

Chapter 1:

Toward an Empowered Consumer

This chapter outlines the purpose of and audience for this document, gives a brief history of the initiatives behind this document, and defines empowerment and informed choice as they are used in this document.

Our Vision

During our first meeting in Chicago, Illinois (October 2002), the 29th Institute on Rehabilitation Issues (IRI) Primary Study Group (PSG) had the privilege of holding a conference call with Rehabilitation Services Administration (RSA) Commissioner Joanne Wilson. In that meeting, Commissioner Wilson encouraged us to “Look at the system and see if you can put the big rocks in. Look at the philosophy and heart and soul of the system.” The PSG took this to mean that she was challenging us to build a solid foundation describing the values and processes of empowerment, informed choice and self-determination.

The PSG members quickly agreed that our task would require more than laying a foundation. It would require us to provide tools for vocational rehabilitation (VR) counselors and consumers to build the foundation for a successful and empowering VR services program. In the end, the PSG’s challenge included clarifying values, providing guidance for foundation building and, perhaps most difficult, making practical suggestions.

The preamble to the Rehabilitation Act Amendments of 1998 (the Rehab Act)(29 USC 701 et. seq.) states that one purpose of the Act is “to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society.” With this language, Congress made a clear statement that the purpose of the VR program is not simply to find a person a job, but to have “elevated expectations” and find people high quality jobs that allow individuals to become self-sufficient. Consumers are at the center of the empowerment process. In fact, a key tenet of the VR program calls for individuals (and, if appropriate, their family member(s) or other representatives), to fully participate in every aspect of the rehabilitation process. From the time the individual is referred or applies for VR services until the individual exits the program, he or she is to be actively engaged in each decision that impacts the services that the individual receives.

Empowerment and Informed Choice

What is empowerment and why is it important? It means different things to different people. Some people use “self-determination” or “consumer-direction” as a way of referring to empowerment. It can be difficult to make sense of the various definitions found on the Internet, in consumer newsletters and in professional articles. Certain terms are often used by particular

groups. For example, people with developmental disabilities and their advocates often use the term “self-determination” instead of empowerment. After a lot of research, this IRI Study Group has decided that empowerment and self-determination are quite similar. In fact, a previous IRI explored self-determination (Twenty-First Institute on Rehabilitation Issues, 1995). “Empowerment” and “informed choice” are used throughout the Twenty-Ninth IRI document *Promoting Consumer Empowerment Through Professional Rehabilitation Counseling* and are defined below.

Empowerment means control. An empowered consumer has control over his or her own life. An empowered consumer has the knowledge, skills, supports, resources and confidence necessary to exercise that control in determining and achieving life goals. Those goals include things such as employment, economic self-sufficiency, independence and inclusion and integration into society. An empowered consumer knows that decisions about life and life’s goals are his or her own.

Empowerment is an intangible process that is difficult to measure. The word “empowerment” is often used, but it can become meaningless. People often assume that empowerment occurs, but it can be difficult to determine whether a person is empowered. Many people believe that empowerment naturally comes from the rehabilitation outcomes themselves—you get a job; you are empowered. Because of this, it is easy to believe that there is nothing more to do. But consumers told Congress that the Rehabilitation Act needed to be strengthened by adding informed choice.

Informed choice is a decision-making process integral to empowerment. Without informed choice, full empowerment cannot exist. Through informed choice, the consumer accesses and analyzes information and determines his or her vocational goal(s), services and service providers. An empowered individual exercises this decision-making process in all aspects of the VR process. “Choice is more than lists, more than data, more than volumes of printed information. Real choice, the kind that people find useful, must include contact with others who can translate options into real life experiences” (Schroeder, 1995, p.6).

