

AMERICAN REHABILITATION

AUTUMN 2004



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EMPOWERMENT



HOW EMPOWERMENT
CHANGED MY LIFE
"I DON'T HAVE TO LIVE
IN MY CAR ANYMORE..."

ENHANCING PERSONAL
EMPOWERMENT
OF PEOPLE WITH
PSYCHIATRIC DISABILITIES

SELF-DETERMINATION AND THE
EMPOWERMENT OF PEOPLE
WITH DISABILITIES

SLAYING DRAGONS:
BUILDING SELF-CONFIDENCE
AND RAISING EXPECTATIONS
THROUGH ORIENTATION
CENTER TRAINING

EMPOWERING PEOPLE
WITH DISABILITIES
THROUGH VOCATIONAL
REHABILITATION COUNSELING



OUR COMMITMENT TO THE EMPOWERMENT OF INDIVIDUALS WITH DISABILITIES

Joanne Wilson
Commissioner
Rehabilitation Services
Administration

Empowerment is multidimensional. It means, among other things, having decision-making power, access to information, the opportunity to make meaningful choices, understanding of rights and responsibilities, a sense of hope, raised self-esteem and control over the direction of one's life. Since assuming my responsibilities as Commissioner of the Rehabilitation Services Administration, I have traveled a great deal, speaking at length about empowerment, a concept that I believe is absolutely fundamental to the future of our public rehabilitation program and our consumers. In the course of my conversations with colleagues in the rehabilitation field, I have encountered varying responses to this priority. Many professionals appear to be as committed as consumers themselves to the goal of consumer empowerment. Others, however, have been less enthusiastic, claiming that empowerment doesn't work or that empowerment of consumers poses a threat to the professional relationship and role of the vocational rehabilitation counselor in providing effective services.

This edition of *American Rehabilitation* brings together some recent perspectives on the empowerment of people with disabilities. It includes personal accounts from individuals with disabilities about empowering people and the events that have significantly shaped their lives. In addition, the implications of empowerment as it relates

to employment outcomes are explored from the professional point of view, with research data, facts and figures. And, to stimulate and provoke further thought and discussion, there are a few straight opinion pieces.

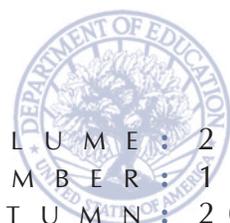
Admittedly, empowerment is not a totally new concept. It has guided recent amendments to the Rehabilitation Act and is a cornerstone of consumer advocacy. As we encounter and begin to embrace and value the process of empowerment, the nature of our professional roles and the way we conduct our business will inevitably change. Strength is implied in the word empowerment, and by empowering our consumers I believe we are strengthening our programs and efforts to secure high-quality employment and opportunity for persons with disabilities.

As you read this edition of *American Rehabilitation*, I hope that you will find some useful strategies and ideas that will be empowering to you and our many rehabilitation partners — consumers, professionals, educators, service providers and advocates — as we work to maximize opportunities and realize positive change in the lives of persons with disabilities.

By empowering our consumers I believe we are strengthening our programs and efforts to secure high-quality employment and opportunity for persons with disabilities.

Photograph: Frank Romano, U.S. Department of Education

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Cover: Erik Weihenmayer — the first blind climber in history to reach the summit of the world's highest mountain, Mt. Everest — was selected for our cover because he so completely embodies the spirit of empowerment, which is the subject of this issue of *American Rehabilitation*. Despite losing his vision at the age of 13, Erik Weihenmayer is a world class athlete: acrobatic skydiver, long distance biker, marathon runner, skier, mountaineer, ice climber and rock climber. He is also a prolific speaker and the author of *Touch the Top of the World: A Blind Man's Journey to Climb Farther than the Eye Can See*. Photo by Kevin Cherilla, rendering by Geoffrey Rhodes.

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HOW EMPOWERMENT CHANGED MY LIFE

"I don't have to live in my car anymore ..."

MARCIE KELLEY

It is through my personal and professional experience that I write this article on empowerment. I have thought about empowerment a lot throughout the years. I have researched it, lived with it and lived without it. I have shared empowerment with others. Without it, I have been utterly alone. Empowerment is simple, yet complex. It pertains to people with psychiatric disabilities and to people with any disability. I learned this through working at a center for independent living. People with disabilities face many obstacles that can be disempowering. It is evident that when the disability community unites and rallies behind a cause, we become more empowered citizens.

I am writing this for the individuals, and for people who know individuals, who feel disempowered and alone. I hope that presenting some of the ingredients necessary for empowerment will facilitate self-directed growth and freedom.

I am the director and systems advocate for the Mental Health PEER Connection (MHPC), a member of the Western New York (WNY) Independent Living Project, Inc., family of agencies located in Buffalo, New York. MHPC is a peer-driven advocacy organization dedicated to facilitating self-directed growth, wellness and choice through genuine peer mentoring. MHPC employs 21 full-time employees who have a mental illness or have recovered from a mental illness. Our peers are located in the state hospital, the county hospital, the county jail, the public mental health system and in vocational programs. We represent fellow mental health consumers by performing individual and systems advocacy to increase the rights, freedom and independence of those with mental health disabilities. We advocate with mental health housing providers, the Social Security Administration (SSA), state and local legislatures, the New York State Department of Vocational and Education Services for Individuals with Disabilities (VESID), public mental health providers in Erie County, the Erie County Department of

Mental Health, the Erie County Department of Social Services and the City of Buffalo Mental Health Court and Family Court. We conduct several self-help and mutual support groups weekly. In 2002, we provided independent living skills training, housing assistance, benefits advisement, advocacy and mobility training to over 350 individuals with psychiatric disabilities. We work with mental health housing providers and the county mental health department via the Community Services Board and advocate for people who are being mandated into treatment under the Involuntary Outpatient Commitment Law in the state of New York.

As the systems advocate, I have guided our center in advocating for what our consumers want by holding several town meetings on consumer issues. This information is disseminated to various stakeholders via position papers. Based on the information gathered at these town meetings, our agency has sponsored a freedom march, informational pickets, parity picnics and legislative breakfasts. We have demonstrated for greater freedom. We held letter-writing campaigns, call-ins, speak-outs, community open houses, a self-help luncheon and a managed care educational campaign. We helped to implement the Consumer Advisory Council in the Buffalo Psychiatric Center, the Erie County Medical Center Psychiatric Department, Gold Choice Family Medicine (a managed care health insurance for people with psychiatric disabilities) and a human service survey that "pokes a hole in West Side neighborhood group arguments that the community is over saturated with social service organizations" (Tan, 2000).

We have directed over \$70,000 for peer services to improve the quality of life of Erie County, New York, mental health recipients. Through MHPC's efforts, many people with mental health disabilities in Erie County have

improved their living standard. In addition, I serve as the co-chair of the Erie County Anti-Stigma Task Force.

In 1990, I came to the WNY Independent Living

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Project for help. I was living out of my car in the streets of Buffalo. I feared everyone due to my mental illness — multiple personality disorder (MPD). When I told the independent living counselor this, she did not look down on me and she did not seem to judge me. She expressed concern that I was living on the streets and that I feared that someone was going to kill me for no logical reason. She told me about housing that was available and convinced me to stay with a friend until the housing was arranged. She seemed to care. I listened. She showed me respect. She told me of other services that were available to me because I had a disability. She said that she knew this because she had a disability too. I did not understand it all. But she said that it was OK and that I could come back if I needed any other information or assistance. She gave me something that I had lost a long time ago. It was something that I never thought I would have again. She gave me hope.

I was severely abused as a child. I developed personalities to deal with it. I could not run away physically, so I ran away in my head. The personalities protected me from the abuse. As an adult, I was no longer being abused. But I still had the personalities — over 280 of them. I did not know that I had these personalities until I was 25 years old, when I was diagnosed with MPD while in a psychiatric hospital. Often, I was suicidal. I never knew why. I went to psychiatric hospitals for help. I have been in psychiatric facilities on 12 different occasions, for months at a time. The more I went, the more I realized that they were not helping me. I felt increasingly disempowered. The hospital staff members were getting frustrated with me as well. At one point, I was on 13 different types of psychotropic medications: anti-depressants, anti-psychotics, anti-anxiety, anti-everything. Eventually, I was on medications to counteract the medications. I was

constantly looking outside of myself for something to fix me: the hospital, the doctor, the pill or the therapy.

Then the most disempowering thing happened to me, changing my life. Ironically, it led to my becoming empowered. Many people with disabilities are driven into the disability rights movement due to their own disempowering experiences. This was true for me. I was hospitalized for the eleventh time. I was suicidal and a danger to myself and to others. I did not care if I lived or died. I was receiving disability benefits. I was not in contact with my family and had no support network. I was utterly alone. The hospital “recommended” electro-convulsive therapy (ECT). This is when they shock the brain to help a person overcome depression. As a trauma survivor, this idea terrified me. The hospital staff developed a treatment plan without my participation. The plan consisted entirely of me making a decision to get ECT. In front of a room filled with hospital staff, I was asked to sign the treatment plan. I signed the plan, but I was terrified. I wanted to leave the hospital because it was clear that they wanted to electrocute me. Most psychiatric hospitals are locked down. This hospital was no exception. They would not let me leave, so I tried to escape twice. The first time, I jumped through a nurses’ station window. The second time, I pushed a doctor out of the way as she entered the ward. Each time, I was “taken down,” shot up with Thorazine and put in restraints in a seclusion room. I could not scratch my nose or go to the bathroom without help. This was the most disempowering time in my life. I could not really figure out how I had gotten to this point, but I had. I had no control over my life. I had no decision-making power. I did not understand that I had rights. I felt totally alone. This was the turning point in my life. I decided that I was sick of this and that I was not going to take it anymore. I begged the hospital staff to let me out of the restraints. I promised them that I would not try to

*I
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and for people
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and
alone.*

*The
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disempowering care
systems for people
with psychiatric
disabilities.*

escape again. I pretended I was happy. I said that I did not feel suicidal anymore. I thanked them for helping me to not hurt myself by trying to escape. I said I was ready to start my life again. So they let me out. I was finally free.

But I was not better. I held onto the hope that I found at the WNY Independent Living Project. But that was all I had. I wanted to get better and I was ready to do what it took to get better. My outpatient counselor told me about a hospital in Texas that treated trauma survivors, especially those with MPD. I was hesitant to go to another hospital, but I wanted to get better. I took the risk and went to Texas in 1994. This hospital was like no other. They accepted Medicare. During previous hospitalizations, the only activity was taking medication. It was very boring. But this hospital was very different. I saw a psychologist for one hour, five times per week. My personalities worked out their issues during these sessions. I attended group therapy, clay therapy, anger therapy, occupational therapy, cognitive therapy and art therapy. I saw a psychiatrist every day. I got better. I was with people just like me. There was camaraderie. We sang songs of hope. We had privileges to go outside.

I left with the desire for a new beginning. I returned to Buffalo with the ambition to begin my life. Later that year, I saw a brochure for an advocacy and empowerment training event for people with psychiatric disabilities sponsored by the WNY Independent Living Project. I signed up and attended. I was scared. I did not know what to expect. But it was great. The presenters spoke of their psychiatric disabilities and hospitalizations and their current role as advocates. They talked about empowerment. It was like they lit a fire beneath me. I was not alone. So many people with psychiatric disabilities were fighting for their rights. They had lost their rights, as I had. I did not know that others had gone through

it as well. As I looked at the presenters, another idea popped into my head. If they could get paid to advocate, I could do it too. I applied for a job as a peer advocate at the WNY Independent Living Project and began employment in 1995.

To this day, my hospitalizations have ended. The advocacy and empowerment training opened my eyes to the disempowering care systems for people with psychiatric disabilities. And the WNY Independent Living Project opened my eyes to the many disempowering systems serving the disability community. I began to understand that the whole disability community is a civil rights movement. I saw this on many levels: through my own experience, through my employees' experiences, through our consumers' experiences and through the communities' attitudinal barriers.

Empowerment must begin with the individual and then expand to the community as a whole. I have witnessed many subtle (and not so subtle) actions that take power away from the disabled individual. However, it is apparent that the Erie County Department of Mental Health is trying to shift the pendulum of power from the professional mental healthcare provider to the consumer of services. The power of the psychiatrically disabled individual is in the hands of the individual, with one exception: When the individual is a danger to himself (or herself) or others, that person may lose his right to choose, his right to freedom and his right to decide what treatment is best for himself.

I met Judi Chamberlin at the 2001 National Association for Rights Protection and Advocacy (NARPA) Conference held in Niagara Falls, New York. I was very impressed by her insights on empowerment for psychiatric survivors. Her article *A Working Definition of Empowerment* (1999) is enlightening. She gathered a dozen leading American consumer/survivor self-help practitioners to form the advisory board of the Cen-

ter for Psychiatric Rehabilitation. Its first task was to define empowerment for psychiatric survivors, which it did as follows:

1. Having decision-making power.
2. Having access to information and resources.
3. Having a range of options from which to make choices (not just yes/no, either/or).
4. Assertiveness.
5. A feeling that the individual can make a difference (being hopeful).
6. Learning to think critically, unlearning the conditioning, seeing things differently (e.g., learning to redefine who we are [speaking in our own voice]; learning to redefine what we can do; and learning to redefine our relationship to institutionalized power).
7. Learning about and expressing anger.
8. Not feeling alone, feeling part of a group.
9. Understanding that people have rights.
10. Effecting change in one's life and one's community.
11. Learning skills (e.g., communication) that the individual defines as important.
12. Changing others' perceptions of one's competency and capacity to act.
13. Coming "out of the closet."
14. Growth that is never ending and self-initiated.
15. Increasing one's positive self-image and overcoming stigma (Chamberlin, 1999).

I believe that these characteristics are necessary for one to become empowered. Often, these aspects are overlooked in government systems, health care systems and the rehabilitation system. I see this as a person who has used the system since the 1980s, as an employer of 21 full-time staff with psychiatric disabilities and as a systems advocate for people with psychiatric disabilities in my county. It is my experience that

these systems of care are not consciously aware of the fact that they are disempowering. They are trying to help individuals, their intentions are good, but the results of their policies, rules and regulations can be devastating. This is due to misunderstanding, numerous waiting lists, piles of paperwork requirements and budget cuts. The person with a disability gets left out of the picture when, in fact, he or she is supposed to be the center of the picture. That is why the 400 independent living centers throughout the United States work so well. People with disabilities have "been there." Often, a person needs a road map to navigate these care systems. Independent living centers have the road maps and they have gone the distance.

Having decision-making power. This is key for the person with a disability. Often, systems of care make decisions about what is best for the person with a disability without even talking to the person. Often, our society does not allow the person with a disability to make decisions. Once, I was helping an individual who was deaf to find an apartment. The landlord decided that the individual would not like living in his building. Taking away the decision-making power can be subtle, as well. While I was having dinner with a friend who uses a wheelchair, the waitress asked me what he wanted for dinner. Government systems of care take away decision-making power as well. While on disability, I applied to VESID for services. My goal was to become a chef. They told me I was unemployable. It was a good thing that I did not listen to them!

Having access to information and resources. There is so much information available for people with disabilities that it is hard to access all of it. The opposite is true as well. Many people with disabilities live in utter poverty and isolation. They have no access to information. For example, the *Erie County Behavioral Health*

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Vocational Task Force Final Report states that:

"Many individuals with disabilities can now work without the immediate loss of cash benefits or health insurance through Medicaid or Medicare through Work Incentives. Benefits Advisement is readily available in the community. Agencies such as Neighborhood Legal Services provide this service and some Behavioral Health Agencies have Benefits Advisors on staff. However, many consumers and providers are unaware of these current rules and are also unaware of where to get accurate advisement (2003, p. 11)."

Thus, many people with psychiatric disabilities fear returning to work or going to work for the first time because they fear losing their benefits (M. Weiner, Erie County Commissioner of Mental Health, personal communication, March 6, 2003). On a more human rights level, many people with disabilities who live in institutions lack the information they need regarding their rights in that institution, such as those stated in advanced directives, the Olmstead Decision, etc. As a systems advocate in Erie County, I have heard many psychiatric survivors talk about being institutionalized. They did not know their rights because when they were given the sheet of paper with their rights on it, the paper was thrown into a secured locker with all their personal belongings.

SSA causes difficulty in accessing information and resources as well. When I returned to work after being on Social Security Disability Insurance (SSDI), I knew that I had a nine-month trial work period; but I was not sure when the trial period started and when it stopped. I just kept receiving checks. Then, I received a letter from SSA that stated that they overpaid me by \$10,080. They asked that I return the overpayment by a certain date. That letter almost sent me back into the hospital.

Having a range of options from which to make choices (not just yes/no, either/or). Most adults in life make informed decisions by weighing the consequences of their choices. Why can't people with disabilities have that right as well? When I was homeless, I had to decide to spend my disability check on either medicine or food. When I was in the psychiatric hospital, I was given no option other than ECT. Many housing providers offer housing under the condition that the person with the disability continues to take his (or her) medication or he will be kicked out. In Buffalo, the winters can be very cold, and medications can have serious side effects. I believe that there is always room to work things out, to find out what people with disabilities want and to discover what their hopes, dreams and aspirations are. It is not necessary to threaten to take them away if they do not cooperate. There is no need to manipulate. It is better to contribute to the conspiracy of hope, to problem solve and negotiate, to obtain a win/win solution.

Assertiveness. Standing up for one's rights without fear of retribution is a very empowering act for a person with a disability. When necessary, people with disabilities must depend on others. When people with disabilities think for themselves, it is a wonderful process. Many have lived their lives with caretakers who have made decisions and plans without asking for input from the person with a disability. When that person becomes assertive and determines what he or she wants, new freedom exists. Many care providers do not understand this. In the mental health system, when people with psychiatric disabilities assert themselves, they are often called "non-compliant." It is important to discuss with the person with the disability what he (or she) wants and to understand why he wants it. Communication is key. There are many good reasons why a person with a disability does not want to follow a certain plan, especially

when the plan was developed without the involvement and consent of that person.

Feeling that the individual can make a difference (*being hopeful*). When I was on disability, I was ashamed of not contributing to society. I was ashamed to socialize with others, in fear that they would ask me what I was doing for a living. I was embarrassed at the supermarket when I used food stamps to pay for my groceries. I felt totally useless. When I started working at the Independent Living Project, I began to feel like I was making a difference. People with disabilities do not want to be a burden, no matter how moderate or severe the disability; but often others see the individual with disability as a burden. All disabled individuals have something to offer, can make a difference in someone's life (if not many lives) and can be contributing members of society.

Learning to think critically, unlearning the conditioning, seeing things differently (e.g., *learning to redefine who we are [speaking in our own voice]; learning to redefine what we can do; learning to redefine our relationship to institutionalized power*). Often, people with disabilities and the people who work with individuals with disabilities only see the disability, not the person. For years, I saw myself as a "multiple," not as anything else. And that kept me down. I saw no recovery. I saw no life outside of therapy. I had no natural supports. My supports were based on group and individual therapy. I had no passion and no desires. When I became an advocate, I began to see myself as something other than my disability. In Erie County, the Department of Mental Health encourages representation of people with psychiatric disabilities in the planning and implementation of services for people with mental health issues. I have been attending such planning meetings since 1995. At first I was

very intimidated to be in a planning meeting with professionals and non-disabled individuals. But, over the years, I have noticed that they have their quirks too. I have as much right to say what needs to be said as they do. I noticed that they did not view me as a mental case but as a person with insight and experience regarding what people with psychiatric disabilities want.

