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

TECHNICAL ASSISTANCE CIRCULAR

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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 judgements 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.

<u>Determining the individual's skill and ability to implement informed choice.</u>

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 judgement 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.

<u>Improving the skills needed by the individual to implement informed</u> 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: <u>Choice Demonstration Projects</u>:

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 \boldsymbol{X}