Informed choice has not been viewed consistently as a method by which empowerment occurs. Some VR professionals believe, “We have been doing this for years” or wonder, “Are you telling us to give consumers whatever they want?” While it is true that many VR counselors have been supporting consumer empowerment gradually, it has become clear that there are systemic issues in VR that must change if consumers are to be truly empowered. There is a real tension between the intent of the Rehabilitation Act and the inherent systemic constraints to implementation. Constraints like state regulations, funding requirements, RSA regulations and accountability requirements all contribute to the challenges facing VR counselors and consumers as they navigate the system.

Brief History

Consumer empowerment has a deep history and has been an ongoing concern of consumers, consumer groups and families. Efforts have also been made at the federal level to guarantee consumer empowerment, self-determination, and informed choice for the past three decades. These three terms have not always been used to describe Federal efforts, but they have been integral values in these efforts.

Four significant Federal initiatives stand out. First, Section 504 of the Rehabilitation Act of 1973 was one of the earliest legislative acknowledgements that people with disabilities deserved civil rights protections in employment and places of public accommodations. Soon afterward, in 1975, the Education of the Handicapped Act (EHA) was approved. The EHA was the first legislation that guaranteed that children with disabilities had the right to a free appropriate public education. It exists today in its most recent form as the Individuals with Disabilities Educational Act (IDEA) of 1998. Third, the Americans with Disabilities Act (ADA) of 1990 was approved. The ADA prohibits discrimination on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation and telecommunications. Finally, in 1998, Section 101(a)(7) of the Rehabilitation Act Amendments required rehabilitation counseling staff to have or be working toward having the professional level skills and preparation needed to support consumer empowerment.

At times, Federal initiatives have been intertwined with consumer group initiatives or goals. In 1997, Dr. Fredric Schroeder, Rehabilitation Services Administration (RSA) Commissioner, implemented a policy of “high quality” employment for consumers using rehabilitation services. Dr. Schroeder was also a leader in the National Federation of the Blind, a powerful consumer organization. His policy initiative, RSA Policy Directive (PD) 97-04, was an important effort to abolish consumer underemployment.

Barriers to Empowerment and Informed Choice

Individuals with disabilities seeking services from the public rehabilitation program often encounter barriers that can interfere with empowerment and informed choice. This may result in an inability or limited ability to exercise informed choice in planning and directing their own programs of rehabilitation. There are many different barriers facing individuals. These include limited knowledge, limited skill and resources, attitudes of professionals and other individuals, constraints of the VR system and disability-specific and psychological factors.

Individuals with a disability may encounter different barriers of different type and magnitude. The IRI Study Group believes that an understanding of the possible barriers is critical to addressing them. Potential obstacles are listed below.

- **Knowledge**

Knowledge is important for becoming empowered to choose, plan and make decisions about one's rehabilitation plan. Two types of knowledge are essential: self-knowledge and knowledge of the world in which an individual wishes to function. Several studies of rehabilitation outcomes have identified limited self-awareness as the major obstacle to attaining successful outcomes. Accurate knowledge of one's strengths and weaknesses, knowledge about one's disability and the impact of that disability on one's goal is very important to identifying one's rehabilitation needs. Without accurate self-knowledge, an individual may have difficulties identifying what is needed in a rehabilitation plan. He or she may encounter difficulty in effectively using the rehabilitation counselor as a resource. Lack of self-knowledge of interests and preferences may limit career development. Limitations in self-awareness may also result in setting vocational goals that may not consider one's strengths and weaknesses, resulting in perceptions by others that the goals are unrealistic or unattainable.

The individual also needs knowledge of the world when exercising empowerment and informed choice. Examples of knowledge areas include knowledge of possible options (work, education, independent living, social), available resources and services, laws and funding possibilities. Individuals must also have knowledge of their rights and the systems they must navigate to get necessary services. If an individual has not had the opportunity to acquire such critical knowledge, he or she may be limited in ability to take control and be effectively empowered. There are various ways of acquiring knowledge if the individual with a disability is limited in his or her ability to understand the complexities of the rehabilitation process. For example, when an individual has cognitive limitations, his or her supporters (e.g., family, friends, advocates) can help provide the knowledge necessary for the rehabilitation process.