Learning about and expressing anger. I have learned that anger is a healthy and natural emotion. People with disabilities have many things to be angry about: Americans with Disabilities Act violations, reduced health insurance coverage for durable medical equipment or personal care attendants, no state health insurance parity legislation, housing discrimination, stigma, and all of the personal issues that people in general get angry about. When a person with a disability gets angry, some find this unacceptable. I remember getting angry in a hospital because a nurse would not give me a nighttime medication so I could go to sleep. I lost my privileges for three days. Some people with disabilities have been institutionalized all their lives or lived in sheltered environments. Some were never taught appropriate ways to express angry feelings. This built-up anger and explosive energy sometimes results in their institutionalization in a psychiatric hospital (for evaluation) or jail. It is important to remember that people with disabilities have feelings too, and one of those feelings is anger. They should be taught appropriate ways to express it.

I think that "***Not feeling alone, feeling part of a group***" is one of the most important qualities of empowerment that Chamberlin cites. Many individuals with disabilities are isolated through living alone, in special housing, with family or in institutions such as psychiatric hospitals or nursing homes. Institutionalized people are often separated from each other by a door or wall, which allows for

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little contact with the outside world. I remember living in a one-room apartment while I was receiving SSDI benefits. I spent my days going to therapy. I felt totally alone. I did not know that there were others just like me. It is very important to network with other people. The Independent Living Project provides opportunities for this on a continuous basis: first, by constantly updating the mailing list and asking everyone served if they want to be on the mailing list; and second, by mailing notices of self-help groups, workshops, town meetings, special events, action alerts, etc. During events and presentations, I introduce myself by saying a little bit about my past, and then the group participants talk about issues that concern them. Friendships are formed, support is developed and that feeling of loneliness disappears.

Understanding that people have rights. MHPC has an educational program on mental health recipients' rights. It is amazing to see how many people with psychiatric disabilities do not know about their rights. This is most clearly seen regarding housing rights in our county. Many people with psychiatric disabilities do not realize that they can leave their current housing. However, if they do leave, their standard of housing would decrease dramatically. New York State has a law called the Involuntary Outpatient Commitment Law, or Kendra's Law, which can force non-compliant mental health consumers into outpatient treatment if they have had many recent hospitalizations or incarcerations and are deemed unable to survive in the community by themselves. Erie County has successfully avoided taking people to court by encouraging the recipient to agree to the program. Recipients are put into the "Diversion Program," which provides increased case management services. Basically, it is the same program recipients would get if they went to court but without the

legal representation. MHPC is concerned that some of these people are forfeiting their rights and may not meet the criteria because they do not have proper legal representation. Because we have found that many mental health consumers do not know their rights, we developed a workbook, we go to places where mental health consumers congregate and we provide education on their rights.

We also have rights regarding our vocational and rehabilitation goals. VESID assists those with disabilities in becoming more productive members of society. However, VESID has limitations and budgetary restraints. When they told me I was unemployable, I did not know that I had the right to seek help from the Client Assistance Program (CAP).

Effecting change in one's life and one's community is another quality for empowerment. In past years, many disabled people simply existed; they were warehoused and overly medicated, with no expectations of recovery or improvement. As the disability rights movement grew, more people with disabilities demanded more out of life than medication and maintenance. They had goals, aspirations and dreams. They wanted to change and improve their lives. As people with disabilities accomplish these goals and continue to effect change, their communities change slowly. When people in my life expected change in me, I did change. But if the expectation was not there, I did not change. Because of the changes in my life, I am effectively altering the community in which I live today. I am affecting understanding and attitudes toward people with mental illness in Erie County, New York.

Chamberlin includes *learning skills* (e.g., *communication*) that the individual defines as important. It is crucial to communicate with the person who is disabled to find out what skills the individual wants to learn and what help he or she wants. During one hospitalization,

I was painting a stained plastic window (they did not allow glass). I put the window away and moved to another part of the ward. I did not paint the item well, but I tried. When I returned to the room, a nurse was painting my window. I said, "What are you doing? That's mine." She said, "I was just helping." I did not want her help. I wanted to learn it myself. But, she

ward the people working with the person with a disability. Just because I acted irrationally or de-compensated last week does not mean that I am always that way. Those of us with disabilities want to be judged on our abilities today, on our record and on our integrity, not on our weakest moment. Like all people, we change, grow and learn from our experiences.

Coming out of the closet. I think this quality pertains exclusively to people with hidden disabilities, such as people with mental disabilities. The surgeon general reports that one in five Americans is affected by mental illness during his or her lifetime. Many people are ashamed to have a mental illness and fear the discrimination and stigma that occurs regularly. But as more people share their disabilities, the more commonplace it will become. The more people talk about it, the more acceptable it becomes. The more acceptable it becomes, the more people will get help. This may result in fewer deaths by suicide each year.

Growth that is never ending and self-initiated is cited by Chamberlin as an empowering quality. People with disabilities should have the same rights as any other person to pursue their dreams to the full-

est extent possible. As providers of services to people with disabilities, we should be facilitators of such dreams and potential.

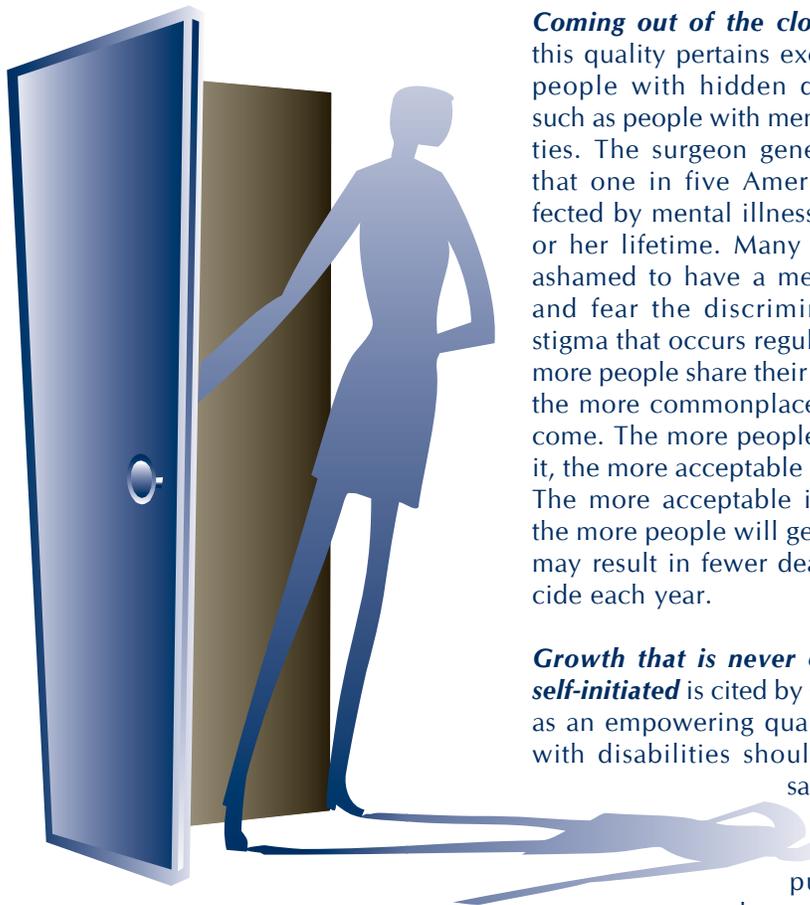
Increasing one's positive self-image and overcoming stigma. This is Chamberlin's final quality of empowerment. Throughout Erie County, people with mental illness suffer from stigma that they have internalized, and by internalizing they affect their self-image and self-esteem. They become the disability. This is often exhibited in their

vigilance about confidentiality — about anyone finding out that they might have a mental illness. There are many good social and internal reasons for this. I have dealt with parents who lost their children in custody battles with their spouses because the judge found out that they have a mental illness. People with mental illness have lost their jobs because they spent time in a psychiatric hospitals. In our region, there is a shelter for battered women, but they will not accept women with mental illness. The shelter managers say that they do not have the staff to deal with this issue. But if everyone who has a mental illness spoke out, maybe, just maybe, discrimination would decrease. As part of the Erie County Anti-Stigma Task Force, we launched an advertising campaign with the following message: "Mental Illness Is Treatable, Treat It That Way." We must overcome stigma in order to improve the cultural and civil rights barriers that the disabled community in America faces today.

What has been my most empowering experience so far? In December 2000, I purchased a house in the suburbs of Buffalo. It is my first house. Ten years ago, I was homeless. I became a bona fide homeowner with all the rights and responsibilities that come with it. In spring 2001, I had a barbeque for the entire MHPC staff at my house. If I can do this, so can others. That is what empowerment is all about: achieving goals and sharing them with others. **AR**

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did not communicate with me. At the Independent Living Project, I have learned that we do not do for others what they can do for themselves, unless they ask. It is crucial not to assume what the individual wants to learn. It is important to know what the individual's goals are and how he or she wants to achieve them.

Changing others' perceptions of one's competency and capacity to act is a quality that Chamberlin cites. I believe this is directed to-



ENHANCING PERSONAL EMPOWERMENT *of* PEOPLE WITH PSYCHIATRIC DISABILITIES

PATRICK W. CORRIGAN, PSY.D.

For most of recorded history, people with psychiatric disabilities have struggled with maintaining personal power over their lives. The centuries-old battle against stigma is the best example of this struggle. The ancient Greeks first gave voice to the concept of stigma noting that those who were marked with mental illness were often shunned, locked up or, on rare occasions, put to death (Simon, 1992). During the Middle Ages, people with mental illness were viewed as living examples of the weakness of humankind, what goes wrong when people are unable to remain morally strong (Mora, 1992). This kind of attitude led families to hide away those with psychiatric disabilities from public view. Not until the 18th century did asylums and treatment centers emerge for mental illness. Before that time, those with serious and persistent mental illness were often locked up with criminals. Although the struggle for personal power has vastly improved during the last century, people with mental illness still encounter stigma and disempowerment. The re-

cently released report by President George W. Bush's New Freedom Commission for Mental Health (2003) issues a clarion call for practices that facilitate consumer empowerment.

The goals of this paper are threefold:

1. Provide a working definition of empowerment as applied to the lives of people with psychiatric disabilities.
2. Identify community and service systems barriers to empowerment.
3. Describe guidelines and other system enhancements that facilitate personal empowerment.

UNDERSTANDING PERSONAL EMPOWERMENT

Empowerment has been defined as personal control over all domains of life, not just mental health care but also decisions related to such important areas as vocation, residence and relationships (McLean, 1995; Rappaport, 1987; Segal, Silverman & Temkin, 1995). This is espe-

*“There is no medicine like hope, no incentive so great,
and no tonic so powerful as expectation of
something tomorrow.”*

cially important in societies that stigmatize persons with psychiatric disabilities. Western cultures, for example, seem to rob these persons of authority over treatment plans and life decisions (Brockington, Hall, Levings & Murphy, 1993; Link, Cullen, Frank & Wozniak, 1987). Research on the construct of empowerment leads to a better understanding of effective services and their impact on quality of life (Corrigan & Garman, 1997). Rosenfield (1992), for example, found a measure of consumer empowerment correlated with quality of life. Rogers, Chamberlin, Ellison and Crean (1997) completed a more comprehensive series of studies on mental health consumer empowerment with their *Empowerment Scale*. Items for the *Empowerment Scale* were first identified by a panel of 10 leaders in the consumer movement and then validated by participants in six self-help programs. An unpublished analysis of 261 responses to the scale, conducted by Rogers et al. (1997), yielded seven factors that describe the construct:

- self-efficacy,
- powerlessness,
- self-esteem,
- effecting change,
- optimism/control over future,
- righteous anger and
- group/community action.

These factors are intercorrelated and seem to correspond with two superordinate factors that describe the impact of empowerment on persons with schizophrenia and on their community (Corrigan, Faber, Rashid & Leary, 1999). These are:

- The impact of empowerment on the self is such that, despite societal stigma, empowered consumers endorse positive attitudes about themselves. They have good self-esteem, believe themselves to be self-efficacious and are optimistic about the future.

and no tonic so powerful as expectation of something tomorrow.”



O.S. Marden
1850-1924

- The impact of empowerment on the community is manifested by the consumer's desire to affect his or her stigmatizing community. Consumers believe they have some power within society, are interested in affecting change and wish to promote community action.

Readers may note that terms like empowerment and disempowerment are frequently interchanged in the remainder of this article. In part, this interchange represents empowerment as a continuum (Corrigan, Faber et al., 1999; Rogers et al., 1997). At the positive end of the continuum are people with psychiatric disability who, despite their disability, have positive self-esteem and are not significantly encumbered by a stigmatizing community. At the negative end are people who report being unable to overcome all the pessimistic expectations about mental illness. One might think that a paper about empowerment would be presented in the affirmative voice (e.g., What might people with mental illness, service providers and the community at large do to promote personal power?). Unfortunately, much of the research and literature on empowerment looks at the negative impact of its absence (What happens when a person with mental illness is disempowered?) (Corrigan & Garman, 1997; Rapp, Shera &

Kisthardt, 1993). Hence, I have chosen to intertwine what is known about disempowerment with what is the vision of empowerment to address the themes of this article.

BARRIERS TO EMPOWERMENT

Stigma is the societal embodiment of disempowerment; it promotes expectations in both the public at large and individual consumers that people with mental illness are incapable of the responsibilities commensurate with living independently. Results of two factor analyses on more than 2,000 English and American participants revealed three common themes to stereotypic attitudes about mental illness that endorse this assertion (Brockington et al., 1993; Taylor & Dear, 1981):

- *Fear and Exclusion.* Persons with severe mental illness should be feared because they are dangerous. As a result, they should be kept out of the community and housed in institutions.
- *Authoritarianism.* Persons with severe mental illness are irresponsible; life decisions should be made for them by others.
- *Benevolence.* Persons with severe mental illness are childlike and need to be cared for.

These kinds of widespread attitudes have two effects on the power of persons with mental illness. First, they rob people of the opportunities that are central to recovery and a quality life (e.g., good jobs, comfortable income, nice housing and good friends). Perhaps of equal concern are the effects that stigma has on some people with mental illness. People living with seri-

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TABLE 1: SEVEN WAYS TO FOSTER EMPOWERMENT.

NOTE: *These are arrayed from those that minimally foster empowerment to those that more fully enhance personal empowerment.*

1. From Noncompliance to Collaboration

A change in perspective from expecting consumers to passively comply with treatment to making care-plans that are user-friendly.

2. Consumer Satisfaction and Other Input on Services

At the absolute minimum, programs that empower participants need to be satisfactory to those participants. Moreover, these programs need to obtain input from consumers to ensure that program design reflects their interests.

3. Lodges and Clubhouses

For more than three decades, the mental health system has supported treatment programs that were largely operated by persons with mental illness. Lodges are residential programs in this mold; clubhouses are social and work programs.

4. Supported Housing and Employment

Instead of the consumer going to the professional, the best treatment occurs when the professional travels to the consumer and all the places in which consumers need assistance. Provision of services in the person's home or community is the hallmark of Assertive Community Treatment (or ACT). Services in real-world job sites is supported employment.

5. Consumers as Providers

Many persons with mental illness are deciding to return to school, obtain necessary credentials, and assume jobs in the mental health system as providers. In this way, they can change the system from the inside.

6. Self-Help, Mutual Assistance and Other Consumer-Operated Services

There is almost a 50-year history of programs developed by persons with mental illness to help peers. These programs provide places where people can provide and receive help from individuals with similar concerns.

7. Participatory Action Research

Much of the current research on psychiatric disability and rehabilitation reflects the perspective of the existing mental health system. Persons with mental illness must be equal partners in the research enterprise for future studies to represent the differing interests of consumers.

ous mental illness who are immersed in a culture that endorses psychiatric stigma begin to believe this stigma and question their own capabilities for independent living (Wahl, 1995). Because self-stigma has such an insidious impact, its effects on empowerment are examined first.

Some people experience stigma as a private shame that diminishes the person's self-esteem (Corrigan, 1998; Corrigan & Watson, 2002). This kind of shame leads to self-doubt about whether the person is able to live in-

dependently, hold a job, earn a livelihood or find a life mate. Even though they may have mastered their symptoms and disabilities, people with mental illness must also overcome stigmatizing reminders that they still have a disability or are not useful members of society. One recent study showed the breadth of discrimination experienced by mental health consumers (Wahl, 1999). The majority of 1,300 respondents reported discouragement, hurt, anger and lowered self-esteem as a result of their experiences. An ear-

lier study by Link (1982) showed the loss of self-esteem that results from stigma also has practical consequences. Participants in their study reported that being publicly labeled with a psychiatric illness had a negative impact on work and income.

ACTIVITIES THAT FACILITATE EMPOWERMENT

Research has yet to examine strategies for overcoming self-stigma, but several candidates show promise (Corrigan & Watson, in press). Inter-

nalizing the kind of messages embodied in recovery may help to diminish self-stigma. Cognitive restructuring may also prove useful in helping people learn to challenge stigmatizing views they may hold of themselves (Corrigan, 1998; Haaga & Davison, 1991). Alternatively, self-stigma will diminish as a person's sense of empowerment improves. Seven sets of strategies have some empirical support for facilitating empowerment of people with mental illness (Corrigan & Lundin, 2001). Each of these is discussed more fully in the remainder of this article.

Empowerment may be construed narrowly in terms of control over the services that help people deal with their disabilities (e.g., problems related to mental illness). It may also be understood more broadly in terms of command over all spheres of one's life, such as succeeding at work, in relationships, during play, spiritually and in as many other domains as possible. Table 1 lists seven strategies that facilitate empowerment. These are loosely ordered from those that should now be obviously accepted by the mental health system — they represent the base of empowerment approaches (like issues about collaboration and consumer satisfaction) — to those that are visionary and need to be more widely accepted and disseminated, such as consumer operated services and participatory action research.

1. From Noncompliance to Collaboration

Many mental health providers must drastically reconceive their viewpoint about the consumer's relationship with treatment for empowerment to occur (Fenton, Blyler & Heinssen, 1997; Ruesch & Corrigan, 2002). The old notion was that persons with mental illness should comply with all aspects of treatment: Professionals knew best; anything that strayed from the prescribed treatment program represented unclear thinking due to the illness. Failure to comply was indicative of unconscious motivations

to resist health. Mandatory treatments and a coercive system rested on these assumptions. Research evidence seemed to clearly support these conclusions. Depending on the study, anywhere between two-thirds and three-quarters of persons did not take their psychiatric medications as prescribed. More than half of all participants in rehabilitation and similar psychosocial programs did not complete the treatment plan as agreed (Cramer & Rosenbeck, 1998). These data suggest resistance is rampant and significantly undermines treatment of serious psychiatric illness.

Considered another way, however, these data might be perceived to yield completely different conclusions. Rather than 66 to 75 percent of persons taking their medication incorrectly, perhaps two-thirds to three-quarters of all mental health providers are prescribing drugs poorly. Lack of compliance may not represent resistance by a person with psychosis as much as meager treatment by the mental health team. Equally sobering statistics suggest that more than 70 percent of *all persons* who are prescribed any kind of medicine (not just psychoactive drugs) do not take it the way the doctor ordered (Rogers & Bullman, 1995). Clearly, incorrect use of medication is not solely a problem of persons with mental illness.

