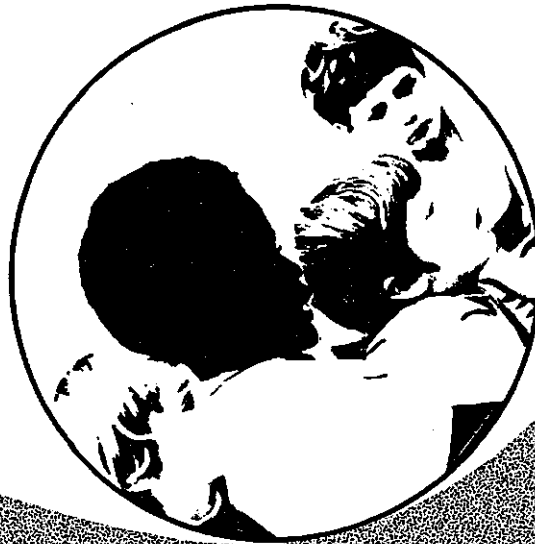


**DD**

# themes & issues

A Series of Topical Papers on Developmental Disabilities

ROLE  
*of the*  
CONSUMER



IN PLANNING  
AND DELIVERING SERVICES

*by* Frank Warren

*Series Editors:* James L. Paul, Pascal L. Trohanis

*Number 5*

## ABOUT THE AUTHOR



Frank Warren is currently serving as a special consultant to the Office of Children in the North Carolina Department of Human Resources. Mr. Warren's long involvement with consumer movements includes helping to establish both the North Carolina Society for Autistic Children, and Parents and Professionals for Handicapped Children. Additionally he has helped to plan and implement a statewide census/registration of children with special needs as well as a public school-linked program for autistic children.

## CONTRIBUTING STAFF

Printing Coordinator  
Editorial Assistant  
Typist

Zena Harvley  
Ann Ramsbotham  
Lynn Harmon

DD Themes and Issues is a series of topical papers for this nation's Planning and Advisory Councils on Developmental Disabilities. Each participating state, territorial, and District of Columbia Council develops and implements a comprehensive State Plan for the coordination of comprehensive services for citizens who are developmentally disabled.

This series is published by the Developmental Disabilities Technical Assistance System (DD/TAS), which is a consultative and assistance system for the Councils. DD/TAS is a division of the Frank Porter Graham Child Development Center, the University of North Carolina at Chapel Hill.

This series was prepared pursuant to a grant from the Office of Developmental Disabilities, Office of Human Development, U. S. Department of Health, Education and Welfare. Grantees undertaking such projects under government sponsorship are encouraged to express freely their judgement in professional and technical matters. Points of view or opinions do not, therefore, necessarily represent official DDO, OHD, HEW position or policy.

Graphic Design and Publishing by  
University of North Carolina Printing Department

Published in February of 1976

## Introduction

The role of the consumer in planning and delivering services should be obvious to DD Council members. A consumer's needs, as seen by him, should be addressed from the very outset; his wants, and they would vary from consumer to consumer, should be taken into serious consideration before any planning begins; and he should not only be consulted, surveyed, studied and evaluated, he should be an active participant in the planning process, wielding decision-making power equal to that of professional planners and providers. In short, the consumer should be a participant in every aspect of the planning and delivery of services designed to benefit him or to solve or alleviate the problems that he faces.

It is the purpose of this article to describe some roles for consumers in planning and delivering services and to identify issues related to those roles.

## The Consumer

The consumer - the retarded, cerebral palsied, epileptic, autistic child or adult - is the focus for people in the business of providing assistance for developmentally disabled individuals. And when a service is provided for a developmentally disabled child or adult who is in the care of another person, family or guardian, it becomes a service for those people as well as for the disabled child or adult.

In the majority of cases, parents, families or guardians are the best advocates for disabled people. As advocates, they speak for them, act in their behalf, and in their best interest. Services for disabled people that meet their real needs also meet the needs of their parents, families and guardians.

## A Need for Cooperation

In order to facilitate a creative and integral involvement of consumers in the planning and delivery of services, a spirit of mutual trust and cooperation must be nurtured between the consumer and the professional. The consumer cannot know everything the professional has learned after years of study. It is equally true that the professional cannot know everything the consumer has learned after years of being, or living with, a developmentally disabled person, often being put down, turned down and cooled out by insensitive professionals who do not know what to do, and who will not or cannot admit it, and by the bureaucratized service system.

There must be communication before any kind of constructive cooperation can occur between the professional who is being paid to help and the parent who has a child with special needs. If the professional considers the consumer incompetent,

how can he expect to gain the respect and confidence of that consumer? How can they work together? If the parent sees the professional as arrogant and unwilling to listen, how can they cooperate for the good of the child?

