

Appendices

Appendix A: Consumer Hand Out for Chapter 2

Making the most of your Vocational Rehabilitation Experience

This brochure contains information to help you make the most of your VR experience and partnership with your VR Counselor.

Questions that might be asked:

- What are your job interests?
- If you don't know, do you want to learn?
- What do you think your strengths are?
- What do you think you need help with?
- Who can provide written information about your disability? (Doctors, Hospitals, family, schools, Social Security Office, others)
- Expect that you may be asked to sign releases for the counselor to obtain information.

This is also the best time for you to ask questions of your counselor in order to be fully informed, and begin working together on your goals

Asking Questions:

- How will the information I provide be used?
- Ask who will see the information. Express any concerns you may have.
- What Can I do to help the counselor get accurate information about me?
- Can I pick up the information for the counselor?
- What type of tests or assessments might I take?
- Who can I talk to?
- When & Where is there a consumer or consumer group I can meet?

- How do you usually work with people who have a disability? This is how I work best with a counselor...
- What are your experiences with people who have my disability or barriers with getting training or a job?

Listening to the Answers:

- Be Honest, if you are not interested in going to work-say so. The counselor may be able to refer you to an appropriate source to have your needs met.
- If you have a question-ask.
- If you do not fully understand, it is your responsibility to ask for clarification.
- Ask how to contact the counselor if you think of questions later.
- Ask about the counselor's availability and practice of scheduling appointments, returning phone calls, responding to e-mail, etc.
- If you need assistance from the counselor to understand the VR process-talk about it.

Making the most of your Vocational Rehabilitation Experience

This brochure contains information to help you make the most of your VR experience and partnership with your VR Counselor.

Appendix B: Vignettes for Chapter 3

When Don first met his rehabilitation counselor, he was asked, “What can I help you with?” Don’s response was, “What services do you have?” Don, like a lot of clients wasn’t aware of the services that were available. His decisions regarding a goal were dependent on his options, and what services were available.

Don’s counselor proceeded to learn more about Don through the counseling relationship. When she later explained the available services, she was able to relate them to Don’s stated interests. While some of the services were not of interest to Don at the time, he was made aware of them for possible use in the future.

When Don decided to apply for VR services, his rights and responsibilities were discussed. Don needed to know what he could do, how his counselor would assist him during the process, and the services and supports that would be available to him in the pursuit of his goals.

An individual expresses an interest in working with children. The counselor has concerns and feels that the individual will get best results if working with elderly adults and presses the individual to accept a position in that area. The individual gives the job a try but is unhappy and eventually quits the job.

An individual applying for VR services had always felt sorry for anyone he saw in a wheelchair. He couldn’t imagine that life was worth living if you couldn’t walk, or run, or dance. He thought his life was over when the effects of a motorcycle accident resulted in amputation of both of his legs. For a long time, this individual wasn’t willing to consider anything his physical therapists and occupational therapists would suggest. He had been a strong man before. It took time for him to finally be willing to risk trying to do something in a different way. His fear of feeling that he was unable to do anything for himself and that family members and others must care for him needed to be addressed before progress could be made.

An individual expresses an interest in becoming employed in an area that will require academic training. The high school transcripts and psychological testing results indicate that the individual’s academic ability is below average. The policy of the local VR office is to factor ability levels into a decision whether or not to support training. Thus, the counselor refuses to support the individual’s participation in academic programming.

The counselor might consider that in many cases the individual’s interest or lack of interest will influence the level of success achieved. Also, since the individual deserves the opportunity to show that he/she can succeed, the counselor might agree to allow the individual to take a course to see if he/she has the ability and interest needed to complete the curriculum, in spite of low test scores. This could be part of the individual’s program and indicating that if attempts to attain the academic goal are not successful, then other areas would be explored.

Vocational Rehabilitation (VR)

VR is an employment focused program for persons with physical and/or mental disabilities whose conditions present barriers to employment, and who are able to benefit from VR services to go to work.

Visit your nearest VR Office at:

Agency Name
Address
Phone
E-mail & Website address

The VR Process:

The VR Process has several steps:

- Referral to the VR Agency
- Participate in an intake interview with a qualified VR counselor
- VR counselor determines your eligibility for the program
- You develop an Individualized Plan for Employment
- You find a job with the help of your counselor
- You can receive additional services after you get a job, if necessary

The following terms will frequently be used during the VR process:

Informed Choice: A decision making process whereby the consumer of the VR program accesses and analyzes relevant information and determines his or her vocational

goal, services and service providers. The individual exercises this decision making process in all aspects of the VR process.

Empowerment: Empowerment means control. An empowered consumer has control over his or her own life and has the knowledge, skills, supports, resources and the confidence necessary to exercises that control in determining and achieving his or her life employment, economic self-sufficiency, independence, inclusion and integration into society.

Roles

Throughout the VR process, your role is to actively engage in obtaining information in order to make the most informed choices/decisions about going to work.

Throughout the VR process, the VR Counselor’s role is to guide you through the process of obtaining information, and to make decisions related to your job goal.

What to Expect

The first visit or phone call to the local VR office:

- Expect to be asked if you are interested in going to work.
- Expect to provide referral information: name, address, phone number so you

can be contacted for an appointment or to attend an orientation.

- You may be offered the opportunity to attend an Orientation to learn more, or you may be able to schedule an appointment over the phone.
- If you want more information before attending Orientation or an Initial appointment, ask to be contacted by a counselor, or supervisor for more information.

Referring Yourself, Family Member or Friend:

Visit or call the local VR Office. Provide your name, address, phone number (Contact Information)

- In order for the Supervisor to match you with a counselor, the following information may be requested:
- What services are you interested in?
 - What is keeping you from working?
 - Tell us the best time to schedule an appointment with you.

Intake Interview & Application

The Intake Interview is the time when a Counselor reviews the VR process with you. It is also begins the counselor’s process of getting to know you-your interests, goals, work skills, barriers to employment, support networks, etc.

