

**THE FAMILY AS  
A CRITICAL PARTNER  
IN THE ACHIEVEMENT  
OF A SUCCESSFUL  
EMPLOYMENT  
OUTCOME**

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## **Prime Study Group Members**

Many thanks for the hard work and contributions of the following Prime Study Group members:

### **Elizabeth Parker**

IRI PSG Chairperson  
Administrator, District of Columbia  
Rehabilitation Services Administration  
810 First Street, NE, Room 10004  
Washington, DC 20002  
Tel: 202-442-8663  
Fax: 202-442-8742  
E-mail: dcrcsal@hotmail.com

### **Thomas E. Finch, PH.D.**

Director, Special Projects Division  
RSA Central Office  
330 C Street, SW, Room 3038  
Washington, DC 20202  
Tel: 202-205-8292  
Fax: 202-260-9424  
E-mail: tom.finch@ed.gov

### **Darlo J. Koldenhoven**

VR Program Specialist  
RSA Region IV  
61 Forsyth Street, SW, Room 18-T-91  
Atlanta, GA 30303  
Tel: 404-562-6331  
Fax: 404-562-0655  
E-mail: darlo.koldenhoven@ed.gov

### **Alfaye Woods**

Michigan Department of Career  
Development  
Michigan Rehabilitation Services  
3850 Second Street, Suite 200  
Wayne, MI 48184  
Tel: 734-722-7431 ext. 304  
Fax: 734-722-8736  
E-mail: woods@state.mi.us

### **Gene Oulvey**

Office of Rehabilitation Services  
623 E. Adams  
Springfield, IL 62794  
Tel: 217-782-9432  
Fax: 217-524-4358  
E-mail: gpjolvvey@fgi.net

### **Brenda Bercegeay**

U.S. Department of Education  
Rehabilitation Services Administration  
330 C Street, SW, MES Room 3332  
Washington, DC 20202-2649  
Tel: 202-205-8291  
Fax: 202-205-9424  
E-mail: brenda.bercegeay@ed.gov

### **Frank Herron**

New Jersey Division of Vocational  
Rehabilitation Services  
P.O. Box 398  
Trenton, NJ 08625-0398  
Tel: 609-633-6420  
Fax: 609-292-4033  
E-mail: fherron@dolsun.dol.state.nj.us

### **Linda M. Quarles**

Indiana Blind & Visually Impaired  
Services Division  
P.O. Box 7083  
402 West Washington Street, W453  
Indianapolis, IN 46207-7083  
Tel: 317-232-1433  
Fax: 317-232-6478  
E-mail: lquarles@fssa.state.in.us

### **Nancy J. Soper**

Ohio Rehabilitation Services  
Commission  
Bureau of Vocational Rehabilitation  
5533 Southwyck Blvd., Suite 100  
Toledo, OH 43614  
Tel: 419-866-5775  
Fax: 419-866-1669  
E-mail: rsc\_njs@ohio.gov

### **Paul W. Power, Sc.D., CRC**

College of Education, CAPS Dept.  
3214 Benjamin Bldg.  
University of Maryland  
College Park, MD 20742  
Tel: 301-405-2863  
Fax: 301-405-9995  
E-mail: pp21@umail.umd.edu

### **Deborah Leuchovius**

TATRA Project  
PACER Center  
8161 Normandale Blvd.  
Minneapolis, MN 55437  
Tel: 952-838-9000

Fax: 952-838-0199

E-mail: dleuchovius@pacer.org  
tatra@pacer.org

### **Sharon Baker, Ed.D.**

Assistant Professor of Deaf Education  
University of Tulsa  
600 S. College Avenue  
Tulsa, OK 74104  
Tel: 918-631-2910  
Fax: 918-631-3668  
E-mail: bakers@utulsa.edu

### **Karyl Jefferson**

Lummi Nation VR Program  
2559 Lummi View Drive  
Bellingham, WA 98226  
Tel: 360-758-2552  
Fax: 360-758-9937  
E-mail: karylj@lummi-nation.bia.edu

### **Jeanne Miller**

RCEP VI Director  
University of Arkansas  
P.O. Box 1358  
Hot Springs, AR 71902  
Tel: 501-623-7700  
Fax: 501-624-6250  
E-mail: jmiller@rcep6.org

### **Jan Rickman**

Administrative Assistant, RCEP VI  
University of Arkansas  
P.O. Box 1358  
Hot Springs, AR 71902  
Tel: 501-623-7700  
Fax: 501-624-6250  
E-mail: jrickman@rcep6.org

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# INTRODUCTION

## **Goals For This Document**

This document is to assist vocational rehabilitation administrators and counselors, consumers of rehabilitation services and their families, and other rehabilitation professionals, including advocacy groups, the State Rehabilitation Council, and members of service support teams, to understand how the consumer's family can be a critical partner in the achievement of successful employment outcomes. This document will also:

1. Provide a guide to administrators to assist rehabilitation professionals in utilizing appropriately and effectively the VR consumer's family as a facilitating resource.
2. Identify and explain both the roles of the VR counselor, consumer, and family; and provide selected skills and tools to help VR counselors establish family involvement as an important component for the consumer's eventual, quality employment outcome.
3. Develop a training guide for vocational rehabilitation counselors and administrators that will provide an understanding of the roles and functions of the VR counselors when working with families, as well as specific tools, all of which will allow counselors to enhance their own developed skills.

These document goals will be explained in respective chapters.

Following the Introduction and Administrator's Guide, chapter 1 will focus on the role of the consumer with a disability, the dynamic role of the family, and the differences the family can make in the rehabilitation process. Chapter 2 emphasizes the role of the vocational rehabilitation counselor in engaging the consumer's family. Chapter 3 is a trainer's guide using information presented in chapters 1 and 2 and incorporates accompanying necessary tools to prepare vocational rehabilitation counselors for family inclusion. Finally, chapter 4 will identify both tools and resources for the counselor, consumer, and families. When necessary, the meaning of such selected terms as family, partnership, and collaboration will be repeated in different chapters in order to provide an important context for the subject matter. Central to all of these chapters, however, are the convictions that consumer and family directed processes empower all members of the rehabilitation team, and that partnerships between consumers, families, and rehabilitation professionals will greatly facilitate the achievement of successful employment outcomes. Successful strategies can lead to successful outcomes, which benefit consumers, families, counselors, administrators, and employers.

## **Introduction**

The family is the natural and primary support system for the consumer. While there has been significant change

in the family structure, the family is still usually involved in the critical points of the consumer's life from birth to death. Most of the major events in the consumer's life take place within the framework of the family. Disability, consequently, is a family affair. The whole family is affected by a disability in one of its members. In recent years the family as a resource in rehabilitation has received increased attention and the family's role is becoming pivotal for human service interventions (Bray, 1987; Dell Orto & Power, 2000; Kerosky, 1984; Sutton, 1985). Recent trends in service delivery approaches recognize that a consumer is part of a larger, interacting family and social system that has significant influence in the rehabilitation process (Herbert, 1989). Studies reporting the impact of family intervention have clearly demonstrated this influence on individual consumer change in areas such as enhancing independence and improving adjustment to work (Goldstein, Cohen, Thames, & Galloway, 1974; McKenna & Power, 2000). Family factors can also directly influence the mental and emotional functioning of the individual (Power & Dell Orto, 1980).

Three factors have contributed to the renewed perspective of the role of the family in rehabilitation. First, disability is not only a physiological or mental condition, but also is influenced by the person's environment. For example, positive factors existing in the family, such as continued support or the

willingness to realign family roles to accommodate the consumer's needs, may facilitate progress toward rehabilitation goals. Conversely, the family may represent a constraining environment for the individual with a disability. Poor communication patterns among family members, severe economic difficulties, or unwarranted, lowered expectations for the VR consumer in the rehabilitation process can each constitute an obstacle for the VR consumer. Second, the rehabilitation counselor's awareness of such environmental influences as family roles, attitudes and expectations has contributed to successful employment outcomes. Equally, an unawareness of family strengths may cause the counselor to miss an opportunity to utilize the family as a valuable resource for enhancing a quality employment outcome. Third, there has been a shift from the traditional model emphasizing the dominant, almost exclusive role, of the rehabilitation professional for the responsibility of service delivery to a consumer directed policy which places the exploration of options and decision making on all involved parties. The Rehabilitation Amendments of 1998 have emphasized this shift.

However, as a potential resource for the counselor in assisting consumers to appropriate vocational rehabilitation goals, there has been little attention to the family in professional practice (Cottone, R., & Emener, W., 1990). Family attention has generally focused on the disability's effect on the family, rather than on the family's effect on

rehabilitation. But rehabilitation counselors can be more effective if they understand how to work with the family to maximize the resources available to the person with a disability for achieving a successful outcome.

### **Contextual Issues**

There are selected, contextual issues which suggest a foundation for understanding this document and the consumer's and professional's role in appropriately engaging the family. These issues include: (1) understanding emerging definitions of family and the meaning of partnership that will be used throughout this document; (2) identifying underlying principles in order to establish a necessary foundation for building a solid rationale for family interaction, and (3) acknowledging diversity when addressing the role of the family in the vocational rehabilitation process.

#### **Defining Family**

Societal views of family have changed in recent years. Traditional definitions of family have expanded beyond the nuclear family of parents, children, siblings, and spouses. Many individuals are part of blended or non-traditional families. An individual's biological family may not be available or relatives by blood or marriage are not the ones actually providing "family support" to the individual with a disability.

According to the Rehabilitation Services Manual (MT#31, February,

1976), “Family member includes any relative by blood or marriage of a person with a disability and other individuals living in the same household with whom the handicapped individual has a close interpersonal relationship. This definition extends beyond the traditional classification of family members (people having membership in the immediate family or extended relationship by blood or marriage, such as grandfathers, grandmothers, aunts and uncles) to include those family members who have been adopted and other individuals living within the same household, where close interpersonal relationships between them and the handicapped individual characterize a family unit.”

Regulations implementing Title I of the 1998 Amendments to the Rehabilitation Act provide the following definitions that relate to the role of the family in the VR process. These regulations were published by the Rehabilitation Services Administration on January 17, 2001, and become effective April 17, 2001:

*(34 CFA 361.5(b)(23)) Family member:* for purposes of receiving vocational rehabilitation services in accordance with 361.48(i), means an individual-

- (i) Who either-
  - (A) Is a relative or guardian of an applicant or eligible individual; or

- (B) Lives in the same household as an applicant or eligible individual;
- (ii) Who has a substantial interest in the well-being of that individual; and
- (iii) Whose receipt of vocational rehabilitation services is necessary to enable the applicant or eligible individual to achieve an employment outcome.

*(34 CFA 361.5(b)(32)) Individual's representative* means any representative chosen by an applicant or eligible individual, as appropriate, including a parent, guardian, other family member, or advocate, unless a representative has been appointed by a court to represent the individual, in which case the court-appointed representative is the individual's representative.

Even broader interpretations of the term “family” emerged from the discussion of the prime study group to include (1) an existing support system and (2) whomever the consumer identifies as family, which may or may not be the biological family.

#### Defining Partnership

The title of this publication expresses the role of the family as “critical partner in the achievement of a successful employment outcome”. The concept of partnership is not new to the public Vocational Rehabilitation (VR) program. From the beginning a partnership existed between the federal



and state governments and continues to this time. Over the years, partnership with the VR system was extended to many other professional groups, which provide services to consumers of rehabilitation services, including Community Rehabilitation Programs (CRP) and Section 121 Projects for Native Americans. Partnerships are productive relationships that benefit the vocational rehabilitation consumer because they add value to the contribution that each entity can provide separately (IRI, 1997).

It is the understanding of the Prime Study Group members that partnership is a relationship characterized by independence, respect, trust, and tolerance. Ideally, each partner acknowledges the value of the multiple perspectives each brings to the partnership of shared responsibility and accountability for decision making. As partnership evolves, each party may assume different roles. Integral to the partnership between the family, consumer, and the rehabilitation counselor is the realization that the family can be the most important source of information about the consumer. There is not a true partnership if the expertise that the consumer and family possess is not recognized and acknowledged. Recent amendments to the Rehabilitation Act in 1992 and 1998 emphasize the consumer's informed choice for his/her rehabilitation program and his/her role in the VR process.

Consumers come to the program for the primary purpose of preparing to enter a new career or resume a previous career that has been interrupted due to disability. The consumer does not pursue this alone, however, but in partnership with other people, notably family and professionals that support his/her activity in preparing for the career and maintaining it. Yet it is understood that when discussing the role of the family in the rehabilitation plan, family participation is at the discretion and informed choice of the consumer. **Participation by the family is the consumer's decision.**

#### Underlying Principles

1. The individual with the disability takes the lead in the rehabilitation team.
2. Informed choice by the consumer should be emphasized and extended to families. The consumer and family's autonomy and judgment should be respected.
3. Family involvement is a dynamic process.
4. Families can be a resource for successful employment. More constructive outcomes are achieved when professionals work together with consumers and families to achieve goals.
5. The vocational rehabilitation counselor's role is to utilize effectively the many interwoven systems that contribute to successful employment, and to collaborate with families and consumers to identify and enhance existing

strengths, and to identify and remove any constraints to effective action in reaching the VR consumer's goals.

6. The rehabilitation professional must recognize and respect the diversity of families.

### Understanding Diversity

It is becoming increasingly important that VR professionals develop an understanding of cultural diversity. It is common for a VR professional to encounter various ethnic cultures throughout their day in addition to the cultures of disability, sexual minority, the underprivileged, the youth and/or the aged. Of course, it is unrealistic to expect that each VR agency has each culture represented in every office, so we seek to develop a staff of VR professionals who have "cultural sensitivity."

When we apply this concept to families of VR consumers, we quickly realize that every family has its own unique way of meeting its needs and supporting its survival. Each family adapts differently to a family member's disability. Each family, in this way, has its own culture. While the VR professional cannot realistically be expected to understand all of the particulars of a family's culture, the goals must be to recognize how the family system/culture works and to appreciate the uniqueness and customs of each.

It is within the context of recognition, acceptance, and appreciation for the vast differences of culture that this Prime Study Group approaches the issues of diversity. Services should be provided for in a manner which emphasizes the whole person and involves the family in a supportive and holistic vocational rehabilitation process. Such provision requires the rehabilitation counselor to have a broad paintbrush with which to paint flexibility, respect, and acceptance.



# ADMINISTRATOR'S GUIDE

This guide presents information that will help administrators develop the resources necessary for their agency to support positive family partnership. As an administrator committed to family involvement, your leadership is essential. For families to be recognized for their critical contributions to successful employment outcomes, and for the VR system to facilitate family involvement in the VR process, it is necessary for the administrator to embrace the concept and strongly advocate for family inclusion.

## **Benefit of Family Partnerships to Administration**

The paradigm shift is well underway in the method people with disabilities receive rehabilitation services. The trend is to no longer focus solely on the consumer who goes alone through the rehabilitation service delivery system. Rehabilitation professionals and other human service providers realize that by involving family participation rehabilitation success is enhanced. Because of the current shift in thinking, as well as beginning organizational changes to facilitate family partnerships between the consumer and Rehabilitation Administration, families are considered critical partners. Along with the rehabilitation professional and other human service providers they are ensuring the success of people with disabilities in achieving employment outcomes.

The administrator's role in fostering productive partnerships with families is

critical. Administrators at all levels are recognized as partners with consumers, counselors, family members and employers in achieving the goals of the VR program. Administrators as leaders set the tone and policy for the provision of services to consumers and family members in achieving a successful outcome. Funds are allocated, by administrators, to purchase services enabling the consumer to pursue and achieve the outcome. Administrators provide the counselors with the tools and staff assistance necessary to develop and support the family as a critical partner. Administrators work with employers to provide career opportunities to consumers who are prepared to assume their role in the workforce.

Family partnerships can assist administrators to achieve program goals, and are beneficial to State programs in the following ways:

Families provide increased awareness of the needs and strengths of the consumer. Management will have a pulse on how effectively the consumer is able to negotiate the rehabilitation system. Communication with family members can enhance effective communication with consumers during the rehabilitation process. Such communication can contribute to family and consumer satisfaction with the rehabilitation program and appeals may be reduced as a result.

Administration can also streamline

processes to increase access to rehabilitation services.

Families provide support for the vocational rehabilitation program. Families who are partners and stakeholders will have intimate knowledge of the program and a vested interest in the need for the program to “work” for the family member. Families can assist in promoting the public rehabilitation program by being involved in advocacy roles and developing political awareness.

Through increased family participation administrators can become alert to consumer and family needs, which in turn, can develop budget and program initiatives that include expansion of services to family members. Public forums, with input from family members, are an integral part of the State plan development process and enable individuals to comment on rehabilitation initiatives. Ongoing customer surveys are other ways families can share their experiences with administration.

Families help improve service to diverse and underserved populations, which is a goal for administrators. Through program initiatives, which include staffing and personnel, marketing and outreach activities can be developed to connect with minority individuals and their families.

With family participation, an increase in the number of job opportunities

may result. A report of a June 1996 study by the Center on Promoting Employment (RRTC Boston) “demonstrates that family members play crucial roles not only in career preparation, but in actual job search efforts. Young adults both with and without disabilities find that using their personal network of relatives, friends, or neighbors is the most effective way to find a job” (*Point of Departure*, TATRA 1996).

The value of the family's participation in the vocational rehabilitation process cannot be underestimated. As noted in *Point of Departure*, families can help to:

- Identify a family member's interests and strengths
- Streamline the assessment process by providing existing documentation
- Collaborate in creative problem-solving
- Participate in their family member's job search by helping to connect them with potential employers through their personal network.

Sometime disability within the family may present numerous challenges that may affect the achievement of a successful outcome. Families are subject to many demands as they address the multiple needs of the consumer. Services are available to support family members in addressing many of these challenges and rehabilitation professionals should be aware of these services and inform the family of their availability to encourage positive partnership.

It is helpful for administrators and counseling professionals to understand the complexity of the family role. The inter-relationships and processes within the family are most at risk and more often challenged and altered when a family member becomes disabled (Ziegler, 1987). Historically, the role of the family has not been fully understood because attention by various programs was focused exclusively on the consumer. Cultural factors may also have impeded past interaction with professionals. Because of traditional service delivery models some families may not have felt empowered or sufficiently knowledgeable about advocacy to understand or accept partnership. Some families have negative feelings about interacting with government agencies because of previous negative experience. Yet, “Families want professionals to work with them and to provide them with advice, not run their lives or make decisions for them.” (Morrone et al).

Rehabilitation legislation has emphasized the role of the family in the vocational rehabilitation process, and a new relationship with families as partners can influence operations and planning. It can also result in benefits for VR professionals, consumers and employers. Some of these benefits are identified in the following section.

### **VR Professional**

In a 1984 article, Tuck discussed the roles of the vocational rehabilitation counselor, including case management,

disability evaluator, family counselor, legal expert, motivator, customer advocate, placement specialist, rehabilitation liaison, social re-enforcer, medical translator, outpatient social worker, and medical manager. The shifts from the traditional service model to a consumer directed policy have far reaching implications for individuals with disabilities, their families, and rehabilitation professionals. Counselors benefit in the following ways with increased family participation.

In addition to the consumer, the family is the most important source of information about the consumer. Family knowledge of the consumer's life, abilities, goals and objectives should be taken into consideration during the development of a collaborative Individualized Plan for Employment (IPE). At the center of this plan is the consumer's assessment of what he/she is going to do with his/her life. In some cases, the VR counselor may be able to help families identify areas of a family relationship that may impede the achievement of the outcome and offer recommendations to the consumer and family for appropriate services. Families are encouraged and assisted in developing the partnership and understanding their role. The activity of the partnership is focused on the employment goals of the consumer.

**Consumer model.** The rehabilitation counselor will no longer expect to assume the all-encompassing role of

being all things to all people. The consumer-directed model of rehabilitation places the responsibility for exploration of options and decision-making on all parties involved. Family partnerships lead to increased communication between the people with the disability, their family member, the rehabilitation professional and other human service providers. It also contributes to the family's awareness of their rights and resources.

**Elevates awareness of stereotyping.**

Holes and Karst (1990) discussed the impact of disability myths or stereotypes on the development of VR consumer/family/counselor relationships. A counselor who possesses mythical attitudes may inadvertently communicate them to the consumer. Family input can help rehabilitation professionals avoid these stereotypes by discussing variables and barriers to employment in an environment that recognizes that family members have expert information that can promote a successful rehabilitation experience. Nurturing this kind of atmosphere is to the benefit of the rehabilitation professional in guiding the individuals to an employment outcome.

**Knowledgeable family participants.** The family can reinforce adherence to treatment and cooperation with the rehabilitation plan. The family can with competence and knowledge advocate, assist, and support the needs of the family member in guiding the

consumer to a successful employment outcome.

### **Consumer**

The consumer, the focus of rehabilitation efforts, may stand to gain by having a network of partners and stakeholders that includes the family to support their vocational rehabilitation initiatives. A recent study reported in *Point of Departure* (1996) found that the kind of support friends and family usually provided were ideas about the type of work an individual could perform, suggestions about where to look for a job, and providing transportation. At the same time, this report also found only a small percentage of families (25%) was perceived as being involved in the job search of their consumer.

Effective family involvement will result in the following benefits to the consumer:

- Consumers benefit from the expertise their families bring to the process, their commitment to their welfare, and the personal family networks that lead to job opportunities.
- The family becomes confident participants in the rehabilitation process. As families are engaged in the rehabilitation process they can provide more focused and effective supports to consumers.
- The family and consumer recognize that quality of life issues for all family members affect the individual with the disability. Family members,

as well as the individual with a disability, may find it necessary to seek outside social and recreational activities to remain healthy.

- With positive family involvement, consumers may be more inclined to believe that improvement is likely and that they can accomplish their employment goals. Self-esteem of the consumer is more likely to exist when family members are participants in supporting the rehabilitation initiatives.

### **Employer**

Many individuals with disabilities have serious difficulties in obtaining employment. For those with severe disabilities, the rate of unemployment is very high. The job market now and into the foreseeable future is one in which the most important resources workers possess are their workplace skills and their ability to learn new skills (IRI May 1999). The individual with a disability will need knowledge, self-advocacy and self-awareness skills to negotiate in today's labor market. The employer benefits from a family partnership in the following ways:

**Employer expectations.** Employers can confidently employ individuals with a disability when individuals have the ability and a range of resources to meet his/her workplace needs, for example, in the area of transportation.

**Untapped workforce.** Families can assist employers in discovering a valuable resource for filling vacant

positions with qualified individuals who come to the table with knowledge, skill and resources to support their employment goals.

The family can provide assistance to the consumer in overcoming obstacles to job retention.

### **Administrative Strategy for Family Participation**

The issues presented in this guide for administrators require the development and implementation of a strategy incorporating several recommended activities that address the involvement of families in the vocational rehabilitation program. The activities also provide support to counseling professionals for understanding the potential role of the family in the achievement of the consumer's successful outcome and for putting these ideas into practice. This strategy recognizes that the choice for family involvement is the consumer's.

Administrative strategy is designed to address understanding, listening, and communication as primary tools in the development and maintenance of family involvement.

Administrators encourage the development of family partnerships by emphasizing values, such as respect, shared responsibility, and autonomy, reducing rules that may inhibit effective communication, and encouraging risk-taking. Values are emphasized when the

staff is trained to encourage family participation in the rehabilitation program for the consumer and organizational activities are directed toward this objective. Administrators are encouraged to allow for risk-taking by staff as the consumer pursues the vocational objective with the family partners without the overlay of uncertainty about the outcome (Marrone, Helm, & Van Geider, no date). Flexible program design is necessary to address the uniqueness of each consumer rather than making the person "fit" the program (Bradley, & Bersani, 1990). Several activities are now recommended as components of the strategy for partnership.

### **Program Evaluation**

It will be helpful to initiate a program evaluation study focusing on a needs assessment that surveys consumers, families and counselors. The results will be valuable in determining a course of action for the agency in developing and maintaining effective partnerships.

Training needs, improved communication, effective policies and family-oriented programs may be identified as issues to be addressed.

Dunst, Trivette et al. (1993) point out that administrators and professionals encounter many challenges in assuring family support. Several points have application to partnership in vocational rehabilitation and are modified here. They provide a suggested structure for



evaluation and analysis of family partnerships.

Does the program activity or practice employ consumer-driven approaches to identifying family needs as opposed to using professionally driven and prescriptive practices?

Does the program activity or practice provide the consumer in conjunction with the family the necessary information to make informed, competent decisions as opposed to having professionals make decisions for the consumer?

Does the program activity or practice promote collaboration and partnerships between consumers, families and professionals rather than employ paternalistic practices for building resource networks for meeting needs? Are families involved in training and policy making, especially from the beginning of training and policy development?

Does the program activity or practice provide resources and supports to the consumer and family members in ways that are flexible, individualized, person-centered and family-centered rather than provide services to families at the convenience of programs and professionals?

