

## **ADVOCACY SYSTEMS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES**

**Context, Components, and Resources**

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## **CASE ADVOCACY: IDEOLOGY AND OPERATION**

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The objectives of this presentation are to provide a view of case advocacy, its goals and objectives, and more detailed information about the operation of a case advocacy program established on a given ideological base.

To begin with, a case advocate may be defined as a professional representative of an individual's interests and rights until the individual is able to represent and protect his or her own interests and rights. In relationship to developmentally disabled people, the goal of case advocacy is for individuals to develop the skills needed to become their own advocates.

As the term is being used here, a case advocate is a professional paid to function as an advocate with a group of individuals. This function includes arranging for individuals to receive the services they need in a manner which respects their interests and rights.

The perspective of a case advocate is not limited to any specific area of a person's life but rather encompasses a concern for the total person, his or her abilities, needs, and interactions with environments. Thus, seeing a person in a variety of environments increases the case advocate's knowledge of a person's needs.

The involvement of a case advocate with a consumer is not limited in time to a specific crisis or a specific age. The definition implies a concern over time or until the individual is able to adequately represent and protect his or her own interests and rights. A case advocacy system should be available around the clock to work with individual crises throughout a person's life. The involvement must be flexible and the advocate sensitive to the unique conditions of each person and each situation.

The purpose of providing a case advocacy system for developmentally disabled people is to arrange for the consumer to develop the skills needed to participate in and contribute to the community through the use of the same community educational, vocational, residential, and other environments and resources available to all citizens.

### Ideological Base

The single most important factor in a case advocacy system, as in any human service delivery system, is the system's ideology with respect to the people it is designed to serve.

Sometimes referred to as the human dignity movement, the following components and underlying assumptions are essential to the delivery of quality services:

1. *Each person has value.* People who have historically been devalued by society are as valuable as other people and should be afforded the same dignity and respect as all other human beings (Blatt, 1972).
2. *The developmental theory.* Every person is capable of growth and learning regardless of the severity of his handicap (Roos, McCann, & Patterson, Note 1).
3. *The normalization principle.* The differences of people who have been devalued by society can be diminished and their images in society enhanced through appropriate learning opportunities. On the other hand, society can become more tolerant of people who are different (Wolfensberger, 1972). The normalization principle requires the use of the most normal alternative to meet the needs of the individual. In the legal field, this principle translates to the principle of the least restrictive alternative (Chambers, 1976).
4. *Consumer participation.* The consumer knows his own needs best, and establishing accountability of service delivery systems to consumers and their representatives will lead to higher quality services.
5. *Human and legal rights.* Handicapped people are citizens with the same rights and responsibilities as other citizens of the same country and the same age.

If a service delivery system is to operate according to these ideologies, then care must be taken to design and continually scrutinize every aspect of the system according to these beliefs. For example, the selection of staff to be case advocates will be discussed later in this paper, and hopefully the relationship to this ideological base will be evident. Human service delivery systems, founded on this

type of ideological base, can lead to maximizing the independence, acceptance, and contributions of developmentally disabled people in relationship to society.

### The Relationship Between Case Advocacy and Other Types of Advocacy Programs

There are many types of advocacy which are all interrelated and complementary to one another. A case advocacy system may extend its effectiveness and provide higher quality services to consumers if there are resources with which it can join forces to meet specialized advocacy needs of individual consumers. The resource might be a parent, citizen advocate, ombudsperson, protective service worker, or attorney. Further, a case advocate may be involved in advocating for systems change for a group of individuals. A case advocate also may act as a program broker or work on legislative change.

Various advocacy programs or models can be classified in a number of ways, including:

1. Individual versus systems models;
2. Models which encompass a broad concern for the individual versus a specific aspect of a person's life;
3. Models which are designed to intervene in specific crises versus those which are available over time.

Accordingly, individual advocacy models can be viewed in a continuum as in Figure 1, ranging from the more narrow crisis intervention services to the more broad and continuous models, with case advocacy generally falling in the latter category. Similarly, systems advocacy models can generally be seen in a continuum as in Figure 2.

A case advocacy program may be operated within a service delivery system or separate from the delivery of other services. Internal and external advocacy approaches are examined in depth by Neufeld (1976). Basically, an internal case advocacy program is more likely to have the advantages of increased communication and easier access to information as well as the support of more resources and enhanced possibilities of interdisciplinary teamwork. External advocacy may have decreased likelihood of conflict of interest and more freedom to use more drastic means of intervention. In cases where conflict of interest is a problem, the case advocate must be free to work with an outside advocate, like an Association for Retarded Citizens, which has the capacity to pursue more drastic alternatives if necessary on behalf of an individual. Even in an internal case advocacy program, a major part of the focus needs to be on advocacy work with generic agencies (agencies providing service to the general public) since the goal in working with handicapped people lies in the community rather than within segregated systems.