Rather than expecting persons to passively comply with care — be it psychiatric care or general medical treatment — what is needed is more enlightened practice that calls for collaboration between providers and consumers. An equal partnership occurs when each party learns from the other: Providers learn about the nature of specific symptoms and corresponding disabilities from the person challenged by these problems; consumers learn the range of treatments and services that address these problems. How do providers and consumers foster a collaborative working relationship? More than a decade ago, we wrote a paper that outlined strategies for answering this question

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TABLE 2: BARRIERS TO COLLABORATION AND WAYS TO OVERCOME THEM

BARRIERS	WAYS TO OVERCOME BARRIERS
TREATMENT TECHNIQUES	
NASTY SIDE EFFECTS OF MEDICATION.	<ul style="list-style-type: none"> • Use new generation of medications that reduce side effects. • Use low-dose medication strategies. • Educate consumer to side effects and teach self-tracking strategies.
COMPLEX TREATMENT PLANS.	<ul style="list-style-type: none"> • Engage consumers in central role in designing treatment plan. • Use simple language. • Clearly explain steps of treatment • Begin simply and slowly; add more complex steps gradually.
LONG-TERM TREATMENT.	<ul style="list-style-type: none"> • Regularly assess goals and relevance of treatments to these goals. • Provide treatment holidays. • Consider place-train options.
TREATMENT DELIVERY SYSTEM	
DEPRESSING AND DINGY ATMOSPHERE OF CLINICS.	<ul style="list-style-type: none"> • Improve clinic decor and ambience. • Offer coffee and refreshments. • Require all staff (including clerks) to be courteous and respectful. • Move most services to the consumer's home or other setting.
LONG WAITS AT CLINICS.	<ul style="list-style-type: none"> • Maintain realistic schedules. • Send reminders to consumers.
PROVIDER-CONSUMER RELATIONSHIPS	
PROVIDER'S POOR INTERPERSONAL STYLE AND LACK OF INTEREST IN CONSUMER FEEDBACK.	<ul style="list-style-type: none"> • Alert administrators about poor provider style. • Educate providers about the importance of "collaborative" roles. • Educate providers about the need for consumer satisfaction. • Pair provider with mentor for remediation.
FAMILY-CONSUMER CHARACTERISTICS	
LACK OF KNOWLEDGE OF OR UNREALISTIC EXPECTATIONS ABOUT TREATMENT.	<ul style="list-style-type: none"> • Educate consumers and family members to treatment options. • Provide opportunities for consumers and family members to share concerns.

Adapted from Corrigan, Liberman & Engel (1990).

(Corrigan, Liberman & Engel, 1990), which are summarized in Table 2. As outlined in our earlier paper, these strategies have some empirical support for fostering the collaboration among providers and consumers.

2. Consumer Satisfaction and Other Input on Services

One of the assumptions of empowerment and collaboration is that treatment teams will design interventions and programs that are pleasing to participants. Hence, assessing consumer satisfaction is a minimal requirement for establishing programs that empower consumers (Corrigan, 1990; Dickey & Sederer, 2001). Although

one might think this to be a straightforward process, assessing consumer satisfaction is more difficult in actuality. Hence, some rules for developing a useful consumer satisfaction scale are provided. Unfortunately, concern with consumer empowerment frequently ends with the assessment phase. Programs collect data on satisfaction but subsequently fail to use it in improving services. A second important part of this process is to consider ways to use information from satisfaction evaluations to further improve the setting.

What goes into a consumer satisfaction scale? When evaluating consumer satisfaction, satisfaction scales should consider four categories

or domains: the *service environment*, the *service providers*, *specific interventions* and *preparation for autonomy* (Corrigan, 1990; LeBow, 1982). What is the quality of the service environment? Are the rooms pleasant, including the decor, lighting, furniture and temperature? If food is provided, is it tasty and plentiful? How are the service providers? Are they knowledgeable and competent in their specific jobs? Are they approachable, respectful and friendly? Can the consumer interact with them informally? How useful are specific interventions themselves? Do they provide the consumer with the needed skills? Do they help the con-

sumer better understand his or her goals? Do they provide the resources and support needed for goals? Is the service preparing the consumer for autonomy? After finishing the program, is the consumer better able to live independently? Is he or she more hopeful about the future?

Unfortunately, this approach to assessing satisfaction can lead to "halo" or "devil" effects (Corrigan & Jakus, 1993a,b). Halo effects occur when the consumer rates everything as satisfactory: The program was great, the staff were great, the food was great, the building was great, everything was great. Research has shown that halo effects are very common in consumer satisfaction studies. Although some services may indeed be satisfactory, rating *everything* highly does not help to identify those components that need to be changed. Service providers would not know where to put their efforts in improving services. Devil effects are provided by people who are angry with the program. They rate all components as highly dissatisfactory. The program was poor, the staff was lousy, the food was rotten, the building was dingy, everything really stunk. Like the halo effect, rating everything alike (in this case, poorly) does not help providers focus on specific aspects of the program.

To avoid this problem, consumers may be encouraged to compare a specific program to another similar service in which the person has been involved in the past (Corrigan & Jakus, 1993b). For example a counselor might request the following from a client:

"Currently, you are participating in the Opportunities Program on Supported Employment. Tell me another similar program you have participated in the past. Write it here _____.
Now answer the following questions by comparing your experience in Opportunities with this other program."

Research has shown this kind of comparative approach yields to better differentiation among components of a program (Corrigan & Jakus, 1993a,b).

Having input on services. The full benefit of evaluating consumer satisfaction will only be realized when providers use the results from these evaluations to actually change services. Unfortunately, this kind of program improvement is frequently done without consumer input. Instead, treatment providers take the findings and decide how to improve program aspects on their own. This kind of approach fails to promote empowerment. The preferred way to handle findings from satisfaction evaluations would be to involve participants in focus groups where they discuss their concerns about aspects of the program and, more importantly, provide recommendations for ways that the program might improve (Rogers & Palmer-Erbs, 1994).

There are two essential roles to fill in these kinds of focus groups: the leader and participating members (Morgan, Krueger & King, 1998). The best leaders for these groups are other consumers who are trained to facilitate these kinds of groups. Although traditional service providers may have skills for running discussion groups like these, members might be hesitant to speak freely because they believe the provider will be biased in favor of the established program. Many consumers are able to lead these groups after one hour of training. We do not have the space here to consider the skills for a focus group leader; the interested reader should consider such resources as Bernard Bass's and R.M. Stogdill's *Handbook of Leadership* (1990).

Focus groups should comprise six to eight members. A good mix of people with different opinions should be invited to the focus group. Include consumers at both ends of the scale — persons who are fully satisfied with the program and those who are highly critical — as well as individuals in the middle. In this way, a polite contrast of opinions is possible. Prior to the meeting, leaders should develop a series of questions to guide the discussion. These questions should be based on the results of the consumer satisfaction evaluation.

The preferred way to handle findings from satisfaction evaluations would be to involve participants in focus groups ...

The lodge program is built on several principles that clearly reflect the spirit of personal empowerment.

3. Lodges and Clubhouses

Consumers have obtained further control of the mental health system and their world in two kinds of programs: lodges and clubhouses. In both settings, people with mental illness have equal authority to that of the professional staff in operating the program. Lodges were started in the 1960s by George Fairweather as residential and work communities for persons recently transferred from long-term hospitals. Clubhouses spontaneously emerged in New York City as a meeting place for people recently discharged from the state hospital. Both of these models represent consumer dissatisfaction with the way mental health providers acted towards persons with mental illness. This dissatisfaction led to a philosophy that clearly echoes the importance of empowerment.

The Fairweather Lodge: Living and working together. The lodge is made up of persons with psychiatric disabilities who live and work together (Fairweather, 1969). Typically, lodges form real-world businesses to maintain themselves (e.g., janitorial services, bulk mailing, copy centers, or temp agencies). Sometimes, lodges hire non-disabled people who demonstrate expertise in areas needed to maintain the business. They may also seek professional help to serve as "consultants" to lodge members, to provide assistance in those psychiatric and rehabilitation strategies needed to help members manage their symptoms and disabilities.

The lodge program is built on several principles that clearly reflect the spirit of personal empowerment (Fairweather, 1969). These principles have been divided into two sets:

- those that help the consumer fill the role of lodge member (living and working with peers); and
- those that help the lodge develop norms which make it a thriving community (or what Fairweather called "a social subsystem").

People are more willing to embrace a role when they have a stake in it. In other words, living and working with

others has to satisfy what the person wants and needs in his or her life now. This means the person needs to have autonomy in his or her role within the lodge. At the minimum, a person's role needs to be voluntary. People cannot be court-ordered to a lodge or sent against their will. In addition, people need the right to self-determination: namely, the opportunity to decide for one's self how to meet his or her responsibilities in the lodge community.

It is the nature of interaction that there be some hierarchy among social roles. Some people need to be supervising others to make sure all needs of the lodge are met. Another principle of lodge programs is that all members have the opportunity to be promoted to leadership jobs and thereby experience the benefits, as well as the demands, of different roles throughout the hierarchy. At the same time, all roles within the lodge must be filled. In this way, the community is assured that all tasks of the lodge are covered.

There is an interesting contradiction between the goals of autonomy and the demands of operating a residential and work community. How does the lodge balance each person's right to self-determination with the community's need to get all its work done? The second set of principles suggests development of community norms that seek this balance. One of the major rules of the Fairweather Lodge is "Members are encouraged to do things as a group" (Fairweather, 1969). Proponents of the lodge program believe that its strength lies in sharing both good times and tough decisions among all members. Group discussion is central to the empowerment and personal growth experienced in this setting. Unfortunately, a second principle of the lodge recognizes that this group must be limited in size. The community can only serve a small number of people in order to meet their work and home needs satisfactorily. This can be a sobering thought for some lodge members; namely, that their community is closed to many others

like themselves who are also in need (Corrigan & Garman, 1997).

The success of the community occurs in a complicated balance between norms. On one hand, the norms of the program must correspond with those of the larger society in which the lodge finds itself. Basing lodge rules on those in the larger society makes sense because these are the rules with which community members are likely to already be familiar. For example, “respect privacy” and “do not steal” should be two familiar rules to most Americans and therefore be incorporated into the norms of lodges in the United States. The lodge also needs to develop norms that reflect the unique character of its community. For example, the prime rule, “Members are encouraged to do things as a group,” is not reflected in Western society as a whole. However, proponents of the lodge program believe this kind of norm is essential for the unique atmosphere needed to develop a community of living and working peers. In like manner, each community needs to consider as a group what other particular rules it will adopt to meet the individual needs of its members.

The Fountain House: A clubhouse for persons with mental illness. During the years after the end of World War II, many people were released from Rockland State Hospital, located outside of New York City, with no community connections. In order to survive, they would meet on the steps of the New York Public Library to provide one another with resources and support. Soon, the group gained notoriety and other persons released from Rockland joined them in this makeshift society they called WANA: We Are Not Alone. In 1948, the group bought a building through the generous donations of a Jewish women’s philanthropic group. The building had a fountain in the backyard; hence its name, Fountain House. It was built around a fundamental philosophy:

“Men and women with mental illness have the right to a life which includes access to meaningful, gainful employment; a decent place to live; a community of support; the opportunities for education and recreation offered by the communities in which they live; and the chance to be needed, wanted and expected somewhere everyday” (International Center for Clubhouse Development, 1948).

Several values characterize the clubhouse. In some ways, these principles overlap with the lodge model; in other ways, they reflect the special charm of social clubhouses (Macias, Barreira, Alden & Boyd, 2001). Persons belonging to the clubhouse are members rather than consumers. They have equal power with the professional staff hired to support clubhouse activities, not only in daily operations but also in decisions about budgetary issues. With membership comes responsibility. All members are expected to contribute to some aspect of the clubhouse’s operations. Clubhouses are designed so that each member is essential for efficient operation. The fully collaborative nature of staff and consumer leads to all members being considered co-providers.

Clubhouses are open every day of the year. Unlike mental health centers, which typically close for holidays, clubhouses are open for their members to celebrate. Clubhouses also provide a wide variety of opportunities, including housing, education, social support, recreation and vocational training and placement. Services are never pressed upon members. Rather, they are used as the individual sees fit. Clubhouses operate according to a work-ordered day with normal 9 to 5 schedules (Besancon & Zippel, 1995). Each day, members (consumers and staff alike) decide among a variety of work units that comprise the necessary tasks to keep the clubhouse running effectively. Work activities at Fountain House have included horticulture, thrift shop, snack bar and dining room, clerical work, education, and research. Participation in this kind of activity reacquaints members with

the demands of the work world as well as its many benefits.

4. Supported Housing and Employment

Even though lodge and clubhouse programs have many values that promote empowerment, they still require consumers to go outside their home “turf” to receive services. Programs of Assertive Community Treatment (PACT) turned the service world upside down (Bond, McGrew & Fekette, 1995; Mueser, Bond, Drake & Resnick, 1998; Stein & Test, 1980). Instead of demanding that consumers go out of their way to the offices of providers, why not bring services to the consumers where they need it, such as in their homes or anywhere that the consumers might deem necessary for resources and support? PACT proponents believe the entire range of services — medications, psychotherapy, skills training, money management and the rest — can be and should be provided in the person’s home or community. A variation of this idea is supported employment, where a job coach provides services alongside the consumer at his or her place of work (Bond, Drake, Mueser & Becker, 1997; Drake et al., 1999).

PACT and supported employment facilitate empowerment in several ways. First, these programs are consumer-centered. Services are defined by the needs of the consumer, not by the provider. Although this may seem obvious now, this value was revolutionary when first proposed. In the past, treatment plans reflected what was best for the consumer AND the provider. Hence, a person would not be referred to an independent housing program if it were outside the case manager’s district. A consumer would not begin competitive work until the agency had an available job coach. Consumer-centered services remind the provider that it is up to the agency to find the necessary resources and supports to help consumers achieve their goals on their timeline.

Having consumers as mental health providers yields several significant benefits for the individual consumer as well as for people with mental illness in general.

PACT and supported employment are also strengths-oriented (Rapp, 1998). This view differs from the disease model that dominates traditional services. Proponents of the disease viewpoint believe that people are defined by their symptoms and other weaknesses that need to be fixed through treatment. The strengths model recognizes that people are described by their skills, not their shortcomings. Awareness of these skills is essential; these are the tools that people use to accomplish their goals. Providers who are consumer-centered make interventions as convenient and efficient as possible. Hence, PACT is comprehensive and cross-sectional. That is to say, it provides services across all domains of need: housing, finances, family, health care, spiritual matters and recreation.

PACT and supported employment are also longitudinal. By this we mean that the needed service is provided by a single team as long as the person needs it. In the past, mental health providers used to have the bad habit of ending services at times not convenient for the consumer. Today, PACT and supported employment continue as the person changes homes or moves in and out of institutions. Sometimes, services are provided indefinitely. Mental health systems of the past had the unwise practice of discontinuing community services for those individuals who had to be hospitalized because of short-term psychiatric emergencies. Unfortunately, these people had to start over with a new team when released a few weeks later. The PACT and supported employment team continue to offer support and resources even while the person is hospitalized or involved in the criminal justice system (Bond, Drake, Mueser & Becker, 1997; Mueser, Bond, Drake & Resnick, 1998).

Effective PACT and supported employment is accessible and available. This means services are provided in places that are convenient to the consumer, typically in his or her home

or place of work. Moreover, service is provided at times that make sense to the consumer. The provider does not ask the person to stay home from work so that the provider may come to the consumer's apartment to discuss shopping. Instead, the provider comes in the evening when the person is home from work and has eaten dinner.

5. Consumers as Providers

What better way to influence the system that provides services than for people with mental illness to assume jobs as providers in these services? In this spirit, consumers have filled almost every conceivable position in the mental health system (Mowbray, Moxley, Jasper & Howell, 1997; Solomon & Draine, 2001). Consumers have become job coaches, they have worked on assertive community treatment teams and they have run support groups. Consumers have also worked at all the professional levels that comprise the treatment team, as psychiatrists, psychologists, social workers and psychiatric nurses. Several well-known consumer advocates have cut their teeth as mental health professionals. Daniel Fisher is a psychiatrist; Fred Frese is a psychologist. Each of these gentlemen has gone through more than 20 years of struggling with the psychiatric disabilities resulting from schizophrenia.

Having consumers as mental health providers yields several significant benefits for the individual consumer as well as for people with mental illness in general. At the broadest level, consumers as providers challenge stigmatizing notions about people with mental illness. Public understanding of consumers reaches beyond the simple idea that they are psychiatric diagnoses. Despite their disabilities — or perhaps because of them — people with mental illness are able to support peers with mental illness by providing them with knowledge about psychiatric symptoms, skills to deal with these symptoms and resources to meet their goals. These abilities chal-

lenge the notion that people with mental illness are incompetent.

Consumers assume roles that traditional providers frequently will not do or are not able to do well. Many jobs related to supported employment and programs of assertive community treatment require long hours and travel into places that are less than desirable. Most people are not willing to meet these challenges unless they have experienced the same struggles. There are some tasks that only consumers can provide. One of these is the "I've been there too" kind of support. Those in the throes of depression or anxiety receive immeasurable benefits by hearing from a peer who has been in the same situation, survived the challenge and thrived to become a mental health provider. There is one last aspect to consumers becoming providers which must be highlighted: *Providing help to others reaps significant benefits for the helper.* This is the principle of mutual help that is discussed more in the next section.

6. Self-Help, Mutual Assistance and Other Consumer-Operated Services

Consumer-operated services differ from the earlier service model in that they are entirely developed, operated and provided by and for people with mental illness (Davidson et al., 1999; Solomon & Draine, 2001). Consumer-operated services are not just another form of clinical treatment (Luke, Roberts & Rappaport, 1994). Clinical treatment reflects a medical model: People seek out services to resolve symptoms (Corrigan & Penn, 1997). Clinical treatment features a hierarchy between healer and person in clinical settings; healers have some special power that they use to help patients resolve problems. The relationship between healer and patient is expected to end when symptoms remit. Consumer-operated programs have been likened more to communities with life-long histories (Maton, Leventhal, Madara & Julien, 1989) or

to grassroots information and support systems (Meisen, Gleason & Embree, 1991). Mental illness may be the common experience that draws people to consumer-operated services. But unlike traditional clinical treatment, this is not where the impact of consumer-operated services ends. Consumer-operated services place an extraordinary value on peer support, hope and recovery (Van Tosh & Del Vecchio, 2000). Consumer-operated services seek to provide safe settings where a person can find the necessary understanding and recognition that society at large is not able to give. In the ideal, there is no hierarchy of roles in consumer-operated programs; members are peers benefiting from interactions with equals. There are no limits placed on the amount of time a person can be involved in a program. Depending on personal needs, some members come and go from consumer-operated programs, while others may stay connected for years (Durman, 1976; Luke et al., 1994).

Types of Consumer-Operated Services.

Three kinds of programs comprise the consumer-operated services: consumer-run drop-in centers; peer support programs; and education and advocacy programs.

Consumer-run drop-in programs provide an open venue for consumers to receive a variety of services as needed in a specific location that is open at set times during the day and week. Individuals participate in drop-in activities on a voluntary, at-will and non-coercive basis. Service components parallel the gamut of traditional mental health activities and may include assistance with entitlements, medication education, clothing, bus or transportation passes and moving.

Peer support programs are typically individual or group-based assistance and encouragement organized around a worldview or 12-step approach that is consistent with empowerment and recovery.

Peer support programs, like drop-in centers, may tackle a broad range of work, housing, health and relationship goals that are needed by participating consumers.

Education and advocacy programs operate under the belief that consumers with knowledge about mental illness and psychiatric services are best able to address their own disabilities as well as to fix what is wrong with the mental health system. Education and advocacy programs use well-defined curricula to teach consumers this kind of information, usually in short-term classroom settings. The education and advocacy program model also relies on peer support to accomplish its goals (Corrigan & Lundin, 2001).

