

*Chapter 8***Empowerment and Consumer Organizations**

Chapter 2 focused on strategies that individual consumers can employ to become empowered and to maximize the benefits of vocational rehabilitation (VR). In this chapter, we will look at ways VR counselors and administrators can partner with consumer groups to optimize consumers' experience with VR and to assist them in building a support system that will continue to provide assistance and encouragement after the consumer's relationship with VR has come to an end.

Non-rehabilitation community organizations—consumer groups and quasi-governmental or government funded advocacy agencies—can be helpful, even critical, in the empowerment process. These community organizations serve as an extension of the rehabilitation counselor in the empowerment process in that they provide helpful information, knowledge, advocacy and mentoring during the counseling process and, potentially, for years after the counseling relationship has ended.

Active and vigorous consumer organizations have played and will continue to play a significant and ever-increasing role in empowering people with disabilities. Some of these organizations represent broad groups of people with different disabilities, such as the American Association for People with Disabilities. Others are disability-specific and represent consumers with one particular disability, for example the National Alliance for the Mentally Ill, the United Cerebral Palsy Association or the National Federation of the Blind. Some consumer organizations are organized on a national level, while others are primarily local organizations.

In addition to consumer organizations, there are organizations in every state that can provide helpful services to people with disabilities, ranging from information and referral through individualized legal representation. VR counselors can call these organizations directly, or refer their clients to these organizations. For purposes of this chapter, however, these organizations are listed but not discussed in detail. The list of helpful organizations includes, but is not limited to disabled student service offices on university campuses, State Rehabilitation Councils, Statewide Independent Living Councils, centers for independent living, university affiliated programs, regional rehabilitation continuing education programs, federally funded university research and training programs, and protection and advocacy agencies.

The benefit of involving the above-mentioned consumer, community and advocacy groups in the empowerment process cannot be overstated. However, it is impossible for a VR counselor to provide information to, or efficiently receive information from, all of these disability organizations by him or herself. As was pointed out above, there is a ready source for needed help—consumer organizations. It is incumbent upon the VR counselor and agency to join forces with the active and progressive consumer organizations in the state to provide the latest

information and to stress the significance of the empowerment model of assistance and support to these community partners.

Most VR counselors and administrators are aware of, and probably members of, professional organizations such as the Association for the Education and Rehabilitation of the Blind and Visually Impaired (AER) or the National Rehabilitation Association (NRA). These professional organizations serve an important role for VR professionals. Consumer organizations can serve an equally important role.

The importance of listening to and learning from consumers was emphasized in an address by Commissioner Joanne Wilson delivered at the National Federation of the Blind Jernigan Institute in Baltimore, Maryland. She stated:

I believe that true rehabilitation, the actual changing of blind people's lives, comes not just from technology experts or blindness professionals like me but from our working in partnership with consumer organizations. Consider the general business picture. When you look around at ordinary companies, you will see that some are just getting along and some are thriving. What makes the difference between these two groups? The successful businesses are able to reach beyond the standard resources that we think of: products, personnel, technology, and financial resources. They are tapping into hidden resources that have been under-used. The evidence shows that they are looking to their consumers, the people to whom they provide services. They invite consumers to join their boards and to take part in analysis of their products and services. In short, they are listening to consumers.

I was on a plane the other day and listening to a program. A man from an organization called Redhead Technologies was being interviewed. He explained that the company had not been doing very well. They looked at their corporate structure and discovered that they had a lot of inbreeding. So they began consciously listening to the people who used their products and making decisions based on what they learned. When they began involving consumers, the business took off. This is what the rehabilitation world needs to do. We can tap a valuable resource if we will partner with the organized blind in doing training and rehabilitation and education. We have vastly under-used that resource. We have maintained a wall between rehab professionals and [people with disabilities.] (*Braille Monitor* June 2004).

In Chapter 1 of this book, the Primary Study Group discusses several “barriers to empowerment and informed choice.” These barriers include the lack of knowledge, skills, support networks and understanding of disability-specific techniques. All of these deficiencies can be ameliorated or mitigated through the help and ready-made support network that exists within consumer group organizations. Consumer organizations can be vigorous advocates and can play a vital role in promoting disability awareness and providing public education about disability.