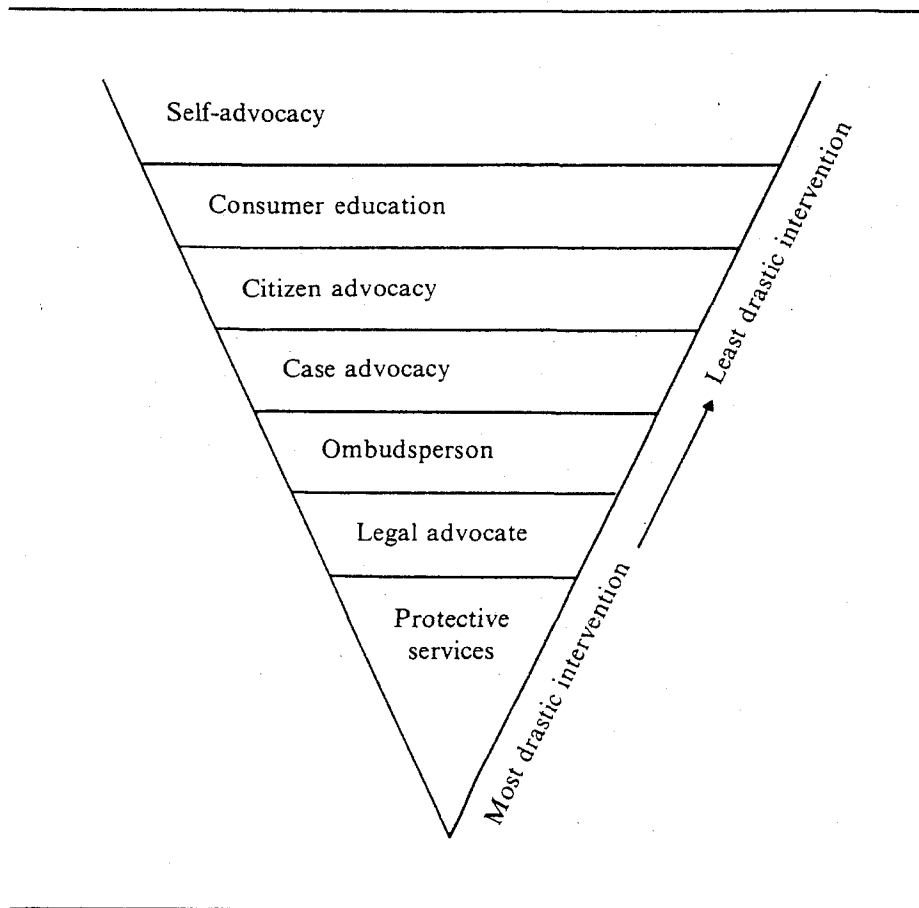


Figure 1. Types of individual advocacy according to the least restrictive alternative (or the least drastic alternative)