7. Participatory Action Research

The purpose of research is to discover what kind of outcomes result from providing a specific intervention program (for example, Programs of Assertive Community Treatment) in a certain way (e.g., using a team of providers instead of individual case managers) with a specific group of consumers (e.g., persons with mental illness recently released from prison). Research is meant to answer questions about programs. Traditionally, this kind of research is completed by academic experts, people with many years of education leading up to a doctorate in social science or medicine and working as a professor in a university. There is widespread belief that social science requires many years of study in statistics and research methodology and can, hence, only be completed by these kinds of experts.

Many consumers believe that this kind of "scientist as expert" view actually causes problems of its own and diminishes empowerment (Rogers & Palmer-Erbs, 1994). They describe a "blame the victim" mentality that permeates much research. According to this mental-

This kind of research is only going to be accomplished when people with disabilities are full partners.

ity, traditional research shows how persons with serious mental illness lack skills, lack work histories, lack motivation, lack family ties, and so on (Rapp et al., 1993). It is these person-centered deficits that account for all the individual's problems and hence should be the focus of research and services.

This point may be better understood if we consider how research in other disabilities — blindness for example — has developed over time (Whyte, 1991). As the result of forceful input from persons who are blind, researchers realized that teaching people how to live with their impairment is not enough. We also need to change the environment so that those who are blind can get around more easily. Research in this area led to Braille in elevators, crosswalks that beep, and better use of dog guides. This kind of research is only going to be accomplished when people with disabilities are full partners.

Participatory Action Research (PAR) describes how researchers and consumers become partners in studying mental illness and appropriate treatment (Rogers & Palmer-Erbs, 1994). PAR calls for a significant change in the roles of consumers and professionals, calling for consumers to actively investigate research hypotheses themselves and enlist trained researchers as consultants to their projects. The goal of PAR is to advance research that supports the fundamental assertions of consumer empowerment. Instead of asking typical research questions (e.g., How does the consumer fit into society?), PAR examines questions such as: What must society provide in terms of resources and accommodations in order to enable the consumer to also be one of society's resources?

Participatory Action Research is no longer a pipe dream. Many federally funded research efforts have incorporated the priorities of PAR into their guidelines. For example, several large-scale projects funded by the U.S. Substance Abuse and

Mental Health Services Administration (SAMHSA) require a consumer advisory panel to have an active partnership in planning and implementing its research projects. As a result, most decisions that govern the projects are made through a sometimes tortuous exchange between the consumers on the project and the science investigators. The result is a research project that represents the best interests and insights of consumer empowerment.

SUMMARY

When President George W. Bush released the final report of the New Freedom Commission on Mental Health in 2003, the commission's charge was to evaluate the state of the American mental health system and propose a guiding vision for the years to come. Central to its message was the idea of empowerment; that a successful service system must rest on personal decision making by the individual who is to benefit from services. The commissioners also noted that evidence-based practices are essential for America to enjoy a high-quality care system. This article contains a review of seven evidence-based approaches promoting individual empowerment for consumers of mental health services. With the charge of the president's commission and the continuing research and development that its report will hopefully generate, empowerment and the greater achievement of life goals for people with mental illness will only blossom. **AR**

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SELF-DETERMINATION AND THE EMPOWERMENT OF PEOPLE WITH DISABILITIES

MICHAEL L. WEHMEYER, PH.D.



The usage note in the *American Heritage Dictionary of the English Language* (2000) states the following with regard to the word *empower*:

"Although it is a contemporary buzzword, the word *empower* is not new, having arisen in the mid-17th century with the legalistic meaning 'to invest with authority, authorize.' Shortly thereafter it began to be used with an infinitive in a more general way meaning 'to enable or permit.' Both of these uses survive today but have been overpowered by the word's use in politics and pop psychology. Its modern use originated in the civil rights movement, which sought political *empowerment* for its followers" (2000, pp. 586-587).

Leaving aside a discussion as to whether empowerment is merely a buzzword (when one is not empowered, it probably does not sound very much like a buzzword), it is worth noting the meaning shift or drift that has

occurred with use of the term since its 17th century origination and the current linkages between empowerment and issues of control over one's life. However, despite the *American Heritage Dictionary's* indication that the term's meaning has shifted, it remains less than convincing that the way in which many people use the term is not closer to the original sense of the term. The problem with that meaning with regard to people with disabilities is, of

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course, that in the end, when one has the power to invest someone else with authority, one also has the power, presumably, to withhold granting that authority. Power and control remain, fundamentally, with the granter in that circumstance. Similarly, the more current meaning, "to enable or permit," seems to offer two synonyms that, in the end, are not equally effective in solving the "granting authority" problem (*American Heritage Dictionary*, 2000). That is, the act of "permitting" implies authority on the part of one person to allow another to do something, or not. The meaning of empowerment (or more accurately, empower), "to enable," is, in my mind, closer to the sense of the term as used when associated with social movements, particularly the disability rights movement, which typically uses the term in reference to actions that "enhance the possibilities for people to control their lives" (Rappaport, 1981, p. 15). Enable

means "to supply with the means, knowledge, or opportunity; to make feasible or possible" (*American Heritage Dictionary*).

Consideration of what it means to empower someone with a disability is more than just a semantic exercise. Well-intentioned professionals across many disciplines mistake empowerment as something that someone grants or gives to someone else, to the end that the effort falls short of the standard of enhancing the possibilities for people to control their lives. There is a bit of a Catch 22 to issues pertaining to empowerment and professionals in rehabilitation, in that many such professionals genuinely want to do whatever they can to empower people with disabilities but, similarly, don't want to err in assuming that any ultimate authority to grant power or control lies within those very same people. The way out of this conundrum is through efforts to *enable* people with disabilities to exert control in their lives and, as a function of such actions, to become empowered to do so to a greater extent. As professionals in rehabilitation, the route to "enablement" is by providing opportunities and supports that promote and enhance the self-determination of people with disabilities.

That this is both an appropriate and important focus is illustrated in the findings of Congress from the 1992 Amendments to the Rehabilitation Act (and in the subsequent 1998 reauthorization), which state "disability is a natural part of the human experience and in no way diminishes the right of individuals to:

- a. live independently;
- b. enjoy self-determination;
- c. make choices;
- d. contribute to society;
- e. pursue meaningful careers; and
- f. enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society" (Rehabilitation Act of 1973, as amended).

The 1998 amendments to the Rehabilitation Act of 1973 strengthened and

emphasized the importance of self-determination by strengthening the role of informed choice in the rehabilitation process. Indeed, there is a national trend toward residential and vocational services that are delivered in a more consumer-driven manner (Callahan, Shumpert & Mast, 2002; Kilsby & Beyer, 2002; West, 1995). In the end, the intent of Congress in the Rehabilitation Act and the impact of the choice mandates will depend on the capacity of rehabilitation professionals to do business in such a way as to genuinely enable people with disabilities to become more self-determined.

WHAT IS SELF-DETERMINATION?

Put most simply, the self-determination construct refers to both the right and capacity of individuals to exert control over and direct their lives. The construct's use in reference to a right is grounded in its meaning referring to the political right of people or peoples to self-governance. Disability advocates and activists have stressed the inherent right of people with disabilities to assume responsibility for and control over their lives (Kennedy, 1996; Ward, 1996). In the 1990s, promoting and enhancing the self-determination of students with disabilities, particularly as a function of the transition planning process, became best practice (Wehmeyer, Agran & Hughes, 1998). These efforts focused primarily on enhancing student capacity to become self-determined and exert control in one's life by promoting goal setting, problem-solving, decision-making and self-advocacy skills; they also focused on efforts to promote opportunities for students to use these skills.

A variety of definitions of the construct have emerged from efforts in special education (see Wehmeyer, Abery, Mithaug & Stancliffe, 2003). Field, Martin, Miller, Ward and Wehmeyer (1998) summarized these various definitions of self-determination by stating that self-determined people apply "a combination of skills, knowledge and beliefs" that enable them "to engage in goal-directed, self-regulated,

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There is a growing body of evidence in the field of vocational rehabilitation (VR) that enhancing choice opportunities leads to better VR-related outcomes.

autonomous behavior. An understanding of one’s strengths and limitations together with a belief in oneself as capable and effective are essential in self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of successful adults in our society” (p. 2). Field et al. (1998) further delineated the common components of self-determined behavior identified across multiple self-determination models or frameworks. These include:

- a. awareness of personal preferences, interests, strengths and limitations;
- b. ability to
 - i. differentiate between wants and needs,
 - ii. make choices based on preferences, interests, wants and needs,
 - iii. consider multiple options and anticipate consequences for decisions,
 - iv. initiate and take action when needed,
 - v. evaluate decisions based on the outcomes of previous decisions and revise future decisions accordingly,
 - vi. set and work toward goals,
 - vii. regulate behavior,
 - viii. use communication skills such as negotiation, compromise and persuasion to reach goals, and
 - ix. assume responsibility for actions and decisions;
- c. skills for problem-solving;
- d. a striving for independence while recognizing interdependence with others;
- e. self-advocacy and self-evaluation skills;
- f. independent performance and adjustment skills,
- g. persistence;
- h. self-confidence;
- i. pride; and
- j. creativity.

IS SELF-DETERMINATION IMPORTANT FOR CONSUMERS OF VOCATIONAL REHABILITATION SERVICES?

There are several indicators to suggest that the answer to this question is “yes.”

First, as mentioned previously, promoting choice and self-determination is mandated by federal disability policy and legislation.

Second, people with disabilities have been unequivocal in their demands for enhanced self-determination (Kennedy, 1996; Ward, 1996).

Third, there is compelling evidence from the special education literature that enhanced self-determination leads to more positive adult outcomes, outcomes that are equally valued by the field of rehabilitation. Wehmeyer and Schwartz (1997) measured the self-determination status of 80 students with mild mental retardation or learning disabilities in their final year of high school and one year after high school. Students with higher self-determination scores were more likely to have expressed a preference to live outside the family home, have a savings or checking account, and be employed for pay. Eighty percent of students in the high self-determination group worked for pay one year after graduation, while only 43 percent of students in the low self-determination group did likewise. Among school-leavers who were employed, youths who were in the high self-determination group earned significantly more per hour (M=\$4.26) than their peers in the low self-determination group (M=\$1.93)(where “M” represents “mean.”)

Wehmeyer and Palmer (2003) conducted a second study, examining the adult status of 94 young people with cognitive disabilities (mental retardation or learning disability) one and three years after high school. These data were consistent with results from Wehmeyer and Schwartz (1997). One year after high school, students in the high self-determination group were disproportionately likely to have moved from where they were living during high school, and by the third year they were still disproportionately likely to live somewhere other than their high school home and were significantly more likely

to live independently. Young adults in the high self-determination group were more likely to maintain a bank account by year one, an outcome most likely attributable to the employment status of students in the two groups. Students in the high self-determination group were disproportionately likely to hold a job by the first-year follow-up, to be working either full- or part-time, and to have held a job or have received job training by year three. For those students across the complete sample who were employed, students scoring higher in self-determination made statistically significant advances in obtaining job benefits, including vacation and sick leave and health insurance, an outcome not shared by their peers in the low self-determination group. Overall, there was not a single area in which the low self-determination group fared more positively than the high self-determination group. German, Martin, Marshall and Sale (2000) found that instruction in self-determination could improve student goal setting and enhance participation in educational planning. Sowers and Powers (1995) showed that instruction on multiple components related to self-determination increased the participation and independence of students with severe disabilities in performing community activities.

Finally, there is a growing body of evidence in the field of vocational rehabilitation (VR) that enhancing choice opportunities leads to better VR-related outcomes. For example, Farley, Bolton and Parkerson (1992) evaluated the impact of strategies to enhance consumer choice and involvement in the VR process and found that consumers who were actively involved in VR planning had better vocational career development outcomes. Similarly, Hartnett, Collins and Tremblay (2002) compared costs, services received and outcomes achieved between one group served through the typical VR

system and another group involved in a Consumer Choice Demonstration Project in Vermont. They found that the Choice group was two times more likely to have completed rehabilitation and that their mean income was 2.7 times higher.

PROMOTING THE SELF-DETERMINATION OF VR CONSUMERS

If the means by which rehabilitation professionals contribute to the empowerment of VR consumers with disabilities is to provide opportunities and supports to enable people to become more self-determined, what are some of the specific strategies that rehabilitation professionals can use to achieve this outcome? It is tempting to take a "skills remediation" approach to "teach" VR consumers skills they do not have that would enhance self-determination. However, it is important that adults with disabilities not be treated as if they are eternal students, which equates too closely with being eternal children. Thus, it is important that efforts to promote skills such as career and job goal setting, decision making, problem solving and self-management be done within a context in which the consumer is in charge of the process. Like other disability systems, traditional vocational services tend to have been "other-directed." That is, in too many cases, decisions about jobs or careers are made *for* people with disabilities instead of *by* people with disabilities. There are many reasons for this, including the fact that many customers of VR services simply have not had the experiences and opportunities necessary to enable them to be more self-directed. VR counselors may experience frustration because they want to support individuals to make their own decisions or take greater control and responsibility for their career advancement, yet the individual's limited capacity and experiences are barriers to those outcomes.

Under the auspices of a special demonstration project of the Reha-

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TABLE 1. PHASE 1, SELF-DETERMINED CAREER DEVELOPMENT MODEL

PROBLEM TO SOLVE: WHAT ARE MY CAREER AND JOB GOALS?

QUESTION 1: <i>What career and job do I want?</i>	EMPLOYMENT SUPPORTS
<p>OBJECTIVES OF VR COUNSELING:</p> <ul style="list-style-type: none"> · Enable person to identify career/job preferences/interests/beliefs/values. · Enable person to identify strengths and needs related to jobs/careers. · Enable and support person to prioritize career and jobs options and select preferred option(s). 	<ul style="list-style-type: none"> · Awareness Training. · Self-Assess Job or Career Preferences/Abilities. · Career and Job Exploration.
<p>QUESTION 2: <i>What do I know about it now?</i></p> <p>OBJECTIVES OF VR COUNSELING:</p> <ul style="list-style-type: none"> · Enable person to identify his or her current status in relation to prioritized job and career option(s). · Enable person to identify knowledge/skills/needs of job/career option. · Assist person to gather information about opportunities and barriers in his or her environments pertaining to prioritized job and career option(s). 	<ul style="list-style-type: none"> · Job Shadowing and Sampling. · Organizational Skills Training. · Problem Solving Instruction. · Choice-Making Instruction. · Decision-Making Instruction. · Goal-Setting Instruction.
<p>QUESTION 3: <i>What must change for me to get the job and career I want?</i></p> <p>OBJECTIVES OF VR COUNSELING:</p> <ul style="list-style-type: none"> · Support person to prioritize needs related to job/career preference(s). · Enable person to choose primary need and decide if action needs to be focused toward capacity building, modifying the environment or both. 	
<p>QUESTION 4: <i>What can I do to make this happen?</i></p> <p>OBJECTIVES OF VR COUNSELING:</p> <ul style="list-style-type: none"> · Teach person to state his or her career/employment goals/objectives. 	

Adapted from Wehmeyer, Lattimore et al. (2003).

bilitation Services Administration, we at the University of Kansas Beach Center on Disability have been involved in the development and evaluation of a model for use with adults specific to the career decision-making and job-placement processes of VR services in the state of Kansas (Wehmeyer, Lattimore et al., in press). This model — the Self-Determined Career Development Model — is designed to enable VR consumers to engage in a self-regulated problem-solving and goal-setting process leading to job placement. The remainder of this article describes this model as an example of how to promote self-

determination and thereby empower people with disabilities through the rehabilitation process. The Self-Determined Career Development Model evaluated in this article was based on the team’s previous work with a model of teaching for students with disabilities. It is simplest to describe the adult version of this model for VR by first describing the school-based model. The Self-Determined Learning Model of Instruction (SDLMI) was designed to enable educators to teach students to self-direct the instructional process and, at the same time, enhance their self-determination (Mithaug, Wehmeyer, Agran, Martin & Palmer,

1998; Wehmeyer, Palmer, Agran, Mithaug & Martin 2000). The SDLMI is based on the component elements of self-determination (Wehmeyer, 1999, 2001), the process of self-regulated problem solving and on research on student-directed learning. It is appropriate for students with and without disabilities across multiple content areas, and it enables teachers to engage students in their educational programs by increasing opportunities to self-direct learning. Implementation of the SDLMI consists of a three-phase process. Each phase presents a problem the student must solve by posing and answering a series of four Student Questions (per phase), which students

TABLE 2. PHASE 2, SELF-DETERMINED CAREER DEVELOPMENT MODEL
PROBLEM TO SOLVE: WHAT IS MY PLAN

QUESTION 1: <i>What actions can I take to reach my career or employment goal?</i>	EMPLOYMENT SUPPORTS
OBJECTIVES OF VR COUNSELING: <ul style="list-style-type: none"> · Enable person to identify alternatives to achieve career/employment goal. · Assist person to gather information on consequences of alternatives. · Enable person to select best action alternatives. 	<ul style="list-style-type: none"> · Exploration of Community Resource/Support. · Problem Solving Instruction. · Self-Scheduling Training.
QUESTION 2: <i>What could keep me from taking action?</i> OBJECTIVES OF VR COUNSELING: <ul style="list-style-type: none"> · Support person to identify barriers to implementing action alternatives. · Support person to identify actions to remove barriers. 	<ul style="list-style-type: none"> · Self-Instruction Training. · Picture-Cue Training. · Decision-Making Instruction.
QUESTION 3: <i>What can I do to remove these barriers?</i> OBJECTIVES OF VR COUNSELING: <ul style="list-style-type: none"> · Assist person in identifying appropriate employment supports to implement selected action alternative. · Teach person knowledge/skills needed to implement selected supports. 	<ul style="list-style-type: none"> · Self-Advocacy Instruction. · Assertiveness Training.
QUESTION 4: <i>When will I take action?</i> OBJECTIVES OF VR COUNSELING: <ul style="list-style-type: none"> · Enable person to determine schedule for action plan to remove barriers and implement supports. · Support and enable person to implement the action plan. · Enable person to self-monitor his or her progress. 	<ul style="list-style-type: none"> · Self-Monitoring Instruction.

Adapted from Wehmeyer, Lattimore et al. (2003).

learn, modify to make their own and apply to reach self-selected goals. Each question is linked to a set of Teacher Objectives. Each instructional phase includes Educational Supports identified for teachers to use to enable students to self-direct learning in a variety of areas including, but not limited to, problem solving, choice making, goal development, self-evaluation and self-monitoring.

The problem to solve in Phase 1 is "What is my goal?" In Phase 2, the problem to be solved is "What is my action plan?" and in Phase 3, the problem is "What have I learned?" The Student Questions direct the student through a problem-solving

sequence in each instructional phase. The solutions to the problem in each phase lead to the problem-solving sequence in the next phase. Question construction was based on theory in the problem-solving and self-regulation literature that suggests there is a "means-ends" problem-solving sequence that must be followed for any person's actions to produce results to satisfy his or her needs and interests. Teachers implementing the model teach students to solve a sequence of problems by constructing a "means-ends chain," a causal sequence that moves them from where they are to where they want to be, a goal state (Mithaug, et al., 1998).