VR counselors are required to provide consumers with sufficient information so that the consumer can exercise empowerment and informed choice. The Rehabilitation Act and its regulations require the VR system to assure that persons with disabilities, including those with the most severe disabilities, be given information and opportunities to choose their own goals and objectives, services and service providers. Furthermore, the Act requires that the Individualized Plan for Employment (IPE) "be developed in a manner that affords eligible individuals the opportunity to exercise informed choice in selecting an employment outcome, the specific vocational rehabilitation services to be provided under the plan, the entity that will provide the vocational rehabilitation services, and the methods used to procure the services..." (Sec 102(b)(1)(B)(x)).

VR counselors and supervisors need knowledge to be empowered, just as consumers do. For example, the VR counselor's ability to find appropriate supports, connect the consumer to community agencies or employment opportunities, and support the empowerment of the consumer depends on his or her knowledge of resources, options and possible solutions. One of the most critical knowledge areas for today's VR counselor is an understanding of cultural

diversity and its implications for VR counseling. Empowerment and informed choice are impacted by the knowledge of both consumer and VR counselor while supported by supervisors, administrators and the VR system as a whole.

- **Resources**

Resources are essential in the VR process. Rehabilitation resources include the services of a qualified rehabilitation counselor, adequate funding for services, accommodations and modifications (including assistive technology), transportation and a support network. Access to vocational training, mentors and jobs are also important resources. Knowledge of and connections with culturally appropriate resources are also important. Achieving success in addressing severe disability often hinges on finding the necessary resources in a baffling and overburdened system.

The VR system's ability to provide appropriate resources is important, too. Systemic resources, such as community relationships and supportive policies, can create an atmosphere in which consumers and counselors successfully achieve the consumer's goals. The VR counselor's ability to identify, utilize and coordinate with resources is also a key to a successful VR process.

- **Skills**

To effectively direct one's own rehabilitation, a number of skills and competencies are important. These can include effective communication skills (both spoken and written), assertion and self-advocacy skills, organizational skills and planning and problem-solving abilities. Other skills and competencies include listening and learning skills, negotiation and compromising ability, self and system evaluation and monitoring skills. Not all such skills are inherent in individuals. There are several ways to address consumers' needs to develop these skills. They include training and supports through counseling, referral to community-based programs (e.g., community colleges or rehabilitation providers), and the use of mentors. To address this need, public VR agencies may even have to develop new resources.

As with previous barriers, VR counselors need those same skills to assist in achieving successful outcomes. Counselors also need effective communication skills, assertion and self-advocacy skills, organizational skills, planning and problem solving abilities, listening skills, negotiation and compromising ability and self and system evaluation and monitoring skills. The need for cultural sensitivity is one challenge in communication and other skill areas influencing the VR process. Cultural sensitivity requires a systemic support, from top to bottom, of responding to cultural differences as they impact the counseling and high quality employment processes.

- **Disability-Specific Obstacles**

In some cases, functional limitations may serve as barriers to self-direction. For example, cognitive disabilities (problems comprehending, organizing, and retaining new information; difficulty making an appraisal of one's own competencies, and difficulty making vocational choices) hinder self-direction. Likewise, the motivation and energy that are required to take charge over one's life and rehabilitation may be limited by any disorder that depletes energy and negatively influences the capacity to experience enthusiasm and interest.

Some disabilities impact communication skills or the capacity to make judgments. While individuals with these impairments are equally entitled to become empowered and self-determined, creative strategies may be needed to enable them to self-direct. When disability-specific barriers are present and cannot be alleviated, it is important to include supportive family, friends, advocates or others in the VR counseling process.

Disability-specific obstacles can be external to the consumer. For example, a local VR office that has staff and administrators with a broad range of knowledge, skills and resources is more likely to have success with the VR process. An office without the necessary breadth, that cannot adequately meet the needs of individuals with particular disabilities, is less likely to have success.