In most cases the professionals are organized, have the mandate to provide services, and are supposed to have the ability and the access to technical knowledge. The consumers, on the other hand, are disorganized, are spread out, and are spending most of their time being lawyers, sharecroppers, businessmen, television repairmen, newspaper reporters, filling station operators, secretaries, farmers or whatever to support their families. It seems only reasonable for the professionals to take the initiative. It is their full-time job to plan and deliver services. And they must take it upon themselves to break down the unnecessary barriers between them and the people they are supposed to serve.

To do this, professionals must look upon the consumer as a valuable person who is doing the best he can within the circumstances of his life. Professionals must give consumers the dignity and respect they deserve as human beings. And make no mistake about it, they deserve it. Professionals must recognize the fact that most parents love their children, want to be near them, want to be good parents to them, and want their problems and handicaps dealt with in sensible, appropriate ways so that they can develop as individuals able to live lives that are as satisfying as possible.

Planners and service deliverers must include the consumer from the beginning - consult him, listen to him, draw upon his knowledge and ability, find out what his real needs and desires are and use his strength and support to accomplish the goals that they together - consumers and professionals - have established. This is the strongest position to work from. Where this has been done, the results have been invariably good ones.

Of course this does not mean that consumers should stand idly by until a professional person decides to let them in on what's happening. It is quite appropriate for them to initiate the action, to pound on the door, if they have to, in order to participate where they rightfully belong.

While some professionals carefully guard their territory from the intrusion of consumers, this is not always the case. Many professionals involved in planning and delivering services actively seek consumer participation when they are in a position to do so. Many others would be amenable to consumer involvement if the structure of the programs in which they are involved permitted it, or if their particular discipline taught that it was appropriate. Many, in fact, enter a discipline holding a liberal view toward consumer involvement, but emerge from their professional education with that liberal view washed away through long exposure to a system that does not value consumers as participants in planning and delivering services.

Consumers, seeking to have an impact on the systems that are supposed to be

serving them, do well to approach professionals as if they were potential friends and allies. Will Rogers said, "Everybody is ignorant - about different things." It may be that the problem is simple ignorance on the part of professionals regarding the value of consumer participation and involvement. When this is the case, it is up to the consumers to educate the professionals. If this is done with tact and persistence from a position of strength, many battles may be avoided and much cooperation gained.

### Consumer Communication, Organization, and Alliances

A common degrading comment that you hear from professionals and people involved in delivering services is that parents don't care; furthermore, they won't participate, you can't get them involved, they won't come to meetings and conferences, they are only interested in their own children and nobody else.

To the degree that this is true, it is because parents of developmentally disabled children tend to be isolated, cut off from regular association with others who have the same kinds of problems, and trained by their association with traditional professionals to believe that they are inept and can't do anything to solve their problems. Many are unaware of the strong effect they can have on professionals and on the services they deliver.

In order for consumers to have some kind of impact on the people who make decisions affecting them and their children, communication and organization must be considered. Communication implies a two-way exchange of facts and ideas. Organization implies a method of continuing the communication. To have any kind of continuing communication among consumers, between consumers and planners, and between consumers and service providers, there must be some form of organization.

Perhaps this sounds too simple to write about, but the fact is that many consumers, overwhelmed by their own problems, are unaware that there are many others who face the same circumstances. They never realize that many problems can be solved and much suffering alleviated through joint action - by letter and phone, through making concerted demands for improved services.

As part of an oppressed minority, the consumer has a powerful platform from which to launch an effort to improve his life circumstances. Many consumers are discriminated against, often having to pay a large price for things, such as education, that other people get free. Both laws and public attitudes exclude the consumer from many things that make life worthwhile. Systems set up at public expense to serve people in a multitude of ways regularly leave him out. Often the consumer is ignored, circumvented, patronized, taken advantage of, used, pitied and, in some cases, his rights as a human being and as a citizen are arbitrarily taken from him.

Consumers must join together and direct all of their energies toward changing the laws, attitudes, systems and individuals who are putting them down and dealing

them out. Consumers must organize. To have any kind of impetus and stability, organization must be based on a common need and aimed toward solving common problems. Consumer organizations can take a great variety of forms: a small parent group may come together to solve relatively simple problems in a classroom; wide-flung alliances of existing consumer organizations may be established to change public attitudes, influence and create legislation, alter systems of service delivery to meet the real needs of disabled people, and make an impact on state and federal government.

The first step toward organizing consumers is to realize that there are a number of people, usually isolated from each other and struggling with their problems alone, who have common needs that could be met and common problems that could be solved if they joined resources and acted in unison.

Here are a few guidelines for consumers attempting to develop an effective organization:

Meet regularly.

Encourage those with the greatest commitment and the keenest understanding of the problem to exercise their leadership ability.

Establish a means of regular communication between members. A well-written newsletter can instill enthusiasm, impart valuable information, enlighten the membership, encourage action and provide a constant link with members who may not be able to attend all meetings. Best of all, it is cheap.