Does the program activity or practice emphasize the delivery of supports and resources in the communities in which the families live rather than provide

services primarily in centralized locations?

Does the program activity or practice promote adoption of empowering the consumer as opposed to paternalistic help-giving practices?

### **Early Contact and Planning**

Early contact and planning by counseling professionals with consumers and interaction with families are ways to assess the family dynamic for involvement. For youth, transitioning programs provide an opportunity for early contact and communication on the part of counselors. Future programming is developed for the transitioning student, which may incorporate referral to a VR program. Encouraging school personnel to include the counselor in the Individual Education Plan (IEP) staffing gives the counselor an early opportunity to initiate contact with the family.

Staffing at hospitals and rehabilitation centers for people who become disabled are early contact opportunities for counselors to meet with families and medical personnel for familiarization with the VR program. This contact, close to the onset of disability, encourages the consumer and family to participate in the VR program when the consumer is ready.

Modification of several practices enumerated by McGonigel (1991) are

useful guidelines for understanding the value of early contact and planning. Early contact respects the consumer's choice for family involvement.

Each family has its own structure, roles, values, beliefs, and coping styles. Respect for and acceptance of this diversity is a cornerstone of family-centered involvement.

All contact must respect the racial, ethnic, cultural and socioeconomic diversity of consumers and families.

Respect for family autonomy, independence, and decision-making means that families must be able to choose the level and nature of early contact that is comfortable for them.

Family/professional collaboration and partnerships are the keys to family-centered early involvement.

Early contact services should be flexible, accessible, and responsive to family-identified needs.

No single agency or discipline can meet the diverse and complex needs of consumers and families. Upon early contact, a team approach to planning and implementation of services leading to a successful outcome is necessary.

### **Communication**

Effective communication is essential to the partnership. Focus groups are effective vehicles for communicating

and discussing issues. They provide the opportunity for consumers, family members, counselors, representatives of community programs, family groups and employers to come together for the benefit of the consumer to listen and share their knowledge about the consumer. The focus sessions can be facilitated by administrators on either a state-wide or local basis. It is important to have the involvement of employers who are in a position to explain current occupational demands and trends to the participants. Of particular value is the culturally diverse composition of the focus group, which gives families the opportunity to share similar experiences with other families.

Communicating information about the program to consumers and family members can take several forms. Printed materials in accessible format can be developed and made available. Video productions, also in accessible format, can be developed and shared with community programs, schools, employers and other entities that can assist the families in understanding the VR program and its objectives. Orientation programs offered by professional staff for new consumers and families highlight the role of partnership with families in the rehabilitation of the consumer.

### **Policies**

A clearly defined policy concerning services to family members should be available to professionals, consumers,

and families. The Rehabilitation Act provides the authority to State VR agencies to provide VR services to family members of an applicant or individual eligible for VR services, if; the services are necessary to enable the individual to achieve an employment outcome. (Section 103(a)(17) of the Act and 34 CFR 361.48(i)). Policies should also outline services available to families that reflect the partnership of the public VR program in the Workforce Investment system and its benefit to the consumer and his/her family. According to Morrone et al, families need to be provided with emotional and tangible supports to encourage and enable their involvement in employment planning and services for the consumer. What is necessary to "Support the Supporters?" The support of family members, counselors, and administrators is necessary.

### **Training**

Training opportunities for professional staff and families on the subject of family partnerships is an approach to increase family involvement and should be included in the training plan. Training needs in specific areas are identified by the evaluation study. Ginter (1996) observes that the rehabilitation counselor through training and experience has a wealth of information regarding disabilities. Counselors already interact with many systems involved in the consumers' lives including workplaces, schools, community agencies, hospitals and state and federal agencies. Additionally the

rehabilitation counselors who understand the family context of rehabilitation are more likely to experience greater progress with the consumers.

University programs, RSA-funded Parent Information and Training projects, and community social programs are additional approaches for implementing the training plan. Training presents an opportunity to discuss current agency policy on family involvement. The program evaluation study will identify areas for professional staff training with an emphasis on training for newly hired professionals. If administrators are advising university programs in Rehabilitation Counseling, a course in family interventions is recommended. An example is the course offered in the Vocational Rehabilitation graduate program at the University of Medicine and Dentistry of New Jersey (UMDNJ). The continuous collection and dissemination of case studies demonstrating both positive and negative effects of family partnership is a valuable training tool for counselors.

Families also can benefit from training to understand their role as partners and advocates. The Technical Assistance about Transition and the Rehabilitation Act (TATRA) project is a major source of assistance for this activity. The TATRA project is funded by the RSA to provide assistance to projects that are part of a RSA initiative providing training to families. TATRA is a project of PACER Center in Minneapolis

(www.pacer.org). The RSA funded parent training projects inform young adults with disabilities and their families about transition, vocational rehabilitation and independent living services and related laws in a limited number of states.

Each family has a unique dynamic, which will have an effect on the outcome for the consumer. As Singer and Powers (1993) write, "Trusting, working relationships rarely sprout fully grown out of an initial encounter. They unfold over time. As a relationship grows, the individuals within it can influence its development. Some relationships evolve in a more or less typical fashion and respond to the normal amount of care and attention. Others evolve in less typical ways and need more careful attention, a more carefully controlled environment, and more skilled tending to mature into full working relationships". Incorporating these beliefs into counselor training programs provides a foundation for an effective outcome.

### **State Rehabilitation Council**

The Rehabilitation Act Amendments of 1998 mandate the membership of at least one representative of a parent training and information center funded by the Office of Special Education Programs (OSEP) on the State Rehabilitation Council (SRC). This brings the perspective of family members to the attention of the SRC, which provides to VR administrators

input on agency policy affecting consumers. The needs of the family and consumer are best served when families are represented on the various agency committees and councils.

"Agencies cannot be truly responsive to the needs of families and consumers if they are unwilling or unable to solicit their input. In addition, service providers cannot fully assess the impact of their programs unless they actively involve families and consumers in monitoring and evaluation. Only with collaboration and cooperation can agency providers, families, and consumers help each other. Two ways in which this collaboration is possible are family/consumer monitoring of services and programs and family/consumer representation on advisory committees" (Bradley & Bersani, 1990).

### **Partnership with the Employer Community**

The role of employers as partners with consumers, families and counselors cannot be underestimated, especially in the Workforce Investment environment. The membership of administrators on boards of state and local business organizations where employers are significantly represented may be conducive to the development of career opportunities for consumers. A VR presence on Local Workforce Investment Boards (LWIB) along with representation of family members on the LWIB may assure that the

employment needs of people with disabilities will be addressed in a specific geographic area. Presentations to state or local business associations, the State Workforce Investment Board (SWIB), Chambers of Commerce, Rotary Clubs or Lions Clubs involving administrators, family representatives and counseling professionals provide a forum for a mutual understanding of the career needs of consumers.

Another group of employers that is often overlooked is found among the family members of persons with disabilities: the "personal network." Family members are employed at all levels of private corporations and government agencies. Given their understanding of the employment objectives of persons with disabilities, they are positioned to recommend the employment of persons with disabilities for various positions in the company or agency. They are a valuable resource available to rehabilitation professionals for the design of specific employment tailored to the unique requirements of the consumer. This partnership should be encouraged and developed with a family member who may also offer employment opportunities.

### **Advocacy by Administrators**

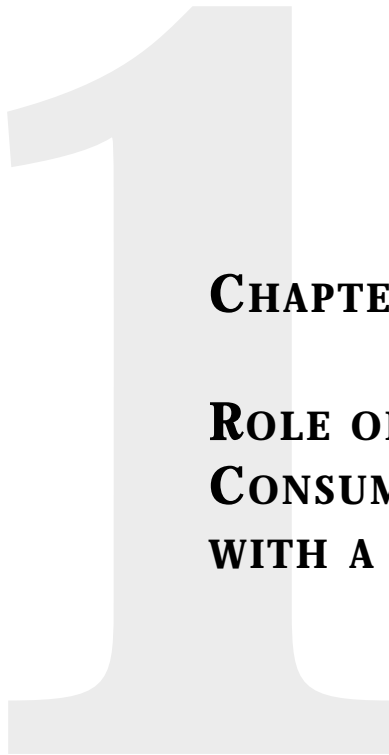
Advocacy and support by administrators for national studies that assess the family partnership is necessary. Effective studies may demonstrate the need for legislative and regulatory change and provide the impetus for increased services to families through the funding

of new projects or increased funding for existing projects.

### **Conclusion**

This recommended strategy provides opportunities to develop and strengthen the relationship of the family to the consumer and the counselors providing services to the consumer with the objective of an appropriate career. A strong, respectful relationship enhances the quality of the career for the consumer and increases the effectiveness of family supports in assisting the consumer to maintain the career. The ultimate outcome will be a satisfied consumer who has achieved a successful employment outcome with the support of family members, counselors, and administrators.





## **CHAPTER ONE**

# **ROLE OF THE CONSUMER WITH A DISABILITY**

Although the focus of this manual is family involvement in the vocational rehabilitation process, the purpose of having family members actively involved is to help the consumer reach his or her employment and independent living goals and maintain them over time. The role of the consumer and the consumer's employment goals remain central. The professional's role in relation to family members is to support and strengthen their ability to support the individual with a disability in reaching his or her goals and to enhance the quality of employment outcomes.

### **Informed Choice**

The importance of informed choice and self-determination for individuals with disabilities participating in the VR program is stressed throughout the Rehabilitation Act, as amended both in 1992 and 1998. The law makes clear the primacy of the individual with the disability's role within the rehabilitation team. "It is the policy of the United States that all programs, projects and activities receiving assistance under this Act shall be carried out in a manner consistent with the principles of respect for individual dignity, personal responsibility, self-determination, and pursuit of meaningful careers, based on informed choice, of individuals with disabilities" (Rehabilitation Act as amended in 1998 Sec. 2(c)(1)).

Language expressing strong support for family involvement in the vocational rehabilitation process is also found

throughout the Rehabilitation Act. The statement “Families and other natural supports can play important roles in the success of a vocational rehabilitation program,” for example, is prominent as an underlying principle of vocational rehabilitation policy (Section 100(a)(3)(D)). Such statements, however, are *always* qualified by the language: “if the individual with a disability involved requests, desires, or needs such supports.”

Vocational rehabilitation counselors must inform individuals with disabilities of their rights and responsibilities as a consumer of VR services. Once the individual has a good understanding of their rights, he or she can become an effective leader of their plan. The way each individual with a disability exercises responsibility and leadership on the rehabilitation team will vary dependent upon the age, type of disability and life-status of the individual. For individuals of legal age, the responsibility for case advocacy and progress is theirs to use or delegate. One right they may choose to exercise is to invite family members to join their rehabilitation team. The 1998 Rehabilitation Act Code of Federal Regulations states that the individual with a disability can designate other persons they would like invited into the process — “any representative chosen by an applicant or eligible individual, including a parent, guardian, other family member or advocate, unless a representative has been appointed by a court.” (34 CFR 361.5(b)(32)). As

Judith Heumann, former Assistant Secretary of the US Office of Special Education and Rehabilitative Services under President Clinton, has said, “Independent living does not mean doing things yourself. It means having control over what’s being done.”

Naturally some consumers do not have families, or their families are unable to participate in the VR process. Some consumers may also choose to exclude their families from the process.

Consumers with disabilities who do invite family members to participate, however, should not turn over decision-making authority to their family members by default. If the individual is legally able to negotiate services and plan goals, the consumer should direct the amount of family involvement. It is the individual with a disability’s responsibility to be an active participant, to express his/her desires, identify goals and advocate for his/her own interests. This basic principle is no different for consumers with significant cognitive disabilities. However, it is the responsibility of VR professionals to facilitate the process and to provide supports to consumers who need them that will enable them to be “active and full partners in the vocational rehabilitation process, making meaningful and informed choices” (Rehabilitation Act, Sections 100(a)(3)(C) and 102(d)(1)).

Balancing an individual’s right to privacy and confidentiality with a family’s need and right to know



relevant information, however, may not always be simple. Generally, if an individual with a disability is of the age-of-majority (age 18 in most states), the consumer chooses the family members or other individuals that they would like to have included in the planning and implementation of their IPE. Adult consumers must give permission to share information with family members by signing an information release. If an individual is below the age-of-majority, a parent or guardian is legally required to be included in the process. In some cases, due to the nature of the disability, family members have been designated by the courts as guardians even after the age-of-majority. In situations where a family member has legal guardianship, family opinions are those that legally need to drive the decision-making and to which professionals should ultimately adhere.

### **Guardianship or Conservatorship Issues**

The law presumes that an adult 18 years or older is capable of managing his or her own affairs. Guardianship is a legal relationship between a person over the age of 18 whose disability causes “incompetency” and a competent adult. Conservatorship is term that refers to a limited form of guardianship. Incompetency has to do with a person’s ability to make informed choice, or with the risk of harm that may result from an individual’s inability to manage their affairs or provide for themselves. The primary test for determining the

need for guardianship focuses on one’s ability to make decisions, and to communicate the decisions once made.

Guardians are appointed by the court to manage the affairs of an adult only when it can be demonstrated that the person does not have the capacity to make or communicate responsible decisions concerning personal or financial matters. In this relationship, the guardian is given the right to make decisions on behalf of the person with a disability. The areas of decision-making on which most guardianships are focused are living conditions, medical care, vocational and educational services, ancillary professional services, caring for dependents, and managing finances.

Each state has specific laws that govern guardianship proceedings and guardianship activities. Mental illness, developmental disability, physical incapacity, chronic intoxication or advanced age are identified by various state laws as the basis for lack of decisional capacity. However, a developmental disability or mental illness is not, by itself, sufficient reason to declare someone incompetent. Nor may a family member assume guardianship because a person acts or uses money in a way that may seem odd to someone else. A court must find the person incapable of managing his or her financial affairs or making informed choices. A guardian’s authority is limited to those areas of decision-making for which there is evidence to indicate that a person is

incapacitated. Some persons are able to make responsible decisions in some, but not all, areas of their lives. (National Guardianship Association, 1999)

### **Consumer Needs Drive the Process**

Family members will involve themselves in the vocational rehabilitation process and often take on additional responsibilities in order to allow family members with a disability to focus on achieving steps that bring them closer to their employment and independent living goals. The type and amount of family support, whether it is physical, emotional, financial or spiritual, will depend on the current needs of the consumer and likely will change throughout the rehabilitation process. For instance, following an accident, a family member may take initial responsibility for filing insurance claims but will step back from such activities later when the consumer can return attention to financial matters.

Family support can also be influenced by the socioeconomic status of the consumer and the family. If the family is given responsibility for providing an accessible home environment, follow-up medical care, and transportation, but does not have adequate resources to follow through, a consumer's chances for success can be compromised. Services and support provided to the individual are primary, but recognition of the need to support the family must accompany the rehabilitation process.

Under the Rehabilitation Act, VR services can be purchased for "relatives, guardians or individuals in the same household who have a substantial interest in the well being of the individual to the extent that they are necessary to assist the individual achieve our employment outcome. (Section 103(a)(17))" The next sections of this manual include more in-depth discussions of family roles, the range of family contributions to vocational rehabilitation, and ways in which VR counselors can support families.

However, no matter how much support a family provides, it is the individual with a disability who must ultimately take full advantage of opportunities as they arise. A key responsibility of the consumer must be to focus on their goals and invest themselves in the vocational rehabilitation process. An essential part of this process is that the person with the disability must learn about their disability and the accommodations they need.

### **It's not a One Way Street**

Consumers can support family members by acknowledging the help they receive and by letting their family know that their help is appreciated. Consumers need to understand the limitations of family members, and to give them permission to give up responsibilities that they are no longer able to sustain. Another way consumers can support their family members is to "lighten their load" by becoming

familiar with and using other available support systems outside of the family, whether they are natural supports or supports available through formal systems. While eligible for VR services, for example, consumers should fully utilize the expertise of their vocational rehabilitation counselor whose professional knowledge of training, postsecondary, and job accommodation resources is broader than their family members.

### **Consumer Family Conflicts**

There will be consumers who are reluctant to have family members participate. VR counselors can encourage consumers to talk with their family about their interests, where they want to work and live, what they want for their future. Consumers who share their goals and dreams with family members may then feel more comfortable enlisting their support as they work toward accomplishing them. Such discussions may also help family members become more supportive and invested in the process. VR counselors might advise consumers of potential benefits that can result from family involvement and may want to point out that individuals who do not have the support of family can be at greater risk of dropping out of the process (Brofenbrenner, 1976; Hall, deFur & Taymans, 1995; Gallivan-Fenlon, 1994; Hill, Wehman, Hill & Goodall, 1985; Johnson and Rusch, 1993; Johnson & Thompson, 1989; Lakin & Bruininks, 1985; Rumberger, Ghatak, Poulos, Ritter & Dornbusch, 1990; Statistical

Profile of Special Education in the United States, 1994; Way & Rossmann, 1996).

It should be noted, however, that consumers might have valid reasons for not wanting to involve family members. Examples might include individuals who simply do not have positive relationships with members of their family, who have been self-sufficient for years, who have profound disagreements with family about their capacity for employment or basic employment goals, or who need to make decisions away from the influence of a domineering family member. For some such a decision might be an important statement of independence. Certainly it must be also acknowledged there are instances of family abuse. Research shows that youth with disabilities are at increased risk for abuse, unfortunately often at the hands of family members (Jones, 1995; National Center on Child Abuse and Neglect, 1993).

When conflicts arise between consumers and their family members, counselors must advocate for a course of action that best serves the interests of the consumer. However, it is vital that family concerns are recognized and explored. It can be helpful for consumers to understand the roots of any concerns their family members have expressed. Are they based on past experiences or generalized fears and worries? It is important that these issues are discussed. An atmosphere of openness and honesty allows concerns

to be discussed comfortably. Skilled counselors can help all parties fully understand the implications of their differing perspectives (Marrone, Helm & Van Gelder, no date). All parties can then either agree and act upon their agreement, or disagree and continue to negotiate.

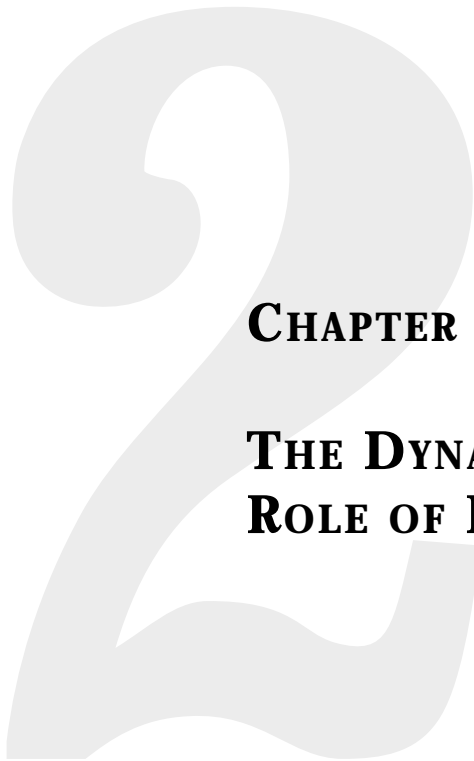
### **Developing Outside Supports**

For some consumers, it may be difficult to know when to ask for help, for others, it may be difficult to know when to take the initiative to do things themselves. However, all consumers need to learn what supports exist for them outside of their family, how to develop their own networks and natural supports, and how to use systems. Consumers can take responsibility for getting out of the house and into the community, seeking out peers with disabilities and locating other resources. Ultimately, both consumers and family members will be reassured when the consumer begins to develop skills that will allow them to find and maintain employment and life in their community when family members are no longer able to provide significant supports.

### **Giving Back**

Consumers who have benefited from vocational rehabilitation and live and work in the community may also want to consider how they can open the doors for others with disabilities. Providing peer support to other

individuals with disabilities is one means of doing so. Individuals might also choose to become involved in disability or advocacy organizations in their community. State VR agencies also welcome input from individuals who have used their services at public forums and often seek volunteers to serve on committees.



## **CHAPTER TWO**

### **THE DYNAMIC ROLE OF FAMILIES**

Traditionally, the focus of vocational rehabilitation has been almost exclusively on the individual with a disability. A person's family has generally not been included as an integral part of either the assessment process or in the development and implementation of a person's individualized employment plan. In fact, tension between rehabilitation counselors and families has often been noted. However, a greater awareness and appreciation of the importance of family involvement in the vocational rehabilitation process is emerging in the field today.

Recent years have seen a great deal of change in attitudes about disabilities and in disability policy and practices. There is a shifting of basic principles away from the medical model of disability to one that is more culturally based. A new perspective now promotes families as "the experts", with professionals assuming more of a consulting role. These changes have resulted in new relationships between families and professionals.

Family involvement in both special education and vocational rehabilitation systems is recognized as best practice (Bailey, Buysse, Smith & Elam, 1992; Goldberg & McDonald, 1996; Hall, deFur & Taymans 1995; Hosack & Malkmus, 1992; Kohler, DeStefano, Wermuth, Grayson & McGinty, 1994; Lankard, 1993; Turnbull & Turnbull, 1991). Family members provide the most long-term and important support in a person's life and can make critical

contributions to successful employment outcomes for individuals with disabilities.

The Rehabilitation Act reflects these changes and specifically cites the importance of family and other natural supports as one of the fundamental principles shaping vocational rehabilitation policy (Section 100(a)(3)(D)). Recent amendments to the Rehabilitation Act give greater emphasis to the role of families, authorize funding for family training on vocational rehabilitation, and enhance opportunity for family members to be involved in the rehabilitation process.

However, real-life day-to-day practice has not caught up with these policy changes, philosophical shifts and recommendations. Families of individuals with disabilities remain under-utilized by vocational rehabilitation professionals. It is interesting to note that although involvement of family members is expected in medical rehabilitation this expectation does not carry over to vocational rehabilitation. The VR system doesn't seem to start with the same assumption that families make critically important contributions to an individual's rehabilitation.

However, a new day is dawning. VR counselors see evidence of the value of family support in their ongoing work with individuals with disabilities. A generation of parents familiar with the

mandate for parent involvement in the special education system is asking to be included as partners in the vocational rehabilitation process. Moreover, as state vocational rehabilitation agencies implement new "order of selection" policies serving individuals with the most significant disabilities first, VR counselors are encountering an increasing number of individuals with significant physical and cognitive disabilities who require complex supports and for whom family involvement is essential.

Societal views of family have changed in recent years. Traditional definitions of family have expanded beyond the nuclear family of parents, children, siblings, and spouses. Many individuals are part of blended or non-traditional families. In addition, an individual's biological family may not be available, or relatives by blood or marriage are not the ones actually providing "family support" to the individual with a disability. Distantly related individuals, friends, neighbors, or coworkers can become significant natural supports for individuals with disabilities working and living in their communities.

### **Continuum of Family Involvement**

An underlying premise of this manual is that families can make valuable contributions to the vocational rehabilitation process leading to successful employment outcomes. Vocational rehabilitation counselors should take time to explore the

potential for positive family involvement and see families as a resource for the consumer before assuming otherwise. Focusing on the strengths of families does not ignore the fact that vocational rehabilitation counselors will encounter challenging families. However, it is simplistic to think of the family's ability to cope with stress in terms of whether they are "healthy" or "unhealthy." Just as there is a wide diversity among families, families will vary in their capacity to support their family member with a disability. One must acknowledge that disability is not the only factor shaping the way a family interacts. The degree of family involvement is a reflection of each unique family system reflecting cultural and socioeconomic background, social issues, financial issues, individual family values and personal choice.

Another premise of this manual is that family involvement is a dynamic process. There is a continuum of family involvement encountered by vocational rehabilitation counselors – from uninvolved to very involved. Extremes of the spectrum may reflect more complex situations. However, we must be careful not to label challenging families too quickly. What at first glance may appear to be uncooperativeness could, in fact, represent difficulties attending meetings because of conflicting work schedules or problems securing childcare. Families from some cultural traditions may defer to professionals out of respect, which could be mistakenly perceived as a lack

of involvement. Unsupportive behavior could also be based on legitimate concerns that need to be addressed. Families may be afraid of losing benefits upon which they have come to rely, or concerned that the consumer will become more vulnerable to violence or exploitation if they live away from home, or work in the community. They may not be supportive because of low expectations, a lack of knowledge, or any number of other issues that could be addressed through education, careful planning or corrective action.

Even so, it is unrealistic to expect all families to participate at the same level. Limited participation can reflect personal choice. Passive participation should not be labeled as uncaring and counselors should not pressure families to assume preconceived, culturally unfamiliar or uncomfortable participatory roles.

However, it is also true that limited family involvement could be a result of a lack of information about available choices and options. Families need to know about their choices, options, and rights. Many families are not knowledgeable in areas that could affect their ability to choose a more active role. When family members do not participate fully, vocational rehabilitation counselors should ensure it is not because of unpreparedness or a lack of information, but is a truly free and informed choice. There will be times in which a family will not be willing or able to be involved, but there

are ways counselors can encourage family involvement. Generally, family members will be much more likely to participate if they feel their participation is valued.

