with disabilities are already overlooking the otherwise "qualified" persons which are clearly described in 29CFR 1630.2 (M). Not only does this section address such issues as whether the individual with a disability satisfies the requisite skills but also the same section includes a reference to both the house and senate reports clarifying congressional intent.

A word of caution, no law is perfect. No law addresses every conceivable situation. The one thing I learned under Ronald Reagan is that whenever one must use a law as a safety net s/he needs to maintain a vigilant search for the holes. It is always prudent to look for authoritative analysis of the law realizing they are never official but can be helpful in seeking a useful understanding of the provisions which are relevant to the issue. Almost all of the national disability groups have issued printed or audio visual materials on ADA. A cautious use of these materials can result in more effective outcomes.



A most useful analytical tool has been developed by the Disability Defense Fund consisting of a 73-page "Explanation of the Content of the Americans with Disability Act of 1990." Not only does this document include a title-by-title review of each provision of the Act, it also contains references which break down sections with accurate reference to the U.S. Code. Therefore, the reader can scan the document easily and locate key provisions which can be utilized to enhance his advocacy position. The Attorney General published another document titled "Americans with Disabilities Act Questions and Answers," utilizing a question and answer approach. The reader has access to a clear interpretation on how the law could be implemented in "the real world situation." Knowledge of ADA can be a powerful tool but, unlike medieval religious scholars who dedicate their lives to one chapter of scriptures, all of the 43 million Americans identified by the Act cannot become authorities on the complete law. Real empowerment lies in developing effective information access skills with which to locate the relevant information independently and use it to meet our needs. This is true empowerment.

As the ways information and services are provided in our society become more complex, the older distinction between who provides what information services becomes harder to maintain. As people in need of information or service begin to assert the right to select their source of information and service, the situation will get much more complicated. Given the maze of information sources, publications, research studies, local ordinances, federal regulations, and public laws, libraries have the responsibility to provide guides through this information maze.

Keith C. Wright suggests that outreach requires bold new initiatives which link library professions with other social service agencies. Wright argues; "Libraries have mandated responsibility to meet the information needs of persons with disabilities, who, in addition to basic information needs, frequently require specifically formatted information and relevant information about their rights under current legislation." As a delegate to the 1991 White House Conference on Libraries and Information Services I participated in a caucus of delegates who represented the interest of persons with disabilities. This hastily formed coalition was successful in securing the passage of the following resolution: "We urge that the President and Congress establish a National Library Service for Persons with Disabilities. All barriers to services should be eliminated to achieve full and complete access as set forth in the Americans With Disabilities Act of 1990, and federal funds be made available to assure compliance."

Improvement of library reference and other needed information services will enhance the ability of the person with disabilities to move into and secure his/her rightful place in the community.

#### References

Americans With Disabilities Act of 1990, P.L. 101-336. 101st U.S.C.

Fair Housing Act of 1988, P.L. 100-430. 100th U.S.C.

## Recommendations

The First National Forum on Peer Support Programs to Promote Independent Living and Career Development of People With Disabilities was held on November 14, 1991 at Louisville, Kentucky. The Forum was sponsored jointly by the Arkansas Research and Training Center in Vocational Rehabilitation, ILRU Research and Training Center on independent Living at TIRR, and the Research and Training Center on Public Policy in Independent Living. There were approximately 50 people in attendance. Most were associated with independent living centers. Some held leadership positions in rehabilitation agencies with a special interest in independent living and a few were from university-based training programs.

After the content sessions were concluded, a general session was conducted to allow participants to discuss issues relevant to peer support and to make recommendations on issues where a consensus was achieved. The discussion was lively and many issues and concerns were covered. The following list of recommendations were enclosed by the group.

1. Promote an Annual Forum on Peer Support
2. Link the Forum to the annual meetings of various disability organizations such as NRA and the President's Committee on Employment of People with Disabilities
3. Organizations or programs that provide peer support services market these services to agencies that do not, e.g., arrangements for vocational rehabilitation agencies to purchase peer counseling services from independent living centers
4. Promote a "community model" of rehabilitation services which is consistent with principles of peer support
5. Conduct more research on strategies for providing peer support throughout the disability service delivery system
6. Join forces with other groups and movements that are interested in reforming the workplace
7. Develop better mechanism for sharing information about peer support
8. Support consumer involvement in all components of the disability service delivery system and consumer control in appropriate components
9. Increase funding for peer support activities
10. Recognize that peer support programming in rehabilitation offers a means of responding to culturally diverse groups that have been traditionally underserved

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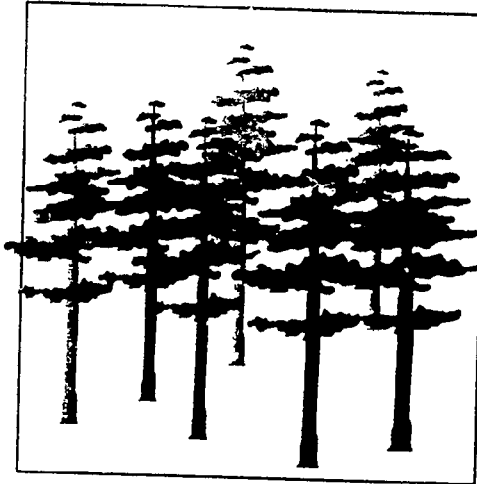
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## Peer Support Programs *A National Forum*

A national forum on peer support programs to promote independent living and career development of people with disabilities was gathered at Louisville, Kentucky on November 14, 1991. The purpose of the forum was to bring together a group of individuals from diverse backgrounds, who were interested in expanding and improving the use of peer support strategies available to the disability service-delivery system, to share information.

The published proceedings of the forum bring together in one volume a representative sample of state-of-the-art programs utilizing peer support. In addition to an introduction and a recommendations section, eighteen presentations are included.

The forum examined a broad range of peer support activities that have evolved in the disability service-delivery system. Such peer support activities may be labeled peer counseling, peer training, peer consultation, support groups, mutual self-help programs, mentoring, networking, advocacy, or general social support. Practice settings included independent living centers, community-based employment programs, medical programs, and educational institutions.

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