### *Consumer Groups—A Source of Knowledge and Information*

VR counselors and administrators can gain a wealth of knowledge from consumer groups representing people with disabilities. Who better knows which services are desired and needed than former consumers who have received VR services and are now successfully employed? VR counselors cannot be expected to know or fully understand disability-specific information for all disabilities. Consumer groups can provide knowledge about the following:

- Pros and cons of services or techniques to be provided or learned
- Effectiveness of a variety of available technology
- Efficient methods for self-advocating
- Information about rights and protections

These organizations can help the counselor in several ways. They allow the counselor to gain insight and a better perspective on various disabling conditions. Thus, the counselor will be better able to assist today's consumers. The members of each of these organizations—those who have had extensive experience with the VR process—can provide firsthand information about which VR programs or services are helpful and those that are less helpful. This information may offer a completely different perspective for the counselor than what is received from a textbook or in a lecture hall or laboratory.

The following paragraphs provide examples of information which VR counselors can receive from consumer groups.

- A consumer who is deaf or severely hard of hearing needs information and knowledge about choices of services. Will the consumer pursue technology to attempt to ameliorate a hearing disorder or choose to learn sign language? What services and equipment are available for telecommunication, communicating with doctors or other medical professionals, or requesting and receiving information about education or employment? Consumer groups of people who are deaf have knowledge and experience available on these subjects. Administrators and VR counselors are invited to participate in meetings and learn firsthand answers to some of these questions. Likewise, the counselor and consumer will both benefit from the perspective gained by discussing issues with consumer groups with different approaches to their disability.
- A blind or visually impaired consumer must make decisions about whether to learn Braille, learn why Braille is important, locate resources for acquiring printed material in Braille, available technology that produces Braille electronically, or decide whether to use voice output devices, large print screen reader technology, telescopes, lenses, and closed-circuit TV services for enhancing the use of low vision. Consumer groups for people who are blind or visually impaired have members who have firsthand experience in all of these choices and decisions.

- One of the greatest frustrations for people using wheelchairs is the lack of accessibility in many locations and environments. At a meeting of a consumer group for people with physical disabilities, a VR counselor or administrator can find information about how frustrating and limiting inaccessibility can be. Members of these groups have experienced inaccessibility due to narrow doorways, lack of curb cuts, constricted aisles and inaccessible restroom facilities. Some members of these consumer groups are expert in bringing about change through group advocacy, providing information about the Americans with Disabilities Act and providing information to the counselor and the consumer about locations for shopping, recreation, eating and other daily life activities. Some of the groups have taken legal action when locations have remained inaccessible.
- Technology is always changing and evolving. Technology used by people with disabilities is no exception to this rule. A VR counselor cannot be expected to, nor would it be possible to, stay current with all the latest software and hardware changes used by people with disabilities. VR counselors are frequently unfamiliar with new technology they are requested to include into an Individualized Plan for Employment (IPE). Members of consumer groups who use technology during their rehabilitation or during their employment can serve as a valuable resource to the VR counselor. A counselor can meet with members of a consumer group and learn how the technology functions and its usefulness to people with disabilities.
- Participating in group meetings, social events, and advocacy sessions with people with mental illness will provide VR counselors with information about the experiences of mentally ill people and choices about medications, treatments and ways to participate effectively in work settings.

The VR counselor and manager who believe in and embrace an empowerment model will participate in and refer their consumers to an appropriate consumer organization of people with disabilities. VR counselors are encouraged to become knowledgeable about and personally involved in the consumer organizations that are relevant to their consumers.

### *Consumer Groups—Adding Perspective to Informed Choice*

Knowledge alone is sometimes not useful. Effective rehabilitation counselors and administrators generally have knowledge about disabilities. Consumer groups, however, can bring the added perspective that makes that knowledge useful and effective.

