



Protecting the Rights of Developmentally Disabled Persons: Establishing a Statewide System of Advocacy Services

A Report by the New York State
Commission on Quality of Care
for the Mentally Disabled

July 1980

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Acknowledgements

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Special thanks is extended to those organizations which helped the Commission develop an inventory of independent advocacy agencies. We especially wish to express our appreciation to the Boards of Visitors of State Developmental Centers, New York State Association for Retarded Children, New York State Association for Cerebral Palsy, New York State Society for Autistic Children, Center on Human Policy, New York State Office of Advocate for the Disabled, Commissioners of the County Mental Hygiene Departments, and the Directors of the State Developmental Centers.

Special thanks are also given to Brian McLane, Chairperson, and to the other members and staff of the New York State Advisory Council on Mental Retardation and Developmental Disabilities, as well as to Commissioner James E. Introne of the Office of Mental Retardation and Developmental Disabilities, for their congenial collaboration and fiscal assistance which allowed the Commission to undertake this review of New York's advocacy system for the developmentally disabled.

Preface

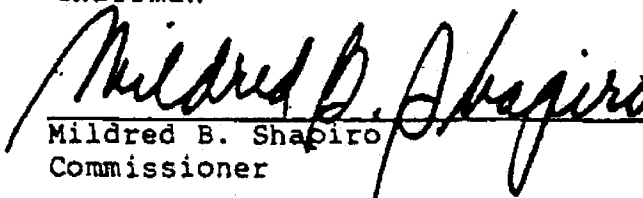
At the request of the Governor, the Commission was asked to undertake a study of New York State's independent advocacy services for the developmentally disabled to assess the means for establishing a comprehensive and cost effective statewide advocacy system. The conduct of this study involved identifying and surveying more than 300 existing independent advocacy agencies serving the developmentally disabled in New York State. The study profiles the State's advocacy agencies; describes the level of coordination among these agencies; and indicates the service strengths and limitations of the present advocacy system. The findings, conclusions and recommendations set forth in the report represent the unanimous opinion of the members of the Commission.

The contents of this report have been shared with the Commissioner of the State Office of Mental Retardation and Developmental Disabilities and the Chairperson of the New York State Advisory Council on Mental Retardation and Developmental Disabilities.

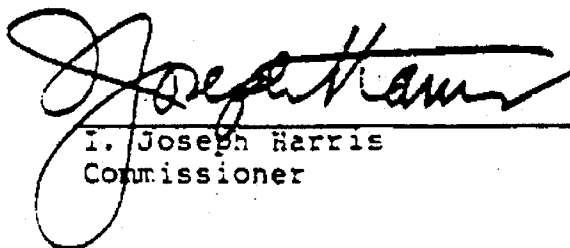
Through this report and its recommendations, the Commission hopes to assist in the establishment of a comprehensive statewide system to promote and protect the rights of all persons with developmental disabilities.



Clarence J. Sundram
Chairman



Mildred B. Shapiro
Commissioner



I. Joseph Harris
Commissioner

Table of Contents

	Page
Executive Summary.....	i
Chapter 1 Background of the Study.....	1
- Purpose of the Study.....	3
- Methodology.....	4
Chapter 2 Profile of NYS Protection and Advocacy Agencies.....	9
- Geographical location and catchment area of agencies.....	9
- Organizational characteristics of advocacy agencies.....	10
- Clients served.....	15
- Types of advocacy services provided.....	29
- Funding level and sources of income.....	30
- Summary profile of NYS protection and advocacy agencies.....	35
Chapter 3 Coordination Among New York State Protection and Advocacy Agencies.....	40
- Coordination policy of agencies.....	40
- Types of coordination practices employed.....	43
Chapter 4 Analysis of the Service Strengths and Limitations of New York State's Advocacy Service Delivery System.....	45
- Client groups most underserved.....	45
- Advocacy services most critically needed.....	52
- Summary analysis of unmet needs.....	53
Chapter 5 Conclusions and Recommendations.....	57
Appendix A - Advocacy Agency Survey Instrument.....	65