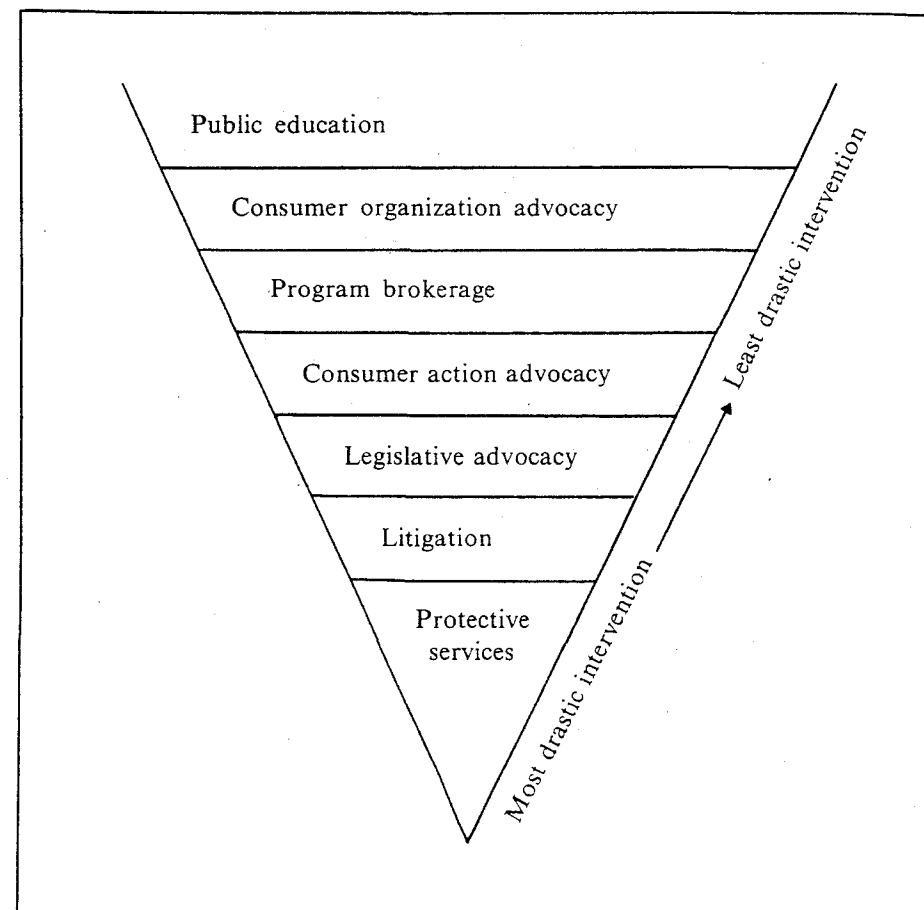


Figure 2. Types of systems advocacy according to the least restrictive alternative (or the least drastic alternative)

In order for a case advocacy program to be effective, it has to be supported by the management, governing board, and/or funding source, regardless of whether the program is a separate entity or a part of a broader service delivery system.

### Operation of a Case Advocacy System

A review of the social sciences literature reveals that the function of case or professional advocacy has been most often seen as an optional role for staff persons who are not formally recognized as change agents. According to Rino Patti (1974), such assumption on the part of staff represents a reversal in the usual direction of organizational influence—that is, from the lowest ranks up to the highest. According to this conceptualization, advocacy may further be construed as a “violation” of the traditional employee-employer contract, thus threatening the balance of power, disrupting the routine, or embarrassing the agency. Perceived as a threat to the status quo, advocates have not been welcomed with open arms into the mainstream of human services. An organization which seriously expects case advocacy to work—that is, to actively protect the interest of consumers of the service—must be willing to tolerate such unconventional patterns of power or communication within its structure.

In the case advocacy system we will be describing below, the advocate’s role is strongly legitimized by the philosophy of the service delivery system. The purposes, goals, staff job objectives, and evaluation criteria all are based on the ideological principles previously outlined.

Though this system is one of internal advocacy, in which the case advocates are employed by the service delivery system, the principles, structure, and function we will describe are, we believe, applicable to any advocacy system, external or internal. The system was developed with an advocate/client ratio ranging from 1:35 to 1:60. Higher ratios may be possible, given plentiful resources to extend the advocate’s role and also given a relatively sophisticated system for developing and monitoring individual program plans. However, our experience has been that more than a 1:60 ratio leads to compromises in the quality or intensity of advocacy.

We will consider the job description, staff selection process, training, resource development, and other factors basic to implementing a case advocacy system.

#### The Job Description

A basic premise of effective advocacy is that the consumer or family is in the best position to define the consumer’s needs. The basic responsibility for case advocacy, therefore, lies with the consumer. The role of the case advocate is to support and/or intervene in the advocacy process, only when necessary (Figure 3). Any advocacy intervention has two purposes: first, the immediate resolution of the