Matt is a 58 year old man with mild retardation, cerebral palsy and blindness in one eye. He has a great sense of humor, a strong work ethic, and a caring family. He had always worked in a sheltered workshop but he wanted a competitive job. Matt's largest barrier was not his multiple disabilities, but his family's concern about the impact of working on his health and social security benefits. Matt was determined to obtain employment with or without his family's support. The counselor helped him understand how important family support would be to maintaining a job. If his family did not support his job, over time Matt would likely not be able to keep his job. Matt and the counselor considered different ways to obtain his family's support. They decided to have a meeting with his family, facilitated by the counselor, to determine the conditions of employment that he and his family could agree on. Matt and his family agreed that Matt would work part time, not more than fifteen hours a week, no more than a twenty minute bus ride from his house, and for a stable employer. They also agreed that Matt's brother would meet the employer and see the worksite before Matt accepted the job. For the last five years, Matt has worked successfully for a local community college.

A consumer was referred to a community rehabilitation program for a functional assessment because she was making no progress toward identifying a vocational goal. She maintained an interest in becoming a dental hygienist, which her counselor felt was an inappropriate goal due to her visual and fine motor limitations. The counselor refused to support pursuit of the consumer's chosen goal. Rather than saying no to the goal, rehabilitation counselors from the community agency structured a series of activities that one would have to accomplish in order to pursue a vocation of dental hygienist. The activities were supported by the staff. The staff prepared the consumer for the experiences she encountered by helping her to frame questions she might answer through her experiences. After a relatively brief period of time, she determined that her previous goal was no longer of interest to her and she ultimately identified an alternative goal that she successfully achieved.

Jeff is a 24 year old man with severe learning disabilities as a result of childhood illness. In high school, Jeff had been advised that he was "not college material." Upon graduation, he had several meetings with his rehabilitation counselor to select a job goal. Through this process, he learned that he had an interest in computers and that he is very creative. He explored this information and completed his VR plan which included vocational counseling & guidance, graphic design training & education, job seeking skills development. He is now actively seeking employment as a graphic designer. From the beginning, Jeff was determined to attain a college degree. This goal kept him motivated throughout his college experience. He credits much of his success to the support of his VR counselor and family who often reminded him of his goal.

Mike is 50 years old and had never worked. His disability is cerebral palsy which limited his movement and speech. When he and his counselor attempted to hire a job developer, no provider would accept Mike. They all felt he was not employable. His counselor understood how important working was to Mike and decided to try another route rather than close his case.

She and Mike pulled together a circle of friends to do future planning that focused on work. Out of the future planning sessions came the idea of Mike working at his church. Mike was close with his pastor. The counselor met with the pastor and over a six month period designed a job for Mike. Co-workers in the pastor's office provided support to Mike in his job.

If the parents of a consumer are reluctant to allow the individual to try new things, the counselor might suggest that the individual could benefit from participating in a vocational assessment to get information related to his/her skills and abilities. To assist the parents to become comfortable with the idea, the counselor might spend extra time explaining the program and address questions/concerns they may have, or invite the parents to participate in some capacity in the assessment. It may prove advantageous if a tour of the site where the services will be provided could be arranged. The counselor might also adjust his/her schedule to allow accompanying the family on the tour.

In a second example, often the reluctance will lie with the individual. In such cases, the counselor might attempt to get information related to areas in which the individual has interest. Since attempting to get the individual to participate in new activities may raise anxiety, the counselor might get best results if he or she started by suggesting that the individual participate in activities with which the consumer is familiar. The counselor can attempt to increase the level of risk-taking by making a list of things to try that includes some additional activities with which the individual is not familiar. Consumers will have a greater chance at success if they begin with activities that are basic and non-threatening and then increase the level of risk/difficulty.

An individual with a cognitive disability that resulted from a brain injury struggled and failed at several attempts at vocational training, many of which included specific remediation for memory and other cognitive "impairments." The remediation efforts were unsuccessful, as were the training attempts. The individual became increasingly pessimistic about his chances for a career. At a peer support meeting that he happened to attend, he heard for the first time that accommodations for learning problems were not only available but required by law in community college settings. This led to enrolling in coursework at a local community college that, for the first time, proved successful. The individual attributed his success to realizing that he did not have to focus on changing himself, but rather could accommodate his limitations through modifications and assistive technology. This had a positive effect on his mood, level of motivation and self-esteem.

An individual approached her VR counselor requesting support to set herself up in a self-employment outcome in a media production business. While the individual did demonstrate interest, skills and experience, the counselor was unfamiliar with the type of work and the nature of the request. As a way of addressing the request, the counselor and consumer agreed upon using a community-based agency that specialized in entrepreneurial enterprises to assist the consumer in researching and developing a feasibility plan for the enterprise. Results of the study confirmed the feasibility and the services and support were provided by the counselor, resulting in a successful outcome.

Although it took a lot of soul searching, Karen finally decided to participate in personal adjustment training at her state's rehab orientation center. She was scared because she was leaving home, but she was also frustrated because her family did so many things for her, just because she couldn't see as well as she used to. At the training center, Karen worked with other students. She noted that at least half the staff was blind. Karen learned adaptive techniques that allowed her to regain her independence. Karen learned to travel with the use of a long white cane and to operate the computer via a screen reading software program. Karen went camping with this group, chopping wood and participating in a wide range of activities.

James is a fifty year old man with a mental health disability. He has lived in and out of institutions his entire adult life. He struggled with managing his anger and has a felony charge on his record for assault. James very much wanted to be a security guard. He did not believe his counselor when she told him that his criminal record would prevent him from getting a security guard job. He became very angry with his counselor. After he calmed down his counselor suggested an alternative plan. Together James and the counselor called all the security agencies in the area and asked them if someone with a criminal record could work as a security guard. After hearing from twenty-five security agencies that they would not hire someone with a felony, James was ready to reconsider his goal.

