DD

themes & issues

A Series of Topical Papers on Developmental Disabilities

Advocacy and the Human Service Delivery System
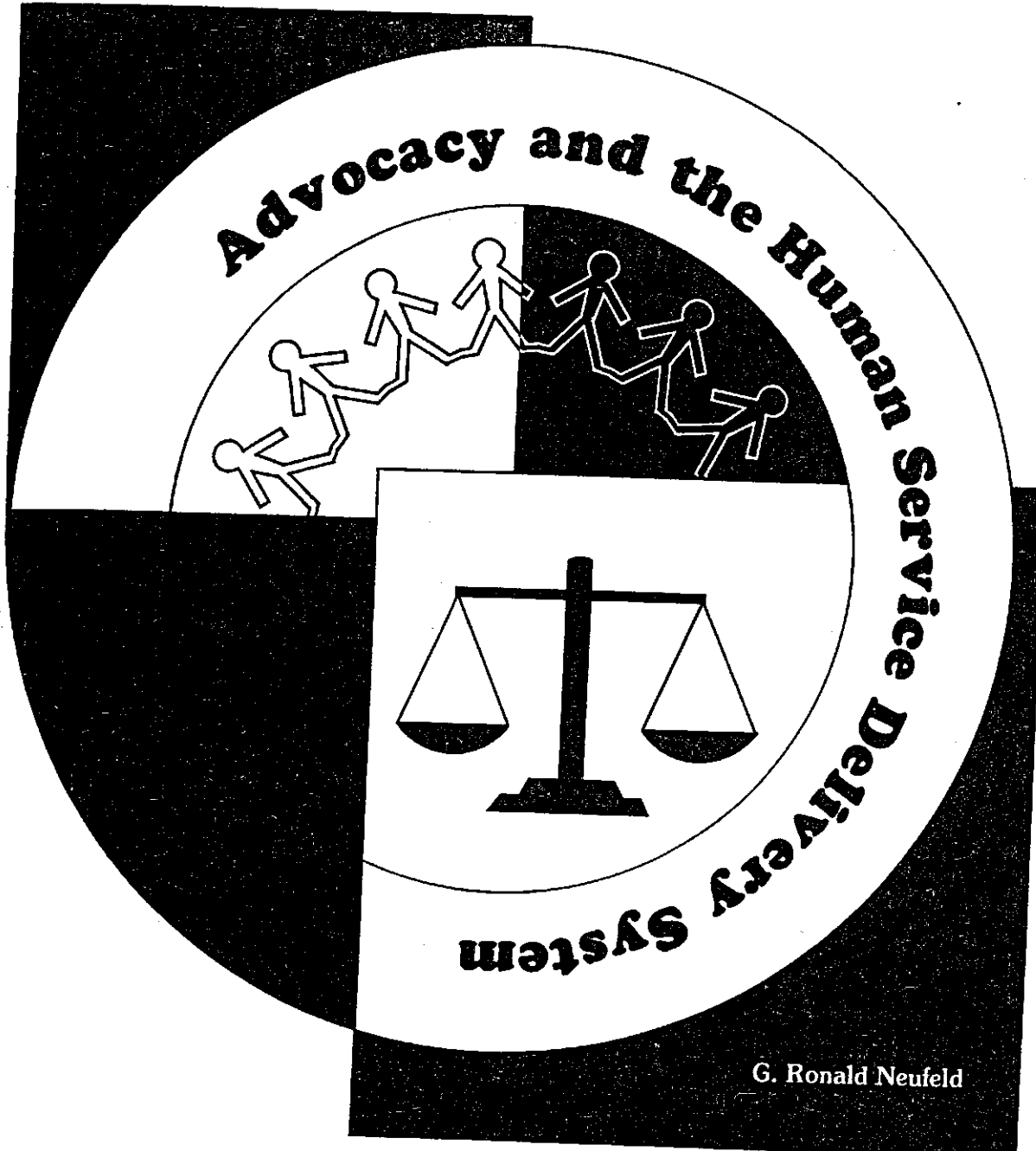
G. Ronald Neufeld

ABOUT THE AUTHOR

G. Ronald Neufeld, Ph. D., is co-director of the Developmental Disabilities Technical Assistance System (DD/TAS) in Chapel Hill, NC. Dr. Neufeld was formerly Coordinator of Services for Children and Youth, Department of Mental Health and Mental Retardation in North Carolina. Prior to coming to DD/TAS, Dr. Neufeld was Director of the Child Advocacy Center, Durham, NC.

