

Value-Added Services: Using Consumer Organizations to Enhance Successful VR Outcomes¹

Suzanne Mitchell, Charlene Dwyer, and W. Scott Forbes

The 2000 U.S. Census found that 56.6% of working-age Americans with disabilities are employed compared with 77.2% of non-disabled Americans (U.S. Census Bureau, 2000). This employment gap points to the need for innovative practices and greater resources in the vocational rehabilitation (VR) process so that persons with disabilities can achieve parity in the work world. When the growing number of Americans with disabilities in need of VR services is coupled with ever-tightening resources in the public VR program, collaboration between consumer organizations and VR can be viewed as both critical and economically expedient.

Consumer organizations have historically been in the forefront of major changes in the Rehabilitation Act as well as in other sweeping legislation affecting persons with disabilities. These organizations can be a mechanism by which both “individual and professional needs and desires are expressed in the political process” (Grabois, 2001). Ann Ford, executive director of the Illinois Network of Centers for Independent Living, noted that consumer organizations, and in particular centers for independent living, can and should advocate to lawmakers and policymakers when rules and laws have unintended negative consequences or

may not be helping. Conversely, she acknowledged that people working in an official capacity with a state VR agency might not be able to be involved (A. Ford, personal communication, January 25, 2005). One rationale for collaboration is to refine, and in some cases revise, public law and policy.

The concept of self-direction and empowerment—that the consumer should direct his or her life and any rehabilitation he or she chooses—is not new. This concept is embedded in the philosophy of most consumer organizations, advocacy groups, and in particular in the independent living movement (DeJong, 1979). The evolution of VR has seen the public VR program move away from a medical model paradigm, in which the “deficit” resides in the individual who needs to be “fixed,” toward an empowerment or independent living paradigm, in which limitations and barriers are viewed in the context of the environment, and services are constructed to allow for consumer empowerment and consumer informed choice. Consequently, the VR counselor’s role has shifted to that of a uniquely skilled “change agent” who assists consumers with disabilities to realize their full potential through knowledgeable expertise, guidance, and counseling. This paradigm shift is clearly consumer-directed and offers an additional rationale for collaboration between consumer organizations and VR.

The 17th Institute on Rehabilitation Issues (IRI) publication (Thayer & Rice, 1990, as cited in Stoddard & Premo, 2004) examined collaboration between VR and one variant of consumer organizations, centers for independent living (CIL). It was noted that many of the services a CIL extends to individuals with disabilities, such as independent living skills training, self-advocacy, and positive peer modeling, are sometimes described as precursors to successful employment (Stoddard & Premo, 2004). Other consumer organizations, most notably those that work with the blind and

¹ Excerpted from Dew, D. W., & Alan, G. M. (Eds.). (2006). *Consumer organizations: Important resources for vocational rehabilitation agencies* (Institute on Rehabilitation Issues Monograph No. 31). Washington, DC: The George Washington University, Center for Rehabilitation Counseling Research and Education; pages 35-36 and 42-47). Downloaded from <http://www.iriforum.org/books.aspx> 9/1/2015

deaf-blind, have been responsible for crafting programs based upon their philosophies to promote success in the VR process.

Another potential role for consumer organizations in the VR process is to assist the VR counselor in helping the consumer learn about probable careers. One way that this is done is through formal and informal mentoring. An example is the Coalition of Citizens with Disabilities in Illinois and its work with the Illinois Office of Rehabilitation Services on Disability Mentoring Day (Hayes & Kidd, 2004). Disability Mentoring Day is an international event officially commemorated on the third Wednesday of October; it was started in 2001 by the American Association of People with Disabilities. The goal of Disability Mentoring Day is to promote career development by allowing students and job seekers with disabilities opportunities for job shadowing and hands-on career exploration. Members of the Coalition of Citizens with Disabilities in Illinois coordinated with staff of the Illinois Office of Rehabilitation Services to place interested students in locations throughout the state. During 2003, RSA provided a million dollars to fund a 5-year mentoring program.

Clearly, consumer organizations have multiple roles to play in the VR process, which can support the vital work of the VR counselor, ranging from political advocacy to mentoring to assistance in traversing the rehabilitation system and the myriad of disability-related programs...

Utilizing Consumer Organizations in the Implementation of the IPE

Consumer organizations can provide services or assist in accessing services required by the IPE. Although certainly not an exhaustive list, several examples are cited below relating to particular aspects of the Act.