Larry was a thirty year old medical student who had had a climbing accident and acquired a TBI and multiple physical limitations. It was very important to Larry that he control his services. When it was time to select a provider, he decided to interview the providers to make sure the chosen provider met his needs. Of particular importance to Larry was that the provider answer to him, treat him as the primary customer, and find him a job that met his specified conditions. The counselor assisted him in designing questions to ask providers and helped Larry evaluate the responses. When Larry chose a provider, they entered into a performance-based contract that delineated Larry's expectations of the provider, including timelines for services and the type of job to be secured and the provider's expectations of Larry. Larry's satisfaction with the services was a condition of payment.

**Appendix C: Rehabilitation Services Administration Technical Assistance
Circular 98-01 "Support Services for Individuals With Cognitive
Disabilities and Others Who Need Assistance in Implementing Informed
Choice"**

UNITED STATES DEPARTMENT OF EDUCATION
OFFICE OF SPECIAL EDUCATION AND
REHABILITATIVE SERVICES
REHABILITATION SERVICES ADMINISTRATION
WASHINGTON, DC 20202

TECHNICAL ASSISTANCE CIRCULAR
RSA-TAC-98-01
DATE: November 3, 1997

ADDRESSEES: STATE VOCATIONAL REHABILITATION AGENCIES (GENERAL)
STATE VOCATIONAL REHABILITATION AGENCIES (BLIND)
STATE REHABILITATION ADVISORY COUNCILS
CLIENT ASSISTANCE PROGRAMS
REGIONAL REHABILITATION CONTINUING EDUCATION
PROGRAMS
RSA SENIOR MANAGEMENT TEAM

SUBJECT: Support Services for Individuals With Cognitive Disabilities and Others
Who Need Assistance in Implementing Informed Choice

CITATIONS: Section 12(e)(2)(F) of the Rehabilitation Act of 1973, as amended. 34
CFR 361.52.

CONTENT: Final program regulations at 34 CFR 361.52 require each state VR agency, in consultation with its State Rehabilitation Advisory Council, to develop and implement written policies and procedures enabling each individual to make an informed choice with regard to selection of a vocational goal, objectives, services, and service providers. These policies and procedures must ensure that each individual receives information concerning the availability of support services for individuals with cognitive or other disabilities who require assistance in exercising informed choice.

This guidance, much of which is derived from the RSA Choice Demonstration Projects, is designed to assist State VR agency staff in understanding the needs of individuals with cognitive disabilities for support and assistance in exercising informed choice and in identifying methods for addressing those needs. Although specifically helpful for working with individuals with cognitive disabilities, use of these methods should allow all individuals to increase their participation in the VR process to the extent that they are able to do so.

STRATEGIES FOR SUPPORTING IMPLEMENTATION OF INFORMED CHOICE

Informed choice is the process by which individuals participating in the VR program make decisions about their vocational goals, the services and service providers that are necessary to reach those goals, and how those services will be procured. The decision-making process takes into account the individual's values and characteristics, the availability of resources and alternatives, and general economic conditions. Implementing informed choice requires communicating clearly, gathering and understanding information, setting goals, making decisions, and following through with decisions. To the extent that the individual participates in the procurement of services, implementing choice may also involve basic consumer skills, such as money management and negotiating in the market place.

Mental retardation, learning disabilities, head injury, and stroke typically result in cognitive impairments that can affect an individual's ability to gather and analyze information, develop and follow through with plans, and decide among various options. Individuals with mental illnesses may have cognitive impairments as a result of the illness or of medications. Organic brain damage associated with conditions such as multiple sclerosis, lupus, and HIV-Aids may result in short term memory loss and other cognitive impairments. Depending upon the nature of the disability and the medications an individual is taking, an individual's ability to do cognitive tasks may fluctuate dramatically from day to day.

Other individuals may also require assistance in exercising informed choice. These include individuals with any type of disability who have not had experience in making decisions for themselves and individuals with severe impairments in communication skills as a result of physical or sensory disabilities.

In general, individuals with cognitive impairments who are eligible for VR services can comprehend information and ideas and make individual judgments if they are provided with appropriate support and assistance. The individual, the VR counselor, and others who are working with the individual need to determine the level of the individual's skills and abilities in these areas. Once the skills and abilities have been identified, a number of strategies can be used to improve the individual's skills and to provide information and assistance with decision-making at the individual's level.

The following discussion describes methods for determining the individual's abilities to exercise choice and for implementing strategies to provide assistance and support, including:

- improving the skills needed by the individual to exercise choice;
- providing support and assistance through other individuals;
- simplifying information; and
- using multiple modes of communication and repetition.

Determining the individual's skill and ability to implement informed choice.

Methods to determine the individual's ability to implement informed choice may vary depending upon the individual's disability and the severity of that disability. For some individuals, both the counselor, the individual, and others can use a checklist to analyze the individual's skills and abilities in areas important to the implementation of informed choice. Such an analysis provides a way for the individual and others working with him or her to identify those tasks the individual can do independently; those tasks for which the individual needs support, accommodations, and skill building; and those that someone else will need to do. Purchased checklists and inventories about decision-making and goal setting skills can be used or agencies can develop such assessments. (VT)

Checklists and inventories are based on comparing an individual's known performance in decision-making against a standard. Those who lack experience in making decisions and those who have difficulty communicating about their past experiences are not easily assessed by such methods. For these individuals, other techniques of discovery are needed to gather the same information.

For example, working with an individual on developing a vocational profile and employment goals will simultaneously yield information about how the person gathers and responds to information and makes decisions. (UCPA) Situational assessments or trial work experiences provide the opportunity to observe the individual in natural life situations that help clarify not only the individual's goal and service needs, but also provide insight and information about how the individual makes decisions. Interviewing family, friends, and others who are close to the individual may also yield the same information. Such approaches are also especially helpful for individuals who are not able to communicate clearly and assertively. Scheduling a longer time period for meetings with individuals who have difficulty focusing on the issues to be discussed helps assure that the individual's thoughts get expressed. The success of these types of discovery depends upon the ability of the VR counselor and others to listen to and observe the individual carefully over time. If the time required for such observation and interaction is more than is feasible for a VR counselor, VR agencies can consider paying someone other than the counselor to work on this task.

