

*Personal Reflections on*

**Consumer Involvement on  
Advisory Boards and Councils:  
An Issue of  
Uncommon Common Sense**

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**Introduction**

Consumer involvement in terms of people taking responsibility for their own lives is a basic theme of the American experience. However, for some Americans the experience of self-responsibility and control has been lost, often to the agencies and organizations that were developed to serve them. In the field of rehabilitation, over the past decades there has been a concerted effort to restore and gain the opportunity for self-determination and control to the individual. Consumer involvement and opportunity for substantial input have become major factors in rehabilitation planning and services. Although by no means universal or complete, there is a wind of change moving in this direction.

Who is a "consumer"? In this paper, "a consumer" is anyone with a disability or who is the parent or guardian of such a person. Some writers define the term more narrowly to mean only those who are currently receiving rehabilitation services, and exclude those with disabilities who may be providers of services (e.g., the counselor with a disability). This paper focuses on the role of consumers (i.e., persons with disabilities and their families or guardians) in positions of responsibility and leadership on rehabilitation advisory boards or councils. How this situation came about, what their responsibilities are, strategies for effective participation, and barriers to this will be considered. The terms "boards" or "councils" are used interchangeably.

The author, who has had a disability since 1955, is drawing on experience over the past 30 years with community, state, and national rehabilitation boards of directors and advisory councils, including 13 years with a State rehabilitation agency (11 years as Council Chair), 18 years with a research and training center, and 5 years with a center for independent living. During this time he also worked as a practicing rehabilitation psychologist, a State rehabilitation agency program director, and a rehabilitation counselor educator.

**History and Legislation**

As a result of the social activism and civil rights movements of the 1960s, a steady succession of attitudinal and legislated changes occurred that led away from the traditional authoritarian medical and casework models and toward the

direction of consumer involvement and empowerment. The Rehabilitation Act of 1973 formally recognized this by mandating the Individualized Written Rehabilitation Program (IWRP) as the basic contract between the individual and the representative of the agency serving him or her. However, it took several more years before the Individualized Written Rehabilitation Program was fully accepted by many rehabilitation counselors. This agreement was designed to be developed jointly by both parties and signed by the person with the disability.

Following the leadership of consumers and Centers for Independent Living (CIL), the 1978 Rehabilitation Act Amendments (P.L.95-602) recognized the growing influence of consumers in determining their own life course by mandating the participation and employment of consumers in Centers for Independent Living. At least 51 percent of the members of the Boards of Directors of CILs are required to have disabilities.

The 1986 Rehabilitation Act Amendments increased the role of the consumers in several ways by including the consumers' statements of their rehabilitation goals in the IWRP and requiring that these be reviewed annually by consumers or their guardians. The 1990 Americans with Disabilities Act (ADA) (P.L.101-336) brought together many of the trends for consumer rights and responsibilities in the areas of employment, transportation, public services, and public accommodations. The 1992 Amendments to the Rehabilitation Act supported this and called for ". . . full inclusion and integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities" (Botterbusch & Menz, 1993, p. 1).

The role of consumers in decision making and advisory capacities on agency boards and councils is one positive outcome of the movement towards consumer involvement. Research and Training Centers funded after 1993 by the National Institute on Disability and Rehabilitation Research (NIDRR) require their Advisory Councils to have consumer representation. As noted earlier, Centers for Independent Living were among the first to require substantial consumer control on their boards and staffs. The 1992 and 1993 Amendments increased the power of the State Independent Living Councils (SILCs) by making them responsible for developing the State's independent Living Plan in conjunction with the state rehabilitation agency, or "Designated State Unit" (DSU). The signatures of both the State Independent Living Council's Chair and the State Agency Director must be on the Plan. This planning and veto power gives substantial control over a rehabilitation service area to a consumer-controlled Council (Weber, 1994).

For many years some State rehabilitation agencies have also required that a majority of the members and their chairpersons have disabilities (e.g., Illinois since 1978). However, the 1992 Amendments (Section 105) require that all State Rehabilitation Agencies have specific groups, including specific disability groups, represented on their State Rehabilitation Advisory Council (SRAC).

The composition of the State Rehabilitation Advisory Council reflects the various stakeholders in the rehabilitation process. Members include representatives from independent living programs including the chair of the State Independent Living Council; parent training and information groups; disability and advocacy groups; parents and guardians; and individuals with physical, cognitive, sensory, and/or mental disabilities. Representatives of community rehabilitation programs, businesses, industry, and labor; rehabilitation counselors; and client assistance workers are also included. These representatives function as equals on the Board and their influence is based on their effective functioning as members.