LIST OF TABLES

Table	Page
1 Number of Advocacy Agencies in the Sample by Catchment Area and County Service Group.....	12
2 Number of Advocacy Agencies in the Sample by Auspices and County Service Group.....	14
3 Number of Advocacy Agencies in the Sample by Size of Paid/Volunteer Staff and County Service Group.....	16
4 Number of Advocacy Agencies in Sample by Staff Status (Full-time/Part-time) and County Service Group.....	17
5 Number of Advocacy Agencies in the Sample by Staff Training Status, Type, Sponsorship and County Service Group.....	18
6 Number of Advocacy Agencies in the Sample by Type of Population Served.....	20
7 Number of Advocacy Agencies in the Sample by Developmental Disability Populations Served and Predominantly Served and County Service Group.....	22
8 Number of Advocacy Agencies in the Sample by Place of Residence of Clients Served and Predominantly Served by County Service Group.....	25
9 Number of Advocacy Agencies in the Sample by Age Group(s) of Clients Served and Predominantly Served and County Service Group.....	26
10 Number of Advocacy Agencies in the Sample by Service Orientation and County Service Group.....	28
11 Number of Advocacy Agencies in the Sample by Type of Advocacy Services Provided and Predominantly Provided and County Service Group.....	31
12 Number of Advocacy Agencies in the Sample by Annual Operating Costs and County Service Group.....	34
13 Number of Advocacy Agencies in the Sample by Funding Sources and County Service Group.....	36

Table		Page
14	Number of Advocacy Agencies in the Sample by Coordination Policy with other Agencies.....	42
15	Types of Coordination Practices by Advocacy Agencies Which Coordinate Their Activities With Other Agencies.....	44
16	Number of Advocacy Agencies in the Sample Perceiving Specific Client Groups as Under- served by Advocacy Agencies in Their Area.....	50
17	Specific Population Groups Cited by Agencies as Under-served/Unserved by the NYS Advocacy Service Delivery System.....	51
18	Number of Advocacy Agencies in the Sample Identifying Specific Types of Advocacy Services as Most Critically Needed in Their Area.....	54

Executive Summary

In seeking to establish a truly comprehensive protection and advocacy system for the developmentally disabled in New York State, the Governor requested the New York State Commission on Quality of Care for the Mentally Disabled to undertake a study of New York's advocacy network for the developmentally disabled with the ultimate goal of identifying the most cost effective manner of establishing a coordinated system. Four objectives for this study were identified:

- (1) to provide a descriptive profile of those agencies providing protective and advocacy services to the developmentally disabled;
- (2) to analyze the level and types of coordination among agencies providing protection and advocacy services;
- (3) to assess the adequacy of protective and advocacy services throughout the State and to identify critical gaps in the availability of these services; and
- (4) to develop recommendations for establishing a comprehensive and cost effective protection and advocacy system.

The conduct of this study involved identifying and surveying existing independent advocacy agencies serving the developmentally disabled in New York State. The criteria for including agencies in the survey were:

- (1) the agency must be currently operated and be composed of more than one person;
- (2) the focus of the agency's advocacy services must be within New York State;
- (3) the agency must be independent of direct care service providers, in conformance with the federal protection and advocacy standards;

- (4) the agency must offer at least one of the following types of advocacy services,
- information and referral
 - systems advocacy
 - legal advocacy
 - individual case advocacy
 - community education; and
- (5) the agency must provide advocacy services to the developmentally disabled as follows:
- by serving the developmentally disabled exclusively, or
 - by serving the general population, the disabled or mentally disabled persons, including the developmentally disabled as a client group, or
 - by serving special population groups, e.g., the low income, the deaf or blind, and including the developmentally disabled with such special characteristics/needs as part of the agency's focus.

These criteria were based on the federal law and guidelines governing the federal protection and advocacy program. Based on these standards, agencies which provide direct care or habilitative services were excluded from the sample for the survey. The Commission does, however, recognize that significant advocacy services are provided for the developmentally disabled by agencies in the service delivery network. Indeed many of these organizations have assumed roles of service providers out of their very commitment to advocate on behalf of the developmentally disabled. Advocacy provided through this system, commonly referred to as internal advocacy, is indeed a vital component of a truly comprehensive advocacy system which recognizes the necessity for both internal and independent advocacy efforts.