In setting the stage for this book, we discussed the definition and importance of informed choice (see Chapter 1). Consumer groups can provide an invaluable resource to the consumer and his or her VR counselor when faced with making decisions under the informed choice provisions of the Rehabilitation Act. In 1995, then Commissioner Fredric K. Schroeder, Ph.D.,

delivered an address in which he discussed the importance of perspective in exercising informed choice. He gave the following example of the importance of perspective when making an informed choice:

Last July, when I began my work at the Rehabilitation Services Administration, I was required to complete the considerable volume of paperwork necessary to instate me as a bona fide federal employee. After I filled out the required documentation, the personnel specialist with whom I was working asked if I would be interested in the government's health insurance plan. When I indicated that I was, she told me that there were a number of plans from which I could choose. She took me to a room and began giving me brochures explaining the various options and suggested that I read each one and let her know which plan I wished to select.

I was surprised to find that there were perhaps fifteen or twenty different plans from which to choose, each with a detailed brochure explaining its individual provisions. Some that required a lower biweekly fee provided less coverage or higher co-payments. Some had networks of doctors; others allowed you to visit any doctor you wished. Some offered a list of doctors for whom you would pay less, but gave the option of paying more and seeing someone outside of its program. Some were HMO's, and others were traditional eighty/twenty plans. Some were hybrids offering various features of both. When I returned to my office, I began wading through the various materials and soon became overwhelmed by the quantity of information and the difficulty of finding common characteristics to use for comparison. Finally, in frustration I got up from my desk and went out into the outer office. There I stopped an RSA employee who happened to be handy and asked, 'Do you have the government health insurance?' He replied that he did. I asked, 'What plan do you have?' He told me he had Blue Cross. I said, 'Do you like it?'

He said, 'Yes, it's fine.'

'Great,' I said, 'I'm getting Blue Cross.' Later I weighed the brochures I had been given and found that I had thirteen pounds of printed material explaining my various options.

I had choice in selecting my health plan. I had all the information an individual could ever want. But my ability to exercise choice was limited, not by the lack of information, but by the lack of useful information. I had choice, but what allowed me to exercise my choice was contact with someone else who had real-life experience. As we look at defining choice for consumers of the VR program, I believe we should begin with an understanding that choice is more than lists, more than data, more than volumes of printed information. Real choice, the kind that people want, must include contact with others who can translate options into real-life experiences. (*Braille Monitor* August/September 1995).

A VR counselor who is concerned about empowerment can sometimes get stuck without a response to questions raised by a consumer. An enlightened counselor will not curtail or limit the employment choices of a consumer simply because the counselor does not see how a person with a disability could possibly do such a job. Empowered counselors can work with consumers and consumer groups to find a person with a similar disability doing almost every job imaginable.

One of the most empowering experiences a consumer can have is to visit with another consumer who has a similar disability and who is employed in a job that the consumer would like to have. Such a conversation can be critical in the empowerment process because the consumer now has a mentor—a person with a similar disability doing the job that has been identified as the employment objective in the IPE. Members of a consumer group can help the counselor and consumer by

- Identifying other people with disabilities who are doing similar jobs
- Identifying mentors who are willing to invite the consumer to job shadow
- Providing role models for identifying and teaching the disability-specific skills necessary to perform the required functions of a job
- Providing information about transportation available in the area
- Networking with other people with disabilities to identify job opportunities
- Discussing available technologies that make jobs accessible
- Identifying training centers, schools or other educational opportunities that lead to the desired job

Despite a counselor's best efforts to help a consumer learn and understand the VR system, the consumer might feel overwhelmed, confused and frustrated. A consumer group usually has members who have experienced the rehabilitation process. Consumer group members can help explain the VR process, and can even assist by making suggestions for services or items to be included in an IPE. Consumer group members can share information about the process for completing an IPE, as well as the process for appealing an adverse decision about the completion or implementation of an IPE. Most counselors understand that genuine differences of opinion concerning the preparation or the implementation of an IPE will sometimes occur. Ensuring that consumers have the opportunity to meet with and learn from other consumers who are similarly situated is a critical part of helping a consumer to be empowered. Rather than feeling threatened or annoyed, a counselor concerned with consumer empowerment will welcome the input and suggestions from the consumer group members who have already been through the process.