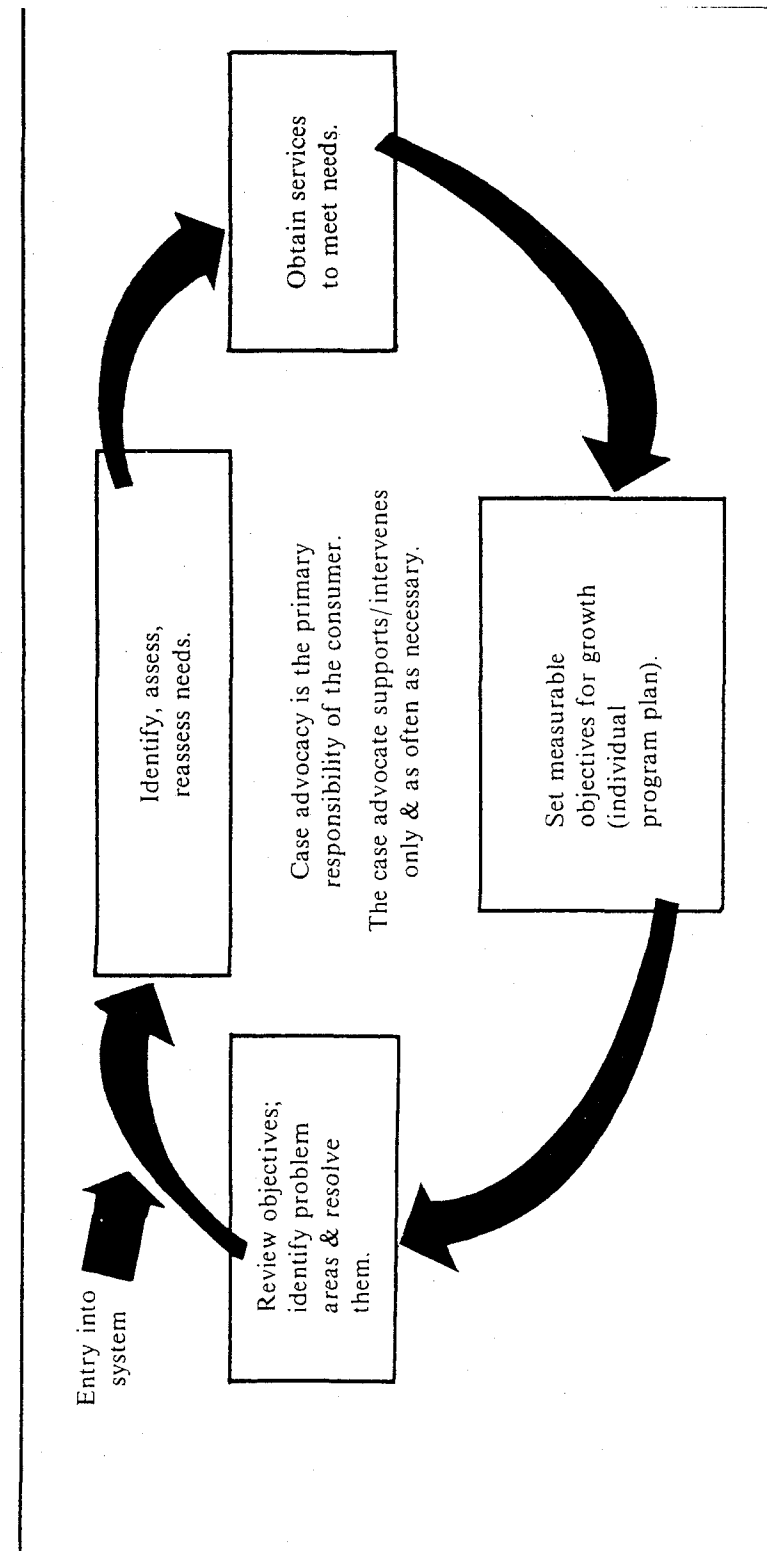


Figure 3. The process of case advocacy: Major task areas

problem presented by the consumer; and second, teaching the consumer some or all of the steps that will enable him or her to recognize and resolve conflict situations on his or her own behalf in the future.

A case advocate is assigned when a person requests services or assistance and follows the person throughout the time he or she needs assistance or until he or she can function as a self-advocate.

The advocate is responsible for an initial and thereafter periodic assessment of the client's needs, abilities, and interests. Based on this assessment, the advocate then becomes a broker for services, assisting the client in obtaining whatever is necessary for his or her growth, from within the service system or from the community whenever appropriate. The advocate continually reassesses the appropriateness of the placement decision; at this point, the advocacy function is likely to be needed. If services are unfair or inadequate, redress may be necessary by the client or advocate.

In seeking redress, the case advocate is guided by a basic belief in the human and legal rights of the disabled individual. The case advocate also seeks alternatives which are the least restrictive of the consumer's freedom and still meet the person's needs. The alternatives for redress are those which apply to any other citizen of the same age and class, thus reflecting the concept of integration of disabled citizens into the normal routines of life. For example, in working with a family that is dissatisfied with a school district's placement decision, the advocate would help the family follow the established appeal procedure, beginning with the persons responsible for the decision and moving upwards as needed to the school board or if necessary into the legal system.

The case advocate role is one of continual assessment, monitoring of planned client growth, follow-up to assure that needs are met, resolution of obstacles, and back again to assessment. The role is ideally one of a continuous feedback system operating at higher and higher planes as the consumer's skill level develops, with maximal independence being the final outcome.

For each of these major task areas, specific activities of the process of case advocacy should be listed and defined so that the advocate has a clear understanding of the operational nature of the advocacy process. The job description also should state the standard or criterion of performance expected and thus form the basis for periodic evaluation of advocates' effectiveness.

### Staff Selection

The case advocate role is intrinsically stressful. No matter how tactfully carried out or how strongly legitimized, it remains essentially a position likely to be seen in adversary terms and may in extreme cases require adversary action. The role

demands repeated negotiations and confrontations with many representatives of social institutions.

Persons recruited for the case advocate role must have the personal characteristics to carry out the complex and stressful functions of the job. Our hiring process involves a variety of techniques for predicting the job functioning of potential case advocates. In addition to the traditional interview and reference checks, in our system applicants are asked to respond to a set of work samples—simulated situations likely to be encountered on the job. Oral and written simulations are administered, and the applicant may also be asked to work for a brief period of time with an advocate. This process yields a great deal of information, including evidence of attitudes and values, problem-solving strategies, judgment, ability to communicate clearly, and value-related commitment to the job.