(iii)

The survey of identified independent advocacy agencies was conducted through a telephone interview with the agency director or president or his/her designated representative. The structured interview schedule assessed several aspects of an agency's operations, including:

- (1) staffing patterns;
- (2) types of advocacy services provided;
- (3) types of clients served;
- (4) catchment area of the agency;
- (5) critical gaps in the advocacy network and clients most unserved or underserved;
- (6) financing of advocacy services; and
- (7) level of coordination among advocacy agencies.

Over 300 agencies were surveyed. Based on the findings of the telephone survey, those agencies which did not meet the study's criteria for an independent advocacy agency serving the developmentally disabled were deleted from the study's sample. A total of 265 agencies constituted the study's final sample.

While these agencies represent the vast majority of existing independent advocacy agencies in the State, it should be emphasized that the study's time constraints did not permit an exhaustive search to identify all such agencies. As such, the 265 agencies surveyed are a representative sample, but may not constitute the totality of the State's independent protection and advocacy network.

The study's findings are presented in three chapters entitled:

- (1) Profile of NYS Protection and Advocacy Agencies;
- (2) Level of Coordination Among NYS Protection and Advocacy Agencies; and

(3) Analysis of the Service Strengths and Limitations of NYS Advocacy Service Delivery System.

The profile of protection and advocacy agencies highlights the heterogeneity and capability of New York State's advocacy service delivery system for the developmentally disabled. It also illustrates the potential of existing NYS advocacy agencies to serve as the essential components of an effective and comprehensive advocacy network for the developmentally disabled.

The study's findings, summarized in the descriptor statements listed below, highlight the heterogeneous nature and potential capability of the 265 agencies surveyed.

° Geographical characteristics

1. Advocacy agencies vary in the size of the geographical catchment area they serve, but the vast majority of agencies (80 percent) serve county or multi-county areas.
2. All counties in the State are served by at least four advocacy agencies and a majority of counties are served by 4-9 agencies.
3. Urban areas of the State tend to be the most served areas by advocacy agencies, with the largest concentration of agencies in the New York City metropolitan area.

° Organizational characteristics

1. Organizationally, New York's advocacy agencies are a diverse group, with some large, long-established, well organized agencies and many more small, newly established, informally organized groups.
2. New York's advocacy service delivery for the developmentally disabled is located largely in the private sector. Only one-fifth of the service delivery system is constituted of public agencies.

3. Most advocacy agencies rely heavily on volunteer part-time staff; however, a simple majority of agencies do employ paid staff and, generally, on a full-time basis.

° Client characteristics

1. While many agencies (40 percent) providing advocacy services for the developmentally disabled tend only to serve individuals with disabilities, nearly one-third of the advocacy agencies serving this special population are generic providers serving the general population. Another significant minority group of agencies (20 percent) primarily comprised of legal advocacy agencies, serve only persons with low incomes.
2. Advocacy agencies serving the developmentally disabled tend to serve all or at least three of the four most commonly identified developmental disability populations (mental retardation, epilepsy, cerebral palsy, and autism). Seventy (70) percent of the agencies serve each of these developmental disability populations, and over one-third predominantly serve each population.
3. The service focus of advocacy agencies is on children, adolescents, and adults residing in the community. Fewer agencies devote their service to institutionalized clients and the elderly.
4. Advocacy agencies serving the developmentally disabled client also tend to serve his/her family.
5. A significant minority of advocacy agencies serving the developmentally disabled serve a narrowly defined special group or class.

° Advocacy services provided

1. Almost all advocacy agencies (90 percent) serving the developmentally disabled provide information and referral services to clients.
2. Over two-thirds of the advocacy agencies surveyed also provide three other advocacy services; community education and training, individual (case) advocacy, and systems advocacy.

3. Legal advocacy is less often provided by advocacy agencies than other advocacy services. Only 38 percent of the agencies surveyed provide legal advocacy; nearly one-third of the agencies providing legal advocacy are identifiable as legal agencies, predominantly legal aid societies.
4. The predominant advocacy service provision of agencies tends to be information and referral, individual (case) advocacy, systems advocacy, and community education and training. There is, however, significant variance in the predominant advocacy service provision of agencies within each county service group.