Counselor judgment and observation are a primary source of discovery throughout the VR process. How the individual followed the process of obtaining VR services and how he or she processes information and responds to questions during interview and intake provides information about some of the skills related to informed choice. Probing for the reasons that an individual says "no" to a particular option helps to determine if the individual is responding because of lack of information or because of fear. Assessing changes in the individual's skill in implementing informed choice and adapting supports appropriately is a continuous evaluative and educational role for the counselor.

Counselors may also find **RSA Program Assistance Circular (PAC) 90-7: Guidelines for Determining Whether a Person With Specific Learning Disabilities Has a Severe Handicap for Vocational Rehabilitation Program Purposes**, issued September 28, 1990,

helpful. The guidance for evaluating an individual's capacities in the areas of self-direction and communication can be applied to evaluating the individual's capacities for implementing informed choice. The concepts are applicable to other types of disabilities.

Self-discovery is also an important factor in the implementation of informed choice. *Employment outcome* as defined in the final regulations for the VR program (34 CFR 361.5(b)(15)) includes the element that the employment outcome "is consistent with an individual's strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice." The more complex the individual's situation or disability, the more difficult it is for others to help the person consider all the factors necessary for making informed decisions. Using techniques that teach individuals to develop an awareness of how their disability affects them, how they function on a daily basis, and how they respond to information and make decisions may be a better investment of the time and efforts of rehabilitation personnel.

One method of self-discovery is for the individual to keep a diary/log/journal, either in writing or by audio tape. (TDTI) Individuals can record information such as variations in their energy level, times and conditions when they feel good and are doing their best work, variations in symptoms, and other revelations about the VR process. The log becomes a self-management tool, providing insight into behavior patterns and forming the basis for strategies to maximize the individual's functioning level.

Improving the skills needed by the individual to implement informed choice

The ability to make choices grows with experience in decision making. VR agencies can purchase or provide an array of services that help individuals to move further along the continuum of independently making decisions and taking personal responsibility for those decisions. Consumer empowerment training, training and experience in goal setting and decision making skills, and self-assessment techniques are services that can improve the skills and abilities needed to implement informed choice. In addition to training, the VR counselor and others working with the individual can provide structure to help the individual determine what information is needed, ways to gather that information, what options are available, and ways to decide among those options.

Assisting the individual to gather information can begin during the assessment process by shifting from a process in which an evaluator talks to the VR counselor about the individual to a process that includes the individual in the discussions or allows the individual to direct the discussions. A method common to the choice projects is to facilitate the relationship between the evaluator and the individual. Reports are provided to the individual and must be written so the individual can understand the information. The individual can clarify and discuss the information with the provider, the counselor, a peer group, a rehabilitation team, family members, or others. The goal is for the VR participant to be able to explain what the information means, how it affects that individual's life, and what he or she wants to do as a result.

Individuals can also be taught to gather information about goods, services, and service providers. To provide structure for gathering such information, the VR counselor and participant can

develop a list of questions to ask providers. For example, an individual who is seeking the services of a job developer might want to ask if the job developer specializes in certain types of jobs, how the developer gets job leads, how much time the developer will spend per week working with the individual, and what the developer is expecting from the individual. (SWBIRA) VR agencies can support this method by developing a list of core questions to be supplemented by specific individualized questions as appropriate and by reimbursing the individual for any telephone or travel expenses incurred while gathering information.

To provide experience in planning and decision making, these processes can be broken down into small steps. A series of short-term vocationally-related activities and experiences provides the individual with experience in implementing the choice process and gives the counselor opportunities to observe the individual's growth in planning and decision-making skills. As these skills grow, both the individual and the counselor develop more confidence in the individual's ability to make decisions. The counselor learns how the person works best and what accommodations are needed to facilitate that person's decision-making.

To increase the participation of those who are reluctant to make decisions, the counselor can ask the individual what he or she wants the counselor to do. Another method is for the counselor to state what he or she is willing to do and then ask the individual what they are willing to do. Both methods invite the individual to begin to make decisions, exercise control, and take responsibility.

Getting support and assistance from others

Individuals close to the person can provide support and assistance in implementing informed choice. For orientation and other important meetings, the individual could bring a family member to help with understanding the information, remembering the next steps in the process, and asking questions. In some cultures, individuals naturally rely heavily on the support of their families throughout the decision-making process.

This strategy works best when the family is a neutral party. When the family is not neutral or not available, consumer connectors, mentors, advocates, a buddy system, and peer support groups can be used. One project used a mentor paid by the project who served as a job coach, moved with the individual through a series of short-term work experiences, and provided continuity of feedback to the individual, family, and others working with the individual. The mentor was recruited through a local literacy council. (AR) A peer group of individuals with disabilities may have extensive experiential knowledge that, when shared, becomes a resource for others to use in gathering and analyzing information and making decisions. Individuals with disabilities have an understanding about how they learned to do certain processes and may be able to provide information in a way that another individual with a disability is more likely to understand.

The VR counselor also plays a key supportive role by following up with the individual frequently to see how they are doing and by modifying or developing strategies to help the person improve their planning and decision-making skills.

Simplifying information

Access to appropriate information allows an individual to identify opportunities and solutions to problems, assess strengths and weaknesses, ask appropriate questions, locate resources, and, if necessary, advocate effectively. Access to appropriate information allows an individual to influence, and to be influenced by, the vocational rehabilitation planning process. For individuals with cognitive impairments, access to the information necessary for implementing informed choice can be achieved by breaking information down, taking more time for information gathering, using simpler language, symbols, and tangible methods of conveying information, and providing supports and accommodations.

Written program materials can be simplified by incorporating one thought per sentence, avoiding professional language and terminology, and supplementing text with pictures and graphics. To simplify verbal discussions, break information down into small components, explain more clearly, ask the person to repeat what has been said, note important points stated by the consumer, and review these at the end of each session.

