

FURTHER EXPLORATIONS OF
ADVOCACY MODELS FOR
THE MENTALLY DISABLED

EXECUTIVE SUMMARY

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The following summary describes the conduct and findings of an evaluation of ten advocacy projects providing services to mentally disabled persons around the country. Both the assessment and the advocacy projects were supported by funding from the Department of Health and Human Services. The study results are based on information gathered during the second and final year of a two year evaluation process. The discussion is divided into five parts: introduction to advocacy services, overview of the projects, outline of design and methodology, summary of findings, and recommendations for the future.

I. INTRODUCTION

Advocacy on behalf of mentally ill persons has been manifest in several ways over the past decade and a half. Efforts to improve the life chances of this group of disadvantaged citizens have included pressure for legislative reform, filing of large class action suits, intensified education regarding client entitlements, expansion of independent legal services for individual client problems, and -- most recently -- development of advocacy groups run by and for mentally ill persons themselves.

Though there are still endless debates regarding the parameters of advocacy and, in turn, who is entitled to the designation of advocate, most of those concerned with the well being of mentally ill persons would agree that a system or network of advocacy services is not limited to any one approach but rather is characterized by a variety of components. Gerard Fitzpatrick describes the ideal "mental health advocacy system"

as being comprised of four elements.*

1. A rights protection mechanism within the service delivery system;
2. A legal advocacy mechanism independent of the service delivery system and capable of taking legal action against it in cases beyond the competence of the internal agency;
3. A citizen advocacy mechanism;
4. An agency capable of training mentally ill and mentally retarded individuals to advocate on their own behalf whenever feasible.

II. OVERVIEW

The evaluation described in this summary is not directed at a system of advocacy but rather at individual component parts. Two of the projects, the Client Advocacy Program in Wisconsin and the Patient Advocacy Office in California, fall into the first category -- internal rights protection organizations. Five of the projects, Vermont Mental Health Law Project, Idaho Mental Disability Law Unit, North Shore Children's Law Project, Denver, Legal Center for Handicapped Citizens, and the New Jersey Division of Mental Health Advocacy, can be classified as independent legal advocacy mechanisms. One of the projects, Rubicon Independent Living Program, trains mentally disabled persons to advocate on their own behalf. The remaining two projects, Patients' Rights Advocacy Services of San Francisco and

* Gerard Fitzpatrick, Mental Health Advocacy and Public Policy: Enforcing the Rights of the Mentally Handicapped in the Aftermath of Judicial Intervention, Mental Health Policy Monograph: Number 12, Vanderbilt University, September 1981, pp. 164-165.

Mental Health Advocacy Project of Santa Clara County, provide legal and other advocacy services in partnership with local government. Though the activities of some of the other projects also span more than one category, as a rough organization of the demonstration programs, this typology is instructive.

The range of projects evaluated indicates that the study was more an assessment of discrete approaches to mental health advocacy than an analysis of an interconnected network of advocacy programs. It is also not totally exhaustive since the evaluation did not include projects devoted predominantly to "citizen advocacy."

The projects studied also varied widely in terms of their auspices (e.g., public, private, public contractor, etc.), the level of their resources, the target population served, staff training and qualifications, and scope of services. Thus, the projects studied should be seen as characteristic of certain types or classes of advocacy enterprises rather than as a coherent whole.

III. DESIGN AND METHODOLOGY

When the evaluation project began, there was widespread interest in the Department of Health and Human Services and the United States Congress regarding the development of a nationwide advocacy system in the wake of the report of The President's Commission on Mental Health.* In the fall of 1980, the Congress

* President's Commission on Mental Health, A Report to the President, 1978.

passed the Mental Health Systems Act which included provision for state advocacy programs. The passage of the Act generated even more interest in the potential shape and content of an expanded advocacy system.