The work simulations are part of a structured interview in which the same or similar questions are asked of all applicants. The responses are summarized on a rating scale, making it possible to compare all applicants to the same standards rather than to one another.

All interview information and other input (references, resumes, applications) are synthesized by at least two and preferably three interviewers/raters, and the results are summarized as scores on a 5-point scale for each of 11 job-related characteristics. Each characteristic is weighted in relation to its significance, and by application of a multiple regression equation, a global score is obtained. This score indicates the relative standing of any number of applicants. Of course, the final decision rests on the judgment of the interviewers, but this process should eliminate many chance or discriminatory factors.

The 11 job-related characteristics and their corresponding ranks and weights are given in Table 1. Some of the more subjective characteristics may require more explanation.

*Attitude.* What is the applicant's attitude toward people who have historically been devalued by society or perceived as deviant in some way? What values are reflected? Does this person see handicapped people as capable of change and growth? Though this characteristic relates closely to the philosophy of normalization, the applicant is not judged on his or her formal sociological knowledge. The important factors are the applicant's value base and ability to apply his or her values to practical human situations.

*Independence and initiative.* The case advocate role is not structured as to hours or specific responsibilities. The advocate is expected to implement a concept; considerable flexibility and autonomy are required. The person must be able to work independently, organize and structure his or her time, and show initiative in recognizing and resolving consumers' problems.

TABLE 1  
Characteristics of Case Advocates

Rank	Weight	Characteristic
1	5	Values people who are devalued by society and has the ability to apply values to individual situations
2	5	Ability to work independently
3	4	Communication skills—oral
4	4	Communication skills—written
5	4	Ability to cope with stress
6	4	Personal commitment
7	3	Experience and education in human behavior and development
8	3	Manner in which person presents self
9	3	Professional experience
10	2	Knowledge of community resources
11	2	Educational level

*Communication skills.* A great deal of skill is demanded of the advocate with respect to both spoken and written communication. Complex issues are likely to arise which may require the use of clarification, negotiation, or confrontation techniques. The selection process should provide numerous opportunities to observe the person's ability to communicate in a clear and logical fashion, to present an effective and logical problem-solving strategy, and to manage conflict.

*Ability to cope with stress.* The advocacy role demands actively seeking out issues, which may frequently engender defensiveness, conflict, and opposition. The case advocate must be able to tolerate varying demands and an uneven workload and be able to respond calmly in a crisis.

Over an extended period of time, an individual whose coping defenses are not adequate will become a victim of burn out and will cease to be effective as an advocate. Inadequate coping mechanisms might include consistent overidentification with client problems, or physical illness which results from ineffective management of stress. Those persons seeking job regularity, security, and structure and having low tolerance for ambiguity and anxiety will quickly become frustrated and ineffective in a job of this nature.

*Personal commitment to the job.* This characteristic refers to the type and quality of the individual's motivation and career goals within the human services field. Those persons whose personal aspirations and values may conflict or compete with the philosophical basis, goals, and objectives of the agency will not function as successful advocates. Applicants for the case advocate role should express a consistent, strong, value-related rationale for their participation in the human services field. Because the most valuable asset of the effective case advocate is his or her own humanity and ability to make value-based judgments, this area is most crucial. More specific values will of course vary with the individual. The primary requirements are that the person's values are compatible with those of the advocacy system and that personal values do not adversely interfere with representation of clients. Strong personal commitment is also essential to offset the effects of job stress.

Other factors taken into consideration include previous experience in specified fields, related education, knowledge of behavior and human development, knowledge of the community, and manner of presentation.

The use of a highly structured interview in our program and the screening of applicants based on a number of clearly defined, job-relevant characteristics, judging objective as well as subjective criteria, allows a fair and accurate comparison of a number of applicants. The relevance of the criteria to successful job performance is at this point primarily empirical, though tentative evidence of validity has been demonstrated with a small number of staff.

### Staff Training

The emphasis on screening and hiring activity should be the selection of persons with the essential personal and attitudinal characteristics to perform the case advocate function. Many of the other skills and knowledge needed for the job may be obtained in a relatively short, intensive training program for new staff, and maintained and updated for other staff by periodic in-service training in relevant areas. Individuals should not be screened out on the basis of lacking skill or information that could easily be imparted in orientation. Orientation and training in our program includes the following topics.

*Normalization.* The basic component of orientation involves developing an understanding of the philosophical basis of the agency. A thorough knowledge of the Program Analysis of Services Systems (PASS), a normalization-based rating of the quality of human services, is invaluable not only as a philosophical statement but as a reflection of the principle of normalization in practice, as it may be observed in physical, social, and even governmental interactions in human services. Various other readings on the philosophy of normalization are also assigned. Whenever the opportunity is available, case advocates attain suf-

ficient proficiency with PASS to serve as a PASS rater and participate in the evaluation of human service programs.