Under Sec. 103(a) of the Act, VR services are defined as follows:

any services described in an individualized plan for employment necessary to assist an individual with a disability in preparing for, securing, retaining, or regaining an employment outcome that is consistent with the strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice of the individual, including—

- 1) *an assessment for determining eligibility and vocational rehabilitation needs by qualified personnel, including, if appropriate, an assessment by personnel skilled in rehabilitation technology (p. 71).*
- Rehabilitation counselors have an ethical responsibility to provide informed choice to consumers. Consumer organizations very often have a good sense, particularly in the area of rehabilitation technology, of qualified and knowledgeable personnel based upon their own experiences. Together, they can help consumers make an informed choice by providing feedback and information on assessment resources and professional providers based on their experience and satisfaction levels.
- 2) *counseling and guidance, including information and support services to assist an individual in exercising informed choice consistent with the provisions of section 102(d) (p. 71).*
- Several consumer organizations offer training in self-advocacy and self-determination for individuals with disabilities.
- 3) *referral and other services to secure needed services from other agencies through agreements developed under section 101(a)(11), if such services are not available under this title (p. 71).*

- Consumer organizations are an excellent source for providing information and services outside the scope of those offered by VR. Specifically, a CIL can provide VR consumers with information about community resources such as transportation and disability-related programs and services.

- Several consumer organizations have worked collaboratively with prescription drug services, technology providers, medical suppliers, and others to offer low-cost alternatives. For example, the American Association of People with Disabilities offers a low-cost prescription plan to its members.

4) *job-related services, including job search and placement assistance, job retention services, follow-up services, and follow-along services (p. 71).*

- Consumer organizations often have job related services that can benefit VR consumers and assist VR counselors, such as Jobline (1-800-414-5748), which is operated through the National Federation of the Blind but is accessible to anyone with a disability.
- The American Association of People with Disabilities offers a Federal Information Technology Internship Program in conjunction with Microsoft for disabled college students to work on Capitol Hill and in various federal agencies during the summer. This is in addition to sponsoring a Congressional Internship Program and a national Disability Mentoring Day. The American Council of the Blind maintains a nationwide job bank on its website, www.acb.org.

5) *vocational and other training services, including the provision of personal and vocational adjustment services, books, tools, and other training materials, except that no training services provided at an institution of higher education shall be paid for with funds under this title unless maximum efforts*

have been made by the designated State unit and the individual to secure grant assistance, in whole or in part, from other sources to pay for such training (p. 71).

- Adjustment-to-disability services (or adjustment services) are a comprehensive and integrated set of services that include counseling, mentoring, and other services designed to provide individuals with disabilities with the confidence, disability-specific skills, interpersonal skills, and positive attitude toward disability needed to achieve competitive employment and independence. These services, which are especially critical to individuals with significant disabilities, may include any services that assist the individual in living and working with a disability or lead to holistic adjustment. Examples may include orientation and mobility services for individuals who are blind, training in the use of communication aids for individuals who are deaf or do not speak, and activities of daily living training. There are a host of consumer-driven service providers associated with consumer organizations who offer these services, especially in the blindness, deafness, and mental illness arenas.
- Collaboration with consumer organizations 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. Furthermore, consumer organizations possess experience and knowledge concerning the providers of adjustment services and are well prepared to assist VR counselors and individuals in the selection of the providers best suited to deliver these essential services.