By answering the questions in this sequence, students are supported to regulate their own problem solving by setting goals to meet needs, constructing plans to meet goals, and adjusting actions to complete plans. The questions differ from phase to phase, but represent identical steps in the problem-solving sequence. That is, students answering the questions must:

- identify the problem,
- identify potential solutions to the problem,
- identify barriers to solving the problem, and
- identify consequences of each solution.

TABLE 3. PHASE 3, SELF-DETERMINED CAREER DEVELOPMENT MODEL
PROBLEM TO SOLVE: WHAT HAVE I ACHIEVED?

<p>QUESTION 1: <i>What actions have I taken?</i></p> <p>OBJECTIVES OF VR COUNSELING:</p> <ul style="list-style-type: none"> · Enable person to self-evaluate and articulate progress toward goal. 	<p>EMPLOYMENT SUPPORTS</p> <ul style="list-style-type: none"> · Self-Evaluation Instruction.
<p>QUESTION 2: <i>What barriers have been removed?</i></p> <p>OBJECTIVES OF VR COUNSELING:</p> <ul style="list-style-type: none"> · Assist person to compare progress with his or her desired outcomes. 	
<p>QUESTION 3: <i>What has changed to enable me to get the job and career I want?</i></p> <p>OBJECTIVES OF VR COUNSELING:</p> <ul style="list-style-type: none"> · Support person to re-evaluate goal if progress is insufficient. · Assist person to decide if goal remains the same or changes. · Collaborate with person to identify if the action plan is adequate or inadequate given revised or retained goal. · Assist person to change action plan if necessary. 	
<p>QUESTION 4: <i>Have I achieved what I want to achieve?</i></p> <p>OBJECTIVES OF VR COUNSELING:</p> <ul style="list-style-type: none"> · Enable person to decide if progress is adequate, inadequate, or if goal has been achieved. · If this goal has been achieved, enable person to decide if a different goal is needed to achieve his or her employment or career goals. 	

Adapted from Wehmeyer, Lattimore et al. (2003).

These steps are the basic steps in any problem-solving process and they form the means-end problem-solving sequence represented by the Student Questions in each phase. The first time a teacher uses the model with a student, the initial step in the process is to read each question with or to the student, discuss what the question means and then, as needed, change the wording to enable that student to better understand the intent. In wording changes, the problem-solving intent of the question must remain intact. Going through this process several times as the student progresses through the model should result in a set of questions that a student accepts as his or her own.

The Teacher Objectives within the model provide suggestions for teachers to enable and support students to work through the Student Questions by scaffolding instruction¹, using direct teaching strategies, or collaborating with students to determine the best strategies to achieve goals. The Educational Supports are educational and instructional activities to enable teachers to support students' efforts to answer questions. The emphasis in the model on the use of educational supports that are student-directed provides another means of teaching students to support themselves.

By using the Student Questions, students learn a self-regulated problem-solving strategy to use in goal attainment. Concurrently, teaching stu-

dents to use self-directed learning strategies provides skills that enable them to begin to become the causal agent in their lives.

The Self-Determined Career Development Model is equivalent to the SDLMI, except that it has been modified for use to support adults and it is specific to the career decision-making process. The three phases of the model are depicted in Tables 1, 2 and 3. The problem to solve in Phase 1 is "What are my career and job goals?" Within all three phases, supports focus upon job and career issues. Objectives have been reframed from teacher objectives to VR counselor or other VR personnel objectives. Supporting the VR consumer to answer each of the questions in Phase 1 leads to the second

phase, where the problem to solve is "What is my plan?" The problem in the final phase, Phase 3, is "What have I achieved?"

Wehmeyer, Lattimore et al. (2003) conducted a pilot evaluation of the career development model using a single-subject research design with six VR consumers identified by a counselor as needing more support with career decision making than was traditionally available in the VR system. Within this pilot evaluation, all participants were able to set career and job-specific goals, to assist in the design and implementation of an action plan to achieve those goals and to self-monitor and evaluate their progress toward the goals. Five of the six par-

ticipants showed progress toward achieving that self-set goal. All participants were able to engage with the facilitator to address questions in the model and to self-set an employment or job-related goal. The VR counselor who referred participants to this pilot evaluation conducted an informal assessment in consumer satisfaction. All except one participant indicated that they had benefited from their participation in the process. Perhaps the most suggestive indicator of the potential for the process to empower people with disabilities involved one woman who made considerable progress toward her goal and, after nine years of unemployment, obtained a job shortly after her involvement with the model. This per-

son expressed her satisfaction with her participation in the process and mentioned her improved confidence to the facilitator. She was, we suggest, empowered not by the professionals with whom she worked but by the skills and positive attitudes she gained by her use of the model. **AR**

NOTE

1. Instructional scaffolding is the provision of sufficient supports to promote learning when concepts and skills are being first introduced to students. Retrieved July 23, 2004, from http://encyclopedia.thefreedictionary.com/Instructional_scaffolds.

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SLAYING DRAGONS

BUILDING
SELF-CONFIDENCE
AND
RAISING
EXPECTATIONS
THROUGH
ORIENTATION
CENTER
TRAINING

SANDY TIGGES, PH.D.



Saint George and the Dragon, Raffaello Sanzio (1493-1530)

In his 1919 fable, "The 51st Dragon," Heywood Broun describes the exploits of Gawaine, a young student in knight school who is so timid and fearful that he is in danger of being expelled. Instead, the school's headmaster decides to take Gawaine under his wing and train him to slay the countless dragons plaguing the countryside that year. In preparation, Gawaine studies all about dragons and their habits, and he practices beheading paper and wooden ones on the practice field.

When the faculty feels he is ready to confront real dragons, Gawaine is given a diploma and a new battle-ax. The headmaster calls him to his office for a few words of advice: "Here you have learned the theories of life but, after all, life is not a matter of theories. Life is a matter of facts. It calls on the young and the old alike to face these facts, even though they are sometimes unpleasant. Your problem, for example, is to slay dragons." Unconvinced, the whimpering Gawaine asks for an enchanted cap to make himself invisible. The headmaster offers him something better: a magic word. All Gawaine has to do is say "rumplesnitz" and he can lop off the heads of dragons easily and fearlessly.

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The magic word works, at least for the first 49 dragons. Gawaine grows so brave that he even slays one with his right hand tied behind his back. He becomes so confident that, at night, he engages in long drinking bouts at the village tavern. On the day he confronts his fiftieth dragon, his mind has become so sluggish that he cannot remember the magic word. As the beast charges, the word flashes into his mind, but he has no time to utter it before swinging his battle-ax and chopping off the dragon's head.

Puzzled, Gawaine goes to the headmaster's office for an explanation. The headmaster laughs, believing that Gawaine has finally figured out that his own bravery and not the word rumplesnitz is responsible for his success: "It wasn't magic in a literal sense, but it was much more wonderful than that. The word gave you confidence. It took away your fears. If I hadn't told you that, you might have been killed the very first time. It was your battle-ax that did the trick."

Convinced that Gawaine just needs to kill another couple of dragons to get his confidence back, the headmaster drags him out of bed and into the forest the next morning and shoves him into a thicket where a small dragon is hiding. But Gawaine never returns. All that is later found of him are his medals.

Like the knight school's headmaster, we at the Iowa Department for the Blind's Adult Orientation and Adjustment Center give students magic words by which to live: "It's OK to be blind." Unlike those of the knight school headmaster, however, these words do not disguise hollow confidence and insufficient preparation. Instead, we back them with effective blindness training based on an approach that will give students a solid foundation in the skills, positive attitude and self-confidence they need to slay the many dragons

they will encounter as they strive to live independently and work competitively.

We use the words, "It's OK to be blind," to help students to progress through the three stages of adjustment to their blindness: dependence, rebellion and interdependence. Like Gawaine when he first began his knight school training, students enter the center with a great many insecurities, fears and low expectations, ranging from being afraid to cross the street alone to worrying about ever holding a job, having a family or being accepted socially. They will often accept more help than necessary and will avoid such "dragons" as going up and down stairs and crossing streets alone. Once they have overcome some of these fears and have slain a few dragons of their own, they begin to gain confidence and to realize that they can get about safely and efficiently and perform day-to-day living activities competently. Proud of their accomplishments, they often assert their independence by rebelliously swinging their battle-axes against any sighted person who might offer assistance. When students reach the end of their training, however, they see that the magic words take on the substance of truth, reinforced with the skills and self-confidence they need to slay any dragon they may ever encounter. They come to understand the natural interdependence that exists in society and begin to view an offer of help not as an insult but as an opportunity to educate.

The training we provide at the orientation center is based on a positive philosophy of blindness. In fact, this philosophy is the foundation for all of the Department for the Blind programs, including Vocational Rehabilitation, Independent Living, Transition, the Business Enterprises Program and the Library for the Blind and Physically Handicapped. The department is committed to the belief that center training must be an integral part of the rehabilitation process, for re-

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habilitation can only be truly achieved when consumers have reached their fullest potential in personal independence, employment and integration into the community. This approach is powerful, because it gives blind people control over their own lives as well as responsibility for their own successes and failures. This philosophy further contends that the real problem of blindness is not the physical loss of eyesight but rather society's misconceptions about it.

The majority of orientation centers in this country base their training on the notion that the individual who has become blind is "broken" and therefore must be "fixed," both physically and psychologically. The training they provide is based upon the beliefs that the problems of blindness are inherent in the blindness itself, that blindness imposes upon a person severe limitations that cannot be overcome, that visual techniques are intrinsically better than non-visual ones and that the degree of one's success is inextricably tied to the degree of one's visual acuity. Nurses and a psychologist are often on staff, and emphasis is placed on the teaching of skills, avoiding blindness techniques as much as possible and maximizing residual vision through the use of low vision aids.¹

The training we provide at the Iowa center, on the other hand, is successful because we recognize that the problems of blindness stem not only from the blindness itself but, again, also from public misconceptions about its true nature. Center students must not only learn the blindness skills needed to cope with the physical loss of eyesight, but they must also adopt new positive attitudinal concepts to replace the stereotypes that both they and society accept about blindness. To accomplish these goals, students receive training that has four objectives:

- Learn efficient and effective blindness techniques.
- Develop self-confidence and a positive attitude about blindness.
- Learn how to deal with public misconceptions about blindness, including those of family, friends and employers.
- Develop strong work habits and appropriate social skills.

TRAINING IN EFFICIENT AND EFFECTIVE BLINDNESS TECHNIQUES

To learn the skills they need to function competently, efficiently and comfortably, our students take eight hours of classes each day covering home and personal management, cane travel, communications and industrial arts. They learn non-visual techniques for cooking, cleaning, doing laundry and sewing. They learn to use a long white fiberglass cane to go up and down stairs, walk along sidewalks, cross busy streets and take public transportation to wherever they wish to go. They practice reading Braille and writing it with a slate and stylus, and they become acquainted with such assistive technology as computers equipped with speech synthesizers. They become comfortable with tactile measuring devices and power tools, and then they choose a project of their own that could involve woodworking, metalworking, welding or engine repair.

The training provided in each of these classes is rooted in the structured-discovery method of instruction. First developed to provide more effective instruction in the area of independent cane travel to blind persons, this approach has been proven to be superior to the guided learning approach used by traditional orientation and mobility instructors, who themselves are usually sighted persons.¹ In guided learning — commonly called route or point-to-point travel — the instructor continually provides very specific instructions and feedback while closely monitoring the student visually. Teachers

place strong emphasis on rote learning, ensuring safety and maximizing the use of residual vision. As a result, students do not develop the ability to generalize what they have learned and become too dependent on the instructor for help. Students are not expected to solve the problems they encounter independently or to apply what they have learned in one lesson to another.

The structured-discovery approach to travel training, on the other hand, is based upon the concept of training teachers of the blind to teach their students the same non-visual techniques that have proven to be most successful by blind persons. Cane-travel students are first given specific instructions that will allow them to master such basic techniques as holding and arcing the cane. The focus then quickly shifts to generalized instruction that emphasizes problem solving by providing the students with only minimal information, forcing them to rely upon themselves to explore their environment and gather and process the information they need to move about safely, freely and efficiently. Through this method, students learn more, retain it better and develop greater confidence in their own ability to travel independently.

Through the implementation of the structured-discovery method of teaching, the center emphasizes the use of alternative techniques of blindness, high expectations and the development of self-confidence and problem-solving skills. Blind students with residual vision and sighted students training to be instructors receive lessons under sleepshades, or blindfolds, from instructors who are either blind or who have also received intensive blindness training under sleepshades. Students are encouraged to rely upon their own ingenuity when they encounter a new problem or situation instead of turning repeatedly to the instructor for guidance and reassurance. After being taught a basic set of tech-

niques, they are asked to experiment, explore, solve problems and apply what they have learned in one project to another as they move through a progressive series of more and more challenging activities. Once shown how to boil and drain pasta for one recipe, for example, they are expected to figure out how to apply that training to the cooking of not only pasta but of any food that must be boiled and drained. As a result, they develop confidence in their own ability to solve problems and to use techniques that will be effective no matter what level of vision they have.

DEVELOPING SELF-CONFIDENCE AND A POSITIVE ATTITUDE ABOUT BLINDNESS

Through learning and practicing their problem-solving skills, students develop confidence in themselves and a more positive attitude about their blindness. As a result, they raise the expectations they hold about their own capabilities, leading to vocational goals that are more fulfilling and more likely to be achieved. The learning of skills and the development of self-confidence and a positive attitude are inextricably intertwined. A student who walks around the block alone for the first time becomes eager not only to advance to crossing streets but also to take his or her children to the park after completing the center's training program.

Developing self-confidence and a positive attitude about blindness are critical to a student's progress. Without self-confidence, students will not use the blindness skills they have learned, and without a positive attitude they will cling to the negative misconceptions and stereotypes about blindness. The vast majority of students begin their training with very negative attitudes about their vision loss. Often, many of them sat at home for years — cared for by their friends and families — rather than admit that they are blind, especially if they still have some remaining vision. Some-

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Students must learn that they and not their families, friends or society as a whole should control their attitude about themselves and their blindness.

times they will refuse to recognize that blindness has had any detrimental effect on their lives, even though they no longer read, drive, work, go out or take care of their homes. Many believe that the adjustments they have made — limited as they are — are the best that can be made under the circumstances. Others look for a quick fix, usually through technology, so that they can ignore the devastating effects blindness has had on their lives. Lacking self-confidence, they avoid taking risks because they fear failure and do not expect success.

Self-confidence is a difficult concept to define. Self-confident people have positive, yet realistic, views of themselves and their situations. They trust their own abilities, have a general sense of control in their lives and believe that, within reason, they will be able to do what they wish, plan and expect. They take risks and remain positive even when they fail. Because they accept themselves, they do not feel the need to conform just to be accepted by others.

Adult students at our center have defined self-confidence in a variety of ways, as evidenced in a group discussion held on September 15, 2003. One student said that it is what allows you to walk instead of crawl through life. Another said that self-confidence is knowing that you are capable of doing things with dignity, like taking public transportation and going through a buffet line without a mishap. A third said that it is what allows you to participate fully in school, work and the other things in life. A fourth student put it best: "You know you have self-confidence when you can trust yourself to figure out how to overcome successfully the fears and challenges you must face every day."²

The development of self-confidence and a positive attitude about blindness are linked. Students must learn that they and not their families, friends or society as a whole should control their attitude about themselves and their blindness. In his

1982 book, *Strengthening Your Grip*, Charles Swindoll described the importance of attitude this way:

"The longer I live, the more I realize the impact of attitude on life. Attitude, to me, is more important than the past, than education, than money, than circumstances, than failure, than successes, than what other people think or say or do. It is more important than appearance, giftedness or skill. It will make or break a company, a church, a home. The remarkable thing is we have a choice every day regarding the attitude we will embrace for that day. We cannot change our past. We cannot change the fact that people will act in a certain way. We cannot change the inevitable. The only thing we can do is play on the one string we have, and that is our attitude. I am convinced that life is 10 percent what happens to me and 90 percent how I react to it. And so it is for you ... we are in charge of our attitude!" (p. 126).

The development of self-confidence and a positive attitude about blindness are the focus of every class in the center. This process is a lengthy one, because it requires students to make a 180-degree turnaround in their attitude. For this reason, students train in the center for an average of six months. They must come to trust the teachers who are demanding so much of them, and teachers must learn to gauge the right levels of sensitivity, encouragement, prodding and confrontation that will help each student achieve this objective.

The story of Janice is typical. Throughout her training, she struggled with the notion that she could become competent as a blind person and as a result had to be told constantly to keep her sleepshades down. For their final cooking project — a seven-course dinner — students are expected to write their menus and recipes in Braille, take the city bus to the grocery store, purchase their groceries from lists they have written in Braille, and prepare and serve the meal for their families and friends. As she confronted this dragon,

a tearful Janice became paralyzed with fear and threatened to pack her bags and go home. Letting her avoid this dragon was not an option, since it would undermine any self-confidence she had acquired and make it easier for her to hide from the next dragons she would inevitably encounter. Reasoning, encouragement, and prodding had no effect on her. Finally, taking the risk that she might run, as the program administrator I resorted to confrontation and called her a quitter. At first she was angry, but after thinking about it for awhile she decided that she had to prove me wrong. She unpacked her bags and successfully went to the store, bought her groceries and prepared and served a wonderful dinner to almost 50 people.

A variety of center activities help students build self-confidence and a positive attitude about their blindness. We tell students that "a class is a class is a class" — that everything they do while at the center, day and night, contributes to their training. We expose them to many ordinary experiences that they thought no longer possible, like grilling steaks, shopping, going to a museum or play, bowling, camping, hiking and canoeing. Just as important as formal classes are their walks to a local restaurant for dinner and their long conversations in the evening about their blindness, fears and plans. Veteran students give tours to prospective students and serve as mentors to new ones. By participating in speaking engagements at schools, clubs and service groups, students become comfortable talking about their blindness and develop the self-confidence they need to educate the public.

In a discussion group we call the "Business of Blindness," we deal directly with the subjects of our philosophy and of skill and attitude development. An essential part of center training, the group discussion provides students with an open environment where they can talk about their hopes, fears and problems and where they can challenge the prevail-

ing negative myths about blindness and the devastating impact these myths can have on their lives. "Business class," as one student put it, is "the glue that holds everything together."² Most important, it is where they will come to accept their blindness and truly believe those magic words: "It's OK to be blind."

As the center's program administrator, I serve as facilitator for the class. I liken my role to that of an orchestra conductor, but sometimes I feel more like I'm sitting on the lid of a pot ready to boil over. I must maintain an atmosphere of openness and respect so that students feel comfortable talking freely and sharing some of their most intimate feelings with each other. Through questions, comments and active listening, I guide the discussion of that day's topic. My goal is not to give them the "right answer" but to teach them how to discover it for themselves. After all, when they complete their center training, they must be able to solve similar problems on their own.

To achieve this goal and maintain interest, I use a variety of formats and media. I invite competent blind persons to talk about their jobs and the effect center training has had on their lives. We watch movies and go to plays featuring blind characters and we read articles and short stories that I have gathered from magazines, journals, newspapers and the Internet. To expose students to a variety of blindness techniques for reading, I read to them in Braille, use readers and play cassette tapes.

The subjects we discuss come from a variety of sources. I maintain a large outline of resources and am always on the lookout for new items to add to it. While I try to plan ahead, a topic may come up that needs to be discussed immediately, such as a student's negative encounter with a sighted family member. We may have an expert explain Social Security incentives or a blind person talk about consumer organizations. Each October, we talk about Iowa's White

Just

as important

as formal classes

are their walks to a

local restaurant for

dinner and their long

conversations in the

evening about their

blindness, fears

and plans.