Some states have gone beyond the requirement for participation of consumers on the rehabilitation agency council and have mandated that persons with disabilities and their families be represented on the boards and councils of all state human service agencies serving persons with disabilities or their families. State officials believe that these persons should participate in the decision-making process and add their perspective to issues and services that affect them. Illinois, for example, since September, 1992 (Act 4007), has legislated that "persons with one or more disabilities and their families" be included in the "membership of every State human service agency's advisory boards" or similar committee that provides service or support for persons with disabilities. This includes "local community based agency's governing boards" that receive funds from state human service agencies. It also includes legislative commissions or boards concerning persons with disabilities and those who set up standards or eligibility criteria for such persons.

Thus there has been a steady movement towards increasing consumer responsibility and involvement in their own rehabilitation. It has moved beyond the individual focus and now includes involvement in the decision making and policy setting level of programs and services that affect the lives of persons with disabilities. This includes programs and agencies on local, regional, state, and federal levels.

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## Roles and Responsibilities

### Consumer's Role

In light of this opportunity for participation on advisory and policy setting bodies, what is the role of the consumer? How can she or he participate most effectively?

First, beware the role of "token." The current legislation is serious in its mandate for full and effective participation of consumers in an advisory and policy-setting capacity. Tokenism is not what this movement is about. Advice from these individuals and their constituencies is relevant and significant, and it is the responsibility of consumers and other members of these boards and councils to ensure that their input is seriously considered.

A consumer's input to an advisory body has special value in that it is based on personal experience and brings a unique perspective. The consumer has lived with disability in the real world and has insights not available to someone who has not had that experience. An individual who has personally experienced an authoritarian and judgmental professional worker, who has met the subtle devaluation of negative attitudes, or who has watched a family member have similar experiences, provides essential and realistic information not easily gathered otherwise. Likewise, sharing the positive impact of dealing with a sensitive and committed worker may provide insight into ways to replicate success. Personal experience provides a valuable human dimension and gives the consumer's perceptions validity.

While it is important for personal experiences to be shared when relevant to issues of concern to a board or council, the consumer should exercise caution in this sharing so that the comments remain relevant. In the shady area where insightful critical comments can overlap with personal complaints, insights can lose their strength.

It is helpful when generalizations can be made from a personal observation, but an attack on a specific worker or a personal gripe provides little value. For example, members who talk at length about discrimination in their work place, or who personalize the experience too greatly, may jeopardize the value of their observation. In addition, the consumer who focuses on personal concerns may lose credibility when commenting on more substantive issues.

It is also important to note that there is great diversity among consumers. Different disabilities, life experiences, and cultural backgrounds create varying perspectives. Individuals with recently acquired disabilities may perceive things differently from those who have long-term, or life-long, disabilities. Age, gender, and racial differences influence perspectives. Experience with the rehabilitation process and the agencies that provide services may be highly different, both quantitatively and qualitatively. Thus, there is no one consumer viewpoint; each consumer's perception is different.

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Consumers usually serve on boards in one of two capacities, either as an individual with a disability or family member or as a representative of a particular group or constituency. Current legislation calls for both roles. The 1992 Amendments required that specific groups be represented (e.g., Statewide Independent Living Councils) and certain broad areas of

disability (e.g., physical, cognitive). Within these parameters, individuals are selected as council representatives by the agency requiring the council or board or by appointment of the governor. Selection of representatives of specific disability groups can be made by constituency peer nomination or by solicitation or recruitment by the agency.

Sources of prospective consumers who will be effective in board positions usually include the various consumer groups representing specific disabilities. These groups provide leadership training opportunities through their organizational activities, and members are generally knowledgeable about issues important to consumers. Listings of these groups can be found through the state rehabilitation agencies. Other candidates include individuals with disabilities who are active in community affairs, in positions of responsibility, or in rehabilitation-related organizations. While previous experience on boards is helpful, some effort should be made to broaden the base of consumer representatives in order to get input from a variety of perspectives. Otherwise the same persons tend to serve on many boards.

The actions of the members may differ depending on whether they are representing themselves or a constituency. For example, an individual representing a disability group may have an agenda of concerns to put forth that have grown out of the collective experience of individuals with that disability. Some disability groups are politically experienced and have developed a clear and

specific direction that facilitates action by their representatives. If, on the other hand, the members were representing only themselves, their participation may be more personal and less focused.

Specific skills desirable in a board member include the ability to communicate with the other members and to express ideas and concerns. An ability to express ideas, to frame useful questions, and to effectively present alternate arguments and positions are important responsibilities of the effective member. Some disabling conditions, however, present barriers to communication. In these situations, the use of interpreters, hearing aids, communication boards or computers, and brailled or large print materials are appropriate and can be especially effective in increasing disability awareness.

The role of the chair and other members is critical in recognizing the communication needs of all persons and in ensuring sufficient time for them to fully present their ideas, even if using a time-consuming communication system. Often people who serve on boards and councils have positive socialization skills; these skills are also important for consumers to informally communicate and to develop relationships between members. Members should be knowledgeable about the issues confronting the council, be able to articulate their perspective in a useful way, and have the self-confidence to speak up.