Information and alternatives can be made more tangible by a series of short-term volunteer placements that provides experiential knowledge about working in different types of situations. Other rehabilitation objectives, such as learning to travel and developing social skills, may also be achieved during such experiences.

Pictures and graphics, substituted for written materials, also provide tangible ways to gather and exchange information. A picture checklist of factors that the individual is looking for in a job enables the person to remember all the factors and to check off the appropriate factors when visiting any potential job site. Involvement of the individual in selecting the pictures from graphics available on the computer assures that the person understands what the pictures symbolize. Comparing the checklists from various sites provides a more tangible way of selecting among options. (WA)

Some individuals will benefit from use of accommodations for receiving, organizing, and retrieving information. (BCIL) A quick assessment of whether an individual may need accommodations for reading can be obtained by observing how they respond to the application form. In addition, the VR counselor can ask whether the individual needs accommodations, such as someone to help with reading and writing. If so, the individual can bring someone to help with those tasks or the program can provide a reader. The counselor can provide, or help the individual acquire, tools for organizing and retrieving information, such as a calendar, an organizer, and business card slot holders. For individuals with deficits in attention, working in a distraction-free space or using familiar surroundings may enable the individual to better attend to the information being presented.

Using multiple modes of communication and repetition

The implementing regulations at 34 CFR 361.52(a) require state VR agencies to ensure that individuals receive information about choice in appropriate modes of communication.

Appropriate modes of communication, as defined at 34 CFR 361.5(b)(5), means specialized aids and supports that enable an individual with a disability to comprehend and respond to information that is being communicated. The definition provides examples of appropriate modes that include but are not limited to graphic presentations and simple language materials discussed previously in this document. For individuals with cognitive impairments, comprehension and retention of information is enhanced when information is provided in multiple modes of communication and repeated over time.

Audio taping information allows the individual to listen to it multiple times. Family members can help repeat information, such as a fact sheet, by reviewing it at home multiple times. Making information available in auditory, visual, and experiential modes provides the individual with multiple options for acquiring information and assures repetition. Group discussions among peers or rehabilitation teams helps with understanding. Over time, group members will discuss the same issue in many different ways, thus providing the opportunity for multiple presentations and different opportunities to achieve understanding. Information resource centers allow individuals to drop in and repeatedly review information and to discuss information with other individuals using those same resources. Documenting, in writing or other media, what needs to be done and then documenting what was done is helpful for individuals with short-term memory loss. A series of experiences arranged as part of the comprehensive assessment or as short-term objectives on the individualized written rehabilitation program (IWRP) provide experiential and repetitive methods of acquiring information. Use of multiple modes and repetition, especially over a period of time, also provides accommodations for individuals with cognitive impairments whose ability to perform cognitive tasks varies significantly from day to day.

Both the individual and the counselor have a role in discovering the modalities in which the individual achieves the best understanding and in assisting the individual to acquire information in those modalities. The role of the VR agency is to provide opportunities for information to be presented in various modalities.

SUMMARY

There are many methods that State VR agencies can use to provide support services for individuals with cognitive and other disabilities who require assistance in exercising informed choice. A number of the methods discussed above provide support for a variety of needs. Within the discussion, selected specific strategies are accompanied by acronyms for the Choice Demonstration Projects. More information on these specific strategies can be obtained by contacting the projects listed below.

In many instances, use of the methods described above will require spending more time with the individual and allowing for a trial and error approach to planning, gathering information, and making decisions. Agencies have the option of deciding whether the counselor will spend that time or whether they will pay for someone else to provide that service. Often, the time used for such approaches can occur simultaneously with the provision of other rehabilitation services that are directed toward achieving an employment outcome. The individual's skills in exercising informed choice can grow in a parallel fashion along with growth in specific vocational and employment skills.

Both the VR counselor and the individual have responsibilities in determining the individual's skills for exercising informed choice, deciding on methods for improving those skills, and developing needed accommodations and supports. The counselor and the individual can also enlist the aid of others, either paid or voluntary, to help in these efforts.

INQUIRIES: Choice Demonstration Projects:

Arkansas Rehabilitation Services (AR)
Nancy Sullivan/Sterling Hughes
 501-661-9407/501-534-1372

Berkeley Center for Independent Living (BCIL)
Terry Herkimer 510-841-4776

Southwest Business, Industry, and Rehabilitation Association (SWBIRA)
Lee Lanning 602-275-0180

The Development Team, Inc. (TDTI)
Harry Hall 904-247-4640

United Cerebral Palsy Associations (UCPA)
Michael Callahan 601-497-6999

Vermont Division of Vocational Rehabilitation (VT)
Michael Collins 802-241-2186

Washington Division of Vocational Rehabilitation (WA)
Abby Cooper 206-587-4444

Rehabilitation Services Administration:

RSA Regional Offices

RSA Central Office:

Suzanne Tillman 202-205-8303

Fredric K. Schroeder, Ph.D.
 Commissioner

CC: CSAVR
 NAPAS
 RSA Regions II, IV, V, VIII, and X

**Appendix D: Rehabilitation Services Administration Information
 Memorandum 98-03 "Advice, Information, and Choice."**

UNITED STATES DEPARTMENT OF EDUCATION
 OFFICE OF SPECIAL EDUCATION AND
 REHABILITATIVE SERVICES
REHABILITATION SERVICES ADMINISTRATION
 WASHINGTON, DC 20202

INFORMATION MEMORANDUM

RSA-IM-98-03

DATE: November 4, 1997

ADDRESSEES: STATE VOCATIONAL REHABILITATION AGENCIES (GENERAL)
 STATE VOCATIONAL REHABILITATION AGENCIES (BLIND) STATE
 REHABILITATION ADVISORY COUNCILS
 CLIENT ASSISTANCE PROGRAMS
 REGIONAL REHABILITATION CONTINUING EDUCATION
 PROGRAMS
 RSA SENIOR MANAGEMENT TEAM

SUBJECT: Advice, Information and Choice

CONTENT: The attached paper discusses concepts on the roles of advice and information in helping individuals with disabilities become informed and make effective decisions in the selection of their vocational goals, services, and service providers. The paper was developed by the directors of the RSA Choice Demonstration Projects.