Don't bite off more than you can chew. A problem solved well gives credibility to your organization and a sense of accomplishment to members.

On the other hand, don't whittle your goals down to the point that they are worthless. Work toward an ideal, and measure your accomplishments against it.

Don't give up in despair when members of your group fall short of the commitment you think they ought to have. Remember that every member has a different level of commitment to the cause, depending on the circumstances of his life. Rejoice in the participation that you get, and move on.

Don't turn your organization into a vehicle for personal gratification or ego satisfaction. Give credit where credit is due, and dole out praise and encouragement in large quantities - whether it is deserved or not.

Once you have found your consumer element, identified a common problem and begun to meet, then it is time to make an assessment of what your group wants to accomplish. Start with an ideal. Don't be awed by the task ahead of you. Take it on a piece at a time. Share responsibilities.

Examine existing approaches. It is likely that most of the things your group needs are already being provided to others through systems that are already in operation, but from which your people are excluded. If such is the case, and if these systems are funded by tax money, there is no good reason why they cannot be altered to serve your people as well.

Think long and hard before you decide to work toward the establishment of a separate system to meet the needs of your consumer element, while another, parallel system is serving others but excluding you. Sometimes this has to be done if it is clear that your people would be served inadequately and their special needs lost in the larger system. But the goal should be to get the needs of your element met in appropriate fashion by the agencies and systems already set up to serve the people.

It is of utmost importance to gather carefully all the facts and information that you can before setting a course of action. Study the alternatives and work toward the solution of your problems in the most appropriate manner.

Use your organization and your systems of communication to let all of your people know what the possibilities are.

Be sure that the goals you set are ones that will meet the real needs of your consumer group. Then go to work!

More and more it is becoming apparent that consumer organizations must form alliances to gain services and education for developmentally disabled children and adults, services and education that they all commonly need, but that some groups would be hard pressed to get on their own.

It is a disservice to all developmentally disabled people for consumer groups to work alone and cause a separate system to be set up for each when they could work together, bound by the realization of their common needs. Joint action can result in the establishment of systems that address themselves to the real needs of disabled people, rather than to categories of disability.

When categorical service delivery systems are set up, they arbitrarily exclude people on the basis of a label, and not because those people cannot benefit from the service. This is wasteful and it is harmful to the excluded people. An alliance of consumer groups for developmentally disabled people can bring strong leadership together, provide situations in which they can discover areas of common interest, and plan unified action that can benefit all of those concerned.

This is not to say that separate organizations, societies and associations are not needed. They are essential. They need to be strong and active. Each element of disabled people has special needs that are understood better by them than by anyone else. But when they come together in an alliance, they can learn more about

each other and realize that their areas of common need are vast, and the possibilities for unified action are many. Alliances of consumer groups are the wave of the future. They are already being formed. And where they emerge in ways that do not threaten the special needs of individual groups, their impact is substantial and invariably beneficial.

### Monitoring and Evaluation by Consumers

One of the best ways for consumers to be sure that services and programs set up to serve them are actually doing the job is through constant monitoring and regular evaluation of these systems and programs. Consumer organizations can monitor classrooms, day care centers, training programs, school boards, town councils, county commissioners, commissions and committees of local and state governments - any service for developmentally disabled people and any public body with authority to affect the lives of disabled people.

Consumers, who know what they ought to be receiving from particular programs, are in a good position to make these kinds of judgements. Common sense tells us, and research has borne it out, that people do what they are employed to do with a keener sense of responsibility when they know they are being observed. And if the observation is done by someone who can intervene in case of laxity or transgression, the sense of responsibility is apt to be heightened considerably.

If consumers are not in a position to correct problems discovered through monitoring and evaluation, they can see to it that an accurate statement of the difficulty is presented to people who can. And if the problem is not solved satisfactorily, they can proceed up the line of authority, presenting the problem accurately and firmly at each level, until something is done about it. If all else fails, they can take it to the people through the news media.

Anyone attempting to monitor or evaluate a program must have a clear understanding of how the program is supposed to affect the individuals served by it, what its goals are, and how it goes about meeting them. Standards can be developed from these goals and the program judged on the basis of how well or how poorly it meets these standards. It is elementary that the goals of a program serving disabled people must be those which benefit them directly, meet their needs, and improve the quality of their lives.

Monitoring and evaluation require time, energy, and commitment from consumers. But this does not mean that consumer organizations should shy away from doing it. A system of monitoring and evaluation should be an integral part of every program developed to serve disabled people. Consumers involved in planning services can insist that this be done.

Unfortunately many programs already exist which have no monitoring and evaluation component, and many of these actively resist its installment. It is clearly the responsibility of consumer organizations to overcome this resistance



through progressively insistent activity, using strategies adapted to the particular situation, so that program and service delivery systems become clearly accountable to the people they serve, and so that the programs and services are appropriate and beneficial to the consumer.