Our students are often surprised to learn that their own behavior can perpetuate or help dispel these myths.

Cane Law and the effect of similar legislation on their lives. We explore the purpose of center training so students will have a better understanding of the program and their involvement in it.

Gradually, students come to understand that once they have developed self-confidence, a positive attitude and good blindness skills, the real problem of blindness is not the loss of vision but, again, the misconceptions both they and the public hold about it. Blindness is no longer the controlling factor in their lives, and they begin to make important life decisions based not on it but on their interests, talents and abilities. Instead of being ashamed of their vision loss and the blindness skills that represent it, they view their blindness as another one of their personal characteristics, like their height, their age or the color of their hair.

DEALING WITH PUBLIC MISCONCEPTIONS ABOUT BLINDNESS

As students begin to learn effective and efficient blindness skills, develop self-confidence and overcome their own misconceptions about their blindness, they become frustrated by the negative treatment they receive from family members, friends and the general public. They grow angry when their spouses do not let them go down the basement stairs to do the laundry, a friend asks them not to take their cane on an outing or a waitress speaks to their companions rather than directly to them. Students come to recognize that there is not only a need to change these notions and their manifestations but that they share in the responsibility to help bring that change about.

In the center, we provide students with a variety of ways to learn how to deal appropriately with negative attitudes and reactions toward their blindness. In Business Class, we explore the origins of these misconceptions and talk about the best ways to deal with them. Our stu-

dents are often surprised to learn that their own behavior can perpetuate or help dispel these myths. We encourage family members to visit and sometimes even to attend classes under sleepshades. Giving tours of the center and participating in speaking engagements gives students opportunities to practice educating the public about their blindness. Training is frequently provided in such public settings as malls, restaurants and parks so that students will become skilled at handling negative public reactions to their blindness.

The ability to cope with these uncomfortable situations tactfully is critical to future success in job interviews and in workplace situations. Most of the students who come to the center are vocational rehabilitation consumers of the Iowa Department for the Blind and will either go to school or to work upon completion of their training. At least twice a year we hold a "Job-Seeking Skills Seminar" for students to explore careers that meet their talents, interests and abilities. They also learn techniques for dealing appropriately with blindness issues in the resume, in the job interview and on the job itself.

THE DEVELOPMENT OF STRONG WORK HABITS AND APPROPRIATE SOCIAL SKILLS

Many students come to the center with low expectations about themselves and what they will be able to accomplish as a blind person. Lacking self-confidence, they sometimes avoid the risk of failure by procrastinating, getting too involved in the problems of other students or refusing to try at all. Burdened by the low expectations of their families and teachers, students who have been blind since an early age have often not been expected to support themselves at all and so were never taught the strong work habits and socialization skills necessary for them to become fully integrated into the lives of their families, workplaces and communities. Unless they receive training that raises their expectations,

students will leave the center only to live on the edge of life, going through college with few or no friends, surviving on Supplemental Security Income or Social Security Disability Insurance, and unable to develop the social contacts so important for success in the workplace.

Center training helps students build their expectations in a variety of ways. We constantly remind them, both subtly and overtly, that they will not just work but that they will do so successfully and at their fullest potential. We treat them like adults, giving them keys to their own private rooms and to the building that houses the center. We teach them how to manage their own budgets and medications and to contact staff that live in the building only for emergencies. We expect them to attend their classes on time and to do their best in them.

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s o -

When necessary,
we teach them such
social skills as

table etiquette, ballroom dancing and communicating in social situations. Fashion, makeup, hair styles and other aspects of grooming may also be covered.

We also raise expectations for students through what we call “the three have-to’s” of the orientation center. In order to participate in training, students must agree to take all of the classes, wear sleepshades if they have any residual vision and carry their canes at all times. Students who do not agree to these requirements can choose from other training options, such as individual and group training in their home communities or attendance at another orientation center that they feel better meets their needs. These have-to’s are designed to help students confront and overcome the biggest dragons they face as a result of their blindness: the fear of injury, the fear of failure and the

fear of being identified by others as blind. If students are not given opportunities to overcome their deepest fears, they will never believe they can and they will suffer the fate of Gawaine — being eaten by a small dragon that leaves only their meaningless medals behind.

Students are required to take all of the classes. Orientation center training is like a jigsaw puzzle — the pieces must all be in place before the whole picture can be seen. Not taking a class is like losing one of the puzzle pieces and therefore losing the total effect of the training. If students were allowed to pick their classes, they would choose the

Center

training

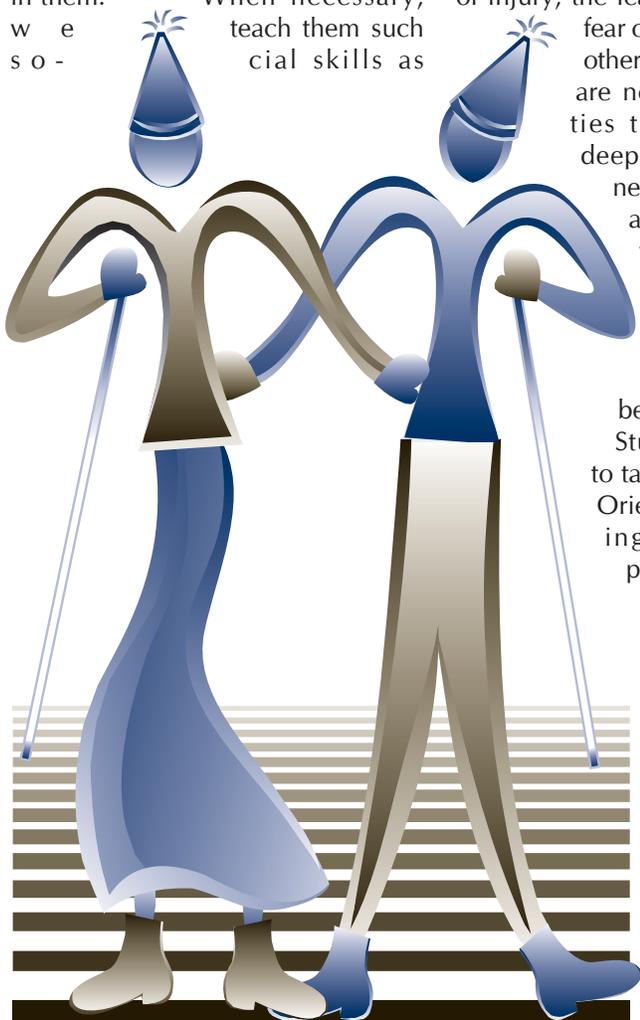
helps students

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"safe" ones, like Braille and computer. They would avoid the classes where they fear injury, like burning their hands on a hot stove, cutting off their fingers with a power saw or losing their lives to a speeding car. Students receive individualized instruction within each class to meet their needs. A young blind man who has never been in the kitchen must learn both how to cook and how to use the blindness techniques for cooking. A newly-blind woman who has prepared meals for her family for years, on the other hand, needs only to learn the relevant blindness skills. A diabetic student who has been sedentary for years may need frequent rest periods as he builds up his stamina.

To help dispel the "can't see, can't do" fallacy, students who have any residual vision must receive their training under sleepshades. In order to determine the effectiveness and efficiency of the blindness techniques they are learning, students must practice them constantly under sleepshades until these skills become habitual. When they take their sleepshades off, they can then combine the non-visual techniques they have mastered with visual ones to their greatest efficiency. They will also come to understand that the problems faced by the partially and totally blind do not differ significantly. Without the use of sleepshades, they will constantly want to rely on and attribute any successes they may have to their remaining vision, no matter how poor and inefficient it may be. Those students who have the most success are the ones who have the maturity to see the relevance of sleepshade training to their lives, come to understand that the degree of their success is not contingent on the degree of their vision and replace "can't see, can't do" with "I can do it — I just have to figure out how."

Finally, students must carry the long white fiberglass cane — better known as the Iowa cane — at all times. To become proficient travelers, students must constantly practice using their canes. By doing so, they

also become desensitized to public reactions to their blindness and to being identified as a blind person. The cane then becomes for them both a tool for safe travel and a symbol of pride and independence. Because they can be easily hidden away, folding canes and cane holsters are not permitted.

Students do not receive training at the center for any fixed length of time. While the average stay is six to eight months, some students stay fewer months and some stay more. Students themselves are responsible for evaluating their progress and for determining when their training is complete. As the center's program administrator, I meet with students and their vocational rehabilitation counselors at critical times during their stay to discuss their progress and goals and to determine if any modifications in their program need to be made. Students usually decide to leave the center when they can competently and efficiently use their blindness skills, when they have the self-confidence to put those skills into practice, when they thoroughly understand and have a positive attitude about their blindness, and when they are aware of and able to deal effectively with public misconceptions.

THE BOTTOM LINE

The success of the orientation center and its program can be measured through statistics, through continued relationships with the center and through the long-term positive effects the training has had on the lives of former students. After completing their training, students may attend college or a vocational training program, enter a new career or return to a former job. The center is an integral part of the services offered by the Iowa Department for the Blind, and the department's success in providing meaningful services that lead to jobs for consumers is also the success of the center itself. The figures for the 2000, 2001 and 2002 fed-

eral fiscal years tell the story. In those years, 171, 175 and 140 vocational rehabilitation cases respectively were closed successfully rehabilitated (Status 26). Consumers who developed Individualized Plans for Employment during those years had an over 83 percent chance of successfully getting a job. They could expect to earn an average of over \$12.40 an hour, and about 68 percent of them would become the primary source of support for their families.

The program's success can also be seen in the relationships that develop when students begin their training and continue long after that training has ended. New students notice quickly that, when they enter the center, they soon become members of the orientation center's "family." This membership continues after they complete their training. Center staff often contacts former students to see how they are doing, and former students frequently contact staff to talk about their latest news or get some advice. Students who have shared the center experience sometimes become lifelong friends. The center itself promotes this unity through a quarterly newsletter detailing the activities of the center and its graduates and through the annual Orientation Alumni Day. Each fall, students host a day of activities for former students culminating in an evening banquet and dance. An average of 200 people attend each year, and many of these are some of the center's strongest supporters.

Most important, though, the center's success can be measured in the long-term positive effects the training has had on the lives of former students. Participation in the orientation center is a life-altering experience for most students. When they complete the program, they find that blindness is no longer the controlling factor in their lives. They have internalized the truth that "It is OK to be blind," and they know they are well equipped to

slay any dragons they might encounter. One former student put it this way:

"I had decided to come to the Orientation Center after completing my high school education. I was led to understand that by attending this program, it would help me to raise my GPA [grade point average] in college. After being in orientation for a few weeks, however, I had discovered that my motives were in the wrong place. This program's purpose is not to prepare me for college, but to prepare me for life and how to live it as a confident blind person. This program works on the attitudes of blind people, helping them to become confident, capable people by letting them know there is life after blindness. Although I have been blind since birth due to cataracts, this program has helped me form a different attitude about my own blindness, as well as other blind people. I have learned that it is OK to be blind, because I know that it does not make me any less of a person. The classes in the orientation center are made up of Braille, home ec [economics], shop, technology and travel. All of these classes combined are not merely to teach the techniques of blindness, but to build confidence by the use of them. My stay at the center has not been an easy one, but it will be one I will take with me and use for the rest of my life."²



NOTES

1. This information is based on the author's understanding from years of experience touring orientation centers for blind adults and studying the subject; thus, no specific source is given.
2. For reasons of confidentiality, the author is unable to give the names of center students who are quoted in this article.

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EMPOWERING
PEOPLE
WITH
DISABILITIES
THROUGH
VOCATIONAL
REHABILITATION
COUNSELING



JOHN F. KOSCIULEK, Ph.D., CRC

As a result of systemic “castification”¹ processes and the rapidly changing world of work, assisting people with disabilities with obtaining and maintaining high-quality employment is an increasingly difficult task. Vocational rehabilitation (VR) counseling thus can be instrumental for enhancing the career success and quality of life of consumers with disabilities. In this article, a framework that describes how effective VR counseling promotes the empowerment of consumers with disabilities is presented. Following a description of the primary model constructs of working alliance, informed choice, self-determination, and empowerment, the implications of the framework for VR counselor training and practice are discussed.

The world of work is changing at a rapid pace, and the changes are likely to accelerate during the 21st century. Employment arrangements such as temporary employment, short-term hires, contractual positions, leased workers, and on-call and part-time workers have and will continue to influence the career development of all workers (Institute on Rehabilitation Issues, 1999). These changes are having a substantial impact on the life roles of individuals with disabilities, the settings in which they live and work and the events that occur in their lives. At the same time, current disability policy in the United States focuses on the inclusion, independence and empowerment of people with disabilities (Kosciulek, 2000). Thus, vocational rehabilitation (VR) counseling with people with disabilities must be a dynamic, creative and highly individualized process. Effective VR counseling can be instrumental for empowering the life choices, inclusion and independence of people with disabilities. In turn, empowerment, inclusion and independence will lead to high-quality employment and fulfilling careers for individuals with disabilities (O’Day, 1999).

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EMPLOYMENT AND CAREER CHALLENGES ENCOUNTERED BY PEOPLE WITH DISABILITIES

The ever-changing nature of work presents new problems for people with disabilities in finding and maintaining suitable employment. Major trends such as globalization of the American economy, technology and population shifts are changing the nature of work and worker skill requirements (Ryan, 1995). Despite rehabilitation efforts, a majority of Americans with disabilities between the ages of 16 and 64 are not employed and that disparity has not changed since 1986, despite the fact that a majority of non-employed people with disabilities in the working age population want to work (National Organization on Disability, 2000). In general, the vocational adjustment of people with disabilities has been characterized by limited salable work skills, low income, underemployment and unemployment (Bruyere et al., 2002; Curnow, 1989).

In addition, according to Harrington (1997), high school students with disabilities frequently leave school without marketable skills or the ability to function independently. Given that work is a central force in people's lives, dramatically high rates of unemployment and underemployment can adversely affect not only the economic and social status of individuals with disabilities, but also their self-image. A distinct set of employment and career challenges encountered by many people with disabilities that can be used as a reference point for VR counselors includes:

- limitations in early life experiences,
- career decision-making difficulties, and
- a negative worker self-concept (Kosciulek, 2003).

Limitations in Early Experiences.

Frequently, people with disabilities arrive at adulthood with few career options (Chubon, 1995). Limited early vocational and social experiences encountered by people with disabilities restrict the array of career options they perceive, impede decision-making

ability and impair future vocational development. The effect of limited early vocational experiences has been described by Holland (1985) as a precursor to the development of career-related problems. Such problems may include failing to develop a consistent and differentiated personality pattern and a clear vocational identity and trying to make a career of a job that does not match their abilities or experiences (Holland, 1985). Unfortunately, such developmental patterns are not unusual among people with disabilities.

Decision-Making Ability. Lack of opportunities to participate in decision making, to form a perception of oneself as a worker and to test self-competencies can be the outcome of limited early experiences and can impede career development. The poorly defined self-concept, ambivalence about obtaining work and limited occupational information reported by people with disabilities is indicative of distortions that could result in unrealistic vocational aspirations or decisions. Harrington (1997) and Parent (1993) have aptly described how many individuals with disabilities have had little opportunity for successful experience in decision making and, therefore, lack competence in making decisions.

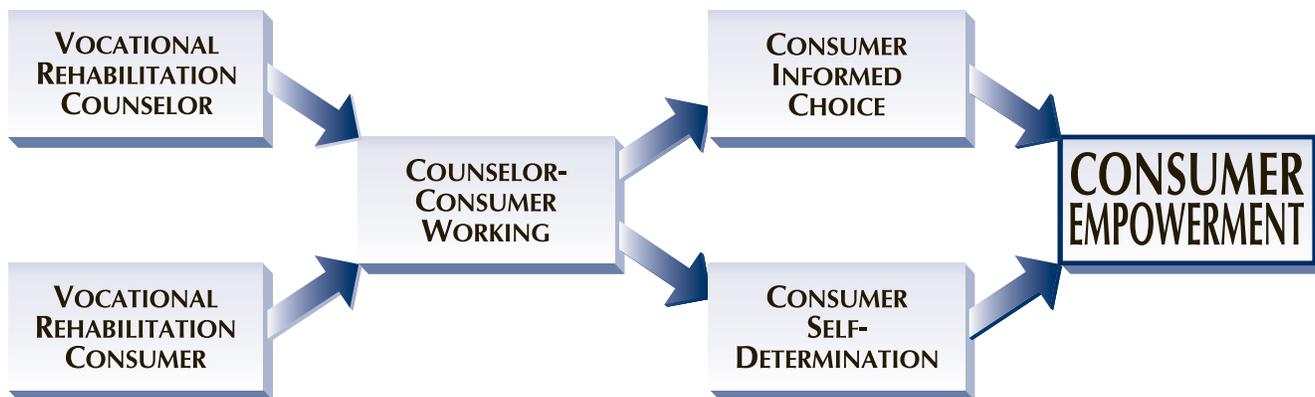
Negative Worker Self-Concept Resulting from Castification Processes.

Lack of experience and difficulty in decision making are not solely the result of disability, but also an outcome of social attitudes and stereotypes. Social attitudes toward disability may be as important as the disability itself in that the negative attitude of others plays a part in shaping the life role of the individual with disability (Fitch, 2002). The outcome of this long-term exposure to prejudicial attitudes may result in a negative self-appraisal and a negative worker self-concept.

Society generally holds diminished expectations for people with disabilities (Schroeder, 1995). These attitudes are pervasive; they influence all of us to some degree. As a class, people with disabilities have suffered discrimination. Individuals with disabilities face common social problems of stigma,

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FIGURE 1. VOCATIONAL REHABILITATION COUNSELING EMPOWERMENT FRAMEWORK



marginality and discrimination, similar to those faced by members of racial and ethnic minority groups (Fine & Asch, 1988). Further, given that disability rates among racial and ethnic minority group members are proportionally higher than rates in the U.S. population overall, many individuals with disabilities face double jeopardy (Trueba, 1993).

Szymanski and Trueba (1994) maintained that at least some of the difficulties faced by people with disabilities are not the result of functional impairments related to the disability, but rather are the result of castification processes embedded in societal institutions for rehabilitation and education and enforced by well-meaning professionals. Castification processes have their roots in a determinist view in which people who are different are viewed as somehow less “human” or less capable (Trueba, Cheng & Ima, 1993). Problems of castification plague services to people with disabilities because the same categories of impairment and functional limitation (constructed mostly by people without disabilities) are used to determine eligibility for services, to prescribe interventions and, on occasion, to explain failure. The constructs and those who use them become agents of castification.

The disempowering nature of these classification systems is often all too apparent to people with disabilities applying for rehabilitation services in an effort to enhance self-sufficiency and personal independence (Scotch, 2000). Rather than being treated as adults with

free or equal status, they may be confronted by persons asserting a right to determine what kinds of services they need. Thus, it is critically important that VR counselors reject paternalistic castification processes and actively work to foster empowerment among consumers with disabilities during the VR process (Kosciulek, 2003). To accomplish this important task, we need conceptual frameworks useful for understanding and guiding empowering VR counseling approaches.

VOCATIONAL REHABILITATION COUNSELING EMPOWERMENT FRAMEWORK

In this section, a framework that describes how VR counseling engenders the empowerment of consumers with disabilities is presented. The key constructs in this model include the VR counselor-consumer working alliance, informed choice, self-determination and empowerment. Figure 1, a visual depiction of the empowering VR counseling framework, illustrates the following conceptualization:

A consumer with a disability enters the state-federal VR system. The level and quality of the working alliance formed between the VR counselor and consumer determines the level and quality of consumer informed choice and self-determination during the VR process. Together, informed choice and self-determination influence the level and quality of consumer empowerment resulting from the VR process.