The continuum of family involvement can be used to represent not only the range of differences between families, but also the changing dynamics of an individual family. Family relationships and the degree to which family members are involved in the lives of one other can change over time. Families may assume greater or lesser roles in the lives of their family member as that individual matures or masters new skills, experiences setbacks, or in response to other responsibilities and stresses in their lives that require time and attention. Families deal with multiple priorities that at times must take precedence over working with professionals on behalf of their family member with a disability.

Family members can be an important source of support for people with disabilities of all ages; however, transition-age youth are one age group where vocational rehabilitation counselors can expect to see a high amount of parent and family involvement in the vocational rehabilitation process. Parents provide valuable guidance and support for most young adults, with or without disabilities. However, many students with disabilities have had limited opportunities to go through early stages of career development and may be less

ready than students without disabilities to make critical decisions at the end of high school (Syzmanksi, 1998). In addition, many parents of transition-age youth have been involved participants in special education, which expects parent and family involvement.

The type and severity of the family member's disability can also affect family inter-relationships. Progressive disabilities require families to continually adapt and change roles. Families can become exhausted from acting as primary caregiver to individuals with spinal cord injury or other chronic medical conditions, or from stresses resulting from a family member's traumatic brain injury or psychiatric disabilities. Families of individuals with cognitive disabilities may assume lifelong roles as guardians and conservators.

Age of onset of disability can also affect family relationships and family involvement. Parents may be more protective of sons and daughters with congenital disabilities in contrast to family members of individuals who acquire a disability after they reach adulthood and have already demonstrated independence. Likewise, an individual's prognosis will affect family relationships. Illnesses that are expected to shorten life can be very difficult for a family to deal with. Families in this situation may want to insulate the person with the disability from stress that results from assuming normal responsibilities. The position of



the person in the family system also affects a family's ability to involve themselves in the VR process. Families may be challenged by the difficulty of adjusting to complex reorganizations in lifestyle, role, self-perception, economic security and belief systems.

Even when an individual's disability essentially remains unchanged over a long period of time, a family must continually adjust to the impact of disability on their lives as their family member moves through life's milestones. Each rite of passage presents new challenges and corresponding stress – whether advancing through school, driving a car, applying for college, finding employment, moving away from home, getting married, or becoming new parents and grandparents. Many significant milestones can coincide with an individual's vocational rehabilitation progress. As individuals with disabilities and their families face each situation, they must come to terms with the impact of disability on their lives anew. Family relationships may be strengthened, or individuals may be struggling with their own adjustment, making themselves less available to others.

### **Culturally Diverse Families**

Many cultures are represented in US society, and cultural views about independence, time, gender roles, family roles, work, health, illness and disability vary. Cultural traditions can have a significant impact on a family's

expectations of their family member with a disability as well their interactions with professionals. Likewise, traditions can shape an individual's vocational goals and decision-making in ways that may run counter to mainstream values. For example, an emphasis on the interdependence of the family group is the norm in many cultures and may lead consumers to choices that make his or her needs secondary to family considerations – a course in opposition to the high priority Americans have historically placed on individualism. If such decisions reflect the informed choice of a consumer, they should be respected instead of opposed by counselors.

Individuals from diverse cultural backgrounds may communicate in languages other than English. It is important to communicate and share information with a family (as well as the consumer) in their preferred language. Such communication allows for family input that can lead to a more accurate assessment of a consumer, by clarifying misconceptions about a person's level of functioning that may be based on differing cultural background, limited English language skills, or other gaps in information. The Rehabilitation Act specifically states that a copy of the consumer's IPE shall be provided to the individual and, when appropriate, to the individual's family or other chosen representative in writing and in their "native language or mode of communication" (Rehabilitation Act Amendments of 1998, Sec. 102(b)(1)).

Ideally, VR offices should reflect the diversity of the populations they serve and have multilingual and bicultural counselors available to help communicate with families from diverse cultural communities and put them at ease. The current shortage of qualified staff makes this impossible, however, and a counselor's own cultural values often may not parallel that of the consumer. This should not prevent counselors from providing culturally competent service however.

VR counselors must be aware of the need to utilize interpreters and other minority professionals when appropriate. However, even when English is the native language of a consumer and his or her family, language difficulties can exist. This could be a literacy issue or may just reflect the unfortunate use of professional jargon that creeps into conversation as well as written materials. The VR counselor can help the consumer and their family understand their rights, responsibilities and options by carefully explaining and restating information when necessary, and by helping them to feel comfortable asking questions.

It is not possible for any counselor to have advance or in-depth knowledge of the cultural traditions of all the individuals they will encounter in their career. Cultural competence stems from a counselor's more basic appreciation of the fact that differences between the counselor's and the consumer's

background may result in differing values that need to be explored and understood. Counselors should assure consumers and their families that their cultural values will be respected and convey that they are interested in learning more about them. If consumers or their families have negative perceptions of disability that are culturally based, VR counselors can sensitively offer alternative explanations.

Of course, assessments of family strengths must be individualized rather than categorized by ethnic group. Regardless of cultural heritage, each family will have developed its own way of interrelating. Moreover, a family's traditional values may not correspond with those of the individual with a disability. The consumer may have had a broader bicultural experience than other family members, including exposure to the disability community and disability culture, which may have expanded the range of options they are interested in exploring.

Counselors must be sensitive to how race and disability can limit the opportunities available to consumers and the resources of their families. Inadequate education, inaccessible health care, lack of employment opportunities and poverty are all factors contributing to an escalation of disability rates in minority populations (Asbury et al, 1991). Disabilities coupled with these harsh realities can

impede an individual's progress towards their employment goals.

Racial discrimination is a fact of life for many Americans. It exists in the business community and among service providers and other agencies. Studies have documented the fact that the vocational rehabilitation system itself has not provided equal services to culturally diverse individuals. Minorities with disabilities are less likely to have been found eligible for vocational rehabilitation services, and if accepted, were less likely to be successfully rehabilitated (Wright & Leung, 1993). RSA spent less on services for individuals with disabilities from culturally diverse populations, provided them with fewer opportunities for academic training, and placed minorities in lower paying jobs (Wright & Leung, 1993; GAO, 1993; "Culturally Sensitive Rehabilitation," 1993). Counselors cognizant of these facts should be alert to identifying subversive cultural biases of their own that may lead to inequitable treatment.

Counselors will have to work hard to establish trust with consumers and families made wary from prior negative experiences with publicly funded social service programs. Counselors can try to counteract this skepticism on a broader scale by building relationships with organizations serving families in minority communities. Such efforts have the potential to identify eligible individuals who might otherwise be unaware of, or reluctant to apply for, VR services and to identify other

natural supports within cultural communities.

### **Family Contributions**

Disability clearly has an impact on the whole family. Yet, despite all the stresses related to a family member's disability, families are resilient. Love and caring can be the source of motivation, energy, action and commitment to the well being of their family member with a disability. The categories below reflect a range of roles families may assume that enhance their family member with a disability's ability to reach successful employment outcomes.

### **Families Provide Crucial Supports**

- Diminish stress for the consumer
- Provide lifelong commitment and assistance
- Provide emotional support for family members with disabilities throughout the VR process, during the inevitable rejections that follow job interviews and adjusting to the workplace.
- Facilitate recreation and socialization
- Cultivate relationships that lead to natural supports in the community
- Assist with activities of daily living and personal cares
- Provide financial support
- Advocate for benefits and access to services
- Act as guardian, conservator or power of attorney

## **Families Facilitate Rehabilitation Growth**

Parents of youth with and without disabilities help prepare their sons and daughters for work from an early age by instilling values and work ethics, assuming future employability, building work and social skills, increasing independent thinking and action, cultivating personal responsibility, and enhancing self-image. However, family contributions to employability and the development of work skills can be life-long. The following examples are some of the ways family members support the rehabilitation of an individual with a disability whether they are a parent, sibling, child, or spouse. Families

- Contribute crucial information to determination and vocational rehabilitation assessments
- Help identify employment goals
- Allow consumers to focus on rehabilitation goals by helping with
  - 1) legal issues
  - 2) insurance companies
  - 3) coordinating medical care
- Access services systems that provide supports to their family member (e.g. transition, vocational rehabilitation services and medical care)
- Advocate for benefits and access to services from other sources
- Identify consumer needs and suggest ways to address them
- Motivate family members with high expectations
- Provide encouragement, coaching & feedback.

- Help family members practice new skills
- Promote self-determination by encouraging family members with disabilities to take responsibility for themselves, trusting in their ability to make good decisions – or to learn from their mistakes
- Combat stereotyping based on gender or disability
- Link consumer with local CILs and other disability organizations for peer support
- Participate in Person-Centered Planning

Person Centered Planning is a process especially worth considering as a means to effectively involve families in vocational rehabilitation. Person Centered Planning focuses on an individual's strengths and empowers individuals with disabilities and their families. It provides a structure for the consumer, family members, the vocational rehabilitation counselor, others who are providing natural supports, and representatives of agencies providing formal supports to come together as a team. The person, who is the focus of planning, and those who love the person, and know him or her well, are the authorities. It can help VR counselors identify a range of natural supports available to families and clarify roles family members will play in the vocational rehabilitation process.

Meetings are held to 1) identify individual skills and interests that will

lead to employment goals based on personal choice; 2) define work qualities that will enhance job successes and satisfaction; and 3) pool resources to assist in information gathering, the provision of support, and potential job leads. Concrete and comprehensive plans of action are developed and responsibilities spread out among individuals on the team. The process promotes collaboration and can result in more satisfying job placements as well as creative solutions to a variety of related issues and concerns (Massachusetts Rehabilitation Commission, 1999).

#### **Family Contributions to Successful Employment Outcomes**

Both research (Hill, Wehman, Hill & Goodall, 1985; Johnson & Thompson, 1989; Lakin & Bruininks, 1985; TATRA Project, 1996; Way & Rossmann, 1996) and anecdotal evidence (Schoeller, 1997: TATRA Project, 1999; Urbain, 1997; VCU & PEATC, no date) support the view that family involvement can increase the number and quality of job placements. Families help family members find employment and retain their jobs. Families can provide crucial supports that enhance job security long after a placement is deemed successful and VR counselors are no longer present.

#### *Finding Employment:*

- Use personal networks of family including relatives, friends, neighbors, community businesses, and a family's religious community to identify job opportunities

- Support an individual in their job search
- Improve quality of placement and job satisfaction by advocating for employment options that reflect the interests and skills of their family member
- Help family member prepare for job interviews

#### *Job Retention:*

- Help employee prepare for work in the morning
- Act as a backup for personal assistance staff
- Maintain assistive technology
- Identify or provide transportation
- Provide information to employer about accommodations that work
- Cultivate external natural supports in the community
- Provide a safe haven for family member with a disability to talk about their job and normal everyday job-related problems and frustrations
- Problem solve with family member on how to deal with challenging workplace situations
- Identify early warning signals for problems an individual is having with a job.

Although families make a number of significant contributions, counselors should not expect families to assume responsibility for all gaps or shortages in the service system. Staff need to both accept and respect a family's limitations, as well as strengths.

## **Impediments to family involvement**

What is standing in the way of family involvement in the VR system? Both attitudinal and systemic barriers exist. Individual counselors may have to overcome past training based on assumptions that family involvement is irrelevant or antithetical to consumer choice. Former RSA Commissioner Fredric Schroeder has cautioned, “Beware of the rugged individualism stereotype. None of us really live independently, family interdependence is the norm.”

Unfamiliarity with systems hinders family involvement. Families faced with a catastrophic event that results in disability must first summon the resources to deal with a crisis, and then face the complexities of understanding a new disability and their emotional response to it. They may have little energy left to devote to navigating service systems and can find them intimidating. Parents and families used to the special education system may have established ways of relying on the educational system, which do not carry over to adult support services. Many parents of young adults with disabilities are unprepared for the move from a single agency to multiple agencies, from mandated services to non-mandated services and from a system that assumes no rejection, a least restrictive environment, accountability and the importance of family involvement to one that does not.

Families may be reluctant to participate for other reasons. For example, families are exhausted from meeting the daily needs of their disabled family member; are tired of dealing with the system, or have had negative experiences and want to avoid further interactions. While professionals encourage maximizing adult independence, they may not understand the impact this will have on a family. Families may fear losing a check they depend upon, or the services of a family member currently providing needed childcare, or anticipate other costs in terms of time or energy. Families may approach the system with fears stemming from previous interactions with government agencies. Culturally diverse families may have been discriminated against or felt disrespected when they sought help from government programs in the past. Aging parents of older adults with disabilities may be equally skeptical of service systems because years ago professionals recommended institutionalization of their family member. Parents may also be influenced by mainstream cultural norms that emphasize less parental involvement in the daily life of their adult sons and daughters.

Families report feeling judged when they come into contact with professionals. When their expressed preferences are quickly dismissed as “unrealistic,” families feel they are not being taken seriously. Professionals can unknowingly send a message to caregivers that they are either doing too

little or too much. Families can feel they can't do anything right –

***If we are concerned, we are overprotective; if we are unconcerned we are neglectful.***

***If we are involved, we are demanding; if we are not, we are detached.***

***If we have high expectations we are unrealistic; if we have simple aspirations we set our sights too low.***

***If we nurture generously, we are smothering; if we nurture less we are withholding.***

***If we offer advice, we are controlling; if we refrain we are disinterested.***

***If we phone, write or visit often, we are pests; if we don't we are uncaring.***

***If we help with tasks or give or loan money, we cultivate dependency;***

***if we don't, we are unsupportive.***

Based on “Why Mothers Have a Tough Time” attributed to Jordan Miller, MD Center for the Study of Women's Psychology

### **Working with Families**

How does a VR professional begin to engage families in the process? Alliance building requires engaging families by creating personal connections.

- **Make families feel welcome.**
- Be an active listener. Genuinely consider their ideas. Time spent listening is the cornerstone of a trusting relationship.
- **Involve families from the beginning in goal setting and developing plans for services.**

- Discuss new ideas and strategies before decision-making and implementation – with enough time to address a family's questions thoroughly.
- Communicate regularly.
- Build trust by following through on promises – particularly important when previous experiences with service providers have not been positive.

Becoming involved in the VR process requires families to commit time and energy. Families need both emotional and tangible supports to encourage and enable their participation. These may include

- Moral support
- Problem solving
- Assisting consumers and their families to develop their own community supports – Both systems and natural and community supports should be developed to strengthen the family's ability to support a person in work.

### **Services and Supports for Families**

The Rehabilitation Act provides several avenues of support for families. The Act authorizes the provision of services directly to family members when necessary to the vocational rehabilitation of an individual consumer (Section 103(a)(17)), and it also authorizes funding for special projects (Title III, Section 303).

Parent Information and Training projects have been funded by the RSA since 1993. These projects educate families about the vocational rehabilitation process, civil rights, independent living services and how to work with vocational rehabilitation professionals. The projects work closely with parent centers authorized by the Individuals with Disabilities Education Act (IDEA), Centers for Independent Living, and Client Assistance Projects. They particularly target the families of young adults with disabilities who are transitioning out of the special education service system.

Transition planning to prepare a student for post school activities, including vocational rehabilitation and employment, is mandated by IDEA and the Rehabilitation Act in Section 101(a)(11)(D). It is required for all students receiving special education services (Storms, O’Leary & Williams, 2000). Many of these young adults will need supports from the adult service system as they work towards achieving their postsecondary education, independent living, and employment goals. Vocational rehabilitation counselors can help facilitate a smooth transition for such students by participating in the transition planning process. Transition services for youth with disabilities that “facilitate the achievement of the employment outcome identified in an individualized plan for employment” are authorized vocational rehabilitation services (Rehabilitation

Act Amendments in 1998, Sec. 103(a)(15). Both IDEA and the Rehabilitation Act require interagency agreements between education and vocational rehabilitation agencies, that facilitate the transition of students receiving special education services to vocational rehabilitation services.

The Rehabilitation Act requires state VR agencies to include an assurance in their State plan that applicants and eligible individuals, or their appropriate representatives (including families), will be provided information and support services to assist consumers in exercising informed choice (Rehabilitation Act Amendments of 1998, Sec. 101(a)(19)). As a limited number of projects are funded under RSA’s Parent Information and Training Program, some State rehabilitation agencies are subcontracting directly with IDEA authorized parent centers funded by the OSEP in their States to provide information and training services to families. These centers operate in every State. (Visit [www.taalliance.org](http://www.taalliance.org) for a list of parent centers.)

In addition to training grants, the Rehabilitation Act specifically authorizes funding for projects serving individuals with disabilities who are migrant and seasonal farm workers and their families (Rehabilitation Act Amendments of 1998, Section 304). The RSA offers additional avenues of potential support for projects promoting family involvement through



its discretionary grants for model projects and inservice funding.

Finally, the Rehabilitation Act authorizes direct services to the family of an individual with a disability if “necessary to assist the individual to achieve an employment outcome” (Rehabilitation Act Amendments of 1998, Sec. 103(a)(17)). Ultimately counselors should approach providing services to families with the same individualized perspective that they apply to working with consumers with disabilities. There are a range of supports and services that must be matched to the individual needs of each consumer’s family. The following are a few examples.

#### **Services and Supports for Families**

- Meetings held at times convenient for family work schedules
- Interpreters and translators to provide information in native language
- Family support groups
- Cultivating natural and community supports
- Information about options, resources and rights
- Contact with successful adults with disabilities
- Counseling (Referrals to outside agencies for therapy beyond the scope of counseling services that can be provided by the VR counselor)
- Day care services
- Respite
- Foster care
- Financial management
- Family planning
- Marital counseling

- Assistance locating housing
- Education:
  - Information on newly acquired disabilities
  - Information on genetic research
  - Training on promoting the consumer’s self determination & advocacy skills
  - Up-to-date information about disability services & systems
  - Understanding their family member’s, and their own, rights and responsibilities
  - Skill development that enables family members to support consumers learning new methods of managing daily personal care and home maintenance
  - Training necessary to support a consumer’s entrepreneurial enterprise to reduce overhead and provide for continuous operation of business

Joining the expertise and resources of families with the knowledge and resources of vocational rehabilitation professionals will create powerful new partnerships supporting individuals with disabilities as they work towards their employment and career goals. VR counselors who understand the family context of disability, who embrace the assumption that families can make positive contributions to an individual’s vocational rehabilitation, and who provide opportunities for families to become active members of an individual’s VR “team” are likely to engage consumers more effectively in the VR process, and ultimately, to foster more successful outcomes.





## CHAPTER THREE

### THE ROLE OF THE V.R. COUNSELOR: WORKING WITH FAMILIES

“Since the origin in 1920 of the federal-state delivery system for vocational rehabilitation services, the VR consumer’s family and the rehabilitation counselor have been infrequent partners.” (Power, *date?*) This is unfortunate considering that literature in the field, based on practical experience, indicates family involvement is important in the rehabilitation process. When VR professionals develop a positive working relationship with the family, they increase the likelihood that people with disabilities will obtain employment. The family can also provide the consumer with supports that ensure far greater likelihood of success in maintaining that employment over time. It is to the credit of Vocational Rehabilitation today that not only has family been identified as a valuable resource, but VR professionals are seeking to identify and implement methods that will help them work with families. New and improved processes which access family support are needed to assist counselors as VR reaches out to serve more people with significant disabilities.

The importance of family in the vocational rehabilitation process has been heightened by IDEA and the subsequent focus on the successful transition of students from school to work. In fact, during the last decade the family has been identified as critical to the success of transitional students as they move from school to work. For students with disabilities, family involvement during transition is not

only important, it is essential. Supportive families, actively involved in their young member's transition to the world of work, greatly increase the chances for successful transitions. However, young adults are not the only age group that benefit from the natural supports that families provide.

The family can provide critical supports for any member who is seeking employment or working to maintain employment. The family is a source of identity. It educates its members, provides encouragement, and assists its members in problem solving. As our population ages disability will become an even more natural part of the family experience. It is to our benefit to further acknowledge the importance of the family as a natural support within the broader context of rehabilitation.

Yet even when we understand the value of and need for family involvement, even when we are empowered to act, we remain hesitant. Perhaps our hesitancy arises, in part, from confusion over the role and function of the rehabilitation counselor. Our profession continues to struggle with the limitations of the medical model, which focuses on disease and deficits. When such pathology dominates our thinking we continue to look for evidence of disease, deficiency, or malfunctioning when assessing the family. Instead, we should shift our primary focus to family strengths. We should assess those strengths and work with the family rather than working

around the family or standing in opposition to the family. As vocational rehabilitation enters the 21st century, our challenge must be to create a new model that creates a true partnership between people with disabilities, families and rehabilitation professionals.

Nevertheless, working with families currently represents a minimal part of the vocational rehabilitation counselor's daily work. Perhaps, because we pride ourselves on offering individualized services, we have forgotten how important the family is as a support group for all people. As a result we overlook a most important prognostic indicator and resource. Without losing focus on meeting the needs of the consumer, the rehabilitation process should be always viewed within the context of a larger social system involving family, friends, and community. Counselors, instructors and other VR professionals working directly with consumers should perceive the individual as a member of this larger interactive system rather than a solitary entity.

Many rehabilitation counselors believe they lack the proper training, time, and resources to work extensively with the family. However, as noted in the previous section, some of the most important things counselors can do to effectively engage families do not require extensive training or resources. Counselors can facilitate family involvement by simply making an

effort to make families feel welcome, listening to what they have to say, following through on promises and generally building trust.

Furthermore, although counselors may doubt their ability to work with families they may, in fact, be more effective than many other community professionals such as social workers, psychologists, etc. (It should be noted that within the context of this manual, “working with families” refers to involving the families in the VR process, not to therapeutic clinical intervention, such as formal family therapy). One has only to consider the roles and responsibilities VR counselors have assumed since the profession’s birth in 1920 to realize that the skills used when working with individual consumers could easily be applied to working with family members.

VR counselors have expertise in diagnostics and assessment, vocational counseling, individual and group counseling, case management and service coordination (including the development of support systems), and family and multicultural issues. Successful VR counselors have strong interpersonal skills and communication skills. They are creative and flexible. They are both challengers and advocates.

Rehabilitation counseling has been described as a process whereby the counselor works collaboratively with the consumer to understand existing problems, barriers, and potentials in

order to facilitate the consumer’s effective use of personal and environmental resources for career, personal, social, and community adjustment following disability (Jacques, 1970). The family can easily be viewed as a personal and/or environmental resource. In cases where families are the guardians of, and advocates for, individuals who cannot speak for themselves, they become the voice of the consumer and will play an even more significant role in the collaborative process.

### **Collaboration with Families**

For the purposes of this manual a narrow definition of family (e.g., the nuclear, biological family) would be inadequate. Many people with disabilities do not have, or may not wish to have, access to their families of origin. Moreover, given that the purpose of this document is to assist rehabilitation professionals in finding ways to form problem solving partnerships with families, a broader definition of family that allows for a wider array of resources is preferable. It is more helpful to adopt a definition where family is thought of as a small human society with structure, patterns, and properties that organize stability and change. The family’s members tend to maintain contact, have emotional ties, and a shared history (Minuchin, 1998).

For our purposes a workable definition of *collaboration* is a process of joint decision-making among stakeholders

who act in coordination to further their shared interests. Stakeholders can be both individuals and organizations. Actors retain their independent decision-making powers; relationships are characterized by mutual respect, trust, and tolerance; there is a change-oriented nature to the relationship; and each actor acknowledges multiple perspectives, shared responsibility, and accountability for decision making.

The Prime Study group believes that the following basic principles are key to successful collaborations with families:

- The rehabilitation process goes beyond the individual to include both the individual's support system and the context in which this system is embedded
- All stakeholders in a collaborative process deserve to be heard and respected, although not necessarily in agreement
- The rehabilitation professional plays the role of collaborator, colleague, and team member

### **The VR Counselor as a Systems Consultant**

Human service workers help individuals and families deal with challenging forces in their lives. These forces can include poverty, various forms of violence, and the disruptions in life patterns brought about by disability. Vocational rehabilitation professionals operate at the center of these intertwining forces. The breadth

and depth of their mandate, to work with the complete range of employment and independent living issues brought about by disabling conditions, require them to excel at assessing, networking, and synthesizing at multiple human systems levels.

The increasingly complex problems people with disabilities face today have created a need for a shared vision across human service agencies (Wylie, 1992 ). It is not uncommon in urban areas, for example, to find individuals who have a mental illness, plus an HIV infection, plus a history of substance abuse, plus a multi-generational history of poverty. The role of a systems consultant, a professional conversant with, and capable of acting as a change agent in the full array of human systems, has been proposed as a way of creating this shared vision (Wynne, 1987). It is one of the main arguments of this chapter that the VR counselor is already well suited to fill this role.