### Consumer and Advisory Boards

Often it falls to the consumers to take the initiative and use the strength of their combined efforts to turn systems around and make the right things happen. Clear ideas, well thought-out plans, plain and sensible proposals designed to fit the real needs of disabled citizens are the best tools to use in altering established systems which are ineffective if not harmful. When these plans are presented with determination by large numbers of organized consumers, they cannot be ignored.

In recent years, largely as a result of persistent consumer action, the federal government and many state and local governments have begun to recognize the value of consumer participation in the planning and delivery of services. The idea of professionals holding complete control of service delivery systems is slow to die, but much new legislation requires that non-professional people serve on boards that plan and direct service delivery.

When this is the case, one of two things can happen: The consumer board member can accept a secondary, passive role in which he becomes a "yes man" to the professionals. When this occurs he has not only negated any value he might have had as a board member, but he has also provided the professionals with license to do whatever they wish with token consumer consent; or, the consumer can take an active role as board member. There are a number of ways in which actively involved consumers can contribute to and influence boards on which they may serve:

Be informed; attend board meetings prepared to offer ideas and suggestions;

Gain a full understanding of the board's purpose, activity and power;

Insist that clear and complete explanations be given for all of the board's actions;

Insist that money be spent and priorities set in ways that are fair to every consumer element to be served, and that a full accounting be made;

Insure that committee appointments include fair consumer representation;

See that a minority report is issued if action is taken with which consumer members strongly disagree;

Join with other consumers and take issues to the public through the news media if other channels fail to prevent actions which are felt to be unfair.

An active, informed consumer can give life to a sluggish board and make things happen for the good of the consumers that the board was established to serve. And the consumer need not be a parent, guardian or someone advocating for disabled people. He may be a disabled person whose disability does not prevent him from being an advocate and who knows, first hand, about the needs of disabled people.

A consumer serving on a board that is planning services must be cautious not to become so involved with professional people that he adopts the professional attitudes and reactions that have shut consumers out of the planning process and service delivery systems for years. It can happen without his even being aware of it. The result is that the real consumers are shut out once again. They are no longer consulted, since the professional consumer speaks for them. Their real wants and needs go largely unheard. And the service delivery systems can once again drift into patterns of delivering services that are less and less appropriate to the situations they were designed to alleviate.

A consumer serving on a board that is planning services can avoid the "professional consumer" pitfall by observing a few simple "dos" and "don'ts":

DON'T assume that because you are a consumer you automatically know everything every other consumer knows. Be confident that your own viewpoint and your own experiences are valuable. Express that viewpoint and share those experiences. But understand that they may not be universal.

DON'T speak for all members of your consumer element until you have a real grasp of what their needs and wants are. Make every effort to know their needs.

DO consider that you are a representative of the consumer group of which you are a part. As a representative, you have a duty to see that they are contacted, talked with, involved, polled and listened to; and that their needs are met by the services you help provide.

DO insist that every element of any program you help design has consumer input and involvement, and that every element is accountable to the people it serves.

If these points are observed, the plans and services that emerge from the work of the board will be much more likely to respond to the real needs of the consumer.

### Summary

Consumers, whether they are disabled people or advocates for the disabled, have the right and the obligation to play a leading role in the planning and delivery of services that affect their lives. They have a right to know that their share of the tax dollars is spent in ways that are beneficial to them. Consumers have the same obligation as other citizens to see that this occurs.

Professional people must recognize the value of the consumer as a participant in planning and delivering services. They must encourage his participation and respect his ability so that, together, they can accomplish things in which they are commonly interested.

And consumers, themselves, must unite their efforts. When they are separated, in competition with each other, ignorant of their potential power, they can be overlooked, mistreated, preyed upon and used by people who have things in mind other than the well being of the disabled person. But when consumers come together with determination to solve their problems, they can become a potent and influential force that cannot be ignored.

The DD Council provides an excellent forum for consumer initiative. Here, consumers can be key members of groups responsible for planning, developing and improving the quality of services for developmentally disabled people. The Council can also provide support for consumers at the local level in securing their rightful places in service delivery activities. Finally, the Council can be a source of information to consumers and a resource for incorporating local consumer data and perspective at the state level.

# themes & issues

DD/TAS

Suite 300 NCNB Plaza

Chapel Hill, North Carolina 27514

BULK RATE  
MAILING  
U.S. POSTAGE  
PAID  
CARRBORO, N.C.  
PERMIT NO. 12

310-00429000  
ROGER STRAND  
8TH FLOOR 802 CAP SQ BLDG  
550 CEDAR ST  
ST PAUL, MN 55101

*DD/TAS is a division of the Frank Porter Graham Child Development Center  
University of North Carolina at Chapel Hill*