Therefore, one of the reasons that both the advocacy projects and the concurrent evaluation were extended into a second year was to generate a more cogent framework for the development of national policy and a broadened based of information from which to assess the implementation of such policy. Even though the Mental Health Systems Act was superseded by the ADAMHA block grant, advocacy for mentally disabled persons remains a key federal concern for the following reasons:

- Language in the Omnibus Budget Reconciliation Act of 1981 gives the National Institute of Mental Health the responsibility of providing technical assistance to the states in a variety of areas including monitoring and quality assurance.
- The federal government continues to provide funding for state Protection and Advocacy agencies for developmentally disabled persons.
- National consumer and professional groups will continue to seek federal legislative and regulatory reforms that will affirm and enforce the rights of mentally disabled persons.
- A worsening economic climate and a squeeze on all public resources has exacerbated the plight of many mentally disabled persons, and may accelerate institutionalization and reinstitutionalization, and may erode some of the gains made by this population over the past two decades.

With these broad concerns in mind, the objectives of the evaluation study can be outlined as follows:

- To describe each of the ten advocacy projects in terms of:
 - * staffing;

- * sociopolitical context;
- * project history and current mission;
- * clients served.
- To describe commonalities and differences across projects in terms of:
 - * goals for direct services to clients;
 - * goals for programmatic activities (e.g., public education, resources development, etc.);
 - * approaches or strategies used to resolve individual client grievances;
 - * outcomes of advocacy activities;
 - * costs (i.e., distribution of resources).
- To establish a listing of commonly-valued goals of advocacy and to assess the extent to which project activities have:
 - * changed the delivery of services to mentally disabled clients in institutional and in community settings;
 - * succeeded in promoting and implementing patients rights in institutional and in community settings;
 - * effected systemic change and reform in terms of extended rights protection for mentally disabled persons and/or improved service delivery.
- To document perceptions of the utility and effectiveness of advocacy services among clients, direct service providers, administrators in institutions and state agencies, and others in the communities served by advocacy programs.

Because this evaluation took place during a period of diminishing funding for human services, the results of the evaluation also provide descriptive information on the impact of funding cuts on these ten programs -- and on the services available to their mentally disabled clients.

In the second year of the advocacy assessment, the evaluation design was expanded to include a focus on the

selection of goals and priorities, the determination of appropriate strategies to achieve the goals, and the factors that inhibit or promote the reform of service delivery systems. In order to ascertain what the goals were for each of the ten projects, the initial project activity involved a "goals negotiation" process. Evaluation staff worked with key staff in the advocacy agencies to elicit their four primary client-targeted goals and their two most important system reform goals. These six goals formed the core of the evaluation for each of the ten advocacy projects.

Four instruments were used to collect information on a number of variables related to the six selected goals:

1. Individual Client Profile -- This instrument consisted of two sections. The first portion included information about individual client characteristics, problems presented, strategies used, and interim and final outcomes for the case. The second section recorded staff time spent on activities related to the case in six activity areas. Each project was instructed to complete individual client profiles for a selected sample of 24 clients each month, beginning when the case was opened and ending the month in which the case was closed. The sample included four groups of clients reflective of the four client-targeted goals.
2. Aggregate Client Data Collection Instrument -- This tool was used to record information on all cases opened and closed by the project during each month, for all six months of the data collection period.
3. Project Overview Instrument -- This format was completed bimonthly by each of the projects over the six-month period. It recorded general information about project caseloads and requested structured narrative concerning all system reform activities undertaken in the identified areas.
4. Staff Time and Budget Instrument -- This form collected detailed information on project resources and costs, including figures for income sources, staff salaries and overhead expenses. Staff also indicated the proportion of their time spent in each activity area.

Additionally, two to three day site visits were conducted at each agency. During the site visit, evaluation staff observed the advocates' routines, talked with clients, and interviewed relevant key informants at the state and local level including state mental health officials, judges, legislators, hospital administrators, generic service providers, residential proprietors, and other advocates.