By their nature, the goals of assisting people with disabilities to work and to live independently require collaboration with a diverse array of organizations and professions. To the standard repertoire of evaluation, physical therapy, occupational therapy, rehabilitation nursing, speech-language-hearing therapy, psychological counseling, vocational assessment, training and placement, and training with prosthetics and orthotics are added the more recent services of recreational therapy, drivers training,

marital and family therapy, sex counseling, pain control, dental care, transportation, remodeling of home and workplace, visiting home nurses, meals on wheels, community support groups, and Centers for Independent Living (Albrecht, 1992)

To serve each VR consumer, the rehabilitation team, and in particular the VR counselor, must advise and advocate for that VR consumer within the familiar service network, or use their expertise to go beyond that network to create new partnerships and new services.

One level of human systems frequently overlooked by the rehabilitation system is the family. A number of authors have described the limitations inherent in the VR program's traditional focus on the individual to the exclusion of the family (Cottone, 1989; Cottone & Emener, 1990 ). In fact most VR counselors are not trained to work with families in the employment process, and frequently view them as irrelevant or as a barrier to achieving rehabilitation goals (Oulvey, 1999).

The Prime Study Group believes that the family, the primary emotional support system for most people in human society, is a largely untapped resource in the practices of the rehabilitation system. We further believe that the concepts and skills necessary to work effectively with families are the same skills needed to realize the full potential of the systems consultant role.

The primary skills needed to work with families are those necessary to build collaborative relationships to solve problems. These skills are applicable in a variety of VR related contexts, including developing partnerships with sister human service agencies; analyzing the needs of, and making connections with employers; working effectively with complex programs such as the Social Security Administration, and with emerging programs at the State level, such as those engendered by the Workforce Investment Act legislation; and adapting new technologies, such as the Internet, to the use of people with disabilities.

From this perspective, working with families naturally enhances the ability of VR counselors and other VR staff to produce successful outcomes. A counselor's collaborative and problem-solving skills become even more crucial as recent changes in Social Security legislation, freeing many people with disabilities to seek work without fear of the loss of health care benefits, coupled with an unprecedented strong economy should focus the rehabilitation system to an even greater extent on those people with disabilities.

## **Levels of Involvement**

Each consumer's situation, and the relationships, resources and experiences of each family, will determine the counselor's level of collaboration and involvement with families. At times this might include discussing family expectations for the consumer, their family and the world of work. At other times it might mean enlisting the family's assistance and strength to ensure better prognosis for their family member. The following chart provides a way of characterizing the range and differing levels of counselor interactions with families. VR counselors making a proactive effort to involve families in the VR process will likely operate in the range of Levels 2 to 4. Level 1 does not reflect the active involvement of families. However, it may still be appropriate in specific situations, for example, when the consumer does not want to involve their family. Level 5 needs demand more involvement than most VR counselors can provide and would likely require referrals to outside providers of intensive family therapy.

*(Adapted from Baird & Doherty, 1986)*



**COUNSELOR/FAMILY INVOLVEMENT LEVELS**

<p><b>INDIVIDUAL AND FAMILY THERAPY</b></p> <ul style="list-style-type: none"> <li>- Understand system dynamics and intervention strategies for multi-problem families.</li> <li>- Skills include the ability of the therapist to:             <ul style="list-style-type: none"> <li>• Maintain self-leadership in intensely emotional and adversarial situations</li> <li>• Apply complex treatment approaches</li> <li>• Intervene decisively in crisis situations</li> <li>• Diagnose and prescribe interventions for major illnesses</li> </ul> </li> </ul>	<p><b>LEVEL 5</b></p>
<p><b>SYSTEMATIC ASSESSMENT AND PLANNING</b></p> <ul style="list-style-type: none"> <li>- Understand multiple perspectives and levels in human systems.</li> <li>- Understand the VR Counselor's own relationship to multiple systems, including the consumer's system, the family systems, the institutional system, the community system, and their own internal system.</li> <li>- Skills include the ability to:             <ul style="list-style-type: none"> <li>• Assess consumer issues on many levels engage consumers and their families in planning (including families reluctant to participate or who have difficulty communicating their ideas and perceptions)</li> <li>• Redefine problems in ways that suggest solutions</li> <li>• Identify and understand those aspects of the consumer's and family member's personalities that may impede the setting and attaining of goals</li> <li>• Promote the consumer's self-determination skills and the potential for growth of all participants through the negotiation of roles and responsibilities in the problem-solving process</li> <li>• Educate and lead members of the interdisciplinary team towards an effective collaboration supporting the goals of the consumer</li> </ul> </li> </ul>	<p><b>LEVEL 4</b></p>
<p><b>SUPPORT AND ENCOURAGEMENT</b></p> <ul style="list-style-type: none"> <li>- Knowledge of individual and family development stages and the impact of disability on the developmental tasks at each stage.</li> <li>- Awareness of the VR counselor's own feelings in the counseling relationship.</li> <li>- Skills include:             <ul style="list-style-type: none"> <li>• Empathic listening</li> <li>• Encouraging efforts at coping</li> <li>• Giving advice that meets the unique needs of consumers</li> <li>• Making referrals that reflect an understanding of the unique consumer and family circumstance</li> </ul> </li> </ul>	<p><b>LEVEL 3</b></p>
<p><b>INFORMATION</b></p> <ul style="list-style-type: none"> <li>- Some knowledge of relationship systems.</li> <li>- Willingness to work with consumers and their families collaboratively.</li> <li>- Skills include the ability to:             <ul style="list-style-type: none"> <li>• Communicate clearly</li> <li>• Accurately convey information about consumer options (providing the basis for informed choice)</li> <li>• Select key family members to relay information</li> <li>• Identify problems and make referrals</li> </ul> </li> </ul>	<p><b>LEVEL 2</b></p>
<p><b>MINIMAL CONTACT</b></p> <p>Deal with the family only when necessary or required by law.          The family is viewed as superfluous or as a hindrance to the rehabilitation process. (Unfortunately, this may characterize the current attitude of many rehabilitation programs.)</p>	<p><b>LEVEL 1</b></p>

## **Engaging the Family**

It is ultimately the consumer's choice as to who is invited to the meeting, just as it is up to the consumer to decide who is or is not part of their family. If the consumer is reluctant to invite the family, the counselor might give them the option of inviting one or two members. In the definition of family used for this document, the invitees chosen by the consumer might be a caseworker or a friend.

After obtaining the consumer's permission to speak with family members, the counselor can contact the family to arrange a meeting. Engaging some families might prove challenging. If family members are reluctant to join the consumer's vocational rehabilitation team, it is helpful to remember that there could be numerous reasons for doing so. Some families see intervention by medical and vocational professionals as intrusive. Because medical and psychological interventions are usually focused on the individual, this may be a new experience for some families. Some families may have developed a basic distrust of professionals. Verbal reinforcements may be helpful in encouraging and supporting these families during what might be uncomfortable dialogue for them. The counselor could then suggest how the family could be important to the process, and how it could assist its member to be successful in job acquisition and maintenance.

Once the family is engaged, the counselor can obtain information critical to the rehabilitation process, particularly specifics regarding both potential barriers and supports. Contact should be brief and might only consist of one to three visits. Counselors might find it beneficial to include all family members in at least one meeting in order that each member could become aware of issues and concerns of the other members.

The first meeting with the consumer and their family is the initial opportunity to begin the partnership. It can have a major impact upon the success or lack of success of the rehabilitation process. There are four critical goals at this stage. The first is to establish a connection with the consumer. Second, enlist the participation and support of the family. Third, provide information the VR consumer and family will need. Fourth, come to a mutual understanding of the family's strengths and constraints.

After acknowledging confidentiality, the counselor must strive to put aside his/her perceptions and judgments. At first it is most important to listen and to be sensitive. The counselor should pay careful attention to his/her own communication style and body language. Although family needs may not be identical to professional needs, families want professionals to respect them and work with them.

Even if counselors do not share the culture or language of a consumer's family, they can demonstrate positive regard and empathy. Vocational rehabilitation counselors working with families cannot be expected to be experts on all cultures. However, certain cultural patterns have been identified which differentiate the family experience of different cultural groups. During the assessment stage, counselors must demonstrate respect and appreciation of diversity of culture, ethnicity, race, gender, economic level, and religion. Counselors should determine who is part of the family; how the disability is perceived by the family; how the family makes decisions; what members expect of each other; what level of support is received from friends and community; whether, and how closely, the family adheres to traditional values; and, how willing the family is to accept help (McCallion, 1997).

The counselor should also create an open dialogue regarding the appropriateness of family involvement in the rehabilitation process and the importance of having the consumer's needs and wishes drive the process. During assessment key issues and players must be identified.

If we choose to view the family as a resource, it is critical that the rehabilitation professional have a sense of how extensive a resource the consumer's family could be. One approach counselors might consider is to ask the consumer and their family

members to draw a map of who is in the family.

The counselor could ask the consumer and the family members to show "who is in your family or who do you know that you can count on for support?" While there are elaborate methodologies for constructing family trees or genograms, the VR counselor can simplify the process. Family members can be instructed to use squares for females and circles for males and to write names in the circles and squares. The professional might encourage the family to think beyond immediate members by asking questions such as, "Who else is concerned that Samantha doesn't have a job? Who might be pleased if she gets and keeps employment? Who might help in the process? Who might interfere with the process?"

### **Identifying and Cultivating Family Strengths**

The counselor should assess strengths the family brings to the rehabilitation process as well as identify any constraints that exist. If these strengths are unidentified, the counselor is left without valuable resources that could positively impact vocational prognosis. Questions counselors should explore include:

- What is the composition of the family?

- What are family strengths? Are there strengths in communication, problem solving, planning, etc.?
- What are family communication patterns?
- How has the family influenced the development of their member's work personality?
- What is the family's perception of the disability?
- What is the family's perception of their member's potential for increased independence in the community and at work?
- How have family members responded thus far, both emotionally and behaviorally?
- Are coping mechanisms in place, and if so, what kind? (Many families cope effectively and have, in fact, been strengthened by presence of disability.)
- What kind of supports does the family currently provide to the consumer?
- What is the knowledge level of the family regarding the disability, employment opportunities, and community resources?
- How effectively does the family utilize community resources – or have they chosen not to seek help?
- If they have chosen not to seek help, is it due to previous negative experiences or to cultural differences and expectations?
- What does the family need?
- What does the family most want?
- Is there a correlation between the consumer and the family objectives?
- Are there family issues (e.g. estranged relationships, differing goals, limited resources, work disincentives) that might negatively affect the vocation process?
- Openly discuss disincentives. In particular, families often have concerns about loss of entitlements to Social Security and Medicaid.
- Would the families prefer to not jeopardize their member's benefits and entitlements?  
If so, why?
- Have they been made aware of alternatives to loss of benefits?
- How will the loss of entitlements affect the family, as well as the specific family member?
- Are their concerns realistic, or are they based on a lack of knowledge or a reflection of other issues?

### **When Families Need Help**

Following the assessment process, the counselor can begin to help families address any issues that have been identified. The family's mental health, as well as the consumer's, is important in the rehabilitation process. Anxiety might be reduced by increasing family knowledge of the vocational rehabilitation process, relevant services and programs. Such terms as "vocational assessment" and "job coaching," while common to Vocational Rehabilitation professionals, may be foreign to family members. If there is a need, the counselor can help the family understand and accept their family member's disability as well as their feelings about the process. Services to families may include education about the specific disability and the availability of community resources and alternate support systems. Some families have lived with disability for many years and have well established coping mechanisms. Sometimes this includes a fierce independence and reluctance to trust community options. These families can be assisted to reach out for additional support.

In addition to these concerns, counseling could focus on developing problem solving skills needed for family support in achieving vocational goals. Some families demonstrate behaviors that are an impediment to the vocational process and may benefit from a referral for appropriate clinical therapy. The VR professional can teach such families about the benefits of

obtaining new skills. Even when all efforts for support have been exhausted, some family members may be a liability rather than an asset to the vocational rehabilitation consumer.

Some level of conflict is normal in human relationships and a skillful counselor can channel such tension toward productive outcomes. Sometimes a VR counselor has to "know when to hold 'em, know when to fold 'em" and know when to walk away. These situations require a great deal of finesse and skill in conflict resolution. When families need help, the Vocational Rehabilitation counselor can be a catalyst for positive change.

### **Reframing: A Helpful Skill**

Individuals and families define their options by the assumptions they have about themselves. Listen closely to the "stories" told by the consumer and their family for evidence of family strengths. The stories they tell reveal their perceptions of their capabilities. These perceptions can expand or constrain choices by recognizing or denying strengths. Even when consumer and family stories are overwhelmingly self-negating, counselors can use the technique of *reframing* to highlight strengths. Reframing can help the VR consumer find the positive spin in their descriptions of their ability to solve problems and to express their competency.

Reframing provides a means for the rehabilitation professional to:

- Challenge negative explanations in a nonaggressive way  
*(“Maybe it wasn’t a failure to quit that job. Maybe you had learned enough about your interests to realize that it was not for you.”)*
- Remind consumers and family members when they unintentionally describe strengths  
*(“Are you saying you were able to help Samantha get to work on time for a month last year?”)*
- Recognize signs of connections between members of the family  
*(“You know when you come down so hard on John, it sounds like you are really wanting him to succeed.”)*
- Suggest alternative explanations for actions that are as true as the one preferred by the family  
*(“I’m not disputing your opinion that Mike is lazy. Perhaps just another way to say that is that the illness drains him of the ability to motivate himself.”)*
- Underline adaptive abilities  
*(“ You know, with everything you’ve been through as a family, it is amazing that you are doing as well as you are. How do you find the strength to get through these things?”)*

Common rehabilitation techniques, such as On-the-Job-Training experiences, provide excellent venues for recognizing and exploring alternative explanations and behaviors.

## **Development and Life Stage**

Research on family development has led to the general conclusion that families tend to go through predictable stages. Looking at the stage of life cycle the family was in at the time of the emergence of the disability; and the life cycle tasks the family would usually be experiencing at the time rehabilitation issues are considered can provide insight into the impact of disability on a family (Rolland, 1987).

**Traditional Stages of the US Family Life Cycle (late 20th Century)**  
**Adapted from McGoldrick, M., and Carter, B. in Walsh, F. (1987)**

<b>STAGE</b>	<b>TASK</b>	<b>CHANGE PROCESS</b>
Young adult	Separate from parents	Establish own identity apart from family origin, develop intimate peer relationships, establish identity as a worker
Marriage	Commit to couple	Emotional, financial, investment in new primary relationship, redefinition of relationships with families of origin, friends, employers, etc.
Young children	Focus on new generation	Make space in marriage for children, take on parent roles, establish relationships with grandparents, etc. Redefinition of work relationships and priorities for each parent
Adolescents	Recognize children's independence	Open family boundaries for children, focus on mid-life career and marriage, concerns for seniors
Children leave	Accepting exits and entrances into family	New emphasis on the marriage, adult to adult relationships between parents and children, accepting new in-laws and new role as grandparents, disability and death of seniors
Later life	Change of generations	Individual/couple identity in face of disability and decline, explore new role options, leadership of middle generation, value wisdom of seniors, support of seniors without taking away their power, coping with death of spouse, friends, life review and preparation for own death

As individuals with disabilities move through this life cycle, enter new stages and focus on new tasks, they may encounter new disability related limitations. Adjustments required by these transitions can disrupt established patterns and cause increased stress and a new sense of loss for both consumers and their family members.

## The Family is a System

In the past 50 years there has been much discussion of systems and systems theory. It is now generally held that the ability to think systemically is a fundamental skill for most professional level employment (IRI, 1995). For the purposes of this document a systems perspective has to do with connections, with the way that components relate to each other.

Within any system repetitive patterns exist. Family patterns are established through generations of behavior. They define expectations and limits, so that members of the system know what is and is not acceptable. The stability of these patterns tends to serve as a barrier to change, and to the family utilizing their full range of potentialities.

All systems go through periods of stability and periods of change. In periods of stability a system functions effectively through familiar patterns. In periods of dramatic change, such as typically occurs in families when a member or members first acquire a severe disability, the members of the system search for patterns that preserve what is valued while allowing adaptation to the new reality.

The Vocational Rehabilitation counselor can be influential in the family system. They can bring about change at many different levels within the system.

Together the counselor, VR consumer and family:

- Define the problem or problems;  
*("I can't get a job.")*
- Determine barriers;  
*("What keeps you from deciding what career you wish to pursue?" or "What would happen if you knew what kind of work you'd like best?")*
- Mutually decide how to lift the constraints.  
*("We as a family agree that Tom needs to go to work and we will support that. He needs to get a second opinion on his medications. We all need to work with a family therapist because we recognize that we have trouble supporting each other. This Work Incentives Improvement Act that you say just passed might allow Tom to keep his medical benefits.")*

The process is repeated as new problems and potential constraints emerge (Breunlin, 1999).

## Roles Within the Family System

Within any system different players have many and varied roles. There are a number of models defining the potential cast of characters. The Vocational Rehabilitation professional often becomes a member of the cast. An ability to recognize these roles and use effective strategies in counseling can help a family to identify barriers and potential solutions. One model to help



counselors identify family roles (Internal Family Systems) is included in the Appendix. Activities such as “Creating a Family Map,” explained in the Training Tools Section, can also be helpful.

### **A Model for Family Problem Solving**

The Illinois Department of Rehabilitation Services and the University of Illinois Family Systems Program (Oulvey, 1997;1999) modified a family counseling model (Breunlin, 1997) to improve Vocational Rehabilitation counselors’ level of skill and comfort in collaborating with families. This model, entitled the Clinical Externship in Rehabilitation and Families (CERF), provides a theoretical framework combined with techniques for analyzing family barriers. It focuses on the stages and levels of how human beings change (Mahoney, 1992) and offers a system of analysis that can assist the rehabilitation worker to face the increasingly complex issues and challenges of the 21st century. This model is described in detail in the appendix.

The Vocational Rehabilitation counselor holds the key to successful collaboration with families. Helping families problem solve can be very challenging and time consuming but can provide great benefits to the Vocational Rehabilitation consumer. Crucial aids in this process are models and methods that are complex enough to account for the issues faced by people with disabilities and their families, and simple enough to be used in rehabilitation practice.



# 4

## CHAPTER FOUR

### TRAINING TOOLS

#### ACTIVITIES, MATERIALS, AND TOOLS

The information in this document is substantial and, as the title indicates, critical. Because of the benefits of collaborating with families, this section has been developed to facilitate the transference of information to vocational rehabilitation professionals in the field. The materials may be used during independent study or to learn as a group. You may even find some of the activities and materials useful when working with families. It is not intended that you use all the materials and activities that are provided. Instead, select the ones that are most appropriate for your needs.

#### Goals of this Section

- To provide readers with activities and materials to help them understand the affects that a disability may have on the family as a whole
- To help readers understand and acknowledge the influence that families have on rehabilitation outcomes
- To help readers develop ways to capitalize on strengths that families bring to the rehabilitation process
- To help readers develop strategies to work effectively with families, especially those that may seem challenging
- To help the reader recognize the role that cultural, economic, religious,

and ethnic factors may play in determining the family's ability and/or willingness to participate in the rehabilitation process

- To provide counselors with tools, links, and resources that can be used to better support VR consumers and their families and to engage families in the rehabilitation process
- Families are diverse and the rehabilitation professional must recognize and respect this diversity in order to seek their involvement during the rehabilitation process.
- The vocational rehabilitation counselor's role is to effectively utilize the many interwoven systems that contribute to successful employment.

### **Principles of Understanding**

Before beginning the discussion on positive contributions the family can make to the rehabilitation process and methods to engage family members, we must acknowledge selected contextual issues which suggest a foundation for understanding this document and the VR consumer's and professional's role in appropriately engaging the family.

They are:

- The individual with the disability takes the lead in the rehabilitation partnership.
- Informed choice by the VR consumer should be emphasized and extended to families.
- Families can be a resource in the rehabilitation process and may contribute to successful employment.
- Family involvement is a dynamic process that varies from family to family.

**Activity: Remembering Your First Job**

**Purpose:** To help participants recall how they were able to get jobs through personal contacts or family members. To help participants begin to broaden their perspective on the definition of family.

**Description:** Ask participants to think back to when they were young and describe how they got their first jobs. This can be handled in a variety of ways. One example would be to set up four flip charts with the titles: First Job, Second Job, Third Job, and Fourth Job. Have participants write on the flip chart the person that was most instrumental in assisting them in getting the job. Discuss how family members or networks of friends contributed to their employment.

**Materials:** Flip charts and markers.

**Discussion:** Families are often very instrumental in assisting their child in getting a job or in developing early work habits that lead to successful employment. At this point in the training, the goal is to have participants broaden their definition of family and identify how various people helped them personally get jobs.

**Activity: Definition of Family:**

**Purpose:** To help participants understand the broader, more inclusive definition of family.

**Description:** Discuss what family in the federal regulations means. Then, open the discussion and allow participants to talk about real-life experiences in which families were involved.

**Materials:** Handout. Federal Regulations and the Rehabilitation Act.

**Discussion:**

Even broader interpretations of the term “family” emerged from the discussion of the prime study group to include (1) an existing support system and (2) whomever the VR consumer identifies as family, which may or may not be the biological family.

**Definition of Family**

Regulations implementing Title I of the 1998 Amendments to the Rehabilitation Act provide the following definitions that relate to the role of the family in the VR process. These regulations were published by the Rehabilitation Services Administration on January 17, 2001, and become effective April 17, 2001:

*(34 CFA 361.5(b)(23))Family member:* for purposes of receiving vocational rehabilitation services in accordance with 361.48(i), means an individual-

- (i) Who either-
  - (A) Is a relative or guardian of an applicant or eligible individual; or
  - (B) Lives in the same household as an applicant or eligible individual;
- (ii) Who has a substantial interest in the well-being of that individual; and
- (iii) Whose receipt of vocational rehabilitation services is necessary to enable the applicant or eligible individual to achieve an employment outcome.

*(34 CFA 361.5(b)(32)) Individual’s representative* means any representative chosen by an applicant or eligible individual, as appropriate, including a parent, guardian, other family member, or advocate, unless a representative has been appointed by a court to represent the individual, in which case the court-appointed representative is the individual’s representative.

Even broader interpretations of the term “family” emerged from the discussion of the prime study group.

An individual’s biological family may not be available or relatives by blood or marriage may not be the ones actually providing “family support” to the individual with a disability.

For purposes of this document/training the prime study group defines family to include (1) an existing support system and (2)

whomever the VR consumer identifies as “family”, which may or may not be the biological family.

## **Activity: Continuum of Family Involvement**

**Purpose:** To clarify that family involvement is a dynamic process that falls along a continuum.

**Description:** Read the case studies. Discuss who in the cases would be considered as “family” members. Show the overhead transparency, which is blank, and ask participants to complete the various points of family involvement on the continuum for each case study. Discuss where the families in the cases might fit on the continuum. How might the family’s involvement change throughout the next year? Next, discuss the following questions.

- How have families participated in the rehabilitation process?
- Is there great variation from family to family?
- Is family involvement static or dynamic?
- Ask participants to give some examples.

**Materials:** Case studies, overhead transparency

**Discussion:** Families can make valuable contributions to the vocational rehabilitation process and provide support that contributes to the VR consumer’s successful employment outcomes. It is critical that the vocational rehabilitation professional

take advantage of the strengths that each family brings to the process. Focusing on the strengths of families does not preclude the possibility of encountering challenging families. Families are quite diverse and will vary in their capacity to support their family member with a disability. Vocational rehabilitation counselors should take time to explore the potential for positive family involvement and see families as a resource for the VR consumer.

In most cases there is a continuum of family involvement from uninvolved to very involved. Behavior that appears to be unsupportive may actually be due to factors that are beyond the control of the family members. For example, families that are viewed as uncooperative or uninvolved may be experiencing difficulties attending meetings because of conflicting work schedules or problems securing childcare. Unsupportive behavior could also be based on other reasons, for example, families may be afraid of losing benefits upon which they have come to rely, or concerned that the VR consumer will become more vulnerable to violence or exploitation if they live away from home or work in the community. On the other hand, they may not be supportive because of low expectations, a lack of knowledge, or any number of other issues that could be addressed through education, careful planning or corrective action.



Even so, it is unrealistic to expect all families to participate at the same level. Limited participation may reflect parental choice. Passive participation should not be labeled as uncaring and counselors should not pressure parents to assume preconceived, culturally unfamiliar or uncomfortable participatory roles.

However, limited family participation may not reflect “informed choice.” Many culturally diverse families may not be knowledgeable in areas that could affect their ability to choose a more active role. When family members choose minimal participation options, vocational rehabilitation counselors should ensure these choices are not due to lack of information, but are truly free and informed choices. There will be times in which a family will not be willing to be involved, but there are ways counselors can encourage family involvement. Generally, family members will be much more likely to participate if they feel their participation is valued.