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DD Themes and Issues is a series of topical papers for this nation's Developmental Disabilities Planning Councils. 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.

Advocacy and the Human Service Delivery System

by G. Ronald Neufeld

Introduction

An advocate, simply defined, is one who is trying to maintain or promote a cause. From an individual perspective, advocacy is acting in behalf of or pleading a cause for another. It often involves fighting for someone who can't fight for himself. Direct, individual advocacy is the cornerstone of all advocacy, and it is as old as the human race. The basic goal of all advocacy activity is to improve the quality of life for some person or group of persons. Individual advocacy is usually defined as a one-to-one relationship between a capable volunteer and a disabled person in which the advocate defends the rights and interests of the disabled person and provides practical and/or emotional reinforcement. The purpose of this paper, however, is not to deal with personal, one-to-one advocacy but rather to consider advocacy activity in its relationship with the human service delivery system.

Problems in the Human Service Delivery System

The past twenty years have brought about unusual growth and expansion in the field of human services. In many states growth in the human service system has resulted in the development of organizations at several geographic levels, including local, regional within state, multi-state regions and national. To a citizen at the local level this multi-layered bureaucracy might resemble a huge onion. No matter how many layers are stripped away, there always seems to be another layer. Pressing the onion metaphor a bit farther, a person attempting to strip away the bureaucratic layers is likely to be driven to tears before an accountable agent is found.

The human service network is sometimes referred to as a system or a machine. This analogy is weak since the terms "system and machine" imply relationships among the parts. At the same bureaucratic level, as well as across levels, we witness a great deal of fragmentation and lack of communication. At the Federal level we are confronted with piecemeal evolution of legislation and confused agencies trying to implement legislation, and maintain coordination and communication between the many parts of the huge Washington structure. Communication and interaction between agencies is not much better at the state level. State agencies spend much of their energy in political warfare with other agencies: activity aimed at gaining support for their programs from governors and legislators. Similar interagency warfare, and "turf-defense," takes place at the local level. Professionals disagree over theory, philosophy and intervention strategies. These conflicting viewpoints are played out in the warfare among service providers. In some instances, local agencies fight for control over the same clients while the needs of a majority of disabled citizens go unmet.

The tragic aspect of this waste and confusion is that the *loser* is the citizen who needs the service but can't get it. Our human service system has become so large and complex that even competent individuals need help in making their way through the organizations that constitute our delivery system. Perhaps the best analogy for our human service system is that of a giant maze. The maze runners are not rats but humans who are trying to obtain the services and re-

sources which are the reinforcers at the end of the maze. One gets the feeling that only a very small proportion of the total reinforcers or resources set aside for disabled persons are dispensed to them. The largest proportion of the resources are absorbed in maintaining organizations that exist in and for themselves. In keeping with Darwinian theory, only the fittest maze runners survive. In this system, handicapped people are always the losers. Maybe that's what advocacy is all about — trying to minimize the losses for developmentally disabled citizens.

Given the size, complexity, and unresponsive nature of the bureaucracy, it is unlikely that an individual advocate, alone, will be successful in moving the system. If advocacy for an individual calls for change in the human service system in order to render it responsive to an individual's needs, then advocates must have access to a source of political power. Advocates should create their own organization, one that takes on the characteristics of a social movement. In this connection, advocates can learn from civil rights activity or the women's liberation movement. Advocates resemble civil rights leaders; they represent a minority population whose basic human rights and needs are often ignored. If the voice of this minority population is to be heard in the relentless flow of the political and bureaucratic stream, then advocates and handicapped citizens must organize and present a strong, unified front. We cannot afford division among the rank and file of citizens who wish to bring about responsive governments, yet there are two conflicting approaches to bringing about accountability in human services.

Two Advocacy Approaches

Advocacy activity that interacts with the service delivery system and attempts to render human service organizations more responsive to the public has resulted in two conflicting viewpoints. One viewpoint contends that the only kind of advocacy that can possibly succeed is "external advocacy," or advocacy that operates on the human service delivery system from outside and is externally supported. A second viewpoint says that "internal advocacy," or advocacy that is supported internally and works from inside the system, is a superior advocacy approach. There are strengths and weaknesses in each approach.

Internal Advocacy

An internal advocate is an advocate who is paid by the system in which he works. It is the contention of the internal advocate that the system needs reform and renewal and that this can be accomplished most effectively by activity from within the system. The internal advocate is committed to identifying individuals whose rights and needs are not being met by the system in which the advocate is employed. The advocate's work consists of activity aimed at changing the system to be responsive to the client and his needs. Concerning style, internal advocates first try to negotiate with service providers and bureaucrats; confrontation is avoided if possible.