*Human and legal rights.* A case advocate must have the knowledge and the attitudes necessary to monitor the human and legal rights of those he or she represents. A training program in the area of rights has been developed to provide the information needed to identify actual or potential violations of consumers' rights and to intervene as appropriate.

During this training, the case advocate becomes familiar with the nature and definition of a broad range of personal rights and their basis in the Constitution, statutes, or other applicable standards. Rights areas include but are not limited to: the right to life, education, due process, medical care, the least restrictive living or treatment alternatives, a guardian if necessary, rehabilitation, training or employment, marriage, sexuality, and procreation. For each right, training also covers the provisions for protection of the right and the legal safeguards should it be necessary to modify that right. Therefore, when effectively trained and functioning, the case advocate is able to accurately identify actual and impending violations of rights (and to teach consumers to identify them). The advocate is able to immediately implement action to assure that consumers' rights are protected or, if after the fact, that the proper grievance process is followed. The advocate is also fully aware of the safeguards, should a modification of a right be essential to the consumer's welfare.

*Individual program planning.* In Chapter 3 of this volume, John McGee and Bertine Loop mention the relation of technology—an important element of staff preparation—to ideology which as previously indicated, is central to an advocacy system. Individual program plans (IPPs) can be used as a tactic to demand additional accountability. The accuracy and sophistication of the IPP—that is, how closely it corresponds to the client's growth—is a major factor in how efficiently the case manager can operate. With a good system to monitor client progress, a case advocate is able to serve more people and delegate some advocacy functions.

*Communication.* The function of the case advocate demands a great deal of diplomacy in order to resolve problems without producing unnecessary or counterproductive defensiveness or hostility. Case advocates need to develop the ability to manage conflict and to operate within an effective problem-solving, decision-making model. A human relations training model, with emphasis on problem solving, is the basis for this training.

Once staff are selected and trained, their main role is with the consumer as well as with the service agencies and potentially with broader social services change. The case advocate's role in relationship to each of these groups will be discussed next.

## The Role of the Case Advocate in Relationship to the Consumer

The role of a case advocate may differ dramatically not only from one consumer to another but also with one consumer in several situations, according to the consumer's understanding of the situation, the alternatives, and the consequences of various possible decisions, as well as the case advocate's assessment of the gravity of the situation.

A case advocate may be involved in assisting a person in interpreting an event, such as understanding an employer's correction in the person's job performance. This action could be interpreted as an indication that the employer wants to help the person improve his job performance rather than an indication that the employer dislikes the person or is trying to put him down.

A case advocate could assist a person in understanding the contents of a contract she has signed, informing her of her rights and alternatives such as seeking the services of a public consumer fraud service.

In a situation where a person is making a decision without full understanding of the consequences, the case advocate may negotiate with the person to take advantage of some learning opportunities prior to proceeding. If a person is making a decision which is a threat to his welfare, the case advocate may seek intervention in the person's decision through means which protect the consumer's legal rights.

The relationship of the case advocate with the consumer, according to the least restrictive alternative, is illustrated in Figure 4. This illustration displays case advocacy according to the philosophy and goals described earlier.

## Teaching Consumers to Advocate for Themselves

The role of a case advocate is ideally to provide interim support or intervention—that is, until the consumer is able to advocate for his or her own needs effectively. This interim role is essential in terms of dignity and eventual independence. Thus, as the case advocate *advocates*, he or she also teaches. The skills and knowledge required of the case advocate are identical to those that he or she ideally teaches the consumer.

The process of teaching a consumer to advocate for himself or herself is basically parallel to the staff training process outlined above.

The process of self-advocacy, in which a person represents his or her own interests and rights, is a developmental process, similar to any other human characteristics. The consumer may have needs for self-advocacy at any level—from very passive receipt of information regarding oneself, to active leadership in decision-making organizations. In contrast to a case advocate who is a generalist with