Despite repeated assurances to the contrary, a consumer who receives a referral from his or her counselor to visit with a Client Assistance Program (CAP) may question or mistrust the referral made by the counselor. A suggestion by the counselor that the consumer visit with other members of the consumer group about the CAP program, or his or her appeal rights, can bring assurance and added empowerment to the consumer.

One of the most beneficial elements of consumer groups to a VR counselor and consumer is the networking and information-sharing aspect. A VR counselor concerned with a consumer's empowerment will encourage the consumer to contact other people with similar disabilities to gain information about employment opportunities, education, and skills necessary to perform the required duties of their employment.

The views of veteran VR consumers within consumer groups will be based upon the experiences—both good and bad—that they and their friends have had. The new consumer can then judge for himself or herself whether those experiences relate to the goals and ambitions he or she has.

### *Advocacy*

Consumer groups all across America have become very informed about the legislative process and have organized efforts to bring about changes on behalf of people with disabilities. Some states even have formal organizations consisting of members from a variety of consumer groups who focus on proposed legislation in their state. These consumer organizations have been successful in bringing about much-needed reform in a variety of areas relating to disability issues. There are few groups more effective and efficient in grabbing the attention of state and federal legislators than a well organized consumer group armed with an important issue. VR counselors and administrators can benefit from the land swell of enthusiasm for change and improvement generated by well-organized and legislatively-minded consumer groups.

State Rehabilitation Councils (SRCs) are a vital part of the VR system in every state. By law, people with disabilities must occupy several positions on SRCs. VR administrators can contact consumer groups to receive nominations for individuals to serve on SRCs. Nominees from consumer groups will bring the information and perspective representative of their consumer groups. Encouraging consumer groups to provide nominees to serve on the SRCs ensures a broader base of representation on the part of people with disabilities. [Since this writing, RSA has initiated a series of trainings focused on empowering SRC participants to advocate for improvements in the VR program in order to enhance opportunities for high quality employment for individuals with disabilities. For more information on this training contact the Regional RSA offices.]

Consumer groups can also serve as advocates for individuals dealing with environmental and attitudinal barriers to employment. Although civil rights legislation is in place, VR

consumers still sometimes experience discrimination in the workplace, educational settings, social environments, etc. This is very nearly impossible to face and overcome alone. If the consumer is aware of and connected with an organized and strong consumer group, he or she will have a built-in support system and an established mechanism for challenging and overcoming the discrimination.

The Disability Law Center in Utah was contacted by a deaf individual requesting assistance in an appeal before that state's Medicaid agency. The issue facing the deaf consumer was an archaic state regulation and the lack of understanding on the part of the state's Medicaid agency concerning technology that was medically necessary for the individual's rehabilitation. The staff of the Disability Law Center contacted the deaf consumer group in that state to learn more about the technology being requested, the deafness condition experienced by the consumer, the advantages and disadvantages of technology used by deaf and hard of hearing individuals and information about deaf and hard of hearing culture. The deaf and hard of hearing consumer group provided the deaf consumer and her representatives with perspective about the technology being requested and a support network of other deaf individuals using the same technology. The consumer group was able to suggest vendors and providers of service and helped provide the Disability Law Center with good information as it proceeded to represent the individual before the Medicaid hearing officer. Because of the collaborative effort of the VR counselor, the staff of the Disability Law Center and a deaf and hard of hearing consumer group, the state's Medicaid policy concerning medically necessary technology for deaf and hard of hearing people was improved and the individual received the needed technology and moved further along the road of empowerment.

Another example of effective advocacy by consumer groups is illustrated by a consumer group that came to the assistance of a blind school teacher. This blind individual attended a training center where she learned the skills necessary to read and write Braille, to travel independently and to maintain her independence. The VR agency that had provided the rehabilitation training was also instrumental in assisting her in obtaining employment as a school teacher, which was her employment objective. Despite excellent annual performance ratings, the school district terminated the blind school teacher based solely on the fact that she was blind. The National Federation of the Blind learned of this situation and advocated, wrote letters and provided legal representation on her behalf. The result was that the school district corrected its erroneous decision. The VR agency was not required to help find another job and the blind individual remained successfully employed and empowered.