There are many critics of the internal advocacy mechanism who contend that it cannot work. "Whose bread I eat, his song I sing," observe the antagonists of this approach. The major concern with the internal approach is that when system maintenance or staff interests conflict with client needs, the internal advocate will compromise the interests of the client. However, no one is a "pure" advocate, that is, one who can always dedicate himself exclusively to the welfare of another. It should therefore be pointed out that when one fails, or chooses not to promote the best interest of a client, and gives way to demands from the system — at that point one ceases to

be an advocate.

To the extent that an advocate can resist being co-opted by the system, there are some strong advantages to advocating from inside the system. For example, advocacy aimed at accessing services for a client often requires detailed knowledge of the system, its organization, and its resources. Such information is much easier to acquire from within the system. Similarly, accurate data concerning program weakness and human abuse to clients can be obtained most readily from inside the system. Another advantage to internal advocacy is that financial support is likely to be relatively stable, enabling advocates to concentrate on the work of advocacy rather than financial survival.

External Advocacy

In contrast to internal advocates, external advocates receive support from private sources outside the human service system and are not accountable to persons in the system in which they are advocating. The external advocate tends to be viewed (and views himself) as an adversary of the system. There is a further tendency by the external advocate to consider the system and all of its parts evil. When insensitive system arrangements are encountered, external advocates are inclined to promote system dismantling. External advocates are prone to think that negotiation is a waste of time and they move quickly to confrontation. It is the external advocates' reputation for confrontation and dismantling that earns them the identity of system adversaries.

The primary advantage of external advocacy is its independence from the system. The external advocate is much less likely to be "co-opted" or "cooled out" by the system. Whereas the power of the internal advocate relies upon the ability to negotiate within the system, the external advocate can resort to force, intimidation and coercion. The external advocate can call upon the threat of courts, exposes through the public media, and pressure from public groups, such as parent organizations, to bring about change and influence the system. Internal advocates would run the risk of losing their jobs if they threatened their organizations with external coercion. Thus, if an advocate is forced to resort to confrontation, it is an advantage to be outside or have external financial support.

The great disadvantage for the external advocate is the likelihood of limited access to the environments or programs in which the clients are served. External advocates must often rely upon information that is reported to them from other sources. To the extent that advocates are unable to collect information personally, the second-hand information upon which they must base their actions may be vague, misleading or even faulty. Nothing erodes the credibility of an advocate more quickly than false data. A cardinal rule for an advocate is to act only upon reliable information that can be verified. The use of unreliable data makes Don Quixotes of advocates: they know the basic issues, but they don't know the enemy. Hence they find themselves bending their lances on the wrong targets.

While a large bureaucracy has a tendency to corrupt its membership and alienate them from individual clients who need service, there are still many benevolent persons in the system whose sensibilities to client needs have not been blurred. These "good gals and guys" in the system might be called natural advocates. External advocates with an adversary perspective tend to view the entire system negatively which prevents their discovering and relating to the natural advocates. With no connections or allies in the system, the external advocate is likely to be rejected from the body of the human service system as an alien organ.

Another disadvantage of external advocacy is its tendency to be financially unstable. Where does an external advocate go for support? There are sufficient interconnections between the various levels of state and federal bureaucracies so that an advocacy organization using government resources of any kind cannot be viewed as truly external. Even programs supported by resources from different levels of the system are subject to pressures and co-option due to connections between different parts of the system.

For an advocacy organization to be truly external, its support must come from a private source. However, advocacy activity is often too controversial to attract funds from private organizations, even when, as in a recent experience, the private foundation carefully examined the proposal and acknowledged a need for the activity. This particular foundation wanted to support activities like apple pie, motherhood, grits in the south, hockey in Canada, crumpets in England, or hamburgers in America, or in other words, an activity that would always result in only good public relations. External advocacy designs have few sources to call upon for financial assistance, and the financial support they obtain may be unstable.

Additional Significant Contrasts

Additional problems for external advocacy programs are created by temporary leadership. Persons who provide leadership for external advocacy programs tend to be highly charismatic individuals who depend largely upon part-time employees or volunteers. Whereas internal advocates recognize that to bring about system renewal, activity must be long-term, external advocates tend to adopt short-term, limited goals aimed at solving specific problems. When the problem is solved, appears to be insoluble, when financial support runs out, or when the leader vanishes, external advocacy activity dissolves.