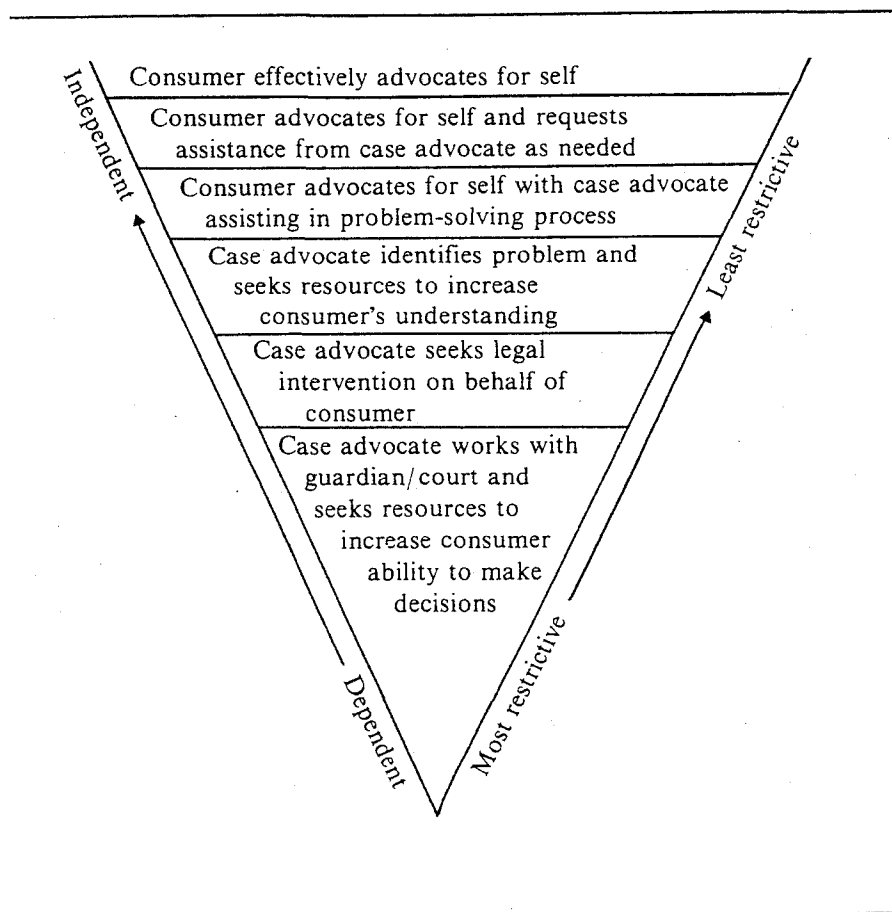


Figure 4. The role of the case advocate with a consumer according to the least restrictive alternative

preparation for a number of issues or areas, the self-advocate is more likely to have a specialized focus—some issue of immediate concern to oneself. This focus may change from time to time as the person develops and his or her needs change.

Self-advocacy may occur on an individual or group basis, formally or informally, depending on the person's needs and abilities at a given time.

On the individual level, the consumer can gradually assume more and more responsibility for his or her own case management. This process might include identifying areas of need, locating resources, identifying barriers to service, and knowing when to request assistance.

Consumers, particularly parents, may also be trained in the use of evaluation techniques which will help them pinpoint issues of quality in the programs or services they are receiving. PASS has served as an ideal tool for helping consumers become aware of the physical and social manifestations of normalization. Because the training process is rather lengthy and requires considerable preparation and effort, it primarily appeals to consumers who are more sophisticated or have necessary time to invest.

Other options in evaluation techniques include the use of checklists or guidelines to help parents identify and evaluate relevant features of the programs in which they are involved. Such guidelines may be developed for a specific program, as is the case with the Coordinated Early Education Project of the Eastern Nebraska Community Office of Retardation (ENCOR). A Parent Checklist was developed so that parents who had recognized the benefits of a quality educational program for their preschool children could continue to monitor quality when their children entered public school programs.

The National Association for Retarded Citizens has published a booklet called *Action Guidelines: Evaluating and Monitoring Education Services for Mentally Retarded Persons*, which can help consumers judge the adequacy of school programs. It is available from NARC, Post Office Box 6109, Arlington, Texas 76011.

Parent-to-parent counseling and assistance are another form of teaching self-advocacy. Programs such as Pilot Parents enable consumers to help one another adjust to problems related to a handicapped child and learn about resources in the community. Most importantly, parents learn about their rights with respect to services, and they learn about the process of identifying and overcoming barriers to quality services.

Self-help or self-government groups are another channel for self-advocacy. In a vocational facility in our system, a worker's forum has been established. Possible areas of involvement have included the traditional Christmas party type of social or recreational activities, but more importantly, workers must have a real



mpact on the policies and procedures governing their work environment. Part of the organizational process should include some basic consumer rights education, and the administration must be willing to make use of the information generated by an organization such as this.

### Extending the Role of the Advocate

A case advocate can increase the scope and effectiveness of the advocacy process in a number of ways. We have already stressed the fundamental importance of teaching consumers to advocate for themselves, which is the best way to extend the role.

Additionally, a case advocate can make use of other advocacy services available in the community, which may either support or replace the case advocate. Examples might include the use of citizen advocates, lawyers, ombudspersons, pilot parents, or consumer groups. The role of the case advocate then becomes one of monitoring the direct intervention, at least temporarily.

### The Role of The Case Advocate in Relationship to the Service Delivery System: Advocating to Remove Barriers to Services

All of us who work in the field of human services are painfully aware that many barriers prevent people from receiving the services they need or deny equal treatment to people with handicaps. A variety of means exists to approach and remove these barriers.