- Some consumer organizations offer training (particularly computer or assistive technology training) that can benefit VR consumers.
 - Several consumer organizations have state or local chapters for students as well as materials to assist students on college campuses.
- 6) *to the extent that financial support is not readily available from a source (such as through health insurance of the individual or through comparable services and benefits consistent with section 101(a)(8)(A)), other than the designated State unit, diagnosis and treatment of physical and mental impairments, including—*
- (A) corrective surgery or therapeutic treatment necessary to correct or substantially modify a physical or mental condition that constitutes a substantial impediment to employment, but is of such a nature that such correction or modification may reasonably be expected to eliminate or reduce such impediment to employment within a reasonable length of time;*
 - (B) necessary hospitalization in connection with surgery or treatment;*
 - (C) prosthetic and orthotic devices;*
 - (D) eyeglasses and visual services as prescribed by qualified personnel who meet State licensure laws and who are selected by the individual;*
 - (E) special services (including transplantation and dialysis), artificial kidneys, and supplies necessary for the treatment of individuals with end-stage renal disease; and*
 - (F) diagnosis and treatment for mental and emotional disorders by qualified personnel who meet State licensure laws (pp. 71-72).*
- Although consumer organizations do not generally provide any of these services directly, they have collective experience with these services and the outcomes of these services that may be of some benefit in offering information about the advantages and disadvantages of a particular service or service provider and, thus, enable the VR consumer to make a more informed choice.
- 7) *maintenance for additional costs incurred while participating in an assessment for determining eligibility and vocational rehabilitation needs or while receiving services under an individualized plan for employment;*
- 8) *transportation, including adequate training in the use of public transportation vehicles and systems, that is provided in connection with the provision of any other service described in this section and needed by the individual to achieve an employment outcome (p. 72).*
- A handful of consumer organizations provide transportation services or handle local contracts for transportation services. Several more are available to train persons with disabilities in the use of public transportation. Since transportation has been viewed as a major barrier to employment, it has received attention from many consumer groups who continue to advocate for improvements in transportation. An example of a local consumer organization that provides transportation is Affiliated Blind of Louisiana, Inc.
- 9) *on-the-job or other related personal assistance services provided while an individual is receiving other services described in this section (p. 72).*
- Independent living centers may assist in providing personal assistance services or assisting consumers in accessing needed services.

10) interpreter services provided by qualified personnel for individuals who are deaf or hard of hearing, and reader services for individuals who are determined to be blind, after an examination by qualified personnel who meet State licensure laws (p. 72).

- Consumer organizations can assist with information about interpreter services and other related services and information for individuals who are deaf. A website with lists of organizations can be found at <http://clerccenter.gallaudet.edu/InfoToGo/184.html>.
- Through the efforts of consumer organizations of the deaf or hard of hearing, states have developed relay systems and hearing aid programs.

11) rehabilitation teaching services, and orientation and mobility services, for individuals who are blind (p. 72).

- The National Federation of the Blind created a National Blindness Professional Certification Board to certify qualified specialists in work with the blind. The rigorous process for the National Orientation and Mobility Certification represents the professional excellence endorsed by consumers and offers an alternative to traditional certifications with equally demanding standards.
- Quality service providers have emerged or transformed their operations to reflect the philosophies, choice, and interests of consumer organizations in recent years and offer alternatives solidly based on both professional and collective consumer experience. Examples include nonprofits such as the Louisiana Center for the Blind, Colorado Center for the Blind, BLIND, Inc. in Minnesota, and several public state operated programs.

12) occupational licenses, tools, equipment, and initial stocks and supplies (p. 72).

- National consumer organizations may be a source of tools, equipment, and supplies related to occupational needs, and some consumer organizations, such as the National Federation of the Blind, have established licensing or certifying bodies.

13) technical assistance and other consultation services to conduct market analyses, develop business plans, and otherwise provide resources, to the extent such resources are authorized to be provided through the statewide workforce investment system, to eligible individuals who are pursuing self-employment or telecommuting or establishing a small business operation as an employment outcome (pp. 72-73).

- Grassroots consumer organizations in mental health and mental illness offer a conduit to many programs that assist individuals in employment.
- Consumer groups such as the Randolph-Sheppard Vendors of America and the National Association of Blind Merchants offer valuable assistance and consultation to individuals pursuing entrepreneurial activities.

14) rehabilitation technology, including telecommunications, sensory, and other technological aids and devices (p. 73).

- The American Association of People with Disabilities provides its members a low-cost option from America Online for Internet access.
- The International Braille and Technology Center operated by the National Federation of the Blind provides technical assistance and training.
- The American Association of Deaf-Blind provides information and referral related to technology and manufacturers.

- The National Association of the Deaf provides extensive information on assistive technology devices and services.
- Several consumer organizations offer local and statewide seminars and training on assistive technology.

15) *transition services for students with disabilities that facilitate the achievement of the employment outcome identified in the individualized plan for employment (p. 73).*

- The American Association of People with Disabilities and other organizations sponsor mentoring programs and activities for transitioning youth.
- The National Federation of the Blind helps sponsor summer training and employment programs in various states to assist transitioning students.
- Self Help for Hard of Hearing People produces *A Peer Guide for the College Student Who is Hard of Hearing*, which can be found on its website at www.shhh.org. Self-Advocates Becoming Empowered (www.sabeusa.org) has People First organizations in virtually every state who provide self-determination training and advocacy training to assist students with disabilities who are transitioning.

16) *supported employment services (p. 73).* Many consumer groups for the mentally ill have worked to secure employment for their members in the supported employment arena.