A final disadvantage of the external advocacy approach is that an advocate is vulnerable to becoming so caught up in the process of struggling with the system that the interests of the client are forgotten or ignored. The legal advocate is particularly vulnerable at this point. In an attempt to win a decision in the courts, the welfare of an individual client may be sacrificed for months or even years. When an advocate becomes entangled in the web of system adversary, it is entirely possible to grow preoccupied with the fight. The end becomes winning against the system or even dismantling the system. To the extent that a system adversary activity loses sight of the welfare of individual clients, that activity is not advocacy at all. Courage is an admirable trait; however, a system adversary or a lone advocate trying to effect massive system change may be analogous to a gnat straining at a camel. Advocates need to be more than a trivial annoyance in someone's hindquarters.

In order to maintain an accurate perspective on the contrast between internal versus external advocacy, two points must be kept in mind. First, external advocacy is defined here as a mechanism that receives its support wholly from private sources outside the human service system and external advocates are not accountable to persons in the system in which they are advocating. Very few advocacy programs across the country meet this definition of advocacy. There are, however, a growing number of advocacy programs that receive public resources from one organization in the human service system, and conduct their advocacy work in another part of the system. Such advocacy programs are, in reality, internal even though they may call themselves external and behave according to the external model. Internally funded advocacy mechanisms that adopt an external adversary style usually have a short life. This may partially account for the high

mortality rate among advocacy programs. The second point concerning the description of internal and external advocacy is that in order to provide a clear contrast between two different approaches, the descriptions of characteristics and behaviors have been polarized. Most advocacy programs are a mixture of the two designs. But perhaps advocacy organizations would be in a better position to understand their strengths and weaknesses if they made an assessment of their programs according to the internal and external models described above.

Internal Advocacy: An Example

There are advantages and disadvantages to both models of advocacy. The examination of a specific internal advocacy program illuminates the strengths and weaknesses more closely. In 1970, a statewide advocacy program known as the Child Advocacy Center was launched in North Carolina. It was aimed at developing advocacy principles and procedures. Advocacy activity took place at the State level and in several public residential institutions across the State. The intent of the Child Advocacy Center was to train staff in the areas of institutional reform and depopulation of residents from residential institutions.

At the State level, it was recognized that very weak provisions existed to protect the rights and interests of residents in public institutions. A project was therefore designed to: (1) examine existing law and policy related to the rights of institutionalized persons; (2) develop ideal legislation to protect resident rights; (3) collect data on violations of rights of residents; (4) develop steps for the passage of new and improved legislation; and (5) provide human rights training for institutional residents, parents of institutional residents, and mental health staff.

Along with the State level advocacy activity described above, the Child Advocacy Center provided leadership to develop advocacy programs in four residential institutions throughout the State. Activities in the institutional settings included procedures to return residents to the social mainstream, and mechanisms in the institutions to identify human abuse, and locate program gaps and weaknesses. After three years of operation, the Child Advocacy Center, as a statewide program, closed its doors. Four years after the Child Advocacy Center was launched, only one of four participating institutions had an active and flourishing advocacy program. The reasons for this record of dismal failure should be examined.

The first reason for the failure of the Child Advocacy Center is that it was engaged in a number of highly controversial activities that called for confrontation within the system. Both the press and the courts became involved in several activities that the Child Advocacy Center initiated. While battles for clients were won, the Child Advocacy Center as a mechanism lost its war for survival with the bureaucracy. Involvement in highly controversial activity forced the Child Advocacy Center into a higher profile than it could survive; the Center itself, rather than the rights of clients, became an issue. The activities and ideals of the Child Advocacy Center resulted in many attacks, and in attempting to respond, the staff discovered that the majority of their time was spent justifying the existence of the Center to State bureaucrats and administrators from residential institutions. As increasing amounts of its energy were spent justifying its own existence, the Child Advocacy Center became an institution. In other words, it became an organization that exists primarily for itself and its staff. Another way of looking at the dilemma of the Child Advocacy Center is to examine the "fit" between its ideals and mission and its activities. When attacks upon the advocacy program became too heavy, staff members were unable to do their work. At that point there was a breakdown of the "fit" between mission and activities. The Child Advocacy Center staff adopted a position that, from a moral and ethical viewpoint,

such programs should close their doors.