The continuum of family involvement can be used to represent not only the range of differences between families, but also the changing dynamics of an individual family. Family relationships and the degree to which family members are involved in the lives of one other can change over time. Family involvement is a dynamic process. Families may assume greater or lesser roles in the lives of their family member as that individual matures or masters new skills, experiences setbacks,

or in response to other responsibilities and stresses in their lives that require time and attention. Families deal with multiple priorities that at times must take precedence over working with professionals on behalf of their family member with a disability.

## CASE STUDIES

### Case Study #1:

Jimmy is a high school senior who has been attending a vocational school for the last two years studying drafting. He would like to go to work after graduation; however, the drafting instructor has reservations about Jimmy's ability to work as a draftsman because of his limited communication skills. Jimmy is the youngest child of a single mother who emigrated from Germany when he was an infant. She has a strong work ethic and worked nights at a local factory during most of his school years. Recently she quit the factory and started her own lawn care service. All of her sons work for her part-time, Jimmy more than the other three brothers who have full-time jobs. Jimmy was born profoundly deaf and his high school teachers suspect that he also has a severe learning disability. He has difficulty with reading and writing, which he often must rely on when communicating with individuals who do not know sign language. Jimmy's vocational rehabilitation counselor feels that Jimmy has the potential to work competitively as a draftsman; however, he realizes that Jimmy will need to have a great deal of support if the placement is to be successful. Jimmy will need a job coach to help him get established on the job. In addition, Jimmy will need an interpreter. However, only one certified interpreter lives in the rural, agricultural area in which the family resides and she works full-time at the local public schools. The only other people who

know sign language in the community are Jimmy's family members and another draftsman who is deaf and who works at the local oil drilling company where Jimmy is applying to work. Jimmy's mother volunteered to serve as an interpreter, if Jimmy agrees, during the winter when her lawn care business is slow. However, she insisted that Jimmy would have to be provided an interpreter when spring came and her business picked up. In addition, she suffers from carpal tunnel syndrome caused from repetitive stress injuries at the factory, so there are times when she cannot sign.

### Case Study #2

The VR consumer is a 27-year-old male who sustained a spinal cord injury in his senior year of high school in a diving accident. He has quadriplegia at the C-5 level and functions from a motorized wheelchair. Although he is bilingual, his parents are from El Salvador and have minimal English skills. They are employed in factories for meager earnings. Despite the income limitations they purchased a home and moved from their inaccessible apartment to a house that they renovated for wheelchair use. With VR assistance a ramp was built but they did all the interior work on their own. The VR consumer entered a local college after his injury.

Because the VR consumer's family could not afford to purchase a van, the consumer received a donated van from Kessler Institute. His uncle did the

mechanical work at no expense to the family to be sure it was in good working condition for his use. VR funded the adaptive equipment so he could travel to school and see his counselor in the VR office. At one point when the vehicle broke down and there was a delay in getting it repaired, the VR consumer went by bus to New York City to complete an internship in media arts. Family members would wait at the bus stop with each morning to flag down the bus, which would consistently pass him by.

This family's love and support have enabled him to adjust to his disability, to have a positive self-image and has allowed him to mature as a responsible hard working adult in media arts. Without the support of his family, this would not be possible.

#### **Case Study #3**

The VR consumer is a 20-year-old single woman living with her parents. She has significant learning disabilities and facial deformity. She was not able to secure work on her own for a year after completing high school. Her mother intervened by contacting a former Child Study Team professional who referred the consumer to VR. Evaluation and discussion of career options and service plans resulted in a job-coached placement at a bakery.

Since the VR consumer was not working full-time, she was idle too much. The mother advocated for a steadier job in the food service industry. A full-time job with benefits was

secured and coached. This family member's advocacy led to a suitable job commensurate with the interests and needs of the VR consumer.

#### **Case Study #4**

The VR consumer is a 40-year-old single parent living with her two adolescent children. She had a significant history of abuse as a child, with serious substance abuse on her part, and depression and anxiety in her adolescence and early adulthood. After her husband abandoned her and the children, she was faced with the care of her children as a single parent. She rolled to this responsibility, resolved to abstain from substances and became very active in Alcoholics Anonymous. Being a caring individual, she aspired to earn credentials where she could help others. With VR help she is now employed full-time as a Substance Abuse Counselor for deaf persons, an area of great need. She commented that in addition to VR help, it was her children who enable her to "hold it together" and to "keep going". Her role as a parental caregiver and her children's appreciation of her as a role model played a major part in her achievement of a career of interest, value and adequate earnings.

## **Continuum of Family Involvement**

Create a continuum that depicts the dynamic nature of involvement of families in the rehabilitation process.

**Activity: Factors that Contribute to Family Involvement**

**Purpose:** To help participants understand the various factors that may contribute to family involvement or lack of involvement.

**Description:** Ask for a volunteer to represent the family unit and have them stand at the front of the room. Place a sign around their neck on which the word *family* is written. Make sure their hands are free of constraints. Ask participants to identify factors that families have to deal with that may impede their ability to support the VR consumer. As a factor is identified toss the person representing the family a small ball. The volunteer will probably be able to handle a few balls, but eventually will be juggling them. Some will fall to the floor. Some may end up in a small basket representing resolved issues.

The trainer should hold back a few balls to throw at the end. The factors that you identify should be ones that would create a great deal of stress on the family such as loss of a job or permanent disability.

At the end of the activity have a discussion of family interaction (see below).

**Materials:** Small, soft balls (approximately 15), a basket labeled Unresolved Issues, and a large card on which the word family is written. The card should have a string/ribbon

attached so that it can be worn around the neck.

This activity can be modified by using bean bags.

**Discussion:**

Numerous external factors may contribute to the family's ability or inability to participate in the rehabilitation process. A family may have very good intentions, but the day-to-day responsibilities of caring for the family may preclude their involvement on a consistent basis. Others may begin in a supportive role, then have a situation occur that requires a great deal of attention and effort, such as when an elderly parent requires assistance. At that time a family member may not be able to give the same level of support. The goal for the rehabilitation professional is to help the family determine the level of support they are able to give at that particular time, realizing that families may not be able to maintain this level for a long period of time. However, the rehabilitation professional should not assume that the level of support would decrease; in fact, changing circumstances may allow the family to increase the support level they are able to provide.

## **Activity: Cultural Diversity**

**Purpose:** To recognize the cultural richness in your area and to discuss how cultural differences may influence the level of support from some families. To help readers begin to think about issues related to diversity.

**Description:** Make a collage of brochures that reflect the cultural, historical, and economic factors of your area. Participants may be asked to bring brochures, newspaper articles, advertisements, etc. to add to the collage.

Brainstorm a list cultural, racial, ethnic, and economic factors in your area. Discuss how they might effect family participation. Read and discuss the list of questions in the handout.

**Materials:** Brochures, maps, newspapers, advertisements, etc. of your area. A bulletin board or poster board on which to place the collage.

**Handout:** Questions Regarding Culture

### **Discussion:**

It is becoming increasingly important that vocational rehabilitation professionals develop an understanding of cultural diversity. It is common for a VR professional to encounter various ethnic cultures throughout their day in addition to the cultures of disability, sexual minority, the underprivileged,

the youth and/or the aged. Throughout the VR profession, it is accepted that persons of diverse culture are more successful when the VR professional is of like culture. Of course, it is unrealistic to expect that each VR agency have each culture represented in each office, so, we seek to develop a staff of VR professionals who have "cultural sensitivity." Ideally, the term "culturally sensitive" would not be limited to having understanding for and knowledge of particular cultures but be broadly coined to project a professional who has developed an appreciation for the culture and the role of culture for all people. This sensitivity will go a long way to overcoming barriers cultural diversity may pose to the VR process.

**Questions Regarding Culture**

<b>FOR THE CONSUMER</b>	<b>NOTES</b>
What aspects about your family make proud and you would not want to change?	
What in your family would change if the disability went away? Are there positive aspects to the disability?	
What do you think are the roles of (men-women-children-seniors) in your family?	
Have you moved since you became disabled? What is different about where you are living now?	
Who in the family works outside of the home (including going to school)? What has changed since you became disabled? Has the way you relate to people at work changed?	
Have your relationships with relatives changed since you became disabled? With friends? Neighbors? Others in your community? How often do you have contact with (each category) now?	
Are there particular aspects of your cultural heritage that help you to deal with the issues surrounding the disability? That seems to make it more difficult to deal with?	
With what agencies, professionals, institutions, groups, etc., does the family interact on a regular basis? How would you describe these relationships (e.g., helpful, respectful, interfering, blaming, confusing)? Who has helped the most? Who the least? Who involves you in decision-making?	

<b>FOR THE REHABILITATION PROFESSIONAL</b>	<b>NOTES</b>
What do I find really interesting about this VR consumer and family's cultural background? What would I like to know more about?	
Are there cultural attitudes that seem to either promote or inhibit the family's adaptation to the disability?	
Does the nature of the disability carry a strong social stigma in the VR consumer and family's culture? How has the family adapted to this?	
What community resources/referrals might be useful for this family? For individual members?	
What attitudes in this family regarding the role of men, women, children, seniors might have particular impact on attainment of the VR consumer's goals?	
Who from other helping systems could the VR consumer, family, or I invite in to help the team reach its goal? Do the VR consumer and family agree with my recommendation?	



**Activity: How Can Families Be Supportive**

**Purpose:** To help participants develop a list of ways families can be supportive in the rehabilitation process.

**Description:** Before giving the handout, have participants brainstorm a list ways families can be supportive. Compare the brainstorm list to the handout.

**Materials:** Flip chart and markers, handout.

**Discussion:**

A report of a June 1996 study by the Center on Promoting Employment (RRTC Boston) “demonstrates that family members play crucial roles not only in career preparation, but in actual job search efforts. Young adults both with and without disabilities find that using their personal network of relatives, friends, or neighbors is the most effective way to find a job” (*Point of Departure*, TATRA 1996).

## How Can Families Be Supportive

### Job Assessment/Exploration

- Identify a family member's interests and strengths
- Streamline the assessment process by providing existing documentation
- Collaborate in creative problem solving

normal everyday job-related problems and frustrations

- Problem solve with family member on how to deal with challenging workplace situations
- Identify early warning signals for problems VR consumer is having with a job

### Finding Employment

- Family members can use their personal networks of relatives, friends, neighbors, community business, and religious community to identify job opportunities
- Support an individual in their job search
- Improve quality of placement and job satisfaction by advocating for employment options that reflect the interests and skills of their family member
- Help VR consumer prepare for job interviews

### Job Retention

- Help VR consumer prepare for work in the morning
- Act as a backup for personal assistance staff
- Help maintain assistive technology
- Provide transportation
- Cultivate external natural supports in the community
- Provide a safe haven for VR consumer to talk about their job and

### **Family Contributions**

Families will contribute to the rehabilitation process in a variety of ways. Some will make significant contributions; however, counselors should not expect families to assume responsibility for all gaps or shortages in the service system. Vocational rehabilitation professionals need to both accept and respect a family's limitations as well as strengths. Professionals can unknowingly send a message to caregivers that they are either doing too little or too much. Families may feel they can't do anything right –

Based on “Why Mothers Have a Tough Time” attributed to Jordan Miller, M.D. Center for the Study of Women's Psychology.

*If we are concerned, we are overprotective; if we are unconcerned we are neglectful.*

*If we are involved, we are demanding; if we are not, we are detached.*

*If we have high expectations we are unrealistic; if we have simple aspirations we set our sights too low.*

*If we nurture generously, we are smothering; if we nurture less we are withholding.*

*If we offer advice, we are controlling; if we refrain we are disinterested.*

*If we phone, write or visit often, we are pests; if we don't we are thought uncaring.*

*If we help with tasks or give or loan money, we cultivate dependency; if we don't, we are unsupportive.*

**Activity: How to get Families Involved**

**Purpose:** To learn ways that families can be involved in the rehabilitation process.

**Description:** This part of the training involves a discussion of how to get families involved in the rehabilitation process.

**Materials:** Handout

**Discussion:**

*Why should families be involved?*

It is well known that one of the best ways to find a job is to ask for job leads from family members, friends, and neighbors. A recent study reported in "Point of Departure" (1996) found that the kind of support friends and family usually provided were ideas about the type of work an individual could perform, where to look for a job, and assistance with transportation to the job. At the same time, this report also found only a small percentage of families (25%) were perceived as being involved in the job search of their VR consumer.

Working with families continues to represent a minimal part of the day-to-day work of the Vocational Rehabilitation counselor. Emener (1991) stated "It would appear very appropriate and helpful for rehabilitation counselors to occasionally

ask themselves, is it possible that one of my VR consumer's family members could be more helpful to the VR consumer, and if this is the case, how can I facilitate the family member's providing such helpful assistance?"

*Involving Families*

Many rehabilitation counselors believe they lack the proper training, time, and resources to work extensively with the family.

*How does a VR professional begin to engage families in the process?*

It can be done with little expenditure of time or money. *The first and most important step* is to get the VR consumer's permission to involve family members in the process. The next step would be to do an assessment of the family situation. During this assessment stage, counselors must demonstrate respect and appreciation of diversity of culture, ethnicity, race, gender, economic level, and religion. It is during this stage that key issues and players must be identified.

**FACTORS TO CONSIDER WHEN INVOLVING THE FAMILY**

QUESTIONS	NOTES
What is the composition of the family?	
What is the family's perception of the disability?	
How have they responded thus far, both emotionally and behaviorally?	
What are their communication patterns?	
Are coping mechanisms in place, and if so, what kind? Many families have coped effectively and may be strengthened by the presence of disability.	
What does the family need?	
Is there a correlation between the VR consumer and the family objectives?	
What is the family's perception of their member's potential for increased independence in the community and at work?	
Are there any specific limitations that pose impediments to the vocation process?	
Are there strengths in communication, problem solving, planning, etc?	
What is the knowledge level of the family regarding the disability, employment opportunities, and community resources?	

How effective have they been in utilizing community resources, or have they chosen not to seek help?	
If they have chosen not to seek help is it due to previous negative experiences or to cultural differences and expectations?	
Openly discuss disincentives. Is the loss of the member's benefits and entitlements an issue? If so, why?	
Have they been made aware of alternatives to loss of benefits?	
How will the loss of entitlements affect the family as well as the specific family member?	
Are their concerns realistic, or are they symptomatic of dysfunction?	

**QUESTIONS ABOUT FAMILY ROLES**

<b>FOR THE FAMILY</b>	<b>NOTES</b>
Who in the family decided to contact this agency?	
How has your role in the family changed since the disability? (Ask each member of the family)	
How are decisions usually made in the family? Has that changed since the onset of disability?	
What long-term plans or goals has each of you canceled, postponed, or altered as a result of the disability? When and what would it take for you to resume these plans?	
How has the family's financial situation changed since the accident or illness?	
Is someone in the family more knowledgeable than others about health issues?	
Do you feel more comfortable asking for more information from your (doctor, caseworker, lawyer, teacher, etc.)?	

<b>FOR THE REHABILITATION PROFESSIONAL</b>	<b>NOTES</b>
Does the family seem able to express ideas to each other clearly and to have those ideas heard?	
Do there appear to be hidden issues, especially regarding the persons with the disability?	
Does the general anxiety level in the family need to be lowered?	
What do I tell the family about the reasons for asking these questions? How can I frame these questions in ways that show my respect for them?	
(Ask each member) Who seems most involved with the disability (other than the person with the disability)? Who gets along with whom? Who is close to whom? Farther apart? Tries to please whom?	
Are there issues the family seems to be avoiding (e.g., alcoholism) by focusing on the disability?	
Does blaming and judging seem to be characteristic of the family's interaction style? How can I separate the family members from the disability in terms of blaming? How can I help them "keep the disability in its place?"	
How has the family's emotional style (as they describe it) changed since the accident or illness?	



<p>How might the family better balance individual needs with the needs brought about by the disability?</p>	
<p>By my actions do I tend to reinforce or to take away the VR consumer and family's authority? What can I do to strengthen the VR consumer and family's autonomy and strength? What can I do to support the VR consumer and family's authority in interactions with other agencies? With my agency? Other systems?</p>	
<p>What are my range of skills as a transformational leader in regards to working with VR consumers and families? What other skills do I need to add?</p>	
<p>What is a good balance between letting the VR consumer and family lead the process and my role to promote change toward goals the VR consumer has selected? When I consider the principles of good judgment, parsimony (or doing the most with the least effort), and effective coordination of effort as the keys to effective team functioning, how well do I tend to express these?</p>	
<p>What other resources do I need to do my job (e.g., more training, more time, Internet access)? How can I negotiate with my agency to access these? Who can help me do this?</p>	

**Activity: Identification of Opportunities for Collaboration with Families in the Rehabilitation Process**

**Purpose:** To identify opportunities for collaboration in the participants local area.

**Description:** During this activity participants will brainstorm opportunities in their settings for collaboration in the rehabilitation process with families. Use a flip chart to write down responses.

Potential opportunities for collaboration with families involved in the rehabilitation process:

Community mental health agencies, Centers for Independent Living, advocacy groups (e.g., the United Cerebral Palsy Associations), community family agencies, home-based family programs, family businesses, churches, the military, health care agencies, school systems, parent training and information centers, university-based family programs, etc.

**Materials:** Flip chart and markers.

**Discussion:**

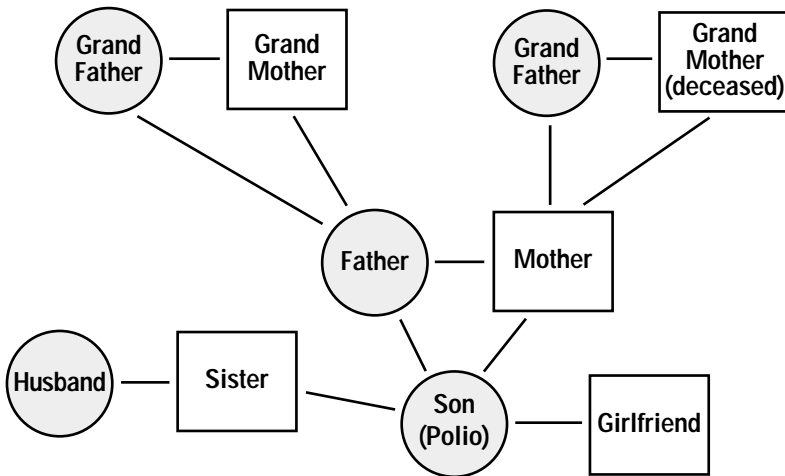
For our purposes a workable definition of *collaboration* is a process of joint decision-making among stakeholders, both individuals and organizations, with a convergence of interests using shared

rules, norms, and structures to further these interests. The actors retain their independent decision-making powers, relationships are characterized by mutual respect, trust, and tolerance, there is a change-oriented nature to the relationship, and each actor acknowledges multiple perspectives, shared responsibility, and accountability for decision-making.

**Activity: Map of the Family**

**Purpose:** To enhance collaboration with families in the rehabilitation process. To help VR consumers broaden their view of family and identify family members on whom they count for support.

**Materials:** Circle and square cut outs, sheets of paper, markers, and adhesive.



**Description:** It is critical that the rehabilitation professional have the ability to determine how extensive a resource the VR consumer's family could be. The rehabilitation counselor might consider asking the VR consumer and family members to draw a map of the family.

Draw a map of the people included in the family. Construct family trees or genograms, which are diagnostic tools to identify patterns of family strengths

and challenges. Genograms provide visual representations of trends in the family that impact on the VR consumer and family such as genetically based disabilities, patterns of abuse or alcoholism, patterns of immigration, marriage, death, etc. that cross generational lines.

Ask participants to "Show me who is in your family or whom you know you can count on for support?" The family members can be instructed to use squares for females and circles for males.

When actually using this exercise with VR consumers and their families, the professional might encourage the family to think beyond immediate members by asking questions such as, "Who else is concerned that Samantha doesn't have a job? Who might be pleased if she gets and keeps employment? Who might help in the process? Who might interfere with the process?"

Individuals and families define their options by the assumptions they have about themselves. The stories that they tell about their capabilities can expand or constrain choices by recognizing or denying capabilities

## **Activity: Reframing**

**Purpose:** To help VR consumers and family members reevaluate the situation to look at the positive aspects of the situation.

**Description:** Have participants practice reframing the following:

- The VR consumer wants to be an RN. She consistently fails her science classes in college.
- A person with chronic pain syndrome finds difficulty managing his current workload.
- A single mother reentering the work force finds that the expenses related to childcare are overwhelming.
- A VR consumer with mild cerebral palsy wants to be a welder but is having difficulty perfecting his skill.

**Materials:** None

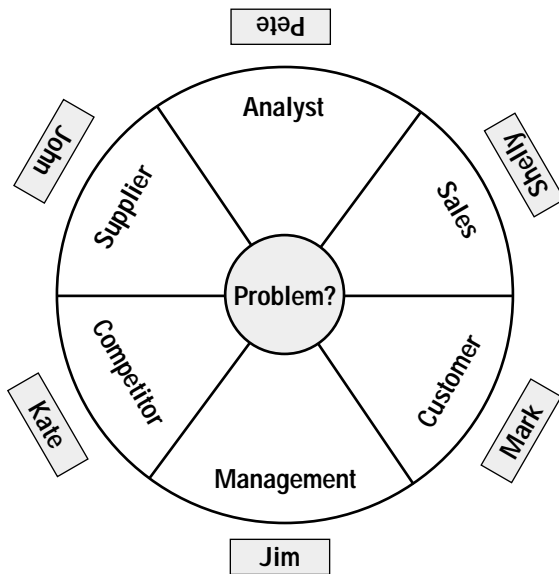
### **Discussion:**

Reframing relies upon the skill of listening for suggestions of strength even when VR consumers and families are overwhelmingly self-negating. The goal is to help the VR consumer find the positive spin in their descriptions of their ability to solve problems and to express their competency.

**Activity: Multiple Perspectives Wheel**

**Purpose:** To allow participants to develop a greater understanding of the issues that families face. To open up or widen a team's perspectives – the points of view from which the members regard a problem, issue, or opportunity. Rotating between roles encourages members to see an important issue from as many vantage points as possible.

**Materials:** Case study, note cards, markers, and thick paper for the “perspective wheel”.



**Description:**

1. Create a disk about 18 inches in diameter from thick paper that can be written upon. Place the wheel in the center of the table.
2. Draw lines across the wheel as if cutting a pie, dividing the wheel into 4-6 equal slices (depending on the number of stakeholders). Write

team member's names on index cards and place around the outside parameter of the wheel.

3. Identify the stakeholders for the problem, issue, or opportunity being explored. Stakeholders may be internal or external. Write the stakeholders titles on note cards and place them on the inside edge of the wheel, one card per section of the wheel.
4. Identify the issues or problems and write them on a card and place in the center of the wheel.
5. When the wheel is turned one space, each member's name will stop in line with one of the key stakeholders. At each turn of the wheel team members must respond or make a statement that reflects the perspective of the stakeholder regarding the issue being investigated.
6. Team members are not permitted to “pass”.

At some point, the team will have full descriptions of each perspective. Now, as a team, you can talk through the situation from each point of view.

**Discussion:**

This tool is used to gain a greater understanding of the perspectives of the stakeholders involved in particular issue, problem, or opportunity. It is often used to increase awareness of barriers that exist.

Adapted from: Senge, P. (1994). *Fifth Discipline Fieldbook*. New York: Doubleday.

## Case Study

Luke, age 47, was a sturdy, industrious, and dependable employee for a Northeast electric company for 24 years, with a specific responsibility for several repair crews. There is evidence that he was highly regarded by his employees. According to his wife he had always been vigorously healthy until, at age 45, he experienced a severe cerebrovascular accident. He was hospitalized for five months under the medical supervision of a specialist and a general practitioner engaged by his employer. Damage resulting from the stroke included right side weakness and occasional grand-mal seizures, which are now generally controlled by medication. During his hospital stay speech and physical rehabilitation potentials were evaluated, and therapy engaged. There was an excellent response to these efforts, as now he has very good use of his left side and moderate mobility in his right hand and right leg, though he must use a cane when walking. He is unable to do any prolonged standing. Upon visiting the home it was found that the situation had been well organized to receive Luke. During his hospitalization arrangements were completed for the 19 year-old son to move in with a friend in order to provide more space in the family home. Two rooms and a bath on the ground floor of the home were equipped for Luke and his wife. A hospital bed and other necessary equipment were purchased to facilitate his care at home. A visiting therapist

has commented that though she has given Luke a full set of range of motion exercises to perform daily, these are only done when she visits twice a week. There are days when Luke does not leave his room, his own choice, yet he has commented to the physical therapist that he would like to begin working again. Though he feels strongly that more than likely, he could never return to his former job. Inquiry was made about Luke's interests and personality prior to this cerebral accident. His wife describes him as a man who needed at all times to be going somewhere and doing something. His preferred diversions were hunting and fishing, which he liked his two sons, age 19 and 14, to share with him. There is also one daughter, age 11. Before his illness he had, on the weekends, consumed at least a six pack of beer on both Saturdays and Sundays, and when intoxicated he became quite abusive, verbally, to his family. He has not consumed any liquor, however, since the cerebral event. Luke has no intellectual interests and reads very little except the local paper and manuals related to his work. He graduated from high school, but has received no formal education since then.