Because on some boards much of the work is done by committees, member roles gain importance by the way they function on committees. Additional skills are needed for successful committee work. A willingness to expend time and effort, to write or plan, to participate in small group discussions, and to work between meetings on projects or ideas are all important to effective committee participation and influence. If a committee's work focuses on a specific task that is relevant to a consumer member's real world experience, the consumer can provide valuable and unique input.

Consumers also make credible spokespersons for a council or board, especially on matters related to their disability. If a council is asked for its advice by the legislature, for example, or if the council seeks to provide input on prospective legislation related to its responsibility, a consumer's testimony may have added impact because of the authority of his or her disability.

An important point to remember is that consumers on boards do not only represent consumer issues but participate in discussions of all aspects of organization operation. Thus, they give input on issues or from perspectives not related to their disability as part of their own responsibility. They are expected

to function as full members of the board, not only from the limited perspective of their disability. Consumers on boards are usually selected for their expertise in matters related to the board's responsibilities; their disability simply enriches their role. For example, an attorney with a disability on the board of a center for independent living can provide valuable input from both legal and disability perspectives. Similarly, a social worker or counselor with a disability can add valuable expertise to a community-based rehabilitation program's advisory functioning.

The reason why one is selected to serve on a board can be important to the individual. To be selected for one's expertise in a specific area, such as research, accounting, computer, design, or legal skills, may feel better than to be selected primarily on the basis of having a particular disability. In actual practice, however, effective functioning on the board requires using all relevant experience.

Before joining a board, prospective members need to investigate the board to be sure they can support the board and its role. Do they agree with the role of the agency? Is the board truly advisory, or does it function as a rubber stamp? What can they give to the board, and what can the experience do for them? How can they help improve the services of the agency by serving on the board? Other questions may be raised by the member. Once the decision is made to join the board, members may develop a keen interest and loyalty to the agency.

### **Role of Council/Board Chair in Facilitation**

Persons chairing the board or council have many responsibilities, depending on the rules and purposes of the specific council. These responsibilities usually include setting the agenda for the meetings, conducting the meetings, and leading discussions. They usually communicate extensively with the management of the organization that the council is advising, both in regard to the meetings of the council and about other matters of concern about the agency. They try to ensure that all matters of concern come before the council.

Chairpersons play a critical role in ensuring that consumers become effective participants in the proceedings of advisory bodies. In conducting meetings, they provide the model for including all members in the board's functioning and the opportunity for full participation of all members. By their behavior, they can encourage or discourage the positive participation of members. If they are flexible and accepting people, as many chairpersons are, they can set a positive tone for the inclusion of each member. However, if they are uneasy or

uncomfortable with dealing with a person with a disability, and this is communicated to that person and to other members, consumer effectiveness will be decreased. Thus, it is important that chairpersons be aware of their own feelings regarding consumers.

It is important also that they be aware of the specific needs of each consumer and facilitate their participation. A member who is visually impaired, for example, can be excluded from participating if minutes to previous meetings are handed out for review in print form and not read aloud. Chairpersons with disabilities must be equally sensitive to these matters; having a disability does not automatically mean that a person is sensitive to the needs of other people with disabilities.

In supporting meaningful discussions of the board, chairpersons must exercise some control of the process. While they must be able to facilitate the participation of the reticent person, they must also be able to manage the dominating behavior of another. Their responses should be similar to consumers and non-consumers alike.

The role and responsibilities of the chairperson may vary to some degree depending on the specific council. However, the chairperson's leadership is a significant element in the degree and quality of a consumer's participation in the decision-making and creative advisement functions of a council.

In addition to the chairperson, it is clear that council members also have responsibilities for aiding in the effective functioning of the board and in ensuring inclusion and participation of all members. This includes being aware of their own feelings of comfort in interacting with consumers and treating all members with the same degree of respect.

### **Role of Council/Board Coordinator**

Most agencies have a staff member who is responsible for coordinating the functions of the council. This person ensures the availability of appropriate resources such as meeting accommodations, audiovisual technology, printed materials, refreshments at breaks, copying/fax resources, overnight lodging if required, vouchering for expenses. This person is important for the council's smooth functioning and is especially critical in meeting consumer's needs.

## Agency's/Director's Attitude

The attitude of the agency, and especially its director, is critical to the effective functioning of an advisory body. Some organizations perceive mandated advisory boards as threats, which might interfere with their specific agenda or programs. Others see them as a necessary nuisance. Their response to such a board will be quite different from that of an agency that sees its board as a helpful resource of knowledgeable people who can help solve problems and point toward positive directions. The degree of openness and respect of the agency and its director towards the board determines to a great degree the effectiveness of the board's functioning and its potential impact. "An advisory council is only as effective as the agency director allows it to be" (Wilson, 1995).