The opinions expressed in the paper are those of the project directors and not necessarily those of RSA. The paper is being disseminated as part of RSA's efforts to facilitate the exchange of information about informed choice between the Choice Projects, State vocational rehabilitation agencies, and other relevant parties.

INQUIRIES: The attached paper provides contact information for each of the Choice Projects. Within the Rehabilitation Services Administration, for matters related to choice the contact person is Suzanne Tillman at 202-205-8303.

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Advice, Information and Choice

Advice and Information: Helping people to become informed and to make effective decisions concerning employment

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Prepared for:

*Rehabilitation Services Administration
Office of Special Education and Rehabilitative Services
U.S. Department of Education
Grant #H235D30067*

1997

Advice and Information: Helping people to become informed and to make effective decisions concerning employment

advice: (from Latin, to look at); opinion given as to what to do. *Webster's New World Dictionary*

information: something told or facts learned; news or knowledge. *Webster's New World Dictionary*

The underpinning of the Choice Demonstration Authority in the Rehabilitation Act of 1973, as amended in 1992, is for projects to insure that customers not only make individualized choices concerning their employment goals, the types of services received and the providers of those services, but that those choices should meet a higher standard—that is, “informed” choice. Each of the seven national demonstration sites uses some form of advice and/or information as primary tools to assure that the choices made by customers are informed. However, just as Webster’s struggles with the difference between the derivation of the word “advice”, which alludes to information, and it’s definition, which is based on opinion, so too have the projects realized that advice and information are separate, but intertwined components of informed choice.

It is critical to recognize the distinction between these facets of choice. Information is usually considered to be based on the unbiased facts concerning an issue. Opinion is inherently subjective, someone’s personal perspective, even if that opinion is based on fact. However, even though information and opinion are different, they are both necessary ingredients of informed choice.

In traditional rehabilitation, information and advice have been fundamental aspects of the counselor/customer relationship. The counselor has been responsible for gathering facts and offering opinions on the customer’s efforts to become employed as well as defining the questions, issues and barriers which need to be addressed. The provision of counselor-centered advice and information has been an area of concern voiced by many persons with disabilities. Each of the seven choice demonstration projects address this issue in unique ways with designs intended to shift the focus away from counselor ownership of advice and information to a broader, more natural and customer-centered basis.

It is important to distinguish between these two aspects of informed choice. Information relates to the body of knowledge or facts associated with an issue or a decision. It would seem that by this definition, information would be free of opinion or personal bias. However, since most rehabilitation personnel work for systems with rules and traditional responses to certain situations, it is often difficult to know whether an interaction concerning informed choice is factual or biased in some way.

Since the opinion aspect of advice is almost inherently biased, good advice should contain alternate avenues for customer consideration, as well as the opinion of those offering the opinion. Indeed, good advice is an individualized blend of information, opinion and workable options offered to a customer in a manner which can be understood and utilized.

In the implementation of the choice-driven projects, a number of factors, considerations or influences affecting informed choice have been identified. The following headings provide an overview of these factors, along with a brief discussion of each.

Understanding how an individual processes information and opinion

Just as with other aspects of employment, individualization is critically important in the delivery of information and advice. Regardless of the relationship with one’s advisor, it is necessary for the person(s) offering input to understand the experiences, the tendencies and

support needs of the customer. This is to say that it is not sufficient simply to give accurate and unbiased advice and information. It is also necessary to get to know the individual well enough to gauge the person's reaction both to the input given and to the source of that input. While it may seem that a customer is making an informed decision based on the information and opinion of an advisor, the reality may be that the customer is seeking to please or to simply follow any advice offered. Understanding the difference requires those giving advice and information to closely monitor all decisions and to consider subtle ways to insure that the customer owns and understands the decision as much as possible. It is important to consider that technology, interpretation services and accessible information formats may need to be available to assure that an individual understands and processes opinions of others. When confronted with new and complex decisions people with disabilities, especially persons with significant intellectual disabilities, may need support and feedback from those most closely concerned about them in order for information and advice to be understood and processed.

Gatekeeping issues

Gatekeeping involves the limitations, inevitable whenever public funds are used by individuals, which are placed on the choices of customers. Since the intention of the choice demonstration authority is to examine the effectiveness of achieving employment outcomes through funds controlled by the individual with a disability, the role of gatekeeping is dynamic and challenging.

When the sole source of information and advice is from a representative of the system, it is easy for that input to become infused with the gatekeeping responsibilities which are a part of any system's policies. Even the choice projects have gatekeeping issues which affect the customer's choices and which often require a blend of information and advice to assist them to make successful, informed decisions. Representatives of the system must recognize the limits of their advice and the possible bias of their information in light of their gatekeeping responsibilities and they communicate those limits to customers. The limits referred to here typically involve monetary issues such as the cost, value or individual's need relative to a service or product. These considerations will arise as gatekeeping issues in any funded relationship—public or private. The choice projects have sought to reduce any arbitrary and limiting rules on the use of funds by placing the customer's needs and satisfaction as first line considerations.

However, there are thorny gatekeeping issues which go beyond money and which can compromise the effectiveness of advice and the validity of information. If physical or emotional harm is considered to be likely, it is often necessary to impose limits as opposed to offering information, options and opinion. Counselors and other gatekeepers must decide if and when it is appropriate to intervene if it seems that harm may occur. Of course, each situation will vary, depending upon specific factors, but decisions to constrain choice cut to the heart of the effort to honor the customer's decisions. In those instances when it is felt to be necessary to not support a customer's decision, we are responsible for accepting a level of discomfort concerning the necessity for placing the restriction, for seeking a wide variety of acceptable options and input and for explaining (possibly even apologizing) to the customer for the necessity of the restrictions which are to be applied.