Upon leaving high school he joined the Army for six years, where he was a radio technician and achieved the rank of Sergeant. Social activity has been restricted to family get-togethers. Apparently, Luke was keenly conscious about his work, rarely missing time because of illness and taking much

satisfaction in participating with his repair crews in some required, dangerous activities. Luke is described by his wife as a stern, demanding husband and parent who expected instant response to his commands. The family is presently maintaining itself financially by Insurance Disability payments, which are able to meet the monthly family living expenses. There is some money in investments and savings and medical expenses are being taken care of by a very comprehensive medical insurance plan. Luke's wife and older son are quite ambivalent about Luke returning to a job, since life is quieter now at home and with the wife working part-time as an accountant, there is little financial strain. They believe that entering the rehabilitation process and eventually training for a job could cause a return to the former, hectic, family life.

Luke tends to see the implications of his disability as something that will "pass in time", though he realizes that he may always have some physical limitations. He realizes that when he is working at paid employment he is quite happy, and employment provides for him status and security. It is also difficult for him to accept a disability which he does not fully understand, yet realizes that he would like to "get going" to establish another career.





# 5

## CHAPTER 5

### RESOURCES

There are innumerable resources for persons with disabilities and their families, and to attempt to list all in any document would be unrealistic and overwhelming, and would result in a book far too large to sit on your desk. So, in this section we have attempted to provide only a starting place in the quest for information and assistance. As with any research, any question leads to another question ... so it is with researching resources – in identifying a resource, we are led to yet other resources.

This was especially true when researching resources on the Internet. Many sites had links to “related sites” and the road never seemed to end.

It is our hope that from this sampling of resources you will be amazed at the vast number, and wide variety, of resources available to you.

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ADVOCATING:

**Americans With Disabilities Act**

Disability & Business Technical Assistance Centers (DBTACs)  
Tel: 800-949-4342 (Voice/TTY)

DBTACs provide information on legislation, rights and resources. DBTACs provide information, referral, technical assistance and training on the Americans with Disabilities Act (ADA) to businesses, state and local governments, and persons with disabilities to facilitate employment for individuals with disabilities and accessibility in public accommodations and government services. The DBTACs also conduct training and promote public awareness on the ADA. Callers are automatically routed to the DBTAC in their region.

**DASH - Disability Advice and Information, St. Helens**

Central Library, Victoria Square, St. Helens, Merseyside, WA10 1DY, United Kingdom  
Tel: 01744-453053

Free, confidential and independent information and advice service for disabled people, their families, careers, or anyone with an interest in disability matters.

<http://www.merseyworld.com/dash/>

**Disability Net**

Suite 5d, North Mill, Bridgefoot, Belper, Derbyshire, DE56 1YD, United Kingdom

Tel: Within UK - 01773 824343  
Outside UK - +44 1773 824343

Disability Net is a worldwide disability information and news service, offering a wide range of services for everyone with an interest in disability.

**Family Voices**

P.O. Box 769,  
Algodones, NM 87001  
Tel: 888-835-5669

National organization of families and friends speaking on behalf of children with special health care needs. Links provided to current state and/or local projects.

<http://www.familyvoices.org/>

**Gippsland Disability Resource Council**

42 -44 Fowler St.,  
P.O. Box 63 Moe 3825  
Tel: 800-625-674

Promotes empowerment and independence for people with disabilities, their family and careers.  
<http://members.net-tech.com.au/gdrc/>

**Nagler Disability Consulting Services**

Disability advocate Mark Nagler's books for sale, offering insights into living with a disability, and guides for caregivers, family, and friends.

<http://www.marknagler.com/>

**National Alliance for the Mentally Ill (NAMI)**

Colonial Place Three,  
2107 Wilson Blvd., Suite 300,  
Arlington, VA 22201-3042  
Tel: 800-950-NAMI (6264)  
TDD: 703/516-7227

NAMI is dedicated to the eradication of mental illnesses and to the improvement of the quality of life of those whose lives are affected by these diseases. NAMI seeks to accomplish its mission through the following activities: coordination of activities of state and local advocacy groups; serving as an information collection and dissemination center; monitoring existing health care facilities, staff, and programming for adequacy and accountability, influencing the pre-professional and continuing education of mental health service providers; promotion of new and remedial legislation; fostering public education; pressing for quality institutional and non-institutional care and individualized treatment of persons with mental illness; promotion of community support programs, including appropriate living arrangements linked with supportive social, vocational rehabilitation and employment programs; improvement of private and governmental funding for mental health facilities and services, care and treatment, and residential and research programs; liaison with other national and international mental health organizations; delineation and enforcement of patient and family

rights; soliciting and receiving funds in support of all of the above.  
[www.nami.org](http://www.nami.org)

**TASH - Disability Advocacy Worldwide**

29 W. Susquehanna Ave., Ste. 210,  
Baltimore, MD 21204  
Tel: 410-828-8274

An international association of people with disabilities, their family members, other advocates, and professionals fighting for a society in which inclusion of all people in all aspects of society is the norm.  
<http://www.tash.org/>

**The National Guardianship Association**

1604 North Country Club Road,  
Tucson, Arizona 85716  
Tel: 520-881-6561

The mission of the National Guardianship Association is to provide educational, training and networking opportunities for guardians.  
<http://www.guardianship.org/>

## ACCESSIBILITY:

### **Accessible Community Transportation In Our Nation (Project ACTION)**

700 13th St., N.W.,  
Washington, D.C. 20005  
Tel: 800-659-6428 (Voice/TTY)

Project ACTION is a national program that supports innovation and cooperation in solving transit accessibility problems. Project ACTION provides various direct forms of technical assistance and training, and maintains a library of information and materials addressing accessible transportation for people with disabilities. Project ACTION disseminates its newsletter *Project ACTION UPDATE*, training curricula, surveys, technical materials, and reports.  
<http://www.projectaction.org>

### **Architectural and Transportation Barriers Compliance Board (Access Board)**

1331 F Street, N.W., Suite 1000,  
Washington, D.C. 20004-1111  
Tel: 800-872-2253 (Voice)  
Tel: 800-993-2822 (TTY)

The Access Board enforces the Architectural Barriers Act (ABA), ensuring accessibility in facilities built, altered, or leased using certain Federal funds. It develops the Americans with Disabilities Act (ADA) Accessibility Guidelines (ADAAG), which are minimum accessibility guidelines for places of public accommodation,

commercial facilities, state and local government facilities, and transportation vehicles and facilities. The Access Board is also charged with developing accessibility guidelines for telecommunications equipment and customer premises equipment. The Access Board offers training, technical assistance, and publications to individuals and organizations throughout the country on removing architectural, transportation and communications barriers.  
<http://www.access-board.gov>

### **National Library Service for the Blind and Physically Handicapped (NLS)**

Library of Congress  
1291 Taylor Street, N.W.,  
Washington, D.C. 20542  
Tel: 202-707-5100 (Voice)  
Tel: 202-707-0744 (TTY)

A free national library program of Braille and recorded materials for persons with visual and physical disabilities is administered by the National Library Service for the Blind and Physically Handicapped (NLS), Library of Congress. With the cooperation of authors and publishers who grant permission to use copyrighted works, NLS selects and produces full-length books and magazines in Braille and on recorded disc and cassette. Reading materials are distributed to a cooperating network of regional and local libraries where they are circulated to eligible borrowers. Reading materials and

playback machines are sent to borrowers and returned to libraries by postage-free mail.  
<http://www.loc.gov/nls>

**Recording For the Blind & Dyslexic (RFB&D)**

The Anne T. Macdonald Center  
20 Roszel Road,  
Princeton, NJ 08540  
Tel: 800-221-4792

RFB&D is a national nonprofit service organization that provides educational and professional books in accessible format to people with visual impairments, learning disabilities, and other physical disabilities that prevent them from reading printed material. This includes individuals who are no longer in school but who are using educational books to pursue careers or personal interests. RFB&D also accepts requests to record books that are not already contained in its 75,000-title Master Tape Library. To become an individual member of RFB&D, you must complete an application form (which contains “disability verification” and “certification” sections) and include a \$50 registration fee and a \$24 annual membership fee. Application forms are available by calling the number listed above.  
<http://www.rfbd.org>

PARENT/FAMILY SUPPORT:

**Family Resource Center On Disabilities (FRCD)**

20 East Jackson Boulevard, Room 300,  
Chicago, IL 60604

Tel: 800-952-4199 (Voice)

312-939-3513 (Voice)

Tel: 312-939-3519 (TTY)

Formerly the Coordinating Council for Handicapped Children, the Family Resource Center on Disabilities (FRCD) is a coalition of parents and professional organizations organized to improve services for all children with disabilities. FRCD provides information and referral services, family support services, transition services, special education rights training, training for parent leaders and distribution of publications relevant to their mission.

**Family Village**

1500 Highland Avenue,  
Madison, WI 53705-2280

Informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature, and much, much more!

<http://familyvillage.wisc.edu/>

**Technical Assistance Alliance For Parent Centers**

**Parent Centers - *RSA or OSERS - differentiate?***

4826 Chicago Ave., S.,

Minneapolis, MN 55417-1098

Tel: 612-827-2966 or

888-248-0822

Parent Centers in each state provide training and information to parents of infants, toddlers, school-aged children and young adults with disabilities and the professionals who work with their families. This assistance helps parents participate more effectively with professionals in meeting the educational needs of children and youth with disabilities. The website provides links, through the **Technical Assistance On Transition & The Rehabilitation Act**, to site links to multi-lingual resources, person-center planning, transition, IDEA, ADA, Family Leave Act and Parent Training Materials and a direct link to a National listing of funded centers: [www.taalliance.org](http://www.taalliance.org) or [www.pacer.org/natl/natl.htm](http://www.pacer.org/natl/natl.htm)

**Family Support Network of North Carolina**

CB#7340, University of North

Carolina at Chapel Hill,

Chapel Hill, NC 27599

A non-profit organization providing info and emotional support to families of children with special needs and the professionals who serve them.

<http://fsnnc.med.unc.edu>

### **Hearts Of Gold**

We are a group of loving People who have gathered together because we have a member of the family with a disability. We are here to support those of you needing someone to talk to. We are here to give comfort. We are trying to get an understanding across to everyone that those with disabilities are still human and have feelings. We would like to promote awareness about many disabilities to everyone.

<http://www.webring.org/cgi-bin/webring?ring=hog;list>

### **Children's Disability List of Lists**

A current, annotated list of mailing lists for families of children with disabilities and special needs. Each listserv on this list has been personally validated for subscription information and family orientation.

<http://www.comeunity.com/disability/speclists.html>

Disability Connection  
P.O. Box 270714,  
Fort Collins, CO 80527  
Tel: 970-229-0224

A family-centered, community resource for families whose children have disabilities and professionals working with these families.

<http://www.fortnet.org/DisabilityConnection/>

### **Through the Looking Glass**

2198 Sixth Street, Suite 100,  
Berkeley, CA 94710-2204  
Tel: 800-644-2666

Provides information, services and training regarding families in which a parent or a child has a disability. Located in Berkeley, California, it is the National Resource Center for Parents with Disabilities, serving the nearly 9 million parents with disabilities in the U.S. Through the Looking Glass emerged out of the independent living movement for people with disabilities, a movement based on self-advocacy and empowerment. More than 80 percent of the staff have personal or family disability experience.  
<http://www.lookingglass.org>

### **Trish and John's Resources For Parents With Disabilities**

A list of resources for parents with physical disabilities, including books, articles, products, organizations, and information on e-mail support groups.  
<http://www.disabledparents.net>

### **Parents of Special Children**

Designed for parents, professionals, and anyone whose life has been touched by a child with a disability.  
<http://anexa.com/parentsofspecialchildren/index.lhtml>

### **Parents With Disabilities Resources**

Project STAR -The Children's Institute,  
6301 Northumberland Street,  
Pittsburgh, PA 15217  
Tel: 412-244-3081  
800-683-5898

A program of Project STAR of The Children's Institute creating opportunities and equal access for parents with disabilities through

understanding, education and  
collaboration.

<http://trfn.clpgh.org/star/>

**Jeune's Family Support Group -  
Jeune's Asphyxiating Thoracic  
Dystrophy**

P.O. Box 41,

Temperance, Michigan 48182 USA

The Jeune's Family Support group is a  
group of twenty-seven children ranging  
in age from one year to twenty-two. We  
have also gathered many articles, so  
that we can send copies to any families  
needing information.

[http://www.geocities.com/HotSprings/  
2179/](http://www.geocities.com/HotSprings/2179/)

**Can Do, Inc.**

1309 South Mary Avenue,

Sunnyvale, CA 94087

Tel: 408-523-4700

A new Internet company that helps  
with the quality of life issues that  
people with disabilities face.

<http://www.cando.com>



TRAINING/EDUCATION:

**Association for Supervision and Curriculum Development**

1250 N Pitt St,  
Alexandria, VA 22314  
Tel: 800-933-2723

Problem-based learning, curriculum integration, performance-based assessment, multiple intelligences, educational management. Print, CD-ROMs, videotapes, audiotapes.  
<http://www.ascd.org>

**Clearinghouse On Adult Education and Literacy**

U.S. Department of Education, Office of Vocational and Adult Education  
600 Independence Avenue, S.W.,  
Washington, DC 20202-7240  
Tel: 202-205-9996 (Voice)

The Clearinghouse on Adult Learning and Literacy provides referral services and disseminates publications of state and national significance and other reference materials on adult education and literacy-related activities. Resource publications include information on English as a second language, adult basic education, family literacy, workplace literacy, adults with disabilities, technology, volunteers and the homeless.  
<http://www.ed.gov/offices/OVAE>

**Foundations for Science and Disability**

236 Grand Street,  
Morgantown, WV 26505-7509  
Tel: 304-293-5201, ext. 2513

The Foundation seeks to improve the quality and accessibility of the educational system for individuals with disabilities, specifically in the various areas of science. The Foundation acts as a clearinghouse for information on science, education, technology, and science careers for persons with disabilities. The Foundation also makes several awards a year to graduate students who have disabilities and are studying in the science field.

**HEATH Resource Center**

American Council on Education  
One Dupont Circle, Suite 800,  
Washington, DC 20036-1193  
Tel: 202-939-9320 (Voice/TTY)

The HEATH Resource Center, the national clearinghouse on postsecondary education for individuals with disabilities, collects and disseminates information nationally about disability issues in postsecondary education. The clearinghouse provides information on educational support services, policies, procedures, adaptations, transition, and opportunities at American campuses, vocational-training schools, adult education programs, independent living centers, and other training entities after high school for individuals with disabilities. Numerous publications are available upon request.  
<http://ace-info-server.nche.edu/Programs/HEATH/home.html>

**National Clearinghouse of  
Rehabilitation Training Materials**

Oklahoma State Univ.,  
5202 Richmond Hill Drive,  
Stillwater, OK 74078-4080  
Tel: 800-223-5219

**State/Regional Resource Centers**

Many states have their own vocational/technical resource centers. A complete list of addresses for state departments of education is found at:  
<http://www.iris.org/~nasdvtec/main.html>  
<http://www.ed.gov/Programs/ERODmap.html>  
<http://www.ccsso.org/sea menu.html>

**ERIC**

1900 Kenny Road, Columbus OH  
43210-1090  
Tel: 800-848-4815, ext. 28625

The ERIC database is a good source of information about instructional materials. A search will lead you to curricula, project descriptions, lesson plans, classroom activities, task lists, and other resources. The database also includes materials on how to develop curricula. You can search ERIC on the World Wide Web <[ericir.syr.edu/Eric/](http://ericir.syr.edu/Eric/)> and at most university, state, and resource center libraries. Staff at the ERIC Clearinghouse on Adult, Career, and Vocational Education (ERIC/ACVE) will conduct a sample search for you.

E-mail: [ericacve@postbox.acs.ohio-state.edu](mailto:ericacve@postbox.acs.ohio-state.edu); <[ericacve.org](http://ericacve.org)>.

**National Transition Alliance**

[http://www.dssc.org/nta/html/index\\_2.htm](http://www.dssc.org/nta/html/index_2.htm)

**National Transition Network**

<http://ici2.coled.umn.edu/ntn/>

**Project Tech Link: Linking Educators  
and Parents to Transition Best  
Practices Through Computer  
Technology**

<http://www.vcu.edu/rrtcweb/techlink/index.html>

EMPLOYMENT & JOB SEARCH:

Tel: 202-275-7377 (Voice, within Washington, D.C.)

Tel: 800-800-3302 (TTY)

**Davis Memorial Goodwill Industries, Inc.**

2200 South Dakota Avenue, N.E.,  
Washington, D.C. 20018

Tel: 202-636-4225 (Voice)

The EEOC is a government agency that handles discrimination complaints about employment based on age, sex, race, ethnicity and disability.

[http://www.access.gpo.gov/su\\_docs/gils/index.html](http://www.access.gpo.gov/su_docs/gils/index.html)

Davis Memorial Goodwill Industries provides vocational evaluation, training, employment and job placement services for persons with disabilities. An information packet is available upon request.

**NISH**

2235 Cedar Lane,  
Vienna, VA 22182-5200

Tel: 703-560-6800 (Voice)

Tel: 703-560-6512 (TTY)

**Department of Vocational Rehabilitation (VR)**

Consult your local telephone directory for the office in your vicinity.

Vocational Rehabilitation is a nationwide program for assisting eligible people with disabilities to define a suitable employment goal and become employed. Each state capital has a central VR agency and there are local offices in most states, as well as Native American Programs in many areas nationwide. VR provides medical, therapeutic, counseling, education, training, and other services needed to prepare people with disabilities for work. VR is an excellent place for a youth or adult with a disability to begin exploring available training and support service options.

NISH (formerly the National Industries for the Severely Handicapped) is the national nonprofit agency that assists community rehabilitation programs (CRPs) nationwide in expanding job opportunities for people with severe disabilities. NISH provides technical assistance to CRPs and helps them obtain federal funding contracts through the Javits-Wagner-O'Day (JWOD) Program. Information is available to the public.

<http://www.nish.org>

**Projects With Industry (PWI)**

Electronics Industries Foundation (EIF)  
2500 Wilson Blvd., Suite 210,  
Arlington, VA 22201-3834

Tel: 703-907-7400 (Voice)

Tel: 703-907-7422 (TTY)

**Equal Employment Opportunity Commission (EEOC)**

1400 L. Street, N.W., 2nd Floor,  
Washington, D.C. 20005

Tel: 800-669-4000 (Voice, outside Washington, D.C.),

The Electronics Industries Foundation's Project With Industry brings together representatives from businesses,

industry, and agencies to help qualified individuals with disabilities succeed in the competitive job market. EIF's PWI continually updates a centralized registry of local employers with specific job openings to match their needs with job seekers with appropriate skills. It provides job-seeking skills training, life skills training, and related services for job candidates with disabilities. It also provides support services to employers and job seekers before, during and after placement to help ensure a successful job match. EIF's PWI also provides awareness training and ADA workshops to employers and supervisors and recommends resources on assistive technologies for the workplace.

<http://www.eiafoundation.org>

### **Social Security - Ticket to Work/WIIA**

For a policy brief to describe the major provisions in Title 1 of the Act, which creates the Ticket to Work and Self-Sufficiency Program, visit:

<http://web1.tch.harvard.edu/ici/publications/pdf/pb3.pdf>>

RECREATION:

telephone number of a local chapter near you.

**Department of the Interior**

Office on Accessibility,  
National Park Service  
P.O. Box 37127 (MS 7253),  
Washington, DC 20013  
Tel: 202-565-1240 (Voice)

**Family Village**

1500 Highland Avenue,  
Madison, WI 53705-2280

There are 370 parks and 7 regional offices under the National Park Service. The National Park Service accepts inquiries on all of its national part activities and facilities. Information on accessibility of park programs, facilities, and services is best acquired directly from the park or area you plan to visit. For general information on park areas and activities and a listing of park phone numbers, call the number listed above.

Informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature, and much, much more!  
<http://familyvillage.wisc.edu/>

**Mobility International USA (MIUSA)**

P.O. Box 10767,  
Eugene OR 97440  
Tel: 541-343-1284 (Voice/TTY)

**Disabled Sports, USA**

451 Hungerford Drive, #100,  
Rockville, MD 20850  
Tel: 301-217-0960 (Voice)  
Tel: 301-217-0963 (TTY)

MIUSA is a nonprofit membership organization for persons with disabilities and other interested people. It works to expand opportunities for persons with disabilities to be involved in international educational exchange programs and to travel. MIUSA members receive information and referral services in the areas of travel and placement in international work camps and educational exchange programs. MIUSA also conducts international leadership training for persons with disabilities. Many publications are also available.

Disabled Sports USA is the nation's largest organization providing year-round sports and recreation activities to children and adults with physical disabilities. In conjunction with its nationwide network of chapters serving people in all 50 states and Puerto Rico, Disabled Sports USA offers such activities as snow skiing, water skiing, bicycling, white water rafting, horseback riding, mountain climbing, sailing, camping, and track and field. Contact Disabled Sports USA for the

**National Institute of Art and  
Disabilities (NIAD)**

551 23rd Street,  
Richmond, CA 94804  
Tel: 501-620-0290 (Voice/TTY)

NIAD operates a creative visual arts center for adults with disabilities and serves as a model for other centers that wish to provide individuals with disabilities with enriching experiences in the visual arts. NIAD has published *The Freedom to Create*, which is widely used to help teachers teach art to students of all ages. It has also published *The Creative Spirit*, a collection of works by NIAD artists, and *Art & Disabilities*, a directory of art centers for people with disabilities. NIAD can respond to requests for information about and referral to local programs. NIAD's Research and Training Center in Art and Disabilities is a national international resource in art and disabilities.

**Sky Ranch Inc.**

27955 Terrace Drive,  
North Olmsted, OH 44070-4962  
Tel: 216-235-2473  
Non-profit, barrier free, family  
campground.  
[http://hometown.aol.com/SkyRanch1/  
index.html](http://hometown.aol.com/SkyRanch1/index.html)

INDEPENDENT LIVING:

**ACCENT On Information (AOI)**

Gillium Road and High Drive,  
P.O. Box 700,  
Bloomington, IL 61702  
Tel: 800-787-8444 (Voice)

ACCENT on Information is a computerized retrieval system containing information on products and devices which assist persons with physical disabilities. Also available is other how-to information on topics as: eating, bathing, grooming, clothing, furniture, home management, toilet care, sexuality, mobility, and communication. For a nominal charge, a search of AOI's database is made on the caller's topic of interest. Callers will then receive up to 50 of the most recent citations for each search. AOI has two sister services: (1) *Accent on Living Magazine*, and (2) ACCENT Books and Products, which publishes and distributes a variety of books of interest to persons with disabilities, along with a buyer's guide that lists equipment devices to assist person with disabilities in daily living activities.

**Access/Abilities**

P.O. Box 458,  
Mill Valley, CA 94942  
Tel: 415-388-3250 (Voice)

Access/Abilities is a consulting problem-solving firm dedicated to finding resources for a better life beyond functionality and independence. Local, national, as well as international resources are available.

This organization can provide information about accessible travel opportunities, aids and appliances, sports and recreation programs, clothing that really fits, shopping, and other customized services. It also offers consulting services concerning architectural barriers and accessibility.

**Family Estate Planning**

1150 N. Lake Shore Drive 9-J,  
Chicago, Illinois 60611-1024  
Tel: 773-296-2331

Forms, checklist, schedules and topical digests can help sort out estate and disability planning options and prepare for attorney consultation.  
<http://familyestate.com>

**Nagler Disability Consulting Services**

Disability advocate Mark Nagler's books for sale, offering insights into living with a disability, and guides for caregivers, family, and friends.  
<http://www.marknagler.com/>

**National Council on Independent Living (NCIL)**

2111 Wilson Boulevard,  
Suite 405,  
Arlington, VA 22201  
Tel: 703-525-3406 (Voice)  
Tel: 703-525-3407 (TTY)

National Council on Independent Living is a national membership association of local nonprofit corporations known as Centers for Independent Living (CIL). NCIL is the only cross-disability grassroots national organization run by and for people

with disabilities. NCIL provides technical assistance, training, and leadership to independent living (IL) centers in many areas of concern to the disability community, including IL philosophy, center operations, and the Americans with Disabilities Act (ADA) through the NCIL/ILRUIL Network Project and ADA Training Project. NCIL also provides information and referral services.  
E-mail: [ncil@tsbbs02.tnet.com](mailto:ncil@tsbbs02.tnet.com)

**Research and Training Center On Independent Living**

University of Kansas,  
4089 Dole Building,  
Lawrence, KS 66045-2930  
Tel: 913-864-4095 (Voice/TTY)

The Center's goal is to develop and disseminate practical techniques that enable people with severe disabilities to live more independently. This includes service delivery systems, skill training methods, and effective techniques to improve human services and community support for people with disabilities. The Center provides training and technical assistance to individuals and organizations throughout the U.S.