In this model, it is hypothesized that the development of an effective counselor-consumer working alliance is a prerequisite for facilitating consumer informed choice and self-determination during the VR process. Further, the framework posits that proficient informed choice and self-determination are necessary for increasing consumer empowerment. In order to enhance reader understanding and application of the VR counseling empowerment framework, each of the model constructs is defined and described in detail below.

Counselor-Client Working Alliance.

The central factor in all successful counseling processes, including VR counseling, is an effective working alliance. Researchers estimate that as much as 30 percent of the variance in counseling outcome can be attributed to the counselor-client working alliance (Lambert, 1992). As one of the essential components for success in counseling, an effective working alliance is represented by a positive collaboration between a consumer and a counselor (Kosciulek, Chan, Lustig, Strauser & Pichette, 2001). The working alliance is comprised of the following components: tasks, bonds and goals (Horvath, 1994).

Tasks are those in-counseling behaviors and cognitions that form the substance of the counseling process.

Goals are the outcomes or target of the counseling process. In VR counseling, the goal aspect of the working

alliance is clear and specific: the attainment of an employment outcome.

Bonds are the positive interpersonal attachments between a consumer and counselor that include such aspects as mutual trust, acceptance and confidence.

Consistent with the working alliance concept, counseling in VR is the collaborative process between the individual consumer and counselor in which they assess the individual's strengths, resources, priorities, abilities, capabilities, interests and rehabilitation needs. In this process, the counselor and consumer also explore, clarify and assess employment and career options, address barriers to be overcome, and develop and carry out a plan of action that will result in meaningful employment for the individual based on his or her informed choice. In discussing the working alliance in the VR process, Lustig, Strauser, Rice and Rucker (2002) noted that the two most significant factors in this realm are the quality of the consumer's participation and the degree to which the consumer is motivated, engaged and joined in the VR process. Consumers with disabilities who are engaged and connected with counselors will benefit most from VR counseling (Chan, Shaw, McMahon, Koch & Strauser, 1997).

The working alliance can be most beneficial and an excellent predictor of outcome for consumers with disabilities when:

- counselors and consumers agree on goals and preferred outcomes,
- counselors collaborate with consumers on tasks to accomplish those goals and preferred outcomes (Lustig et al., 2002), and
- consumers have a favorable view of the counselor-consumer relationship (Bertolino & O'Hanlon, 2002).

An empowerment approach to forming an effective VR counselor-consumer working alliance includes elements that both consumers and counselors bring to the relationship. Primary elements for consumers include taking responsibility for their own decision making and for their

own actions and consequences of their actions. Key elements for counselors include the following: knowing and admitting their limitations (e.g., lack of knowledge of a specific disability condition) and displaying unconditional positive regard for the consumers they serve (National Institute on Disability and Rehabilitation Research [NIDRR], 1994).

Specific counseling techniques that contribute to the development of an effective working alliance and consumer empowerment include the following:

- treating all consumers as adults regardless of the severity of the disability,
- using age-appropriate language and techniques,
- placing emphasis on consumer strengths, and
- respecting consumer values and beliefs.

Consumer Informed Choice.

As employment is a key to independence and improved quality of life for people with disabilities, choice in the selection of employment goals and rehabilitation services necessary to meet those goals is a critical element for empowering persons with disabilities (Kosciulek, 2000). In the VR counseling empowerment framework it is hypothesized that an effective counselor-consumer working alliance leads to productive informed choice in the VR process. Consumer choice in vocational goals and services emerged as an important component of VR in the 1990s. However, choice is not a new concept in the field. Over 40 years ago, Levine (1959) described the partnership between the consumer and counselor and the counselor's role in assisting the individual in making choices and decisions. During this same time period, Patterson (1960) encouraged counselors to facilitate independence by helping consumers "go through the process" of deciding what they should have and should do. He noted, "The counselor can have no stereotypes of occupational choices" (p. 115). Both of these examples fo-

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cus on vocational choice and, although they go back more than 40 years, they are consistent with current principles related to enhancing the counselor-consumer partnership, facilitating empowerment and fostering choice and independence in the rehabilitation process.

The philosophy behind informed choice is that people with disabilities should have control over the processes and services that affect their lives, and that those who have control over their own VR planning will experience better employment outcomes than those who do not. Informed choice is practiced when VR counselors give consumers with disabilities

- the tools to learn how to make choices, and
- the information they need to make their own choices.

Informed choice is the process by which individuals participating in VR programs make decisions about their assessment services, vocational goals, the services and the service providers that are necessary to reach those goals and how those services will be procured. The informed choice process begins with the individual's values, interests and characteristics and proceeds to an evaluation of availability of resources and alternatives, including the labor market. Implementing informed choice requires that the VR counselor listens carefully, communicates clearly and gathers and analyzes information without bias. The VR counselor works with the consumer to make choices and to evaluate their impact. Finally, in an informed-choice model of VR, the counselor supports the individual in setting goals, making plans and following through with decisions, with the aim of achieving meaningful employment.

It is presumed that a consumer's skills and abilities to exercise informed choice can be developed through use of self-assessment techniques, training and experience in goal setting and decision making, and consumer education. In this manner, skills in exercising informed choice could grow in a parallel fashion along with growth

of specific vocational and employment skills, enabling the individual to continue making important, informed life decisions following the completion of VR services. The application of the concept of consumer informed choice in the context of VR services involves a conscious process of choice making with the following typical elements:

- analyzing needs,
- gathering information,
- evaluating the information,
- describing options,
- selecting from among the options and making a choice,
- accepting the risk of failure,
- assuming responsibility for the outcome of the choice, and
- evaluating the results of choice making and using the information in future choice-making experiences.

Consumer Self-Determination. In addition to facilitating informed choice in the VR process, an effective VR counselor-consumer working alliance will enable the development of consumer self-determination skills. Self-determination, a concept and process that has emerged from the fields of rehabilitation counseling, special education and disability studies, provides the basis for an empowerment approach to VR counseling. Field, Hoffman and Spezia (1998) have defined self-determination as a multidimensional concept that includes:

- attitudes, abilities and skills that lead people with disabilities to define goals for themselves and to take the initiative to reach these goals,
- the capacity to choose and to have those choices be the determinants of one's actions,
- determination of one's own fate or course of action without compulsion, and
- the ability to define and achieve goals based on a foundation of knowing and valuing oneself.

Promoting self-determination should be a primary effort of VR counselors working with consumers with disabilities. Self-determination can be enhanced by helping consumers develop

greater self-awareness and by teaching decision making, goal-setting and negotiation skills, which will enable them to exercise greater control during the VR counseling process (Kosciulek, Bruyere & Rosenthal, 2002). The steps in the self-determination development process for consumers include consumers knowing and valuing themselves, consumer planning, consumer action, experiencing outcomes and learning, and making adjustments. Consumer self-knowledge can be facilitated by encouraging individuals to expand their thinking about the possibilities in their life, deciding what is truly important to them, having a keen sense of their strengths, limitations and preferences and knowing what options are available. VR counselors can promote consumer self-valuing by assisting consumers with accepting themselves as they are, admiring their strengths that come from uniqueness, and recognizing and respecting their rights and responsibilities.

The next step in the consumer self-determination process is the development of effective planning skills. Effective planning involves a process of setting goals, identifying action steps to meet goals, anticipating results and visually and orally rehearsing potentially stressful events such as job interviews. In addition to planning, VR counselors can facilitate consumer self-determination by encouraging individuals to act. Consumer self-determined action may include dealing directly with conflict and criticism (e.g., with a family member or coworker) and accessing resources and supports such as assistive technology devices and recreation and leisure services.

As a result of planning and acting, consumers with disabilities will have the opportunity to experience positive outcomes and to learn more about themselves. VR counseling that promotes self-determination can enable individuals to compare performance and outcomes to their expectations and realize successes. In the final step toward enhancing consumer self-determination, VR

counselors can assist individuals with disabilities to adjust their self-perception and expectations with regard to future planning and actions.

Consumer Empowerment. As illustrated in the VR counseling empowerment framework (Figure 1), informed choice and self-determination influence the level and quality of consumer empowerment resulting from the VR process. Emener (1991) described the philosophical tenets necessary for an empowerment approach to rehabilitation. These tenets provide a useful foundation for the provision of VR counseling services to people with disabilities. The four tenets are paraphrased as follows:

- Each individual is of great worth and dignity.
- Every person should have equal opportunity to maximize his or her potential and is deserving of societal help in attempting to do so.
- Most people strive to grow and change in positive directions.
- Individuals should be free to make their own decisions about the management of their lives.

Definition of empowerment. Empowerment is the process by which people who have been rendered powerless or marginalized develop the skills to take control of their lives and their environment (Lee, 1997). As such, in order to begin to improve rehabilitation services and outcomes, empowerment has become the operative term in disability policy development and rehabilitation service delivery. The field of rehabilitation continues to place an increasing emphasis on the construct of empowerment as a conceptual cornerstone of identity (Banja, 1990; Zimmerman & Warschusky, 1998) and critical variable in rehabilitation research (National Institute on Disability and Rehabilitation Research [NIDRR], 1991).

Empowerment is conceptualized as involving both internal or psychological aspects and situational or social aspects. Internal or psychological factors include a sense of control,

competence, confidence, responsibility, participation, solidarity and community. Additional psychological aspects of empowerment include flexibility, initiative and future orientation (Stein, 1997). In this manner, the psychological facet of empowerment entails the acquisition of values and attitudes that are incorporated into the individual's worldview and constitute a foundation for action (Bolton & Brookings, 1996).

Situational or social aspects of empowerment include control over resources; interpersonal, work and organizational skills; decision-making powers; self-sufficiency; mobility; and "savvy" or an ability to "get around" in society (Stein, 1997). Additional situational factors include improved living conditions, increased social status, financial and social support, autonomy, access to information and income. The situational aspects of empowerment are concerned with the interdependence between people's behaviors and their environment. These situational or social factors also suggest that the lack of social, economic, or political resources in the environment is a major contributor to human dysfunction (Rappaport, 1987). Thus, it is argued here that when people with disabilities have control over important resources, they are better able to determine the course of their lives, solve their problems and develop adaptive social networks.

Empowering VR counseling. Empowerment of individuals with disabilities means that they have the same degree of control over their lives and the conditions that affect them as is generally possessed by people without disabilities (Harp, 1994). It entails the transfer of power and control over their lives from external entities, such as VR counselors, to the individuals themselves (Bolton & Brookings, 1996). Thus, as hypothesized and tested by Kosciulek and Merz (2001), the VR counselor committed to an empowerment approach to service delivery should facilitate and maximize oppor-

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counseling
interventions.*

tunities for individuals with disabilities to have control and authority over their own lives.

From an empowerment perspective, VR counseling is not something that can be done to or for a consumer. Rather, it is a process in which consumers must become active, informed participants who learn and control a planning process that they use for short- and long-term career development (Szymanski, Hershenson, Enright & Ettinger, 1996). In addition, the life-long, developmental nature of the process means "unless we plan to work with an increasingly dependent consumer again and again across the decades, our professional responsibility is to assure that each person learns the [career planning] process" (Mastie, 1994, p. 37).

Active consumer involvement is the key element of successful VR counseling interventions (Ettinger, Conyers, Merz & Koch, 1995). In an empowerment approach to VR counseling, consumers are actively involved in:

- gathering information, including self-assessment, and learning about occupations and the labor market;
- generating alternative courses of action and weighing those alternatives; and
- formulating a plan of action.

IMPLICATIONS FOR VOCATIONAL REHABILITATION COUNSELOR TRAINING AND PRACTICE

The VR counseling empowerment framework suggests three important implications for VR counselor training and practice.

First, in both pre-service counselor education and in-service counselor training programs, curricula must focus on the development of effective vocational counseling techniques. In this manner, new and practicing VR counselors will possess the tools necessary for developing effective working alliances with consumers with disabilities.

Second, both new and experienced VR counselors must be knowledgeable of the state-federal VR system informed choice mandates. Further, counselors must be fully informed regarding those

models demonstrated to be useful for enhancing informed consumer choice in the VR process. The informed-choice/best-practice methods described in the Choice Demonstrations Projects Operations Manual (InfoUse, 1999) may be helpful in this regard.

Third, in accordance with the VR counseling empowerment framework, the development of consumer self-determination skills must be a goal of the VR counseling process. As such, VR counselor training programs of all types should direct resources toward increasing counselor knowledge and skill in the area of consumer self-determination. As described earlier in the discussion of Consumer Self-Determination, Field et al. (1998) provided a valuable guide that outlines the steps in the self-determination development process.

CONCLUSION

Due to the ever-changing nature of the world of work and service-system castification processes, assisting people with disabilities to achieve positive, meaningful and stimulating career development can be a challenging task. Effective VR counseling can be instrumental for enhancing the career success and quality of life of consumers with disabilities. Full implementation of the VR counseling empowerment framework presented in this article will enable consumers with disabilities to become active, informed participants who learn and control a planning process that they use for both short- and long-term career development. In this manner, VR counseling will promote the empowerment of individuals with disabilities.



NOTE

1. Castification is fundamentally an institutionalized way of exploiting one social group (ethnic, racial, low-income or other minority group), thus reducing this group to the status of a lower caste that cannot enjoy the same rights and obligations possessed by the other groups (Trueba, 1993a, p. 30).

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CONSUMER ORGANIZATIONS: IMPORTANT RESOURCES FOR VR AGENCIES

Periodically, the commissioner of the Rehabilitation Services Administration (RSA) disseminates memoranda to the RSA Senior Management Team to provide information and guidance on the implementation of priority initiatives or strategies. Last fall, Joanne Wilson, RSA commissioner, distributed the following Commissioner's Memorandum (CM 04-01) regarding the importance of consumer organizations as valuable resources for vocational rehabilitation (VR) agencies. The memorandum clearly articulates the potential role of consumers in empowering persons with disabilities and the agencies that serve them.



MEMORANDUM

**UNITED STATES DEPARTMENT OF EDUCATION
REHABILITATION SERVICES ADMINISTRATION
CENTRAL OFFICE**

**COMMISSIONER'S MEMORANDUM
CM 04-01
Date: October 3, 2003**

TO: RSA Senior Management Team
FROM: Joanne Wilson
Commissioner
SUBJECT: Consumer Organizations: Important Resources for VR Agencies

BACKGROUND

Consumer organizations, whose membership and officers are comprised of a majority of individuals with disabilities, are an invaluable resource for State vocational rehabilitation (VR) agencies. These organizations provide a network of individuals whose knowledge and experiences can significantly supplement the efforts of a VR agency in meeting its mission and in empowering persons with disabilities to achieve their employment and independent living goals. Consumer organizations can provide experience-based information, technical assistance, access to role models and mentors, disability-specific training, job matching, advocacy on behalf of persons with disabilities and the needs of the public VR program, and a variety of other services that VR agencies would find useful in working with persons with disabilities. Whether representing individuals with mental illness, cognitive disabilities, physical disabilities, or individuals from a combination of these groups, consumer organizations specialize in empowering individuals with disabilities to achieve independence and self-sufficiency.

The Rehabilitation Services Administration (RSA) is committed to leveraging the contributions of community organizations comprised of individuals with disabilities. To this end, RSA is developing initiatives to draw upon the contributions of consumer organizations by making their services a more integral resource to the VR program. These initiatives are designed to enhance the effectiveness of the VR system with the practical expertise and knowledge of persons with disabilities who

have successfully overcome barriers in achieving their goals. For example, RSA is funding a mentoring initiative in which students with disabilities will be connected with mentors with disabilities, who possess the practical knowledge and personal experiences requisite to help the students effectively transition to adulthood. These mentors can offer transition-age youth information, support, and hope derived from first-hand and personal experiences that enable them to serve as real-life examples of what people with disabilities can achieve.

This Commissioner's Memorandum (CM) more fully describes both this mentoring initiative and other available opportunities for State VR agencies to utilize the unique contributions that consumer organizations can make throughout the VR process ranging from direct interaction with VR participants to meaningful impact upon systemic issues, such as statewide planning and policy development. RSA considers the development of strong working relationships between State VR agencies and grass-roots consumer organizations to be pivotal in ensuring that agency efforts are effective in meeting the needs of the various disability populations the agencies are serving and the realization of successful outcomes.

MENTORING

The expectations and beliefs that individuals with disabilities have about their own abilities, potential, and competence inevitably influence their choices throughout the VR process. All too frequently, individuals create self-imposed limits based on poor role modeling, lack of disability-specific information, and negative misconceptions about their disability. Ultimately, these self-imposed limits negatively affect their employment outcomes and quality of life. Connecting individuals being served by the VR program with mentors who have disabilities, who possess practical knowledge and firsthand experience, and who have achieved high-quality employment and independence through their participation in the VR process will help guide VR participants to make positive choices regarding their programs and their lives.

Furthermore, while all students encounter difficulties during their school years, many of the challenges encountered by students with disabilities are wholly unique. Students with disabilities often are unable to find summer and part-time employment, struggle with social acceptance and negative stereotypes about their disabilities, are not encouraged or fail to participate in extracurricular activities, and are not always taught the disability-specific skills and techniques they need to succeed at school and life. As a result, dropout rates among students with disabilities are significantly higher than those of the non-disabled population, and their college enrollment is approximately five times less than the general public's. The lack of opportunity to gain the experience and confidence through job training and summer employment combined with low expectations and minimal social skills or disability-specific techniques leave them ill-prepared to enter the workforce.

While mentoring can greatly enhance the experiences of all participants in the VR program, it is a natural and necessary component of any complete package of transition services in light of the significant impact role models can have on youth as they mature. Mentoring provides students with disabilities increased opportunities to explore vocational interests and develop work habits, skills, and attitudes necessary for meaningful careers. Mentors, or role models, with whom students can identify, and who have shared interests, can have a positive impact that will last a lifetime. Thus, providing mentoring services to students with disabilities should be considered in the development of both the Individualized Education Program (IEP) and the Individualized Plan for Employment (IPE).

To highlight the important role of mentoring in the transition process, RSA has developed a mentoring initiative for transition-aged youth and young adults with disabilities. Projects funded

under this initiative will focus on providing mentoring services to students with disabilities to gain the necessary skills, confidence, and education to effectively transition from school to high-quality employment and independence. The mentoring program established under this initiative will accomplish this goal through the development of collaborative partnerships between State VR agencies and consumer-controlled organizations. From the ranks of these organizations, mentors will be identified and matched with students with disabilities. These mentors will possess the practical knowledge and personal experience requisite to help students effectively transition to adulthood and overcome the barriers that typically are associated with a particular disability. The mentors will not only serve as powerful role models, but will support students by assisting them with career and professional development, helping them to develop their life skills and disability-specific techniques that enhance independence, assisting them to attain their academic goals, and providing them with encouragement and moral support.

The initiative focuses on the following objectives:

- Increasing academic achievement and participation in post-secondary education.
- Assisting students to navigate through service delivery systems that may assist them in their transition.
- Developing and improving the self-confidence, community integration, work, self-determination, advocacy and decision-making skills of the students.
- Increasing high-quality employment outcomes achieved by the students.

This effort has begun with a few, small demonstrations and will grow into a national network of mentoring programs. In fiscal year (FY) 2002, RSA funded two mentoring demonstration projects. In FY 2003, RSA funded one project in the amount of \$1 million over a five-year period to develop an information base on promising mentoring models upon which the proposed effort in FY 2004 can build. The Administration, through its FY 2004 budget request, proposes a more expansive effort that will focus on activities to diffuse mentoring programs within State VR agencies.