Believability/reputation

Since one of the traditional counselor roles has been that of a gatekeeper, many customers

have questioned the degree to which advice and information serve their needs or the system's needs. In order for professional input to be perceived as believable, it is necessary for the counselor or advisor to build a reputation of honestly distinguishing between advice and the limiting reality of the gatekeeping needs of the system. To resolve this potential conflict, some projects have separated the roles of gatekeeping and advice while others have sought to provide clear distinctions for customers who receive their advice from sources tied to the funding system.

Ownership of the decision

Perhaps the most important consideration relating to good advice and information is that responsible, viable and final decisions are made by the customer, or by a designated family member, as appropriate. In order to accomplish this, all those in informing and advising roles must strive to provide unbiased advice and information which relates directly to the customer choosing and pursuing a realistic employment objectives. This advice should be adequate for the customer to make an informed decision based on accurate information. The role of system personnel is to provide information, but not usurp ownership by the customer. To enable the customer to make an informed choice that meets their personal needs and wishes while remaining realistic is one of the most challenging aspects of assuring informed choice.

In order to accomplish this, all those in advisor and information roles must consciously give up their prerogative to sway and to direct the decisions made by the customer. This separation is at the core of the changes addressed by the choice projects. It is also one of the most difficult and challenging aspects of choice. The challenge to assure maximum ownership by customers is felt most keenly in regards to gatekeeping. There will always be guidelines and restrictions placed on the use of public funds. Rehabilitation counselors are required by the Rehabilitation Act of 1973, as amended in 1992 (Section 361.52, page 6357), to "ensure that each individual receives, through appropriate modes of communication, information concerning the availability and scope of informed choice, the manner in which informed choice may be exercised and the availability of support services for individuals with cognitive or other disabilities who require assistance in exercising informed choice." This clause in the Act clarifies the duties of rehabilitation personnel, however it does not clearly indicate the limits of the "availability and scope of informed choice." These decisions will likely be made at the state and district level, therefore care must be taken so as to maximize the opportunity for ownership of decisions by individuals.

Factors which affect how customers make decisions

There is a family of factors which impact the decisions made by customers. The relationship between the customer and sources of information and advice will vary, depending upon the relative importance of each factor and the combined importance of how the factors work together to impact the customer and the outcomes.

Complexity

Complexity relates both to the issue under consideration and to its relationship with other issues. It also refers to a degree of anticipated or apparent difficulty that the customer is expected to have in understanding and addressing an issue. The more truly complex the issue, the more likely it is that the customer will feel the need professional/technical information and advice. It is important to consider the distinction of whether a decision is truly complex—one

that is beyond the ability of people to understand without a significant investment of time and effort—from one which can be made understandable by a reasonable degree of effort on the part of the informer or advisor to break the issue down into clear, accessible components. If the information can be offered in a form which is understood by the customer, the opinion of the advisor can be minimized. If the decision is truly complex, the opinion of one or more persons who are familiar with the issue is often necessary to assure informed choice.

It is likely that customers will make decisions regarding truly complex situations by relying more on professional opinion rather than on an understanding of the information about the issue. However, because of this dependence on professional opinion, there is an increased chance of professional “steering” of the customer. In order to assure ownership by the customer, information and advice offered on complex issues must be as free from bias and influence as possible. The use of a “second opinion” from a variety of sources can assist customers to deal with complex information. The need for additional supports rises as the complexity of the information to be considered increases.

Risk

Risk is a factor which relates to the impact or degree of harm to the customer —physical, emotional, monetary—that is a possible consequence of a decision. Risk and impact can also be felt by the counselor, service provider or others. Informing and advising issues here are similar to those described in complexity. The intervention related to reducing risk is a gatekeeping issue covered earlier in this paper. Rehabilitation personnel must first identify the party(ies) at risk. If the risk is to the customer, it is necessary to distinguish between risk related to personal harm or personal impact and the risk of losing money. Decisions which can bring physical or emotional harm and significant life impact to the customer, require intervention and support by the system. If the risk is primarily to staff, an agency or the system, the restrictions placed as a part of gatekeeping must be carefully examined. If a such a decision is not covered by the restrictions of the funding, we must allow the decision to be made.

Cost

The cost attached to a decision is one of the most traditional concerns of advisors in rehabilitation. The roles of gatekeeper and advisor are more likely to be confused and crossed on this factor than any other. Effective feedback in this area should focus on a clear analysis of the possible consequences of different levels of spending of the customers resources and on an effort to get value for the money spent.

Impact on others

Good advice and information helps customers see how their decisions will affect the lives of those who are important to the customer. This is an area in which clear information will probably weigh more heavily than the advisor’s opinion.

Reversibility

The degree to which a decision is reversible, will affect the manner in which advice is offered. For those decisions which can be re-directed or re-considered after problems occur, it is likely that information or options will be all that is desired by the customer.

However, for those decisions which seem to be less reversible, clear opinion might be needed from the advisor as to the best direction in which to proceed.

Bias/impartiality

One of the thorniest issues concerning information and advice is for the customer to deal with the degree of self-interest and bias on the part of system personnel. Virtually all information, opinion and options offered to customers will contain some bias, even on feedback based on what is presumed to be “factual” information. Since the traditional source of information and advice in rehabilitation has been from the counselor, the bias felt by customers was a result of the influence and policies of the rehabilitation system. The choice projects have responded to this by broadening the scope of sources of input to include the family, friends and independent advisors. The role of the counselor has been limited to providing and analyzing information and offering options, with the opinion aspect coming from those chosen by the customer.

There is an inherent conflict between advice and service delivery. The conflict occurs due to the significantly increased bias which arises from the self-interest of advisors who suggest that a customer buys their services. Some projects have implemented policies which constrain advisors from offering services.