Agencies that present issues "after the fact" (i.e., after having formulated a policy and in essence ask for ratification) create the impression that they do not value the input from the council. Input from the council should be sought during the formative stages of policy development and the design of new programs.

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The director's response to input from council members is also critical to the issue of consumer involvement. If they respond differently to input from professionals than from consumers, even subtly, this message is communicated. As one consumer member noted, "agency directors should express their appreciation to the advisory board for their time, their attendance, their

input all on a volunteer basis, and not convey the impression that they have done the advisors a great privilege by merely showing up at the meeting" (Wilson, 1995). In fact, by positively stating the benefits gained from member input and affirming the value of this input at some point during the meeting, the director can be a valuable motivating force for effective board functioning.

## Accessibility of Meetings and Related Functions

Some of the basic considerations are that the meeting be held in an accessible place that meets ADA standards. Meeting sites should be wheelchair accessible, which includes wash rooms and eating areas if a meal is involved. Braille signage and other guides to travel for persons who are blind should be in place. When facilities are being used for the first time, their staff may state they are accessible over the telephone, but sometimes they are found not to be accessible

at the time of the meeting. Whenever possible, planners should visit a new meeting place and make an on-site accessibility inspection.

Informal meeting spots used during breaks should also be accessible to allow for full participation. If social hours or receptions are involved, it is especially important that accommodations be made for full participation by all members since often important contacts and discussions occur during these events. If overnight accommodations are required, rooms should be accessible to mobility-limited persons and should offer accommodations for persons who are blind and deaf. Care should be taken that on overnight stays members are not stranded in their hotel rooms, particularly those with visual impairments who have not had an opportunity to familiarize themselves with their surroundings (e.g., getting to restaurants, meetings, washrooms).

An example of an embarrassing slip-up occurred at an important national meeting when a social hour was held that included the main speaker, a national rehabilitation figure, who happened to be deaf. The interpreters left since they were hired only for the meeting so the guest of honor had to rely on limited lip-reading skills that resulted in limited interaction with those present. While he was understanding, his communication and networking were severely curtailed, and those who wanted to talk with him were disappointed.

Agencies should be aware of the extraordinary effort, preplanning, the fatigue, the stress and often the non-reimbursable expense, that a person with a severe disability, sometimes requiring a personal assistant, endures in order to attend a meeting. It's not as simple as making a phone call, hopping a cab, or boarding a plane. (Wilson, 1995)

During the meetings, a number of simple accommodations and technical aids can be made available to increase consumer participation. Smoking can be a severe irritant for those with breathing difficulties. Tables should allow wheel chairs to fit under them so that users do not bump their knees and spaced so that they can be approached. Although not all persons who are blind read braille, brailled materials can be prepared ahead of time from written copy. Cassette recordings of materials are more convenient for some. Readers can be helpful here. Interpreters should be provided for persons who are deaf, and seating should enable them to be easily seen.

For the hard of hearing, a microphone transmitter can be centrally located and the person can wear an ear phone receiver or "assistive listening device." Some

areas can be equipped with an enclosing wire loop, and ear receivers can pick up anything said within the loop. Ear receivers actually provide an advantage, as at a recent meeting when a consumer was able to go to a nearby washroom and return without missing a word on his ear phone. However, at the same meeting another consumer wore a microphone because of low voice volume, and the ear phones did not pick up anything said on the microphone.

### **Board/Council Functions or Tasks**

Once the board or council is in place, how does the organization effectively use the expertise of the members to greatest benefit? The mandate of the board by its enabling legislation determines its responsibilities. Within its mandate, boards have considerable flexibility as to how they function and what tasks they undertake.

For example, the State Rehabilitation Advisory Council's (SRAC) functions, as defined in the 1992 Amendments (Section 105 [c]), include reviewing, analyzing, and advising the State unit regarding performance; advising and assisting in the preparation of documents; assessing consumer satisfaction with services; preparing and submitting an annual report to the Governor or Commissioner; advising and coordinating with other councils within the State, including the Statewide Independent Living Council; and performing other such functions as the State Rehabilitation Advisory Council determines to be appropriate and consistent. How the State Rehabilitation Advisory Council goes about fulfilling these responsibilities is up to each council. Other councils may have similar but less defined functions.

One common activity at council meetings is for an agency to explain its activities by making presentations. Sometimes this takes the form of the staff person responsible for a program's activities making an oral report. Other times it becomes part of the agency director's report to the council. While it may be most effective if a person near the front line of the activity makes the report, this can become time-consuming. A caution regarding this activity is it can become a "Dog and Pony Show" and can take up time which the council might have used more efficiently for discussion. A full agenda of this type of activity may signify an agency that is not comfortable with its advisory council having too much free time for discussion. Alternatively, the agency may not know how to best make use of its council.