## Mentoring

One of the most powerful tools a VR counselor can provide to a consumer striving for true empowerment is that of a role model or mentor. The members of consumer groups are a ready source for enlightened, educated and empowered role models and mentors. A consumer struggling with self-confidence or self-efficacy issues can benefit immensely from having access

to one of these role models or mentors. These mentors are frequently willing to meet with the consumer in a social setting—one that will inspire and facilitate free-flow of ideas and emotions—to discuss questions and problem solve together.

The mentor will have insight into available jobs, transportation issues, living arrangements, service providers, educational opportunities, recreational opportunities and opportunities to provide service. Information on all of these issues can be provided by a mentor, backed with the resources of a consumer group. These issues play a critical role for a consumer who is moving toward empowerment.

Finally, there is the issue of a consumer's "giving back" and what it can do for personal empowerment. In *Freedom For The Blind*, James H. Omvig (2002) introduces a concept he refers to as "the empowerment circle" (see p. 60). Omvig points out that to close the loop completely on the empowerment circle, the final step in the relationship between the consumer and the consumer organization, i.e. the final link in the quest for empowerment, is for that new consumer not only to become aware of, but also to get outside of himself or herself and to become actively involved in the appropriate organization. His or her personal empowerment will truly be completed by getting involved and helping to make life better for other people with disabilities. Soon, this new consumer will be the empowered mentor, inspiring and encouraging and giving hope to another person with a disability who is just beginning his or her road to empowerment. This new role for the consumer will be empowering, since one gains enormously by giving back.

## Conclusion

This book focuses on empowerment and, as we have discussed, becoming empowered is a collaborative process; it does not happen alone. The empowerment process is facilitated by enlightened VR counselors, managers, administrators, policymakers and consumer groups. The progress toward empowerment is greatly facilitated when a VR counselor and agency acknowledge and participate in the vital role that consumer groups play in the empowerment process with the individual.

VR counselors and managers can take advantage of the critical and effective tools for reaching empowerment provided by consumer groups. Below are a few suggestions for taking advantage of this powerful tool for empowerment.

- Identify the consumer groups in your area dealing with disabilities in which you are interested. These consumer groups can be identified by using the Internet, searching business and commercial sections of telephone directories, making inquiries to your local protection and advocacy program, or contacting your Client Assistance Program.
- Contact a local leader and explain that you wish to learn more about the disability group he or she represents.

- Meet with the local leaders and explain that you would like to partner with them. Explain that you would like to share information with the consumer group about the VR process and receive information about job opportunities, available technology, mentoring and other opportunities which the consumer group may provide.
- Attend a local or state convention of the consumer group and invite consumers to attend with you.
- Request from the local leaders to have a mentor assigned to meet with and serve as a role model for a consumer.
- Recommend that a member of the consumer group be nominated for the Statewide Rehabilitation Council.

### Study Questions

- 1. Consumer groups can provide VR consumers with information on**
  - (a) VR services and procedures
  - (b) Available technology and adaptive equipment
  - (c) Information about rights and protections
  - (d) All of the above
- 2. Consumer groups can support VR consumers facing discrimination by providing**
  - (a) Peer support
  - (b) Access to the organization's legal resources
  - (c) Input to policymakers
  - (d) All of the above
- 3. Consumer groups can provide \_\_\_\_\_ to informed choice.**
  - (a) fun
  - (b) legitimacy
  - (c) perspective
  - (d) choice
- 4. Members of consumer groups can mentor VR consumers by**
  - (a) Inviting the VR consumer to job shadow
  - (b) Connecting them to a network of other people with disabilities to identify job opportunities
  - (c) Providing information about transportation, social activities, training, etc.
  - (d) All of the above
- 5. VR counselors can take advantage of the support and opportunities consumer groups provide by**
  - (a) Referring consumers to consumer groups
  - (b) Recommending members of consumer groups for membership on the State Rehabilitation Council
  - (c) Both (a) and (b)
  - (d) None of the above