In addition to the natural conflicts which often occur between individuals and systems, it is important to recognize the bias conflicts which occur among spouses, family members, friends and advocates. These biases are usually different from those of service providers (but not always) and usually seem to have the interests of the participant at heart. The opinions of those closest to the individual are also likely to be the hardest to reject, if the advice is not in line with the participant’s wishes. It is important for support personnel to become aware of those biases, to balance them by gathering information from differing viewpoints, to gather as much information as possible and to suggest a method to weigh the pros and cons of different viewpoints.

Variety of sources

An effective way to reduce bias in information and advice is to broaden the scope of those offering advice. It is common throughout the choice projects to urge customers to seek input from a variety of sources. Even though the downside of this approach may be to overload customers with conflicting information, the gains available from hearing a number of perspectives on an issue far outweighs any possible confusion. In fact, by viewing advice and information as coming from multi-sources rather than a single, system-provided source, it is possible to include counselors in the mix without violating the principle of impartiality. In those instances where there is significant conflict between the sources of advice, most projects advise customers to rely on sources which are closest to them and who know them best.

There is a reasonable expectation that the advice available to customers be effective to meet their needs and that it be as accurate or “true” as possible. The role of monitoring accuracy is complex. In fact, a new role for the traditional counselor may be to offer opinion to customers not on what to do, but rather, on which sources of advice and information seem the most accurate or useful. The finesse of this counselor role would be to assure that the principle of customer ownership of advice be upheld.

A way to manage this role is to assure that the customer has access to information from a variety of sources. However, when advice is sought from a variety of sources, particularly from non-professional sources such as family members and friends, there is likely to be a conflict between accuracy of information and the effectiveness of a suggestion. It is necessary to recognize this conflict as natural in many life dilemmas. Professionals often have viewpoints based on their experience and education which from which they apply facts and theories to the lives of customers. Family and friends often make suggestions based on their intimate knowledge of the life of the customer. A blending of Professional knowledge and personal perspective can provide customers with advice that is both accurate and effective to meet their needs.

Education

In a given advice relationship there is an array of interactions which might exist between the system and the customer. The endpoints of a triangular model might be thought of as information, opinion and options. The information area is often associated with an educational aspect of advice—teaching the customer to understand both the facts surrounding the decision and their responsibilities in the process of decision-making. A number of the choice projects have implemented formal and informal opportunities for customers to receive training in dealing with advice.

Experience

Possibly the most common strategy used throughout the choice projects is to place customers in the position of receiving advice and to urge them, to allow them and to support them to make decisions. Various, these decisions will result in success and they will result in problems. The repetitive experience of behaving as a person in control of one's life and responsible for making the decisions which affect that life is the most universally accepted approach to the issue of advice in the choice demonstrations.

Strategies Used by Various Projects to Deal with Advice

Arkansas Rehabilitation Services

This project uses Consumer Connectors, who are private vendors paid through the project, to offer advice to customers. The connectors facilitate the project's person-driven career planning process and assure that the customer's voice is heard throughout their entire effort to become employed. This project also encourages customers to involve parents, friends and other trusted persons to assist with advice and offers empowerment training to all customers.

Berkeley Center for Independent Living

This project trains service counselors to act as resource clearinghouses for customers. All of the sources of information in the national and local community—calendars, newspapers, brochures, junk mail, resource directories, etc.—are collected and offered as input. Counselors

urge customers to take control of all aspects of decision-making and will offer advice only if asked. Generic sources of advice are encouraged over system sources: consumer reports, Better Business Bureau, personal opinions of other customers, site visits etc. Empowerment seminars are offered twice a month to support decision-making by customers.

The Development Team

This project prefers to use information, rather than advice, as a category of service. This multi-site project uses a variety of processes for enhancing information with group dialog with peers as the centerpiece. All customers attend weekly meetings where they belong to a peer group of approximately twelve persons with whom they develop relationships and share responsibility for decision-making. Detailed manuals are available to customers which contain information, along with that provided by guest presenters and business volunteers. Project facilitators are not formally expected to offer advice but they may be called on voluntarily by customers for input and perspective. The project also uses self-assessment interviews as a technique to determine whether someone will join the group. The interviewer offers advice to the customer based on the results of the interaction. Customers may purchase advice from outside sources if they feel that they want that perspective.

Southwest Business, Industry and Rehabilitation Association

The case managers in this project provide an array of options throughout the customer's journey toward employment. The case manager further offers various options and their impact and encourages the customer to choose the one that best suits the individual. Customers are informed during the intake process as to who will be available to provide advice and who has the authority to make and approve decisions.

United Cerebral Palsy Associations Choice Access Project

This project primarily recommends that customers use an independent Employment Advisor who is paid by the customer on a retainer basis. Employment advisors are recruited by the project for a pool of advisors held by each site. Advisors may also be identified by the customer from family, friends and advocates in the community. In order to qualify as an employment advisor, the individual must agree to attend at least one free training offered through the project and not to offer service provision to that customer. The role of the employment advisor is conceptually based on a cross between a generic financial advisor and a personal assistant, typically used by persons with physical disabilities. Customers are also urged to broaden sources of advice by seeking out the perspective of family, friends, community advocates and business people.

Vermont Division of Vocational Rehabilitation

This project encourages customers to seek advice from a array of natural sources. Since this project is a choice-focused replication of the state's Vocational Rehabilitation I 10 program,

counselors interact with customers and may offer advice from their perspective. However, the emphasis is for customers to make their own decisions. The counselor's role is to determine how to assist the customer to get effective and accurate advice and to own the responsibility to make decisions. Counselors also teach customers to be accountable and responsible for their decisions.

Washington State Vocational Rehabilitation PEP Project

PEP also encourages customers to seek advice from a variety of sources. However, the project's central strategy for advice involves the use of a Rehabilitation Team which is developed by and available to the customer to assist with the advice needed to make decisions. This team removes decision-making and advice from the traditional counselor-centered perspective by welcoming input from an array of individually-determined sources. Regular classes are offered to customers on topics which span the gamut of employment issues, including advice. Customers work with both natural and professional supporters to help them identify what information and opinion is needed and where that information can be found.