IV. SUMMARY OF FINDINGS

A. Quantitative Findings

With respect to the types of clients served by the ten advocacy projects, it is interesting to note that -- with the exception of one project -- very few children were served. Additionally, across projects, very few elderly individuals were served. Whether the concentration on non-elderly adults is random or by design is not clear. What may be more clear is that there is a need to explore the availability of specialized advocacy services for these two age groups.

It also appears that caseloads among the projects declined during the second year of the evaluation and that persons accepted as clients were more likely to have multiple problems than their opposite numbers in the first year of the evaluation. The decline in caseload can in part be explained by declining resources available to many of the projects. It may also be explained by a conscious narrowing of the caseload in order to focus on more disabled individuals -- a fact that is in part borne out by multiple problems presented by the clients.

With the exception of Wisconsin, New Jersey, and Idaho projects, which concentrated almost exclusively on institutionalized clients, the remaining projects focused a significant portion of their energies on the problems of persons making the transition from an institutional to a community setting or attempting to maintain themselves in the community. This may suggest that the projects are targeting their services on clients who have traditionally "fallen through the cracks" including persons requiring assistance in making the community transition and community-based persons who are not part of any mental health support system. Additionally, projects have taken on so-called entitlement advocacy (e.g., securing Supplemental Security Income, housing, etc.) not always available from traditional mental health agencies.

Reviewing the data on strategies employed by advocacy projects, it is interesting to note that negotiation not litigation was the strategy of choice among the projects. The use of negotiation also resulted in the most favorable outcomes. This finding to some extent dispels the notion that advocacy projects employ confrontational means to represent their clients to the exclusion of other techniques. In fact, virtually every project leaned heavily on negotiation as a means of resolving disputes.

B. Cost Findings

The costs of advocacy programs are difficult to find and compare since projects employ different accounting systems. Estimates of the costs associated with each type of advocacy

service or activity were founded on global estimates by staff members regarding how they distribute their work time. Estimates of the cost per case were founded largely on client-specific time estimates. Given the subjective element involved, and because of the small number of programs and clients under study, the reliability of the cost estimates cannot be established statistically and analyses are necessarily descriptive.

We found that the size of advocacy programs varies markedly in terms of operating expenditures (from less than \$50,000 to in excess of \$1,500,000 annually), and that the relative amounts paid for staff salaries and wages, fringe benefits, and other non-personnel costs likewise vary considerably from program to program.

Personnel costs are the primary costs in advocacy programs and thus the total costs are largely a function of how much staff time was spent and how much staff were paid. We found that state-operated advocacy programs tend to pay higher salaries than privately-operated programs. We found that the distribution of staff time and related personnel costs varies predictably in accordance with program objectives and target populations, and the activities undertaken. For instance, the average personnel cost per case of conducting an investigation ranged from \$30 to \$136, the average personnel cost of negotiation per case ranged from \$5 to \$63 and the average cost of litigation per case ranged from \$5 to \$67. Administrative actions and investigations, at an average personnel cost of \$72 per case, were the most expensive activities. Referral, at an average personnel cost of \$13 , was

the least expensive service per case.

We found that the cumulative personnel cost per case ranged from as little as \$42 to as much as \$566. The personnel cost of children's cases ran higher than adult cases overall and on a service by service basis. Among adult clients, the personnel cost per case for persons with developmental disabilities was higher overall for most categories of service than was the personnel cost per case of persons who were mentally ill.

Advocacy project costs appear quite low. There are a number of factors that account for this phenomenon. Most of the legal services provided are fairly routine and uncomplicated. In fact, most of the programs purposely avoided complicated cases in order to maximize their limited and dwindling resources. Moreover, the costs of the most expensive and complex activity, class action lawsuits, are spread across a number of clients. Finally, the personnel wage rates and non-personnel costs are especially low when compared to other legal and human service agencies.