ADJUSTMENT TO DISABILITY

Adjustment-to-disability services (or adjustment services) are critically important to empowering many individuals with significant disabilities to pursue, achieve, and sustain high-quality employment outcomes in integrated settings. Adjustment services are a comprehensive and integrated set of services, including counseling, mentoring and other services, designed to provide individuals with disabilities with confidence, interpersonal and disability-specific skills, and a positive attitude toward disability that they may require to achieve competitive employment, community integration, and independence. This set of services, which differs from medical rehabilitation services, may consist of teaching orientation and mobility to individuals who are blind, or training in the use of communication aids for those who are blind, deaf, or unable to speak. The provision of such services through the VR program directly assists individuals in adjusting to living and working with a disability, thus greatly enhancing their capabilities to achieve long-term success in the workplace.

Through collaboration with consumer organizations and accessing their expertise, VR agencies can ensure that sufficient and appropriate adjustment services are made available to individuals with disabilities as integral components of their rehabilitation planning. Consumer organizations are excellent resources for information regarding the specific adjustment services required by individuals with disabilities, especially with respect to the development of IPEs appropriate to the needs of

particular individuals with disabilities. In addition, consumer organizations possess a wealth of experience and knowledge concerning the providers of adjustment services; thus, they are well prepared to assist VR counselors and individuals in the selection of the providers best suited to deliver these essential services.

DEVELOPMENT OF THE IPE

The IPE is the vehicle by which individuals participate in the VR program and, ultimately, achieve high-quality employment and independence. It is a planning tool by which individuals identify their employment goals, as well as the specific services and providers needed to achieve those goals. In developing an IPE, individuals require accurate information and perspective in order to make informed and empowering choices. To this end, the State VR agency is required to provide individuals with options for developing the IPE, including the assistance of qualified VR counselors or other persons.

In setting forth the options available to individuals for the development of the IPE, section 102(b)(1)(A) of the Rehabilitation Act of 1973, as amended (Act) states that "...the designated State unit shall provide the eligible individual or the individual's representative...with information on the individual's options for developing an individualized plan for employment, including - (A) information on the availability of assistance, to the extent determined to be appropriate by the eligible individual, from a qualified vocational rehabilitation counselor in developing all or part of the individualized plan for employment for the individual, and the availability of technical assistance in developing all or part of the individualized plan for employment for the individual" (emphasis added). The implementing regulations reinforce the option of the individual to use alternative sources for assistance with IPE development by permitting eligible individuals to develop their IPEs without assistance, or with help from a variety of sources, including qualified VR counselors employed by the agency, qualified VR counselors not employed by the agency, and other unspecified "resources" (34 CFR 361.45(c)(1)).

Consumer organizations are an ideal resource from which VR agencies and individuals can seek assistance when preparing IPEs. Consumer organizations possess extensive knowledge of the VR program and its processes, service providers, and, most importantly, the disability-related and vocational needs of persons with disabilities. By accessing this important resource, both VR counselors and individuals can utilize the expertise of consumer organizations in order to develop IPEs that best meet the needs of the individuals. Such collaboration will serve to connect individuals with people who have firsthand knowledge of disabilities and the VR process, enabling them to make fully informed and effective choices.

PROGRAM EVALUATION

Because consumer organizations represent the collective voice of their members, they are able to offer experience-based input on the effectiveness of a State VR agency's policies, procedures and practices as they affect applicants and individuals eligible for VR services. Strong partnerships and productive dialogue between VR agencies and these organizations can lead to better programming, better agency performance, and, ultimately, better outcomes for persons with disabilities.

In addition to being significant contributors to a VR agency's efforts to evaluate itself and its efforts to empower persons with disabilities to achieve high-quality employment outcomes, consumer organizations can play important roles in the conduct of the comprehensive statewide triennial assessment of the rehabilitation needs of individuals with disabilities required by section 101(a)(15)(A) of the Act. The input of these organizations can be particularly helpful with respect

to the identification of the nature and scope of the needs of individuals who are minorities or who have been unserved or underserved by the State VR agency.

POLICY DEVELOPMENT

Prior to the adoption of any new or revised policies or procedures governing the provision of services under the State's VR program, section 101(a)(16)(A) of the Act requires a State VR agency to conduct public meetings throughout the State to provide the public, including individuals with disabilities, the opportunity to comment on the proposed policies or procedures. In this regard, the agency is also required to actively consult with the director of the Client Assistance Program (CAP), and, as appropriate, Indian tribes, tribal organizations, and Native Hawaiian organizations.

Since the information gathered from these public meetings can be useful to a State VR agency's refinement and improvement of a proposed policy or procedure, the agency should make special efforts to inform consumer organizations of these meetings so that they have the opportunity to express their views, thus ensuring the voice of the larger disability community is heard.

In addition to soliciting public input prior to the adoption of any new or revised policies or procedures at the required public meetings, section 101(a)(16)(B) of the Act also requires a State VR agency to take into account, in connection with matters of general policy relating to the administration of the VR State plan, the views of individuals who are receiving VR services or, as appropriate, their representatives; providers of VR services; the CAP director; and the State Rehabilitation Council (SRC), if the agency is required to have a SRC.

To address this statutory requirement, a VR agency can obtain the perspectives of individuals with disabilities through a variety of other mechanisms. For example, a VR agency can engage in ongoing consultation with consumer organizations by conducting regularly scheduled meetings between agency and organization leadership. Additionally, through participation on policy development committees or focus groups established to study specific areas of interest to the agency, representatives of consumer organizations can provide the agency with additional insight during the various stages of planning and policy development, by participating in initial discussions of the issues, commenting on proposed language, and, finally, by providing information on the effects of the implementation of policy changes on individuals.

IMMERSION ACTIVITIES

Individuals with disabilities can be truly empowered and in control of their futures only when they possess the information, education, training, confidence, and high expectations needed to make effective employment and life-related decisions. VR counselors play a vital role in the empowerment of individuals with disabilities. Counselors and other VR staff can achieve a unique perspective of the capabilities and employment potential of persons with disabilities through participation in activities through which they interact for extended periods of time directly with persons with disabilities in situations other than traditional professional counselor to consumer relationships. In addition, individuals with disabilities also can benefit immensely from participation in these same intensive and experiential "immersion" activities, as they learn from their peers and develop positive attitudes toward their disabilities.

Consumer organizations are ideal resources through which VR agencies can provide immersion activities for their staff and consumers alike. Immersion activities can range in duration and may include attendance at conferences sponsored by these organizations; ongoing participation in meetings and other activities conducted by local chapters and affiliates; and participation in

rehabilitation training programs. Consumer organizations can work with VR agencies to identify and coordinate those activities most appropriate for the needs of their staff and individual consumers. VR staff who have engaged in a variety of immersion activities report: an increased understanding of and sensitivity to disability culture; a greater knowledge of successful accommodation methods; a more positive view of the employment potential of individuals with disabilities; an increased comfort level in working with individuals with significant disabilities; and deeper insight into their own preconceptions of disability. By interacting for an extended period of time with persons with disabilities who function naturally and successfully in the performance of both life and employment skills, VR counselors and consumers can enrich their understanding of the lives of persons with disabilities, the barriers to employment which they have overcome, and those obstacles which they still face, either individually or collectively, on a daily basis.

STATE AGENCY IN-SERVICE TRAINING

Consumer organizations can assist a State VR agency in conducting relevant in-service training efforts that focus on particular disabilities. With their "real world" experiences in addressing various issues resulting from their disabilities with respect to preparing for and obtaining high-quality employment outcomes, representatives of consumer organizations can provide experience-based insight, information, and guidance to State VR agency staff that professional educators, trainers, or books simply cannot offer.

COMMUNICATION AND OUTREACH

Consumer organizations provide established networks for dissemination of information and communication about services, special projects, proposed changes and trends in service delivery or resources, and profiles of agency successes. They are a ready source of referrals and can offer invaluable assistance in reaching culturally diverse or underserved groups to familiarize them with the services that the VR program has to offer. Finally, they can add a significant voice to policymakers on agency requests related to service provision.

SUMMARY

This CM describes various opportunities for collaboration between a VR agency and consumer organizations, and suggests several methods for fostering effective partnerships. VR agencies are encouraged to develop their own innovative practices that utilize the knowledge, expertise, and skills found within these organizations for the benefit of the individuals the agencies serve, thereby enhancing and strengthening the VR program itself.

Consumer organizations play a crucial role in the lives of people with disabilities. Consequently, their involvement in the VR program is fundamental to its success. In partnership with the VR program, these organizations can offer persons with disabilities support, opportunities, and hope. Whether through peer mentoring, leadership opportunities, role modeling, or disability-specific training, consumer organizations are invaluable resources for VR agencies, their partners, and individuals with disabilities alike. VR agencies can draw upon the collective talent of these organizations and the expertise of their individual members as they work to achieve high quality employment and full independence for persons with disabilities.

Any questions concerning this Commissioner's Memorandum should be addressed to Carol Dobak, at (202) 245-7325 or Carol.Dobak@ed.gov.

FREEDOM FOR THE BLIND:

THE SECRET IS EMPOWERMENT

A BOOK REVIEW

ALLEN HARRIS



Available at no cost, except for a fee of \$5 for shipping, from the Regional Rehabilitation Continuing Education Program at University of Arkansas, P.O. Box 358, Hot Springs, AR 71902. Telephone: (501) 623-7700. The entire book is also available online, at: www.nfb.org/books/books1/free.htm

James H. Omgvig's book, *Freedom for the Blind*, which was commissioned by the U.S. Department of Education's Rehabilitation Services Administration (RSA), has just been released. According to Omgvig, the book offers "a non-traditional perspective on the methods and issues that a truly successful employment training program for the blind should embrace."

Freedom for the Blind points out that, as America begins the 21st century, between 70 and 80 percent of its working-age blind people are unemployed. Of those who are employed, far too many are severely underemployed or are destined to be locked in at entry-level jobs for a lifetime. Omgvig asks, "Why?"

The author contends that, putting to one side all of the rationalizations, there can be but two possible explanations for this dismal statistic: First, either people who are blind, no matter how thoroughly trained and adjusted to their blindness they may be, are inherently incompetent; or, second, there is something inherently wrong with America's blindness system — the complex of programs for educating or rehabilitating people who are blind.

Omgvig concludes that the problem is *not* with the people who are blind. The evidence that properly trained blind people can live independent, successful, competitive, normal and happy lives and can assume their rightful position of full membership in society is too overwhelming to conclude that, as a class, people who are blind are inherently incompetent. Therefore, Omgvig reluctantly and cautiously draws the conclusion that the problem has been with the blindness system itself — that educational and vocational rehabilitation (VR) programs for people who are blind historically have not been what they could and should be.

Also, he says that the blind have been thought of by society — and have learned to think of themselves — as a group apart, a helpless and hopeless lot, having neither the right nor the ability to work for their daily bread or to earn their self-respect. As a group, people who are blind have thought of themselves not as unemployed but as inferiors who are unemployable: He sums it up by describing the blind as a "visible minority!"

Omgvig believes that there are additional facts and circumstances at

the root of the unemployment problem: Too many VR programs or residential orientation and adjustment (O&A) centers have also unwittingly embraced society's negative view of people who are blind and have perpetuated these myths and misconceptions in the minds of their VR customers or students, and those customers have been the losers. Such programs have utilized what one might call the enabler model of service delivery.

However, *Freedom for the Blind* contends that there is good news! The age of enlightenment is here, and a new model — a proven cutting-edge formula for success — exists. It is the *empowerment model*.

The book proffers the view that every blind person — man or woman, young or old, educated or not — needs personal empowerment to be whole; and with empowerment comes the freedom people who are blind have the right to expect. It suggests that every progressive VR program or residential O&A center should therefore adopt the empowerment model and do its best to empower every VR customer or student whom it serves. In regard to O&A centers, Omgvig says that a resi-

dential training center's overarching purpose should be to function as an "empowerment station."

The empowerment-station model of an O&A center is one that recognizes that all offered services must be aimed at teaching its students a new and constructive set of attitudes about blindness and "unlearning" prevailing views that are wrong and harmful. Further, such a center will help each blind student strive to achieve the following four personal objectives:

- The person who is blind must come to know emotionally, not just intellectually, that he or she can truly be independent and self-sufficient.
- The person who is blind must learn and become competent in those skills — the alternative techniques of blindness — that will make it possible for him or her to be truly independent and self-sufficient.
- The person who is blind must learn to cope on a daily basis with the public attitudes about blindness — how he or she will be treated by other people because of their misunderstandings and misconceptions.
- Even when the individual who is blind has adjusted emotionally to blindness, mastered alternative techniques and learned to cope effectively with the demeaning things other people do or say, the person who is blind must also learn to "blend in" and to be acceptable to others in order to be successful. He or she must be punctual, reliable, neat and appropriate in appearance and possessed of good social and table manners and the like. Thus the schools and agencies must do the best that they can to achieve this desired result.

Omvg's thesis is that *freedom should be accessible to everyone* and that it is possible, with a willingness to think outside the box, for the traditional VR program to learn to empower and to move its customers toward successful, high-quality employment and increased integration into society. A proven cutting-edge formula for suc-

cess exists and is available for the taking. The blind customer who has received cutting-edge VR services has a markedly higher chance for vocational success than the norm, according to Omvig.

The book details the philosophies, training techniques and the methods that go into the empowerment model and also explains the role a state's separate agency for the blind could play in the process. Given the right kind of training, the average blind person — not merely those whom some observers mistakenly perceive as the "superblind" — can compete on terms of true equality with his or her sighted peers and can become a taxpayer rather than a tax user. Omvig believes that, far from wanting to whimper, "I wonder what it would feel like to be free," the empowered blind person will want to climb the highest mountain and shout, "I am free! I know what it feels like to be free!"

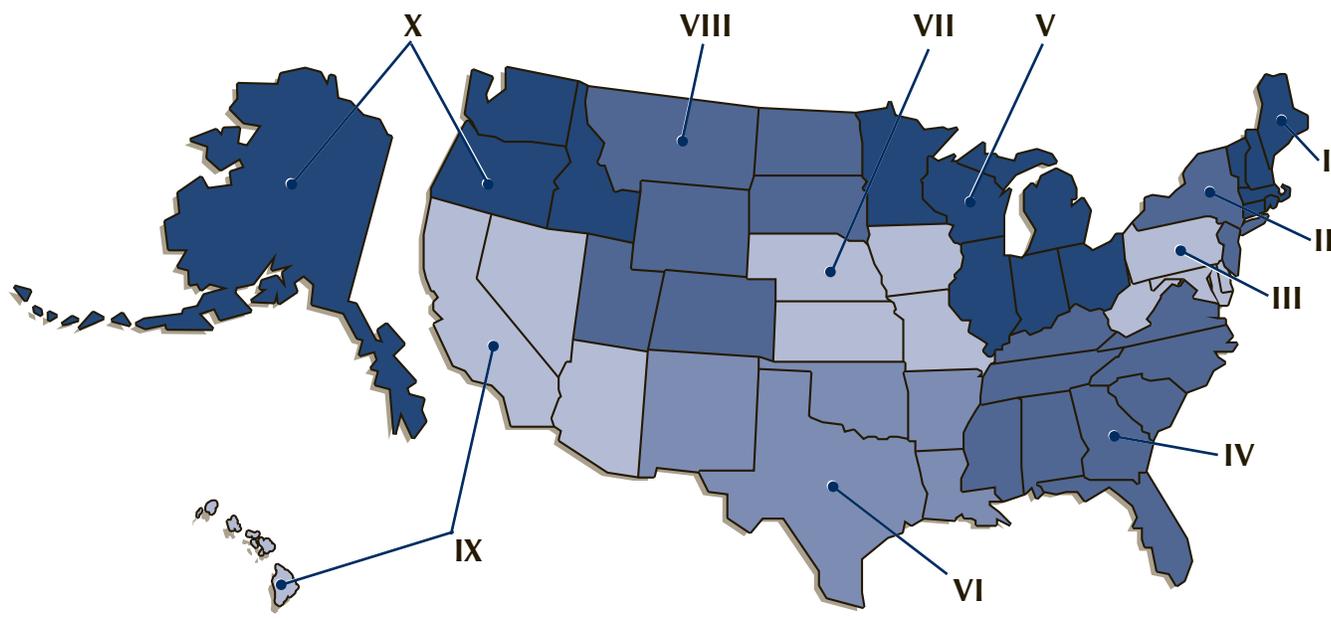
Omvg is a blind attorney and rehabilitation professional from Tucson, Arizona. He spent most of his professional career working with the blind, and in retirement he continues to do consulting, evaluating, writing and teaching in this field today.

He became blind as a teenager due to Retinitis Pigmentosa (a degenerative, retinal disease referred to as RP). After several years of struggling with extremely limited vision while in the public school system, he transferred to a residential school, the Iowa School for the Blind. He graduated from high school in 1953.

Eight years of idleness followed Omvig's high school graduation. Then, in 1961, he became one of the early students in the Adult Orientation and Adjustment Center newly created and directed by Dr. Kenneth Jernigan at the Iowa State Commission for the Blind. He went on to complete college and law school, and then he worked in Washington, D.C., and New York City as the first blind attorney ever hired by the Na-



*The
blind
customer who
has received cutting-
edge VR services has
a markedly higher
chance for vocational
success than the
norm, according
to Omvig.*



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 Boston, MA 02109

Region II
 (New Jersey, New York, Puerto Rico, Virgin Islands)
 Rehabilitation Services Administration
 75 Park Place, Room 1236
 New York, NY 10007

Region III
 (Delaware, Maryland, Pennsylvania, Virginia, West Virginia, District of Columbia)
 Rehabilitation Services Administration
 100 Penn Square East, Suite 512
 Philadelphia, PA 19107

Region IV
 (Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee)
 Rehabilitation Services Administration
 61 Forsyth Street, S.W., Room 18T91
 Atlanta, GA 30303

Region V
 (Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin)
 Rehabilitation Services Administration
 111 North Canal Street, Suite 1048
 Chicago, IL 60606

Region VI
 (Arkansas, Louisiana, New Mexico, Oklahoma, Texas)
 Rehabilitation Services Administration
 Harwood Center
 1999 Bryan Street, Room 2740
 Dallas, TX 75201-6817

Region VII
 (Iowa, Kansas, Missouri, Nebraska)
 Rehabilitation Services Administration
 10220 North Executive Hills Boulevard
 Kansas City, MO 64153-1367

Region VIII
 (Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming)
 Rehabilitation Services Administration
 1244 Speer Boulevard, Suite 310
 Denver, CO 80204

Region IX
 (American Samoa, Arizona, California, Commonwealth of the Northern Mariana Islands, Guam, Hawaii, Nevada)
 Rehabilitation Services Administration
 50 United Nations Plaza, Room 215
 San Francisco, CA 94102

Region X
 (Alaska, Idaho, Oregon, Washington)
 Rehabilitation Services Administration
 915 Second Avenue, Room 2848
 Seattle, WA 98174-1099

Sec. 2. (b) Purpose

The purposes of this Act are -

- (1) to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society ...
- (2) to ensure that the Federal Government plays a leadership role in promoting the employment of individuals with disabilities, especially individuals with significant disabilities, and in assisting States and providers of services in fulfilling the aspirations of such individuals with disabilities for meaningful and gainful employment and independent living.

- The Rehabilitation Act of 1973, as amended

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