The second major problem of the Child Advocacy Center was that it was a *completely* internal advocacy program. It was supported by public funds and attempted to work within the system that was supporting it. Although the Child Advocacy Center had been promised support from the chief executives in the supporting sytem, when controversy began to rage around the program, threatened bureaucrats withdrew their support. This undermined the only power and authority of the Center. An internal advocacy mechanism cannot survive without the unqualified support of the chief executive. In an institution, an advocacy program must have support from the superintendent; in a Department of Mental Health, advocates working at the state level need the unqualified support of the Commissioner of Mental Health. The Child Advocacy Center was unable to survive, because it was compelled to utilize the confrontational arms of the press and the courts in some of its activities. There are very few organizations and administrators willing to support an internal advocacy mechanism that uses external advocacy tactics.

Advocacy that Works

An ideal advocacy program should combine internal and external characteristics in order to be successful. Thus, an advocacy program may look toward public resources for support, and activities may even take place in the same environment in which the advocate gets paid. However, the internal advocate must also seek support from the private sector. In an institution, the advocate may look toward a human rights committee for support. Such a committee would include a number of consumers and parents of consumers employed outside of the system. At the level of state government, organizations like the Developmental Disabilities Council are logical advocacy mechanisms. In theory, the composition of the DD Councils has all of the ingredients of an excellent advocacy mechanism. The Councils include state agency staff, service providers and consumers. Internal advocacy components include agency staff and service providers; the external advocacy component is the consumer.

State agency staff, however, cannot be considered advocates if they come to the Council representing their agency, the Governor, or some political party. In many states key administrative positions are filled due to political patronage. Political loyalties can and often do blur the advocacy mission of a Council. In some instances service providers on the Council use it as a forum to obtain resources for their geographic region or for their specific programs. The consumer representatives are in a unique position to prevent vested interests of state agency personnel and service providers from taking over the mission and agendas of the Councils.

Furthermore, assuming that state agency staff and service providers are natural advocates in the system, consumers can provide protection for them and work toward depoliticizing the human service delivery system. The appointment of staff in the human service system should be based upon their work and experience, not upon their political alliances. It is recognized that as internal advocates, state agency staff and service providers are limited in their ability to confront the system. Adversary roles should be undertaken by the consumers on the Council rather than allowing the internal advocates to place their jobs in jeopardy.

While the success of a Council as an advocacy mechanism depends upon the involvement of consumers on the Council, consumers are not immune from co-optation. As members of consumer organizations, consumers may obtain grants from state or federal coffers to run their programs. In so doing they may be selling their "external" birth rights. Consumer organizations

should be careful to avoid this dilemma. A second problem surrounding consumers on the Council has to do with their membership in a specific consumer organization. Some consumers behave as if they are on the Council representing a specific consumer organization such as the Association for Retarded Citizens or the United Cerebral Palsy Association, etc. Developmental Disabilities Councils have the potential for functioning as an ideal advocacy mechanism. But this will happen only if there is a coalition of all of the interest groups.

Public Law 94-103, the Developmental Disabled Assistance and Bill of Rights Act, contains a provision for the establishment of a statewide protection and advocacy system. Section 113 (a) requires that these systems " . . . have the authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the right of such persons who are receiving treatment, services, or habilitation within the State." It further requires that the mechanism responsible for implementing the protection and advocacy system " . . . be independent of any state agency which provides treatment, services or habilitation to persons with developmental disabilities."

There are many questions for an advocacy organization that is structured and funded in this way. First, what happens to advocacy activity that becomes a large statewide system? Can it operate at the statewide level, dealing with many issues and many organizations, and yet retain its sensitivity to the individual rights and needs of disabled persons? Or, will individual rights and needs give way to the collective needs of the larger body of clients to be served or even to the organization itself? If and when the protection and advocacy system within the state pursues an issue in the courts, will the administrative and political organizations within the state reject the programs, and turn back federal resources because of their disruptive influence in the state?

There is a need for service integration at all levels in the human service delivery system. Will the protection and advocacy systems be disruptive rather than integrative, setting up conflict between agencies, DD Councils and themselves? Or, will protection and advocacy systems, by re-directing accountability to individual disabled citizens, be able to bring about service integration by multiagency support around individuals?

Perhaps the struggle of advocacy programs. Developmental Disabilities Councils and protection and advocacy systems is part of a much larger struggle. If in the area of human services, we are unable to render the system accountable to our citizens, what are the implications of this failure for the principles of democracy? If administrators in local programs can't be open and responsive, and if federal officials do not answer to the public, then government of, for and by the people is a myth. There is too much at stake to allow the concept of advocacy and the mission of Developmental Disabilities Councils to fail.

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DD/TAS

Suite 300 NCNB Plaza

Chapel Hill, North Carolina 27514

SEP 24 1977

310-00071000
ROBERT   BRUININKS
100 CAPITOL SQUARE 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