MULTICULTURAL:

**VILTIS - Lithuanian Welfare Society  
For Persons With Mental Disability**

Voluntary organization, uniting  
Lithuanian families of people with  
mental disability.

[http://www.geocities.com/HotSprings/  
3002/](http://www.geocities.com/HotSprings/3002/)

**Jewish Family and Children's Services  
of San Francisco**

1710 Scott St,  
San Francisco, CA 94115-3004  
Tel: 415/567-8860

Adult mental health counseling,  
adoption, AIDS, bereavement, child  
development, disability, emergency  
assistance, home care, refugee, senior,  
volunteer programs and more.

<http://www.jfcs.org>

**Consortia of Administrators for  
Native American Rehabilitation  
(CANAR)**

Northern Arizona University,  
P.O. Box 5630,  
Flagstaff, AZ 86011-5630  
Tel: 520-523-7054 (Voice)  
Tel: 520-523-1695 (TTY)

The Consortia of Administrators for  
Native American Rehabilitation  
(CANAR) is made up of  
Administrators from Native VR  
Programs and other VR professionals  
interested in advancing the movement  
of culturally relevant VR services for  
Native Americans with disabilities.

## INNOVATIVE PRACTICES:

### **AgrAbility For Pennsylvanians**

Pennsylvania State University  
Project combining the talents of Penn State Cooperative Extension and the Easter Seal Society of Central Pennsylvania. Under the umbrella of the national AgrAbility Project, we bring information and service to farmers and farm family members affected by disability in rural areas of the Commonwealth.

<http://www.cas.psu.edu/docs/casdept/ag ed/agrab/agrabilitypa.html>

### **Self Directed Supports Project**

The Oregon Technical Assistance Corporation  
3886 Beverly Ave., N.E.,  
Building 1, Suite 21,  
Salem, OR 97305  
Tel: 503-364-9943 (Voice)

Originally called the Oregon Family Management Project, this project focuses on inclusion of the family in the rehabilitation process.

<http://www.otac.org/>

### **Service Alternatives**

20 NW 1st St.  
P.O. Box 595,  
Coupeville, WA 98239-0595  
Tel: 360-678-6071

Innovative community and family based services for children with autism and adults with developmental disabilities.

<http://www.whidbey.net/~servalt/>

### **Family Voices**

P.O. Box 769,  
Algodones, NM 87001  
Tel: 1-888-835-5669

National organization of families and friends speaking on behalf of children with special health care needs. Links provided to current State and/or local projects.

<http://www.familyvoices.org/>

DISABILITY SPECIFIC:

**American Society for Deaf Children**

P.O. Box 3355,  
Gettysburg, PA 17325  
Tel: 800-942-ASDC (Parent Hotline)  
Tel: 717-334-7922 (Business  
Voice/TTY)

The ASDC is a national organization for families of deaf and hard of hearing children, providing information, support and encouragement. ASDC assists families in raising a deaf child, promoting a positive attitude toward sign language and deaf culture.  
<http://www.deafchildren.org>

**National Resources for Adults with Learning Disabilities**

A publication for adults who suspect or know they have a learning disability, and for family and friends who wish to help. The guide is intended to provide a starting point for gaining information that can lead to obtaining services at the state or local level.  
<http://novel.nifl.gov/nalld/resource>

**Amputee On Call**

A helping hand to those who are an amputee or the family of amputees. Also a disability advocate for all disabilities. This service is free of any charge and supported by donations.  
<http://www.geocities.com/HotSprings/Spa/9821>

**Juliet's Bipolar Page**

This site is maintained by a woman who suffers from Bipolar Illness. The intent is to offer support and

information to people with the illness and their family and friends. Here you will find information about Bipolar Illness, disability and advocacy, good mental health links, suggested readings, articles, medications, Bipolar Illness and children, etc. A sampling of poetry and writings of people who suffer from the illness can also be found here. Her personal poetry is included as well.  
<http://www.bipolarbrain.com>

**Jeune's Family Support Group - Jeune's Asphyxiating Thoracic Dystrophy.**

P.O. Box 41,  
Temperance, Michigan 48182  
<http://www.geocities.com/HotSprings/2179/>

**Eden Family of Services**

One Logan Drive,  
Princeton, NJ 08540  
Tel: 609-987-0099

Offering community-based, lifespan services to children and adults with autism and their families.  
<http://members.aol.com/EdenSvcs/index.html>

**Amputee Online**

Resources for amputees, family members and medical professionals.  
<http://www.amputee-online.com/>

**Hannah's Story**

Documentary about an autistic girl and her family's determination in dealing with this brain disorder.  
<http://www.hannahstory.com/>

**The Disability Named A.D.D.**

CH.A.D.D.,  
499 Northwest 70th Avenue,  
Suite 101,  
Plantation, Florida 33317  
Tel: 954-587-3700

Issue: Approximately 3-5% of all American children - up to 3.5 million children - have an Attention Deficit Disorder.

[www.chadd.org/index.html](http://www.chadd.org/index.html)

**Auditory-Verbal International, Inc. AVI**

2121 Eisenhower Avenue, Suite 402,  
Alexandria, VA 22314  
Tel: 703-739-1049

Providing the choice of listening and speaking for children who are deaf or hard of hearing through education, advocacy, and family support.

<http://www.auditory-verbal.org/>

**Resources for Californians**

Resources for Californians and others affected by physical disability or disfigurement.

<http://members.tripod.com/~sandygo/index.html>

**Polio Survivors Page**

[www.eskimo.com/~dempt/disability.html](http://www.eskimo.com/~dempt/disability.html)

**Schwab Foundation for Learning**

1650 South Amphlett Boulevard,  
Suite 300,  
San Mateo, CA 94402  
Tel: 800-230-0988

Information for parents and educators of children with learning disabilities.

<http://www.schwablearning.org/>

**Oakdale Child & Family Service Ltd.**

291 Chisholm Avenue,  
Toronto, Ontario M4C 4W5  
Tel: 416-699-5600

For mentally impaired children up to the ages of 18 and respite care for brain injured persons.

<http://www.oakdaleservices.com/>

**Child and Family Studies Program - MCP Hahnemann University**

One Allegheny Center, Suite 510,  
Pittsburgh, PA 15212-4772  
Tel: 412-359-1600

Enhancing the overall quality of life for children who are at risk for, or who experience, developmental disabilities, and their families.

<http://www.asri.edu/cfsp/>

**Georgia Baptist Children's Homes and Family Ministries, Inc.**

Tel: 770-463-3800

Social ministry of multiple services for children, teenagers, families, and adults developmental disabilities.

<http://www.gbchfm.org/>

**Family Village**

1500 Highland Avenue,  
Madison, WI 53705-2280

Informational resources on specific  
diagnoses, communication connections,  
adaptive products and technology,  
adaptive recreational activities,  
education, worship, health issues,  
disability-related media and literature,  
and much, much more!

<http://familyvillage.wisc.edu/>

## ASSISTIVE TECHNOLOGY:

### **Alliance for Technology Access (ATA)**

2175 East Francisco Boulevard,  
Suite L,  
San Rafael, CA 94901  
Tel: 415-455-4575

The Alliance for Technology Access (ATA) is a growing coalition of technology resource centers across the country that provide information, awareness, and training in the use of technology to aid children and adults with disabilities. Services range from hands-on workshops to training for professionals, from guided problem solving to technical assistance to families, individuals with disabilities, employers, and agencies seeking access to technology. Also offered are lending libraries of computer software, assistive devices, print resources, training films, and adapted toys. Callers are referred to the technology resource center nearest them.

<http://www.ataccess.org>

### **Apple Computer, Inc. - Worldwide Disability Solutions Group**

Mail Stop 38DS,  
1 Infinite Loop,  
Cupertino, CA 95014  
Tel: 800-600-7808 (Voice)  
Tel: 800-755-0601 (TTY)

Apple's Worldwide Disability Solutions Group has developed a wide variety of materials in print, video, and electronic form to describe how personal

computers can constructively influence the experience of having a disability. Energies are directed toward ensuring that the power and promise of the microcomputer are available to individuals with a disability. The database Macintosh Disability Resources lists adaptive devices and specialized software available to individuals with disabilities affecting physical mobility, cognition, speech, hearing, vision, and learning. The publication *Independence Day* describes strategies and solutions for tailoring personal computers to individual needs and objectives.

### **Family Village**

1500 Highland Avenue,  
Madison, WI 53705-2280

Informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature, and much, much more!

<http://familyvillage.wisc.edu/>

### **IBM Corps. Special Needs Systems**

11400 Burnet Road,  
Internal Zip 9448,  
Austin, TX 78758  
Tel: 800-426-4832 (Voice)  
Tel: 800-426-4833 (TTY)

IBM's Special Needs Systems serves to help health care leaders, agency directors, employers, educators, and individuals learn how computers can

enhance the quality of life for individuals with disabilities in the home, school, and workplace. While the Center is unable to prescribe an assistive device or software, it does provide information on what technology is available. Information for persons with disabilities affecting learning, hearing, speech and language, mobility, and vision is provided, including vendor and support group names, addresses and descriptions.

**Job Accommodation Network (JAN)**

West Virginia University,  
P.O. Box 6080,  
Morgantown, WV 26506-6080  
Tel: 800-526-7234 (Voice//TTY)

The Job Accommodation Network, a service of the President's Committee on Employment of People with Disabilities, brings together information from many sources about practical steps employers can take to make accommodations for the functional limitations of employees and applicants with disabilities. Brochures, printed materials and a newsletter are available free of charge.  
<http://janweb.icdi.wvu.edu>

**RESNA**

1700 N. Moore Street,  
Suite 1540,  
Arlington, VA 22209-1903  
Tel: 703-524-6686 (Voice)  
Tel: 703-524-6639 (TTY)

An interdisciplinary association for the advancement of rehabilitation and assistive technologies, RESNA is an

organization for rehabilitation professionals. It is concerned with transferring science, engineering, and technology to the needs of persons with disabilities. RESNA is currently operating a Technical Assistance Project, which can help callers identify the program in their state that is responsible for providing information, training, and technical assistance on assistive technology to individuals with disabilities.

<http://www.resna.org/>

**Technical Aids and Assistance for the Disabled Center (TAAD)**

1950 West Roosevelt Road,  
Chicago, IL 60608  
Tel: 800-346-2939

TAAD is an organization created by the Committee on Personal Computers and the Handicapped (COPH-2) to provide options in using personal computer technology to persons with disabilities. The TAAD Center provides advocacy and services with an emphasis on selection and application of microcomputers and assistive technologies. The centers' approach allows users to make informed decisions as to which system or devices best meet their needs. Other services include equipment loans, workshops and product demonstrations, and advocacy before manufacturers. TAAD can also refer callers to their local resource center of the Alliance for Technology Access.

**The Family Center on Technology and Disability**

1660 "L" Street, NW,  
Washington, D.C. 20036  
Tel: 800-USA-5UCP

access for persons with disabilities. All information is available in alternative formats for individuals unable to read or handle print materials.  
<http://trace.wisc.edu>

Family Center on Technology and Disability. Welcome to the Family Center on Technology and Disability. The Family Center was formed by United.  
<http://fctd.ucp.org/>

**Trace Research and Development Center**

S-151 Waisman Center,  
1500 Highland Avenue,  
Madison, WI 53705  
Tel: 608-262-6966 (Voice)  
Tel: 608-263-5408 (TTY)

The Trace Center was formed in 1971 to address the communication problems faced by nonvocal children and adults with severe disabilities. The Center is primarily concerned with research and development in the areas of universal design of electronic and next generation technologies, in order to make accessible computers at the manufacturer's level. The Center does not manufacture or distribute equipment, but will make referrals to specific sources of information regarding equipment, software, services centers related professionals, and other information networks. Publications include the *Trace Resource Book*, a reference volume listing and describing currently available products for communication, control, and computer



GENERAL:

**Office of Civil Rights  
National Organization on Disability  
(NOD)**

910 16th Street, N.W., Suite 600,  
Washington, DC 20006  
Tel: 202-293-5960 (Voice)  
Tel: 202-293-5968 (TTY)

NOD promotes the full participation of Americans with disabilities in all aspects of community life. Its primary program is the Community Partnership Program, a network of 4500 towns, cities, and counties nationwide. NOD's Community Partnerships undertake many different activities to improve attitudes toward people with disabilities; to expand educational and employment opportunities; to eliminate physical barriers; and to expand participation in religious, cultural, and recreational activities. The quarterly newsletter, *Report*, is available upon request.  
<http://www.nod.org>

**National Rehabilitation Information  
Center (NARIC)**

8455 Colesville Road, Suite 935,  
Silver Spring, MD 20910  
Tel: 800-346-2742 (Voice)  
Tel: 301-495-5626 (TTY)

NARIC is a library and information center on disabilities and rehabilitation. NARIC collects and disseminates the results of federally funded research projects. NARIC's collection includes commercially published books, journal articles, and audiovisual materials. Information specialists provide quick

reference and referral services, searches of NARIC's database, REHABDATA, and photocopies of documents for a small fee.

<http://www.naric.com/naric>

**President's Committee on  
Employment of People with  
Disabilities (PCEPD)**

1331 F Street N.W., Suite 300,  
Washington, D.C. 20004-1107  
Tel: 202-376-6200 (Voice)  
Tel: 202-376-6205 (TTY)

PCEPD provides information, training, and technical assistance to Americas business leaders, organized labor, rehabilitation and other service providers, advocacy organizations, families, and individuals with disabilities. The Committee's mission is to facilitate the communication, coordination, and promotion of public and private employment. The President's Committee also serves as an advisor to the President of the United States on public policy issues affecting employment of people with disabilities. Includes a link to the Job Accommodation and Family pages  
<http://www.pcepd.gov>

**Social Security Administration (SSA)**

Department of Health and  
Human Services  
Baltimore, MD 21235  
Tel: 800-772-1213 (Voice)  
Tel: 800-325-0778 (TTY)

The Social Security Administration provides cash benefits (SSI and/or SSDI) to persons with a physical or

mental disability which prevents them from working and which is expected to last at least a year or be terminal. Eligibility for SSI or SSDI may mean eligibility for other services, such as Medicaid, food stamps, or other social services. The amount of money and services received varies in each state. The program also includes work incentives that make it possible for individuals to work without an immediate loss of benefits.  
<http://www.ssa.gov>

**Work Incentives Transition Network**  
Project developed to increase educators', family members', transition age students', and advocates' awareness of Social Security Work Incentives for school-aged youth with disabilities – Plans for Achieving Self-Support (PASS), the Impairment Related Work Expense (IRWE) and the Student Earned Income Exclusion (SEIE).  
<http://www.vcu.edu/rrtcweb/witn/ssi.htm>

**National Information Center for Children & Youth with Disabilities**  
P.O. Box 1492,  
Washington, DC 20013-1492  
Tel: 1-800-695-0285 (V/TTY)

For information on children and youth with disabilities.  
<http://www.nichcy.org/>

**National Council on Disability**  
1331 F. St., N.W., Ste. 1050,  
Washington, D.C. 20004-1107  
Tel: 202-272-2004

Fellowship in Washington, DC. Free Newsletter. The National Council on Disability (NCD) is an independent federal agency making recommendations to ...  
[www.ncd.gov/](http://www.ncd.gov/)

**Office of Special Education & Rehabilitative Services - Tom?**  
*need more description here...RSA...funds VR, CILs, regional offices...*  
<http://www.ed.gov/offices/OSERS/>

**World Institute on Disability (WID)**  
510 Sixteenth Street, Suite 100,  
Oakland, CA 94612-1500  
Tel: 510-763-4100 (Voice)  
Tel: 510-208-9493 (TTY)

The World Institute on Disability (WID) is a public policy, research, and training center dedicated to independence for all people with disabilities. WID's projects include: informing and training public officials, community leaders, and corporations, among others, about the empowerment of people with disabilities; working to design more effective personal assistance services for people with disabilities; and operating the Research and Training Center on Public Policy in Independent Living. Information about WID, its publications and its projects is available upon request.  
<http://www.wid.org>

RECOMMENDED PUBLICATIONS: *Catalog*, contact NICHCY, P.O. Box 1492, Washington, DC 20013.

**Supported Employment Using a Natural Supports Approach : A Handbook for Parents**

by Cathleen Urbain  
Pacer Center, Minneapolis MN, 1997

800-695-0285 (Voice/TTY)  
<http://www.nichy.org>

**HEATH**

**ACRES - Rural Education**

**The Life Planning Workbook: A Hands-On Guide to Help Parents Provide for the Future Security and Happiness Of Their Child with a Disability After Their Death**

by L. Mark Russell and Arnold E. Grant, Attorneys  
American Publishing Co., 1995

**A Family Handbook On Future Planning**

by Richard Berkobien  
Association for Retarded Citizens of the United States, 1991

**Working With Exceptional Families**

by Reed & Turnball  
Beach Center

**INFOLINES**

from Dale DiLeo in Florida

**National Supported Employment**

Virginia Commonwealth University

**National Information Center for Children and Youth with Disabilities (NICHCY) Newsletters/Briefs**

*NICHCY Briefing Papers* are published in response to questions from individuals and organizations that contact the Clearinghouse. For further information and assistance, or to receive a *NICHCY Publications*

## USING THE INTERNET AS A RESOURCE:

The Internet has quickly become an indispensable tool for staying up-to-date with resources and in touch with the information, agencies and individuals that support the VR process. We have tried to include mailing addresses and phone numbers where they were available, and we offer the following guidelines for using the Internet.

### **General Tips:**

Despite differences in each search engine's tools, there are tools that many search engines have in common. The following tools can help narrow your search:

**Quotation marks:** Sometimes you can add characters to your words or phrases to more closely define your intentions for the search engine. For example, enclosing a multiword phrase in quotation marks tells the search engine to list only sites that contain those words in that exact order.

**Plus and minus signs:** If you type a plus sign (+) directly in front of a word, you are indicating that the word or phrase must appear in the search results (for example, Disability +Support +Groups). Similarly, a minus sign (-) indicates that the word or phrase should not be included in the search results (Accommodations -Hotel).

**Boolean operators:** Boolean operators include AND, OR, AND NOT, and parentheses. To work, these operators must appear in ALL CAPS and with a space on each side.

**AND** - Similar to the plus sign, AND indicates that the documents found must contain all the words joined by the AND operator. For example, to find documents that contain the words transition, school, and work, enter transition AND school AND work.

**OR** - Documents found must contain at least one of the words joined by OR. For example, to find documents that contain the word diversity or the word cultural, enter diversity OR cultural.

**AND NOT** - Similar to the minus sign, using AND NOT indicates that the documents found cannot contain the word that follows the term AND NOT. For example, to find documents that contain the word depression but not the word bipolar, enter depression AND NOT bipolar.

**Parentheses** - Parentheses are used to group portions of Boolean queries together for more complicated queries. For example, to find documents that contain the word medications and either the word herbal or the word alternatives, enter medications AND (herbal OR alternatives).

**Title search** - This feature enables you to restrict searches to the title portion of web documents. For example, typing

title:Disability or t:Disability will retrieve all documents that have the word Disability in their title.

### **The Search Results Display**

Search results are displayed in up to four different sections:

**Official Web Sites:** Sites that most closely match your search term.

**Netcenter Pages:** Tools, services and premium content that most closely match your search term. These results link to content within Netscape Netcenter.

**Web Site Categories:** Groups of reviewed web sites related to your search term. These results link to categories within the Open Directory Project.

**Reviewed Web Sites:** Hand-selected web sites that have been reviewed and categorized by a team of editors.

Note that if no results are found in a particular section, that section won't appear. If no results are found within any of the four sections, an Internet search will be conducted through Google.

### **How to Search**

To perform a search, simply enter the terms you are searching for and click on the "Search" button.

For example, a search on C++ will return all the sites that have the word C++ in them.

Searches with multiple terms will automatically insert an "and" between all the terms, so that only sites with all of the search words in them will be returned.

For example, a search on spinal cord will return sites that have both spinal and cord in the site's name and description.

Sites on "spinal taps" or "vocal cords" will not be displayed (unless they also mention spinal and cords). If no sites are found that contain both terms, sites that contain either term will be displayed.

### **Phrase Search**

Sometimes the order of the search terms matters. Using phrase searching can greatly reduce the number of sites that are matched by a search.

For example, if you searched for "Disability Support Groups" You would get only sites containing all three words "disability", "support", and "groups" - in that order.

### **Search Defaults**

All searches use and as the default linking operator between all of the search terms.

Thus, searching for  
wheel chairs  
is the same as searching for  
wheel and chairs

For both of these searches, only those sites with "wheel" and "chairs" in the site name or description will be returned. Sites that mention only "wheel" but not

“chairs” will not be displayed. To get sites containing either “wheel” or “chairs” use the keyword or. See the next section on using Boolean operators.

### **Boolean Searches**

There are several Boolean operators to choose from: or, and, and andnot. Terms linked by the and operator will return only those sites that match all the search terms linked by the and operator. The default is and. If you don't use any Boolean operators, only those sites that contain at least one occurrence of each search term will be returned.

Terms linked by the or operator will return those sites that match any of the search terms linked by or.

For example,  
Parent or family and support

Terms linked by the andnot operator will exclude all sites that match the search term following the andnot. For example,  
Social andnot Security andnot Administration

will find sites about socialization but exclude sites about the Social Security Administration.

### **Wildcard Search**

Netscape Search allows limited use of wildcards in searches. This is useful when you are trying to match a term that may or may not be plural or might use one of several verb tenses. For example, if you wanted to find sites that had to do with disabilities you might use the following search:

disabilit\*

This would match sites on disability and disabilities.

Netscape Search search does not support arbitrary wildcards, so searches on “\*ability” or “dis\*ility” will not work.

### **Shorthand Search Terms**

You can prefix search terms with “-” and “+” to force the exclusion or inclusion of that term. This is really just shorthand for using the andnot and and Boolean operators.

The following example will return all the sites on accessibility except those that mention “braille.”

+accessibility -braille

Note: You cannot begin a search with a “-” term. You must put some other search term first.

### **Complex Searches**

You can mix and match the above search methods to create very complex searches. This search will return all sites on learning disorders, but exclude all the links that mention ADD:

learning disorder\* andnot ADD

This search will find references to family support, except those that are about support groups or educational support:

family + support - groups - education

### **BIBLIOGRAPHY**

“Resources for Adults with Disabilities”  
NICHCY Briefing Paper, Third  
Edition, April 1997



# APPENDIX

## **The CERF Model**

The CERF Model is adapted from the Metaframeworks Model developed by Brunlin, et al. (1997) and modified by rehabilitation counselors, supervisors, and administrators in the course of a 14 month collaborative project. The model is flexible enough to be adapted to the needs of specific agencies and individual counselors. It is comprehensive enough to incorporate the principles associated with the biopsychosocial (Engel, 1977) approach in medicine, psychiatry, business (Lappin, 1999) and in rehabilitation.

This model is useful for professionals to assist VR consumers in identifying a range of options and identifying those factors that appear to prevent them from using the resources they have or can access.

Some key concepts of the CERF Model are:

1. Difficulties in adaptation and change are the result of internal or external constraints
2. Human systems can be thought of in terms of levels and of domains, and constraints to adaptation and the expression of an individual's innate capabilities can exist on any number of these levels or domains
3. The role of the rehabilitation counselor is to collaborate with their VR consumers to identify and remove constraints to effective action at reaching the VR consumer's goals

After becoming familiar with the concepts contained in the model, counselors can refer to domains or levels described in the model as they conduct their counseling and networking sessions. The domains or levels of the model are meant to serve as a reminder of issues to consider, as a stimulus for the creative conversations that form the nexus of the rehabilitation process and as a guide to training. They are not intended to be a rigid formula or an exhaustive list of areas of investigation to be pursued by the VR consumer, family, and professional. The primary advantage of the model presented here is that it provides a set of principles, or lenses, through which to view collaborative efforts with families. Other advantages of the model include its utility as an assessment tool, as a tool for selecting counseling and other interventions, and its demonstrated value as a guide for organizing training (Oulvey, 1999).

## **DOMAINS OF THE CERF MODEL**

### **I. Biology**

**The relationships of body systems and the chemicals and organs that comprise them.**

### **II. Mind**

**The individual personality as a system of multiple potentialities. A healthy and competent Self is at the center of every internal individual system.**

### **III. Leadership**

**Understanding and operating within multilevel human systems. The focus for rehabilitation is on the constraints that limit change.**

### **IV. Development**

**The patterns of change through time of human systems across all biopsychosocial levels, and the interactions between those levels.**

### **V. Cultures**

**Classes of sociocultural contexts including race, ethnicity, education, gender, disability, type of disability, economics, religion, value systems, etc. Emphasis on the integration of these multiple viewpoints into the other levels.**

### **VI. Human Rights**

**Resistance against oppression at all levels of social organization, including (but not limited to) the areas of disability, race, and gender.**

### **VII. Spirituality**

**Focus on human resilience and the human desire to transcend limitations.**



Constraining factors can occur at one or more levels and in one or more domains. They can be straightforward or difficult to detect. In general, the more levels and domains affected the more difficult the rehabilitation process. The distinctions made between the domains are to some extent arbitrary. All domains interact with each other to a greater or lesser degree, depending on the circumstance of the moment, and the system and issues under consideration. One can use these domains to analyze any number of systems. However, this document will focus more narrowly on VR consumer, family and counselor collaborations.