17) *services to the family of an individual with a disability necessary to assist the individual to achieve an employment outcome (p. 73).*

- Perhaps the most valuable service to the family of an individual with a disability is information about and understanding of a disability. Consumer organizations can offer role models, expectations regarding employment and independent living, peer support, advocacy, and, most of all, hope.

Several organizations have parent divisions or activities for siblings.

18) *specific post-employment services necessary to assist an individual with a disability to retain, regain, or advance in employment (p. 73).*

- Consumer organizations offer continued support emotionally along with mentoring to assist individuals in maintaining and advancing in employment. Many organizations have projects with the business community that offer opportunities for jobs and advancement in careers. Others have available opportunities for employment in their headquarters offices, which can provide experience that will lead to other employment.

As specified in the Act, other services “necessary to assist an individual with a disability in preparing for, securing, retaining, or regaining an employment outcome that is consistent with the strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice of the individual” can be provided. Many states have authorized individuals with disabilities to attend professional and consumer organization conferences if they are related to the employment goal (see Appendix).

The Benefits Consumer Organizations Offer to the Rehabilitation Counselor and the Consumer

Increased consumer organization involvement in the VR process can offer many potential benefits to consumers:

- (a) greater control over his or her rehabilitation outcome as a result of advocacy skills and exposure to others who have successfully negotiated the VR process;
- (b) more access to information, allowing for greater informed choice;

- (c) greater networking possibilities;
- (d) development of “soft skills,” including improved interpersonal communication and self-presentation skills;
- (e) decreased feelings of isolation and loneliness;
- (f) access to peer learning and peer counseling, allowing opportunities to get answers to questions in a nonclinical, nonthreatening environment; and
- (g) continued support emotionally and socially.

The benefits to the rehabilitation counselor from increased consumer organization involvement in the VR process can include

- (a) an increased number of successful rehabilitation closures as consumers are empowered to be active participants in their rehabilitation;
- (b) a reduced rate of consumer recidivism because empowered consumers are better able to exercise informed choice;
- (c) positive changes in legislation and policy that result from consumer organization advocacy;
- (d) increased job satisfaction as more consumers are able to achieve their vocational goal;
- (e) an increased understanding of the nature of consumers’ experiences with disability as a result of immersion or joint training experiences between VR and consumer organizations;
- (f) a better working alliance between the counselor and consumer that helps the counselor provide better career guidance; and
- (g) improved relationships with the local community, increasing the counselor’s ability to access information on local employment trends.

Consumer Organizations as Support Systems

The value and importance of an ongoing system of support is recognized only after the consumer’s basic rehabilitation needs have been largely met. In many instances, the consumer seeks ongoing support by entering the revolving door of the rehabilitation system itself. In times of “crisis” the consumer turns to the most familiar system, that which helped in the past to solve ensuing problems—regardless of whether that system is the most appropriate. Consumer organizations can offer an alternative first step for the consumer to address problem areas and receive emotional support. In the event the area of concern requires intervention from the rehabilitation counselor or program, the consumer organization can often assist the consumer in articulating his needs to the rehabilitation counselor. Perhaps the greatest promise of consumer organizations as support systems, however, is the opportunity they present for consumers to “give back” to others what has been given to them. Not only is this empowering to the individual, but it also increases the value and effectiveness of the VR system and the consumer organization.

By now, it is clear that there are many value added benefits to partnering with consumer organizations to serve the common customer — the VR consumer. The imaginative counselor will have no difficulty identifying and locating consumer organizations through many of the following resources and activities: web search engines such as Google; the State Rehabilitation Council; providers of services and community rehabilitation programs; past and present VR customers; colleagues; agency public forums; government disability offices; the state independent living council; the RSA; disability literature; professional conferences; professional organizations; and more. One only has to imagine that he or she is advocating on behalf of a loved one with a disability to learn how to turn over the rocks and discover a plethora of resources including consumer organizations.

In summary, consumer organizations and VR counselors are beginning to discover the benefits and challenges of working together for the good of persons with disabilities. These pioneering partnerships require a sense of trust and mutual respect. In the VR process, the most important results come from the beliefs and expectations of those who surround the consumer. Those beliefs and expectations come from understanding the true nature of disability, and that understanding deepens with exposure to and immersion in each other's cultures—the dedicated professionalism of the VR system and the passion of consumer organizations.

Alone we can do so little; together we can do so much. —Helen Keller