One of the most useful activities for a council is to have open discussion on specific topics of interest to the agency. The discussion may be broad and far

ranging but should represent the experience of the members on the discussion topic. The quality of the council and the positive facilitating skills of the chair or discussion leader are important factors. Careful note taking should occur during these discussions, either by a secretary or by an agency representative who gleans the important points from what is being said. The agency director can be important in validating the quality and usefulness of the discussions and ideas presented. For example, one of the most useful and effective councils the author has served on is regularly commended by the agency director for providing useful input; this is then documented by his summary comments during the meeting and is reflected later in the implementation of the ideas in the activities of the agency.

Council responsibilities are often carried out between meetings within a committee structure. Some committees are required of the council by-laws, while others are ad hoc in nature and formed around a specific task or topic. Committees allow for individual input because of their small size, and some consumers can be especially effective at this level. Members should look closely at the committees and decide where they can make their most relevant contributions.

Another way to effectively use council members is to assign, or have them choose, specific areas or programs within the agency about which they are responsible for becoming knowledgeable. This gives them a specific area of interest, gets them involved between meetings, and sensitizes them to the needs of that area of the agency. At council meetings they then become a resource for discussions about their area of responsibility. With consumer members, it also sensitizes the various staff to their needs and concerns. A more subtle benefit is that placing a consumer in a visible leadership position reinforces the more positive image of persons with disabilities in society.

Following are two examples from the author's experience that illustrate how councils can perform useful projects or tasks for an agency through their advisory function. The first involved the advisory council structure of a state agency that the agency director considered too involved and cumbersome. The advisory council was given the somewhat delicate task of recommending a revised structure that combined and/or deleted some of the 18 advisory groups. The agency provided staff support for the project. Meetings were held to come up with alternative models; these models were presented at a statewide meeting of stakeholders and consumers, most of whom represented the various councils. A "hybrid" model was suggested at that meeting, and finally a model was presented to the director that both streamlined the structure and met legislative

mandates.

The second example illustrates a more extensive use of an advisory council and grew out of needs expressed by state agency rehabilitation counselors. Counselors were having difficulty effectively working with individuals who represented three groups with severe disabilities: severe cerebral palsy, traumatic brain injury, and quadriplegia. The agency director requested that the advisory council study effective ways to serve these groups and provided staff support and funding. The council developed a project that used three approaches. First, a request was sent out to other states' rehabilitation agencies asking what specifically they were doing to serve these populations. Second, the services of a state university were sought to perform a literature review of what was written about effective programs and approaches with individuals with these disabilities.

Third, the State Consumer Advisory Council was asked to conduct a consumer satisfaction survey by telephone of individuals with these disabilities who had received services from the agency during the past four years. A university researcher devised the telephone interview format. After being trained on the format, consumers on the council interviewed recipients in their local area. It was believed that service recipients might be more open to consumers in such an interview than they would be to professional rehabilitation workers. Thus consumer members of two different advisory councils participated in this study. (An interesting outcome of this survey was that service recipients' responses were positive to the services, whether or not the recipients were successfully rehabilitated, if they perceived that they had been treated with respect by people at the rehabilitation office and if they thought that their counselor had sincerely tried to help them.)

Advisory council members can also help with grant applications prepared by the agency. Letters of support and consulting with the grant application committees to help design the project are the two most common. Many government grants now require consumer advice and support, and council members provide a knowledgeable and legitimate resource to fill this requirement.

### **Board Effectiveness and Training**

Prospective board members come to the experience with different levels and areas of expertise; this is especially true for consumers. They may have extensive life experience in the area related to their board responsibilities but may not have experience in how to be an effective board member. Thus, training needs differ for prospective board members. Most members, however, will need

training related to the functioning and activities of the specific board on which they will serve.

Some members may also benefit from training of a psychosocial nature, such as developing assertiveness, mediation skills, or leadership skills. Psychosocial training is most appropriate for consumer members who have limited experience in leadership roles. This training is most appropriately provided before board membership is undertaken and might be provided through a rehabilitation program, an independent living center, or through a consumer organization. Skills in consensus building and compromise are also important. Being able to reach consensus without compromising one's value system can be difficult but is basic to working effectively on a council.

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Some agencies select consumers to serve on their agency improvement teams or projects and provide training for this leadership activity. Stukey (1994) describes consumer training that focuses on team building and problem solving for two days and focuses on self-advocacy skills for eight months. To

reinforce team building, trainees use problem-solving skills identified among Total Quality Management (TQM) techniques. Problem-solving exercises address self-improvement and situations consumers might face. Basic to the process of using these skills, however, is the individual's ability to be a self-advocate and assertive. The leadership skills they acquire through the training generalize to other situations and responsibilities and can aid candidates for advisory council roles.

In seeking to discover how to enhance the effectiveness of boards of directors and to provide appropriate training for board members, Smith and Richards (1987) studied boards of directors that worked with Centers for Independent Living. They consulted with 72 executive directors to devise practical information on how to enhance the effectiveness of boards. Centers for Independent Living require that 51 percent of their board members have disabilities or represent people with disabilities.