In one case, an advocate may merely need to provide a preschool with information about the needs of a handicapped child, and the preschool may decide to serve the child. With another agency, advocacy may mean identifying all the problems involved with serving a particular person and exploring all the alternatives to resolve these problems and the resources which may be available to assist the agency in serving that individual. Advocacy does not stop there. If the individual is still not being served appropriately, the advocate may need to look at means of creating pressure internal to the agency. For example, a parent whose child has been excluded from the public schools could have a case advocate go with the parent to discuss the situation with the director of special education. Using the agency's appeal process is another alternative. When the issue involved is a matter of individual rights or a question of discrimination, litigation may be a possible means of resolving the problem (see Figure 5).

Many of the problems that we face with consumers are highly complex and require multiple strategies, so the alternatives discussed here should not be interpreted as steps that an advocate goes through one by one in a certain order. Making a decision on the level and intensity of intervention requires sensitivity

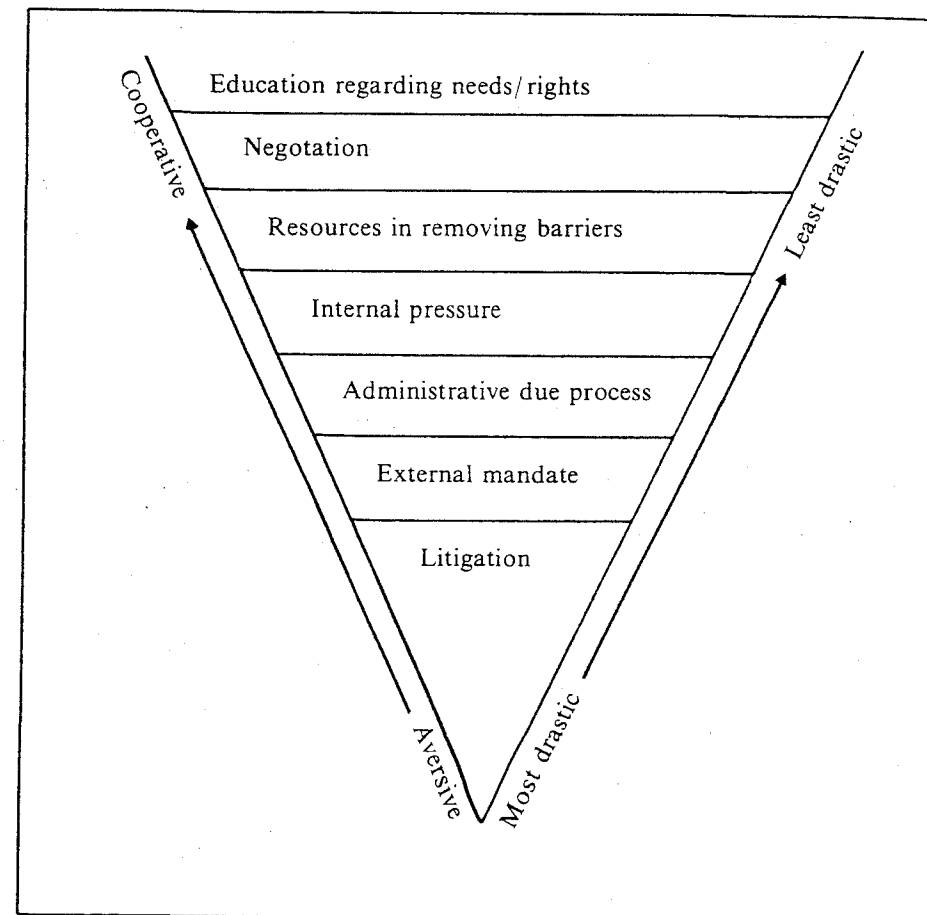


Figure 5. Advocating to remove barriers to service

and flexibility on the part of the advocate. The intent here is not to minimize the difficulties that an advocate faces in attempting to arrange for an individual to receive appropriate services or fair treatment, but rather to present some of the alternatives and to stress that cooperation may accomplish the most.

Whether case advocates are working within a delivery system or external to it, their effectiveness with agencies can be increased if the agencies believe in:

1. Accountability to their consumers, advocates, and the public;
2. The value of the role of advocates on behalf of consumers;
3. Flexibility, openness to change, and responsiveness to individual needs;
4. A teamwork approach with the goal of quality services to the consumer;
5. A strong ideological base.

## The Role of Case Advocacy in Relationship to Broader Change

A case advocacy program serving a broad population of developmentally disabled people has the potential to advocate for broader community, social, and legal changes. Since case advocates identify needs individually, this information viewed collectively may indicate the need for new types of services for groups of people and broad needs for change in the service delivery system and in legislation. Many systems advocacy programs alone do not have such extensive information about individual needs, although advocacy for systems change should be based on needs of individuals. Thus, a case advocacy program, working in combination with systems advocacy programs, has the potential for being a strong force for change.

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