### **DOMAIN I: Biology**

In many cases it is clear how physical and mental impairments resulting from illnesses, injuries or congenital disability limit a VR consumer's ability to function as a worker, spouse, parent, citizen, etc. Rehabilitation professionals are expert at assessing the vocational and independent living implications of these types of disabilities. However, other medical and psychiatric illnesses are more subtle and more easily overlooked or misinterpreted. Varying degrees of stigma are attached to some of these conditions, often related to the prevailing social explanation for the cause of the illness and unpredictability of the symptoms. Examples of these types of disabilities include HIV/AIDS infection, substance abuse/alcoholism, learning disabilities, and mental illness.

Rehabilitation professionals often possess specialized knowledge and skills at assessing the implications and identifying accommodations for both types of disabilities. Some common examples of these accommodations are family education, medical interventions, psychiatric/psychotherapeutic interventions, adaptation of physical work and living space, employer and community education, community advocacy in partnership with VR consumers, and adaptation of computer and other technologies.

The onset, course, outcome and degree of incapacitation brought on by the disability are among the most significant factors affecting the family (Rolland, 1987).

*(Note: Much of the following section is adapted from, A Manual for Applying a Family System Approach to Rehabilitation Services. Ginter, P., 1995)*

### **Onset**

Families are affected differently depending on whether the illness has an acute or a gradual onset. Different types of onset require different means of coping. For example, the rapid deployment of crisis management skills are required in acute onset illnesses such as stroke. Families must tolerate a high degree of pressure and anxiety and have great flexibility, good problem solving skills, and the willingness and ability to use outside resources.

## Course

To a large extent, the constant, progressive, or episodic nature of a condition or disability determine the challenges the VR consumer and family will face. After the initial or acute phase of the illness or injury, a **constant course** illness, such as a spinal cord injury or many types of developmental disabilities, typically involve little ongoing change in roles and resulting readjustments over the course of time. With diseases that have a **progressive course**, such as Alzheimer's or emphysema, the family must continually adapt and change roles. There is often minimal respite for caregivers in these systems. **Episodic illnesses**, such as colitis or schizophrenia, may feature periods of stable symptoms, periods of low levels or the absence of symptoms, and periods of high levels of symptoms that may be life threatening. In some cases these symptom patterns may occur in predictable cycles, and in others they may not.

VR consumers and families attempting to cope with the changes and fluctuations of both progressive and episodic illnesses face constant uncertainty. Family flexibility may be stretched to the limits as any planning can only be tentative and individual and family goals must be developed in an atmosphere of uncertainty. The individual's and family's ability to accept and adapt to the disability is constantly challenged as symptoms

lessen or disappear, and the natural hope for a cure is juxtaposed with what may be decades of disappointment.

## Outcome

A disability that is expected to result in death (e.g., AIDS) can have a profound impact on the family. The degree of this impact depends in part upon the degree of anticipatory grief the family experiences. For some families, illnesses which may or may not shorten life, such as juvenile diabetes or hemophilia, can be the most difficult to deal with. It is a natural tendency of families in these situations to protect the person with the illness, and frequently to resist abandoning this protective role.

In the terminal phase of an illness or disability the family is faced with the separation and grieving brought about by death. The family's values and beliefs about illness, injury and disability and those of the surrounding culture form a powerful context for their behaviors and ability to cope.

## Incapacitation

Greater levels of incapacitation caused by disability usually result in higher levels of stress. Degree of incapacitation interacts with the onset, course, and outcome of the illness, and with the family's beliefs about the disability.

Each phase of an illness requires different developmental tasks. In the crisis phase, the family needs to deal

with changes in environments (e.g., spending large amounts of time at the hospital). In this phase they are also required to develop some level of working relationship with the health care team. At some point the family must create a meaning for the disability event, must grieve the loss of the previous family identity, and must accept the changes brought on by the illness or injury.

In the chronic phase, maintaining a normal life in spite of the disability is the primary concern. Over time, some family members can have difficulty maintaining roles and responsibilities assumed in an earlier phase, establishing comfortable levels of autonomy, and may experience burnout or develop new feelings of resentment.

The extension of the life span of many people with significant disabilities was one of the great achievements of the last century. However accompanying this achievement were new pressures on families and governments to provide for some of these citizens. While many government programs exist they are bound by restrictions and families often fill in the gaps.

## **DOMAIN II: Mind**

The theory of Internal Family Systems (IFS) forms the key structure of the CERF program (Schwartz, 1995). Rehabilitation counselors and administrators who participated in the CERF program found the IFS material to be the most useful aspect of the

training, and the part of the training most immediately applicable to their work with VR consumers and their families (Oulvey, 1999). Through exposure to the IFS material, rehabilitation professionals began to assume and explore a much broader range of potential talents and abilities in VR consumers and their families (as well as others) than deemed possible by previously used methods.

## **Internal Family Systems (IFS) Roles**

IFS theory posits that the individual personality has multiple aspects that play a variety of roles in the individual's internal system. Frequently observed roles were given names that correspond to their functions:

### **SELF**

This term is used to represent the healthy and competent center of everyone's personality. Characteristics include relaxed, secure, open, wise and alert.

### **MANAGERS**

This term characterizes aspects of personality that run the day-to-day life of the individual. Attempt to keep the individual in control, and to protect from feelings of rejection or hurt. Characteristics include dependable, achieving, takes care of others, worrying, denying problems, evaluating opportunities.

### **CREATIVE/YOUTHFUL**

This term reflects aspects of personality that are particularly open to and seek

out new experiences, ideas and relationships. Characteristics include playfulness, curiosity, friendliness, creative energy, joyfulness, accepting. When individuals experience trauma, particularly in early life, these aspects can become exiled from the rest of personality and exhibit characteristics such as fragility, sadness, shame, emptiness, powerlessness, fear, and worthlessness. The Manager aspects of the personality will work to suppress these aspects when the sense of hurt or vulnerability feels overwhelming.

### **FIREFIGHTERS**

This term is used to refer to aspects of personality that are highly protective of the system (the fight or flight responses). These aspects react in extreme ways to protect the system when trauma or despair rise to such a level that the system feels unable to cope. Characteristics include self-destructiveness (e.g., binge eating, promiscuity, substance abuse, alcoholism, violence against others, suicide) and an extreme need for control.

*Adapted from Ginter (1995)*

There can of course be many other roles that individuals can access through the vast potential of the human mind and personality. All aspects of the internal system have a useful function, and when over represented in a particular personality (individual or group) serve to block the ability of that system to capitalize on

opportunity and to grow from experience.

The role of the rehabilitation professional in the IFS approach is to assist the VR consumer and their family to use their internal resources to explore and take action toward new possibilities in employment and independent living. The professional acts as a guide, leading an exploration of those aspects of the VR consumer and family's personalities that both facilitate and hinder attainment of the VR consumer's goals. The goal is to turn the leadership of the exploration over to the VR consumer and their family at every opportunity. CERF participants found that sometimes just introducing VR consumers and families to this way of looking at themselves enabled them to assume new levels of personal leadership.

IFS has also proved useful in helping rehabilitation professionals examine aspects of their personalities and behavior that tended to interfere with rather than facilitate the collaborative process.

### **Aspects of Rehabilitation Professional's Personalities That Often Interact With VR Consumer's and Family's Personalities**

- Manager aspects of the professional's personality that agree with the Manager aspects of the VR consumer or family that pursuing work, training, evaluation, mental/physical

restoration etc. would be too overwhelming.

- Manager aspects of the professional's personality that believe that the VR consumer and/or family is doing well/following through when the evidence is to the contrary.
- Professional's Manager aspects become overprotective when the VR consumer or family expresses vulnerability.
- Professional's Youthful aspects that become easily frightened by angry/protective aspects of the VR consumer or family.
- Traumatized Youthful aspects of the professional's personality feel vulnerable when the VR consumer or family describe their experiences of trauma, and Manager aspects then cause the professional to not hear what the VR consumer and family has to say, or to minimize contact with the VR consumer/family.
- Professional's Youthful parts that feel overwhelmed by so much responsibility, or feel traumatized by the organization in which they work.
- Youthful parts of the professional that don't like people depending on them, and the Manager aspects that cause the professional to feel shame at these feelings, causing more anger at the experience of dependency, etc.
- Protective aspects that attack when the professional feels criticized.

- Achievement aspects that become frustrated when the VR consumer or family is not making as much progress as the professional thinks that they should, even when at a calmer moments it is apparent that the VR consumer or family is doing the best that they can.

*Adapted from Ginter (1995)*

Since the model assumes that all members of a system have a valuable role to play, the introduction of the ideas and the collaborative exploration process must proceed at a pace comfortable for the VR consumer and family. In this rehabilitation process there is no attempt to "change" the individual or to coach them into suppressing or rejecting some aspect of themselves. Rather the rehabilitation professional helps the individual and family to calm down, to recognize when they may be taking extreme positions (e.g., "John can't possibly learn the bus routes. He'll get lost."), and to decide if there are more beneficial alternatives to their present beliefs and behaviors.

It is often easy for VR consumers and their families to begin to think of themselves as having a wider range of possible talents and behaviors than they thought possible. As an example, individuals will often say, "A part of me thinks going to work is hopeless, while another part of me says 'I can do this!'" The following case study is an illustration of how to begin to

introduce this way of looking at things in a counseling session.

### **Case Study:**

VR CONSUMER: It seems as though while I'm doing this job search I'm taking two step forward and then two steps back. The rejections are really hard to take. I try to stay motivated, but sometimes I just want to give up.

COUNSELOR: It sounds like you get so frustrated sometimes that a part of you says, "I should quit working so hard, it just isn't worth it."

VR CONSUMER: That's right.

SPOUSE: When I see and hear Elizabeth getting so discouraged and hurt, I sometimes just want to tell her to quit trying, to quit beating her head against these walls. I really want her to succeed. I'm just not sure that this is good for her health.

COUNSELOR: So a part of you wants to protect her, and a part wants to do whatever you can to help her succeed. Am I on target with that?

SPOUSE: Yes, you are.

COUNSELOR: Elizabeth, would you be willing to say more about the part of you that wants to give up?

VR CONSUMER: Well, it just seems as though there are times when it just isn't worth the hard work. It doesn't seem to

pay off. But then again, I know that if I give up, I will never achieve the goals I've set for myself. I'll feel like a failure.

SPOUSE: Honey, maybe you should give up. I can support us, and you won't be a failure to me.

VR CONSUMER: You know, Mark, that sounds tempting. My mother never worked, and while she seemed bored and frustrated at times, I think she had a good life. But I want something different!

COUNSELOR: So there is this dialogue going on inside you Elizabeth, and you, Mark, about what the benefits versus the costs are of Elizabeth going to work. If I'm hearing you both accurately, I'm wondering, Elizabeth, if this difference in beliefs might in some way hinder you in looking for work. It just sounds to me like it might.

VR CONSUMER: You know, that strikes a cord. I just don't know.

COUNSELOR: Are you comfortable saying more about those parts of you that want to give up?

VR CONSUMER: Yes, thank you, I am. When I said that about my mother, I realized that I've been wondering if it really is my role to work outside of the home. It wasn't the image and model that I grew up with. And since I got Multiple Sclerosis (MS) I've had to work so much harder than everyone else to accomplish anything.

So when I have these other doubts, it's just easy to get to "give up." But I'm not a quitter and I want more in life.

COUNSELOR: It sounds like on the one hand you are, very understandably, wanting to protect yourself from further pain, and on the other considering that some more struggle and, yes, pain might be worth it if you can achieve the goals you've chosen.

SPOUSE: Is my wife jeopardizing her case with your agency by expressing these doubts?

COUNSELOR: Good question. No, she is not. We're here to assist people with disabilities to make choices about their lives, including about how and if they choose to enter the world of work. The doubts that Elizabeth is having seem very normal to me. They are the kind of doubts I've heard from many other people, and the kind that I've had in my life. Going to work is difficult, and for people with disabilities in our society it is often much more difficult. If Elizabeth chooses to go to work I, and my agency, will do everything we can to help her reach that goal. And if she chooses not to I will respect her decision. And Elizabeth, if you do decide that now is not the time, I want you to know that you can always come back. Let me share with you, though, that I hope that you do decide to continue pursuing employment. Your voice sounded very strong when you said that you wanted things for yourself in life, and there are things we can offer

that can make the struggle a little less intense, perhaps actually much easier.

VR CONSUMER: You know I've thought as we've all spoken. I really do want to go to work. Yes, I need to take care of myself and not push too hard, that is the reality of my health needs now. And Mark, I appreciate that you want to protect me. I've always needed and depended on that part of you. And I think I always will. But I have some things I want to do in life, and I know I can do them. It seems a little clearer now. Tell me more about the electronic job search options you had mentioned at the beginning of this meeting. I'm really interested in these new jobs using the Internet that seem to be springing up all the time. They may offer me the flexibility I need with my disability.

COUNSELOR: Can do. Mark, how are you with all this?

SPOUSE: Glad to hear it. I've realized as we've spoken how I tend to overprotect Elizabeth, particularly since the MS. She is a competent woman, and I need to respect that. Those are values she and I shared before the illness, and I didn't realize how far I've moved away from them. (To Elizabeth) And it was good to hear that you still like it when I stand up for you. I've appreciated the many times you've supported me. I'm glad we've had this meeting!

VR CONSUMER: Me too.

COUNSELOR: It's unanimous. Lets draw up some ideas of the steps we'll take from here.

Of course not all families will be able to clarify their values and reach decisions this quickly. There will be some cases where the confusion or conflict in the individual or family are so great that it is beyond the scope of most rehabilitation professional's competence and job duties. It is at these times that the ability of the rehabilitation worker to team up with other professionals, such as mental health or family counseling therapists, is so critical.

### **DOMAIN III: Leadership**

The characteristics that make up effective, creative leadership lie at the heart of the CERF model. It is important to emphasize that, in this model, everyone is considered to be capable of exercising effective leadership on some level.

Research distinguishes transformational leadership styles from transactional styles of leadership (Corrigan, 1995). The former tends to inspire, the latter to maintain a system by rewarding performance and by penalizing lack of performance. Both styles of leadership are essential at different points in a systems life. Styles of leadership that fit one family or organization at a certain time may not work as well at others.

Transformational leadership is most important when a system must change to adapt to new challenges or to capture new opportunities. Leaders capable of transforming systems (e.g. family, vocational rehabilitation systems, etc.) into environments where problems are solved and opportunities are created strive to promote self-determination and vision in themselves and in the individuals and groups with whom they interact. Lack of this leadership can limit systems growth.

### **Characteristics of Effective Leadership**

#### **Balanced**

Allocates responsibilities and resources fairly.

#### **Nurturing**

Makes certain that all points of view are heard, that all receive the information that they need, that all feel valued. Creates an atmosphere where mistakes, problems, and dreams can be recognized and shared.

#### **Competent**

Able to mediate conflict because the leadership has earned the members trust and respect.

#### **Networked**

Capable of developing and sustaining relationships outside of the system to the benefit of the system's members. Willing to convey feedback from the outside in a manner that allows the system to adjust and to grow.



**Ambitious**

Models a consistent drive to grow and achieve without sacrificing the trust and long-term harmony of the system. Willing to share disappointments and failures in pursuit of this struggle.

**Vision**

Has a personal vision and will help members find their vision. Will lead conversations and activities that allow members to share visions and values to enable the development, nurturing, and growth of a shared vision and set of values.

**Unproductive Styles of Leadership**

It is also the case that everyone is capable of, and does from time to time, express the qualities of poor leadership. These include:

**Abdicated**

The leader is unable to handle internal or external challenges to the family or organization. Chaos often results.

**Polarized**

The leader acts or communicates in such a way as to encourage members of the family or organization to enter into conflict with one another. Creativity is often stifled.

**Discredited**

The leader has behaved in such a manner that they lose the respect and trust of the members of the family or organization. In this circumstance it is important that the leader acknowledge

the source of the mistrust and make reparations.

**Biased**

The leader favors him or herself, or selected members of the family or organization, over other members. The resultant polarization leads to increasing disaffection between the leader and the unfavored member or group.

Whatever the setting, the goal is for leaders to acknowledge and strive to transcend their limitations freeing them to express their positive leadership skills.

**DOMAIN IV: Development**

Research on family development has lead to the general conclusion that families tend to go through predictable stages. Looking at the stage of life cycle the family was in at the time of the emergence of the disability; and the life cycle tasks the family would usually be experiencing at the time rehabilitation issues are considered can provide insight into the impact of disability on a family (Rolland, 1987).

## **TRADITIONAL STAGES OF THE US FAMILY LIFE CYCLE (late 20th Century)**

Adapted from McGoldrick, M., and Carter, B. in Walsh, F. (1987)

### **STAGE TASK CHANGE PROCESS**

Young adult Separate from parents  
Establish own identity apart from family origin, develop intimate peer relationships, establish identity as a worker  
Marriage Commit to couple  
Emotional, financial, investment in new primary relationship, redefinition of relationships with families of origin, friends, employers, etc.  
Young children Focus on new generation  
Make space in marriage for children, take on parent roles, establish relationships with grandparents, etc.  
Redefinition of work relationships and priorities for each parent  
Adolescents Recognize children's independence  
Open family boundaries for children, focus on mid-life career and marriage, concerns for seniors  
Children leave Accepting exits and entrances into family  
New emphasis on the marriage, adult to adult relationships between parents and children, accepting new in-laws and new role as grandparents, disability and death of seniors  
Later life Change of generations  
Individual/couple identity in face of disability and decline, explore new role options, leadership of middle generation, value wisdom of seniors, support of seniors without taking away their power, coping with death of spouse, friends, life review and preparation for own death

As individuals with disabilities move through this life cycle, enter new stages and focus on new tasks, they may encounter new disability related limitations. Adjustments required by these transitions can disrupt established patterns and cause increased stress and a new sense of loss for both VR consumers and their family members.

### **DOMAIN V: Cultures**

In this model culture is defined broadly. It assumes that the impact of culture can be found in all systems (individual, couple, family, organization, community, state, nation, international). Thus culture includes consideration of nationality, race, ethnicity, educational level, age, religion, income/social level, immigrant status, regional affiliation (e.g. Midwestern US), nature of the political system, political affiliation, gender, sexual orientation, disability (including type of disability), nature of the economy, and the prevailing technology.

The unique role of the rehabilitation professional requires that they be skilled at finding and building common cause with VR consumers and their family members. Discovering areas of commonality between the culture of the VR consumer and their family and of the rehabilitation professional will facilitate the collaborative process. In this regard the rehabilitation professional's best tools are a respectful and genuine curiosity about the VR

consumer and family's perceptions of their culture, and a willingness on the rehabilitation professional's part to share their own cultural beliefs and experiences when appropriate.

One way to approach the task of multicultural collaboration is to draw a distinction between intracultural, intercultural, and universal beliefs and behaviors. **Intracultural beliefs and behaviors** (within a single culture) provide continuity to a culture by reinforcing shared rules, perceptions and values within that culture. These beliefs are constantly being influenced by historical and political events (e.g., political campaigns and elections).

**Intercultural beliefs and behaviors** flow across several cultural groups because of common experiences and shared perceptions. Traditionally much of this cross-cultural exchange has occurred as waves of immigrants interacted with cultures of the host nation or region. In the modern era technologies, such as the telephone and television, have facilitated this sharing process.

**Universal beliefs and behaviors** are common to all human societies. They include birth, adolescence, disability, death, the need for defense or protection (e.g., against illness or injury), the desire for prosperity, for connection to the natural world, for some level of autonomy, for affiliation (to family, tribe, nation, etc.), and the need to define social roles (such as those of men and women).

A family's cultural heritage provides members with opportunities for affiliation and a sense of belonging. Through the rules and customs of a given culture individuals find both opportunities and constraints. At a given time and in a given situation these constraints may be adaptive, and at other times they may not.

Inequalities arise in societies or cultures when some groups do not have equal access to resources or opportunity. Many VR consumers of VR services and their families have experienced this kind of discrimination. When this occurs, groups of people within a society, such as cultural minorities or people with disabilities, feel a sense of disaffection, a lack of belonging, to the culture or multicultural context. VR consumers and their families are embedded in this labyrinth of influences. Culturally competent rehabilitation professionals can assist VR consumers and families to examine and understand the constraints and opportunities that interlocking cultures afford them.

## **DOMAIN VI: Human Rights**

**The rehabilitation professional's first duty is to the primary VR consumer of rehabilitation services-the people with the disability.** However, the mandate to assist people with disabilities to reach their potential often conflicts with institutional and public policy values, which emphasize cost savings and minimal government intervention. This dynamic tension in

the rehabilitation system has led to a lack of clear ethical standards for the profession (Tarvydas & Cottone, 1991).

At the **organizational level** rehabilitation professionals have the obligation to identify and advocate change in those policies and practices that overtly or inadvertently compromise the ability of professionals to join with VR consumers and their families in seeking the full rights, access, and responsibilities of citizenship for all people.

At the **national and global level** the rehabilitation movement has a proud legacy of advocacy in the area of human rights. Rehabilitation professionals have committed themselves to joining with the people they serve to secure rights such as equal employment opportunity and full participation in the community. From the passage of the Americans with Disabilities Act, to the growth of the Independent Living and Recovery (of VR consumer/survivors of mental illness) Movements, to the many laudable efforts on the local level to make communities more accessible, the rehabilitation community has demonstrated its leadership.

The family is a universal human experience that can be a powerful tool in efforts to achieve full access and rights. This was demonstrated recently by George Mitchell, former Majority Leader of the US Senate and the main negotiator in the Northern Ireland

conflict. After long and fruitless negotiations, Senator Mitchell was finally able to get Catholic and Protestant factions to stop talking about their differences and eventually to agree to far reaching peace proposals by convincing them to sit down together to talk about their children and families.

There are tremendous opportunities and challenges to changing the social fabric to the benefit of people with disabilities and their families. One example is the recent US Supreme Court decision in the Olmstead case. In that case the Court ruled that people with disabilities have the right to the services and supports that they need to live in their communities as opposed to in institutions, such as state mental hospitals and nursing homes. In support of this decision the Clinton administration issued a policy statement requiring states to provide these supports as a condition of continued receipt of Medicaid funding. States are responding that they will have to cut back in services in other areas, which are also of benefit to people with disabilities to comply with this order.

Recent changes in Social Security legislation have created an unprecedented opportunity for people with disabilities to go to work and to continue to receive health care benefits. However, some advocates have expressed concerns that provisions of the Ticket-to-Work legislation, paying

community rehabilitation agencies for their services only after VR consumers return to work and have *stopped receiving Social Security payments* may encourage these agencies to work only with those people with disabilities easiest to place.

On the global level World Wide Web technology has the potential to give individuals and their families access to information and services once the exclusive province of large companies and governments. However, equal access continues to be an issue for people with disabilities.

#### **DOMAIN VII: Spirituality**

For the purposes of this model spirituality, is defined as the experience of or aspiration to transcend the limitations experienced by the individual. This is distinguished from religion, which can be conceived of as the set of rituals, beliefs, rules and institutions that accompany culturally defined communities of worship.

Recently researchers have turned their attention to the study of what has been termed **post-traumatic growth** (as opposed to post-traumatic stress). This is a phenomenon sometimes observed in people, such as prisoners-of-war, who undergo life threatening or otherwise harrowing experiences, and who emerge from these experiences with their sense of self, capabilities, and purpose in life enhanced rather than debilitated.

Common themes emerging from this research are a renewed vigor and interest

in life, lowered fear of death, increased intuitive abilities, greater resistance to stress, and greater interest in forming and strengthening close interpersonal relationships experienced by individuals following a trauma (Morse & Perry, 1992; James, 1936). Disability creates an increased likelihood for experiencing traumatic events.

Perhaps not coincidentally, the Independent Living and Recovery philosophies that underlie the modern rehabilitation movement embody this sense of hope. Indeed it can be argued that the experience of disability and of poverty has always required individuals and families to transcend social definitions and to pursue enhanced life possibilities.

Rehabilitation is at its essence a celebration of the possibilities of human life. It is also a set of disciplines intimately connected to the multiple systems in which it is embedded. To counter the tendency of large systems to ignore the rights of groups who are less powerful, rehabilitation has an evolutionary imperative to frame this cultural dialogue within ethical and moral principles that foster the ability of VR consumers and their families to create together new opportunities for the expression of life.

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