Simply stated, it is obvious from our studies of well-run independent living centers, as well as from formal documentation of other nonprofit organizations, that an effectively functioning board of directors is a major - perhaps the most crucial - key to center success. It is equally obvious that ineffective boards are

the major cause of center failure, as well as the major cause of turnover among executive directors and of executive directors being old before their time. (Smith & Richards, 1987, p.1)

They defined six important characteristics of effective boards. These include:

1. Members who understand key issues and are willing to take stands on significant issues;
2. Members with time to devote to organizational efforts;
3. Strong leadership;
4. A broad mix of persons with disabilities representing different constituencies;
5. Influential persons in the community and those who are knowledgeable about finance, law, management and social policy issues;
6. Planned training activities to maintain board skills and effectiveness. (Smith & Richards, 1987, p. 2)

Board and staff relationships are also important and critical. Differentiating between ongoing day-to-day operations and policy making is a key element. Involvement in policy making is appropriate for the board; involvement in day-to-day operations is not.

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Training for board members is important to enhance their functioning. For training to be effective, it should be something the board itself desires. Members should be a part of the process of selecting the type of training, what content to include, and be willing participants in the process. The

training should be relevant to the mission of the organization and the role of the board within it. Thus, what gets included in board training will vary from one organization to another. There is no one training model that fits all boards, although there are areas common to most.

An example from Smith and Richards (1987) that describes training for boards

of independent living centers includes the following areas:

1. The philosophy of the independent living movement and what that means to activities conducted by the center;
2. Legal responsibilities of board members, i.e., filing of tax documents, . . . assuring liability coverage, etc.;
3. Ethical considerations, i.e., what things a board member might do that would be considered legal but unethical, such as discussing personnel salaries with other people;
4. Specific board responsibilities, i.e., fund raising techniques, advocacy activities, etc.;
5. The role of the board member as compared with the role of the staff;
6. Center specifics, i.e., what kinds of services the center provides, . . . how quality is assessed, how the board can keep current. (pp. 8-9)

Training should be tailor-made for the needs of each board, based on the individual needs of its members. This can be assessed by the board chair and the executive director. The board by-laws provide the direction for training and point out missions as well as the operational guidelines and the powers of the board. Some boards may report to the organization they are advising or directing; others may report to a higher body, such as a state legislature or governor. These responsibilities and authorities are important for members to keep in mind as they fulfill their roles.

Smith and Richards (1987) point out that quality and practical resources for board or council training are available. These include consultants, packaged training programs, college or university courses, other community service agencies, and national and regional organizations. The latter include the state rehabilitation services agency, the Regional Rehabilitation Continuing Education Program, and the Research and Training Centers. Benefits can also be gained by members from serving on the boards of other community or similar level boards or councils. Seeing how other councils operate, and getting experience functioning on other boards in similar roles, can be a highly effective training tool - so long as it does not overextend the board member.

## Practical Considerations

These practical considerations involving interacting with people with disabilities may seem obvious to those with experience in such interactions. Though many people who serve on boards do have disabilities, simply having a disability does not mean a person is sensitive to the unique needs of other disabilities.

In their book on business and social etiquette with people with disabilities, Maloff and Wood (1988) point out the importance of common sense in such interpersonal dealings. The usual rules governing interactions between people apply when dealing with someone with a disability, with some additional factors to keep in mind. In offering help to a person with a mobility limitation, for example, the usual rule is to ask if the person would like help and not be offended if the assistance is declined. Some hesitate to offer assistance, such as opening a door, which they would automatically offer to someone without a disability, because they are uncertain whether it would be accepted. The optimum situation is to get to know the person as an individual and to be aware of his or her personal preferences and needs.

Each person needs unique considerations. For example, in helping a person onto an elevator, see if he or she needs help pushing the button or he/she may be stranded there. Get a group of consumers talking about their experiences with well-meaning helpers and stories abound — being pushed off curbs in their wheelchairs, being pushed into the ankles of people walking ahead of them, having their arms grabbed while they are balancing on their crutches, or a person who is blind being hustled across a street they had not intended to cross. In most cases, however, assistance is helpful and appreciated.

Guidelines for interacting with people with disabilities, as in Chicago's handbook on disability etiquette (McGuire, 1990), generally include to treat adults as adults and use first names only when others are addressed the same way; shake hands when meeting, even if the person has limited arm movement or a prosthesis; in talking with a person in a wheelchair for more than a few minutes, sit at his or her eye level; talk directly to the person with a disability, not to his or her companion; offer your arm to persons with visual impairments, do not grab theirs and steer them along; when greeting persons with severe visual loss, identify yourself and persons who are with you.

