

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

A paper by: Michael Callahan

*Marc Gold and Associates
1147 Robinson Street
Ocean Springs, MS 39564
(228) 205-4586
Fax (228) 205-4597*

With assistance from:

*Abby Cooper, Washington PEP Project
Terry Herkimer, Berkeley Independent Living Center
Nancy Sullivan & Sterling Hughes, Arkansas Rehabilitation Services
Harry Hall, The Development Team
Michael Collins, Vermont Div. of Rehabilitation*

Prepared for:

*Suzanne Tillman Rehabilitation Services Administration
U.S. Department of Education Grant # H235D30067
July, 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 its 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 that 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(IEP) 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 on the customer's 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 buy 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 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 Assn.

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 110 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.