- **Attitudes**

One of the biggest barriers to self-direction is attitude. It might be the attitude that is imbedded within a model defining how rehabilitation is accomplished. For example, the medical model casts the counselor as the expert responsible for making decisions for the consumer. Attitudes may stem from cultural, disability, gender or other biases in the counselor, the consumer or others involved in the VR process. The belief that the rehabilitation consumer is ill equipped or unable to make decisions for himself or herself can also be a formidable barrier. The powerlessness and lack of self-direction felt by people with disabilities are frequently related to the attitudes and practices of caregivers, service providers, funding agencies, social institutions and society in general. Powerlessness is seldom related to limitations or impairments resulting from the disability itself (Parent, 1993). Even professionals who believe they are working in the best interest of the consumer may be impeding personal choice and empowerment. Difficulties faced by people with disabilities are usually the result of "castification" processes within systems, relationships and individuals (Szymanski & Trueba, 1994). Castification refers to the disempowerment of people with disabilities. For example, a person with a disability who repeatedly interacts with people who take control away from him and who make decisions for him may stop attempting to make his own decisions or exercise self-direction. When attempts at self-direction are unsuccessful time after time, a consumer can lose the motivation to persist in those attempts. In order to address attitudinal barriers, an assessment of attitude (counselor, consumer, consumer representative) and its impact should take place. Remedies should be applied if issues arise that negatively impact a person exercising choice.

Counselors should be careful to avoid making decisions for the consumer based on the counselor's perception of the consumer's limitations. Biases may deprive the individual of available opportunities. It is essential to consider consumer interest, motivation, and perceptions of competence. The IPE and final outcome must be consumer driven and consistent with the individual's interests and choice of employment.

- **Dependency and Learned Helplessness**

For some individuals, the experience of having limited or no control over their rehabilitation or educational experiences can create a feeling of helplessness. The experience of disability frequently leaves individuals with a sense of dependency on professional service providers for the advancement of vocational and independent living goals, further impeding their efforts to achieve autonomy. Limited opportunity for varied life and learning experiences, limited opportunity for risk-taking and others' making decisions for persons with disabilities may interfere with their interest in and capacity for self-direction.

A strong case can be made for the efficacy of a rehabilitation model driven by involving rehabilitation counselors in the early and acute stages of recovery from serious injury or illness. Individuals in crisis need to quickly come to terms with a new reality thrust upon them. They can benefit from the expertise and guidance of rehabilitation counselors in making choices about their rehabilitation. The counselor can assist in choices for which such a consumer may not immediately possess relevant knowledge. For example, the individual in the acute phase of a disabling condition may not be prepared to participate fully in deciding the best course of treatment or, for that matter, whether one is clearly indicated. Unfortunately, control is not always returned to the individual as the illness remits. This is one way in which dependency continues.

The problems of dependency and learned helplessness are usually the product of a person's experience (or lack of) over an extended period of time. Enabling an individual to modify those experiences, with considerable support and time, may be necessary to reduce the barriers that these obstacles may create.

- **Fear of Failure**

The individual with a disability may be protected from the opportunity to take risks by well meaning professionals or caregivers. Taking risks, and sometimes failing, provides valuable self-knowledge and knowledge of the world around the individual. This knowledge is critical for successful self-determination. However, an individual may be fearful of taking on responsibilities due to anxiety about the outcome. Support, reassurance and encouragement are essential components of the counseling process that reduce anxiety and fear and enable, even encourage, the individual to take risks, recover and learn from mistakes, and move toward their chosen goals and dreams.

- **Service Delivery System Barriers**

Is empowerment currently happening in the rehabilitation service delivery system? The answer is often “no,” and when it does happen, it is not consistent. An emphasis on meeting agency goals often creates conflict for VR counselors who fully support the consumers with whom they work. Many state and federal policies were originally implemented to benefit consumers. In practice, however, they have become the end rather than the means of empowering people with disabilities. For example, purchasing rules and regulations intended to safeguard against waste or fraud have become barriers to the speedy provision of some services. While the requirement to determine eligibility within a 60-day timeframe was developed to assist consumers in quick access to VR services, for many it has, in fact, delayed such access. In addition, large caseloads may yield greater numbers of employment outcomes to meet agency goals, but create hardship for consumers’ and VR counselors’ ability to form empowering relationships.