With persons with a hearing impairment, speak clearly and naturally if they can read lips, keep your hands away from your mouth and do not shout. Even if an interpreter is present, talk directly to the person who is deaf. With persons with

a speech impairment, listen attentively in an encouraging manner; exercise patience. Let them finish their sentences, do not pretend you understand when you do not, and ask questions if you cannot understand. With persons with cognitive disabilities, talk in short simple sentences, maintain eye contact, and interact on an adult-to-adult basis. These suggestions are clearly not all-inclusive, and individual preferences will differ.

Language issues are also important and complex since language affects attitudes. Use the term "person with a disability" rather than "disabled person" since it focuses on the person, who happens to have a disability, rather than implying that the whole person is "disabled"—a subtle but significant difference. The term "handicap" applies not to the person but to limitations imposed by the environment, such as a set of stairs impeding a wheelchair user or lack of braille signage on an elevator; the person is inconvenienced, the environment is handicapping.

Do not describe a person, or group, by a disability, (e.g., "those C.P.'s" or "she's a polio"). Rather say "she has polio" or "they have cerebral palsy." Use of pitying terms, or superlatives, are not appropriate as people with disabilities generally do not consider themselves "victims" or "inspirational"; they are just people. Wheelchairs are not confining, they are liberating.

Specific disability groups have preferences about language. For example, persons who are short statured object to "midget or dwarf"; persons with epilepsy object to "epileptic"; persons with cognitive or developmental disabilities object to "retarded." The safest procedure is to ask someone with a disability what term he or she prefers.

### **Member Interactive Styles**

The individual member's interactive and communication styles can have a significant influence on how his/her input is accepted by other members of a council. Consumers, for example, may use different language and not be familiar with the jargon that experienced council members may use. Some consumers may express more feelings and passion in their statements than members of councils are used to hearing or are comfortable with. They may let their feelings show and become insistent. The other members may want them to conform to a less emotional approach.

The level of emotion behind a statement, however, may be fueled by personal experience and may be related to a strongly felt need. Consumers may have

experienced some gross inequity related to the topic at hand and it may have far more importance to them than to other members of the council who do not share their experiences. It is precisely here that the other members need to listen most closely to understand the issue being communicated and not be turned off by the emotion.

*Some consumers may express more feelings and passion in their statements than members of councils are used to hearing or are comfortable with.*

An example occurred at a recent meeting when a consumer and an experienced professional interacted on an issue during a meeting. The professional was very reasoned and cool, whereas the consumer expressed some emotion. The professional made her point and then agreed that whatever the group wanted was okay with

her; she responded in the accepted diplomatic way. The consumer, on the other hand, felt strongly about the topic, and pushed the issue; "let's get going on this." Some members commented later they were uncomfortable with the emotion and the insistence. The consumer felt justified in her stance because she had personal experience with the issue, whereas the professional did not. This is one area where the council chair can be helpful in making sure the issues are clarified and recognized, and other members need to listen to the issue and not to the way it is presented.

The council chair can also help balance the degree of emotion and watch for signs that a member may be coming too involved or using emotion as a weapon to intimidate rather than rationally discuss. The council chair can be helpful in educating members as to the most effective ways to present arguments so that they can be understood and will receive objective consideration.

One detrimental outcome that can happen when members present issues and interact in ways different from other members or are perceived as being different is that those persons can be devalued and their input downplayed. They may not be accepted as equals and may experience subtle put-downs that discourage their participation. Clues that this is happening with members include raised eyebrows, looking up at the ceiling, talking to one's neighbor, interrupting, changing the subject as soon as the person finishes speaking, or ignoring or misinterpreting or downplaying the person's point. This may have the effect of reducing the member's participation. While this may make other members more comfortable, it restricts access to that person's unique perceptions and insights not represented by any other member.

When members are devalued, even subtly, they may seek support from other members with whom they identify. Thus, one consumer may seek the support of another, and the possibility of a "we-they" split on the council may develop. This can be divisive to the operations of the council and damaging to the larger agency which the council serves. This split may not be limited to being between consumers and nonconsumers. Sometimes splits and differences between persons with different disabilities can develop. If one group believes their viewpoint is being disregarded or their members are devalued, serious problems can develop in the effective functioning of the council. The council's credibility to the groups it represents can be damaged.

Social hours and breaks during meetings can provide clues as to how the members of a board are interacting. With some boards, consumers and non-consumers tend to congregate and socialize in separate groups. Boards with a number of consumers may also find that members with a specific disability may gravitate together on one committee. This may limit their overall contribution to the board, and form division within the board, and should be discouraged. While these are not necessarily signs of problems, they suggest that some effort needs to be made to bring the members together on a more personal basis to enhance their ability to communicate openly on issues of importance.

There are actions that consumers can do to become more effective as council members. Initially it is important to form positive cooperative relationships with other members of the council. To start this process, when a person with a disability meets another council member, it is important to talk about subjects they have in common; talk about similarities, the way they are the same, rather than how they differ. After they have established the initial similarity, then talk about differences that may be due to their unique disabilities. It is important that they begin the relationship feeling as equals and to project this perception to the other members.