C. Qualitative Findings

An assessment of the projects' efficacy in bringing about more broad based change in the service delivery system suggested the following:

- Over the two years of the evaluation, many of the projects were increasingly seen as resources to service providers in the interpretation and clarification of patients rights regulations.
- Several projects concentrated on institutionalizing or implementing past advocacy gains.
- Other projects worked to codify reforms in state statutes and, in some instances, advocacy staff were seen as a significant source of expertise in the areas of

legislative drafting and constitutional law.

- Several projects used their access to information about entitlements and rights as a means of influencing providers and other advocates. Over time, these projects became seen as sources of technical assistance on key federal regulatory and statutory provisions.
- A few projects stressed self advocacy among clients and were successful in assisting clients to bring about change on their own behalf.

V. RECOMMENDATIONS AND REFLECTIONS

As mentioned in the initial portion of this summary, the second year of the evaluation also provided an opportunity to observe the provision of advocacy services during a period of rapidly declining resources. In fact, by the end of the study, only seven of the original ten projects were still in business. Interestingly, only those projects that had managed to develop a formal funding relationship with a state or local government -- or were part of state government -- remained. Specifically, the projects that ceased operations were Vermont Mental Health Law Project, Idaho Mental Disability Law Unit, and North Shore Children's Law Project. The first two were funded primarily with Legal Services monies, and the third relied on foundation and other private funding. In the case of North Shore, some vestige of the program remains since some of its personnel and services have been merged with a non-profit children's residential services provider.

Of the projects still in operation, two are internal state advocacy projects (California and Wisconsin), one is an independent state-run advocacy project (New Jersey), and one is the state Protection and Advocacy agency (Denver Legal Center for

Handicapped Citizens). The other three agencies -- Rubicon Independent Living Program, Santa Clara County Mental Health Advocacy Project, and San Francisco Patients Rights Advocacy Services -- all have contracts with the local county mental health department.

What do the study findings coupled with this current status report suggest about the conduct of advocacy services for mentally disabled persons? The following are some observations and suggestions:

1. The relationships between mental health professionals and advocates do not have to be adversarial in every instance. In fact, as funding becomes more scarce, the mental health system may have to rely more and more on the skills of advocates to protect the entitlements of mentally disabled persons.
2. Given the current fiscal realities and the pressures that they create on the provision of mental health and related services, there is a potential danger that advocacy agencies may be drawn into more case management-related activities thereby diverting energy and funds from core advocacy services.
3. Both years of the study suggest that advocacy activities are not characteristically confrontational, nor do they involve litigation as a rule. This study, however, suggests that the presence of a lawyer on the staff or in the network of the project enhances the project's effectiveness because potential for litigation is present.
4. Clearly, this evaluation has limitations and it represents a beginning attempt to develop a methodology for assessing the impact of advocacy services. Given the importance of client advocacy in the mental health system, more should be done by way of research into the process and outcomes of a range of advocacy interventions.
5. There is no one model of providing advocacy services. Each of the projects assessed tailored its goals and strategies to the unique context within which it found itself. This fact strongly suggests that if federal legislation on advocacy is resuscitated, accompanying regulations should set broad standards but should not

dictate priorities and/or specific target populations.

6. Like mental health services, advocacy projects suffer from the fragmentation that multiple funding streams create. Thus, a single funding source for the support of advocacy services would result in the maximum stability and coherence for such services.
7. If advocacy programs are to persist, they should be legitimized in state statute and/or regulation.
8. Given the uncertainty of constitutional law in the field of mental disabilities and the shortage of resources, advocates will undoubtedly continue to focus their energies on the implementation of existing laws and regulations.

There are many other implications that can be highlighted, but the general theme that emerges from this two year undertaking is that advocacy services can and should be a permanent facet of any comprehensive mental health system. As we have come to understand, persons with severe mental disabilities are often unable to cope with the complexities and irrationalities of living, and securing and maintaining the resources necessary to meet their basic needs. Advocates provide the signposts and road maps that make the day-to-day struggle somewhat easier.