Structure and Rationale of Document

With the exception of Chapter 1, each chapter of this document addresses a different audience. Several aspects of Chapter 1, “Toward an Empowered Consumer,” are important for understanding the rest of the document. These include the PSG’s vision, the definitions adopted by the authors, a brief history of the movement toward empowerment, the barriers to empowerment and the structure of the document.

The placement of “Empowerment and the Consumer/Individual,” Chapter 2, represents the belief that the empowerment process begins and ends with the consumer. James Omvig (2002) has written that empowerment is evident when “consumers take control of [their live(s)] and become the best that [they are] capable of becoming” (p. 52). Consumers and their families have a long history of advocating for structures that support empowerment. More than ever before, today’s consumer needs the tools of empowerment. American society is complex. Resources are dwindling. And the social, political and cultural climates require increased and sophisticated advocacy and partnership-building. The tools of empowerment, including informed choice, increase the likelihood that consumers will reach the goal of high quality employment.

Chapter 3 addresses the VR counselor. A crucial function of the VR counselor is the promotion of consumer empowerment. This is particularly true in light of the social and cultural changes in people with disabilities, the range and depth of traditional and non-traditional resources available to them, and the decrease in available fiscal and human resources. Better professional and consumer expertise and collaboration will ensure improved consumer employment outcomes. In the end, an empowered consumer experiences social, economic, political and other benefits from high quality employment. In these times of shrinking resources and expanding cultural change, the role of the VR counselor is even more critical than it has been in the past.

Chapter 4 addresses the role and responsibilities of the VR supervisor/manager in consumer empowerment. The supervisor or manager is in a position to make the system work for, or interfere with, consumers and counselors. Providing the support needed for empowerment to be successful is a “wise investment, and must be understood and embraced as such by all VR professionals” (Omvig, 2002, p. 45). Supervisors/managers can find creative ways to allow change to occur. They can recruit and maintain counselors with attitudes and dispositions that support consumer empowerment. They can become politically astute and informed. They can provide counselors with professional development opportunities. And they can practice empowerment for themselves and their counselors. Consumer directed VR processes cannot exist without the active support of the local supervisor/manager.

In Chapter 5, we address VR agency directors/administrators. VR directors and administrators are important links between local VR offices and staff and state-level partners and legislators. The director/administrator is the facilitator of communication back and forth along the state-to-local and local-to-state feedback loop. The director/administrator needs to have a good working relationship with the executive and legislative branches of state government. In a sense, the director or administrator is a politician, too. S/he mediates the processes of deliberation whereby views of stakeholders are expressed, then seeks to create the changes necessary to make the VR system work the way stakeholders need it to work. Through courageous, thoughtful management of funding, staff development, policy-making, and partnership-building, the director/administrator can create a state VR system that supports consumer empowerment from the top-down and bottom-up.

Chapter 6 is addressed to policymakers. Policy can support or constrain empowerment. While policymakers cannot dictate attitudes or dispositions, they can consider and adopt policies that require strategies for empowerment. In addition, the ways in which policymakers structure their initiatives can hold the VR system accountable for consumer empowerment. Regulations, rules, directives, funding formulae, grant criteria, performance indicators and reporting requirements are a few strategies that can be constructed with consumer empowerment in mind. Policymakers can also listen to consumers and consumer organizations to understand what people with disabilities want from the VR system. Local- and state-level VR staff can share information about the intended and unintended consequences of policy. The broader community is also involved in policy through public hearings and formal or informal input. While difficult to do, policymakers can consider ways to seek input on legislative initiatives prior to enactment to avoid policies that do not result in consumer empowerment.