Assertiveness skills are also important in that they enable consumers to speak up and get their points across. At the same time, it is important that they not dominate meetings or take up too much time. Sometimes persons who do not have a disability "allow" this to occur for fear of "offending" the person with the disability who may be dominating the meeting. This is actually patronizing and counter productive; assertiveness skills training would be helpful for all members to deal with such situations.

A useful method to get one's point across is to use a short statement supported by a personal example. Personal examples are most useful if they relate to a

significant issue rather than if they stand alone. Perhaps the most important thing to do is to listen carefully to what other members are saying and, when it is appropriate, to support or challenge what they say in terms of personal experience. Sincerity of expression is highly valued.

*Personal examples are most useful if they relate to a significant issue rather than if they stand alone.*

It is important to differentiate between aggressive and assertive behavior. Aggressive behavior dominates or puts down other people in making its point, whereas assertive behavior focuses on the point to be made without attacking the person opposing it. Assertive behavior is more likely to be convincing, whereas aggressive behavior tends to raise the defenses of the other person and be self-defeating.

### **Empowering Council Members**

It is generally recognized that people "empower" themselves. Therefore, are there conditions that promote "empowered" functioning on the part of council members, and hence promote effective council operations? If so, do these translate to actions that can be taken by the council chairperson?

Czerlinsky and Chandler (1992, 1994) studied how rehabilitation counselors could help empower consumers to be more active participants in their own rehabilitation. Their findings also appear to relate to what could be done, especially by the council chair, to empower council members to be effective participants in the council's actions. These findings are especially pertinent to members who have less experience on councils, as is the case with some consumers. A national sample of more than 300 rehabilitation consumers and consumer activists, service providers, rehabilitation policy makers, rehabilitation educators, and administrators were surveyed in three rounds of questioning to identify, classify, and rank elements they considered vital for creating counseling partnerships that would be empowering to consumers. The critical counseling elements identified fell into six major domains: consumer issues and responsibilities, counselor characteristics, counselor roles, counseling techniques, qualitative counseling elements, and "other" issues. Some of these elements apply to council chair behaviors.

"Empowering issues" important to consumers in their own rehabilitation are that they feel actively involved and responsible, have real choices and are encouraged to make decisions, and have a role in the process. These issues are also directly relevant to ensuring that consumer members are effective participants in advisory

council activities.

"Counselor characteristics" that generalize to the role of council chair and lead to empowerment include the following: Chairpersons who are supportive, encouraging, and accepting; are sensitive to the member's needs; communicate an interest in the member; and are motivated to listen. Further, they are perceived as professional and competent, committed to the process, and willing to confront members in a non-judgmental manner.

The study also identified "counseling techniques," some of which might be adapted by a chairperson to help empower individual members of advisory groups and especially those with less experience on boards: provide an accepting environment, allow for good open communication, be open to member questions, encourage member involvement, promote member responsibility, use empathic listening, and encourage independent thinking and acting.

*Empowering issues important to consumers in their own rehabilitation are that they feel actively involved and responsible, have real choices and are encouraged to make decisions, and have a role in the process.*

"Qualitative counseling elements" can generalize to the council and board meetings to help empower individual members. These apply directly to the chairperson, but also appear to generalize to the board or council as a whole. Among the elements identified were that an atmosphere of trust and mutual acceptance be established that shows respect to all

members. The member should feel the chairperson and other council members are genuinely interested and concerned, that they demonstrate understanding, and that they are sensitive to member needs. An atmosphere of trustworthiness and reliability is important. These qualitative elements, once established, will provide an atmosphere within which members of councils can feel empowered and risk participating at a meaningful and equal level.

### Summary

Consumer involvement at all levels of the rehabilitation field is now recognized through legislation as a basic ingredient of the process. This includes participating as partners, not only in their own rehabilitation but also in meaningful ways on advisory and policy setting bodies. Individuals with disabilities can provide useful and unique perspectives. This paper discussed the roles and responsibilities of the consumer, the council chair, and council coordinator in implementing the consumer's effective participation. Areas of

training and indications of effective functioning were identified. Examples of council projects or responsibilities that utilized consumer expertise were cited. Guidelines for interacting with people with disabilities and appropriate language to use were suggested and methods to help empower council members were presented.

The basic ingredient in an effective advisory process is the individual council member. The council chairperson and members should do whatever is necessary to promote the full participation of all members, especially those with unique and relevant experience. These empowering elements that apply to the counseling process would also appear to generalize to the advisory process.

For further discussion of the role of citizens in the advisory process, read Dorothy Lagerroos' (1982) booklet entitled *Citizens Advisory Committees: How to Make Them Work* (G3163). It is available from the Agricultural Bulletin Building, 1535 Observatory Drive, Madison, WI 53706.

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