Finally, Chapters 7 and 8 address the role and responsibilities of community partners in consumer empowerment. These partners can be categorized in two ways: 1) third-party providers that provide services to people with disabilities, and 2) active consumer organizations that advocate for people with disabilities. Chapter 7 deals with third-party providers, while Chapter 8 addresses the role of consumer organizations. Community partners need to be integrally woven into the VR process and are key to the ultimate success of the consumer.

Limitations of this Document

Any publication has limitations. The PSG members found that, in an effort to reach a wide audience, it sometimes becomes necessary to sacrifice depth. For example, while diversity (e.g., cultural, linguistic, gender, ethnic) is an important consideration, the scope of this document does not allow focus on any particular group or area of diversity. The authors have tried to acknowledge that empowerment and informed choice must be understood within the context of diversity. The PSG encourages all VR stakeholders to be aware of and sensitive to diverse consumer perspectives.

In addition, most efforts to be inclusive end with some form of exclusion. We have attempted to be as inclusive as possible in our discussion of the stakeholders in the VR system as they relate to consumer empowerment. It is possible that we have neglected some groups. Groups whose needs are not fully addressed include consumers with significant cognitive impairments, severe communication disorders or severe mental illness. Individuals with functional limitations may need an advocate to provide support throughout the VR process. If empowerment means that a consumer has control over his/her life, then in the case of a consumer with significant support needs, empowerment means the consumer has control over his/her life with the support of significant others or representatives of the consumer's choosing. This assumes that those significant others or representatives understand empowerment and the need to support consumer-driven processes to the maximum extent possible.

Again, the authors were not able to address some issues that are crucial if consumer empowerment is to become a systemic reality. Capacity-building strategies are needed, as are specific strategies for working with consumers who are members of minority groups or who have significant support needs. The tools described in this document are general and not necessarily the best for all consumers in all situations. Please assess the individual needs of consumers and create rehabilitation plans that meet those individual needs.

Changing Systems, Changing Relationships

The 1998 Rehabilitation Act Amendments were the result of historical, social and political shifts in beliefs and values about people with disabilities. This document is a response to these shifts. Perhaps it will contribute to a new relationship between consumers and VR agencies and counselors. For this to happen, the Rehab Act must become more than legislative jargon. Empowerment requires the system to change the balance of power between the consumer and the system. Systemic structures must change to free VR counselors to support consumer empowerment. Consumers must see evidence that "the system" will support their efforts to be empowered and exercise informed choice. Yet in the end, empowerment boils down to changing relationships between all stakeholders in the VR system. The changes must occur up and down and all through the web of relationships that form the VR system.

Study Questions

- 1. The 29th IRI Primary Study Group defines empowerment broadly as:**
 - (a) Control over one's life
 - (b) Consumer-direction
 - (c) Informed choice
 - (d) Self-determination

- 2. Which of the following does not define "informed choice?"**
 - (a) A decision-making process
 - (b) A pre-requisite to empowerment
 - (c) A list of viable options
 - (d) Access to and analysis of information relevant to goals

- 3. Empowerment is stated as the purpose of which of the following:**
 - (a) The Individuals with Disabilities Education Act
 - (b) The Fair Housing Act
 - (c) The Americans with Disabilities Act
 - (d) The Rehabilitation Act as amended

- 4. An essential element for overcoming barriers to empowerment is described in this chapter as:**
 - (a) Cognitive ability
 - (b) Self-knowledge
 - (c) Socio-economic status above the poverty level
 - (d) A qualified VR counselor

- 5. Skill sets needed to effectively develop empowerment:**
 - (a) Must be taught to consumers
 - (b) Are essentially the same for consumers and VR Counselors
 - (c) Do not include system evaluation and monitoring
 - (d) Are significantly different for VR consumers and counselors

- 6. Some functional limitations may present barriers to self-direction.**
 - (a) True
 - (b) False