° Funding characteristics

1. Advocacy agencies serving the developmentally disabled in New York State, in general, have low annual operating costs (less \$50,000) and rely on several different funding sources to finance their costs.
2. Public funds, private contributions, membership dues, and fund raising activities are the most-common types of funding sources utilized by advocacy agencies. Foundation grants are used significantly less often and client fees are seldom used.
3. Most, if not the vast majority, of advocacy agencies have informal budgetary and expenditure accounting procedures. These agencies often arrange financing on an as-needed basis.

The study's analysis of the coordination among independent advocacy agencies surveyed indicates that the level of coordination tends generally to be low. Even though a significant number of agencies do have working relationships with other organizations, these arrangements tend to be informal in nature and are more characteristic of cooperation rather than inter-agency coordination. Advocacy services are provided in New York State largely by relatively autonomous agencies which have informal linkages to other agencies. The study data indicates that while there are myriad independent advocacy groups in the State, there is

not at present an effective system of advocacy statewide. There is a lack of central leadership to provide the coordination, support services, training and technical assistance needed by the existing agencies, which rely heavily on part-time, volunteer staff. With such leadership, there is the potential for molding the existing advocacy agencies into a coordinated and cost effective advocacy network.

The analysis of the strengths and limitations of New York State's advocacy service delivery system found that while a full range of advocacy services are available to the developmentally disabled, the advocacy agencies surveyed perceive many gaps in this system.

Existing advocacy agencies maintain that despite the advocacy service coverage of individuals with mental retardation, epilepsy, autism, and cerebral palsy, all of these populations remain underserved. Clients residing in the community and in institutions are both seen as underserved by many agencies, and all age groups of the developmentally disabled are perceived to be underserved. At least 26 percent of the independent advocacy agencies interviewed indicated that one or more of these subgroups of the developmentally disabled population are underserved by advocacy agencies.

Advocacy agencies also cited significant needs for specific types of advocacy services. Over one-fourth of the advocacy agencies surveyed perceive a need for additional provision of each of the types of advocacy services identified (e.g., information and referral, individual (case) advocacy, systems advocacy, legal advocacy, and community education and training).

In addition, the service profile of advocacy agencies surveyed suggests the possibility of specific gaps in current advocacy service provision. Presently, significantly fewer

agencies predominantly serve the elderly as opposed to other age groups, and/or the institutionalized client as opposed to the community-based client. These findings suggest a need to more carefully assess the unmet advocacy needs of the elderly and the institutionalized clients.

The study's findings also revealed that legal advocacy is offered by significantly fewer agencies than other advocacy services. Again, this finding, especially in light of the perceptions of agencies, may be attributable to the less frequent need for legal advocacy than other advocacy services, and to the use of litigation as a means of last resort to resolve problems. This finding, however, merits further study and analysis.

The strengths and limitations of New York's advocacy services for the developmentally disabled indicates that existing independent advocacy agencies have substantial capability to provide advocacy services to all developmentally disabled citizens, but that their present ability to do so tends to be less than the need for these services. Furthermore, the many discrete population groups identified by agencies as underserved indicates that advocacy agencies are both aware of and concerned with addressing these unmet needs. While this conclusion highlights the need for New York to augment and strengthen its advocacy service system, it simultaneously implies that the existing advocacy agencies may, with the necessary fiscal and other support, be able to address many of these unmet needs.

The wealth of advocacy agencies and available resources provides New York State with the capability to establish a comprehensive statewide advocacy system. At the same time, independent advocates across the State, in response to the Commission's study, have indicated that such a comprehensive advocacy system does not presently exist.

In order to foster the development of a comprehensive and cost efficient protection and advocacy system, it is critical that an agency with statewide responsibility and jurisdiction be held accountable for these tasks. This agency should ensure that a full range of advocacy services are available statewide, and as such, it must possess the ability to intervene directly, or upon referral from local or regional advocacy agencies, to safeguard the human and legal rights of the developmentally disabled.

The formation of a cost efficient advocacy system requires that the best possible use be made of existing advocacy agencies with the purpose of establishing effective working networks. It is only through such an effort that the unmet advocacy needs of the developmentally disabled can be accurately identified. As a result, projects which are the most critically needed can be targeted, thus maximizing the effect of available resources in safeguarding the rights of the developmentally disabled.

Based on this analysis, the Commission offers three recommendations for establishing a truly comprehensive and cost effective protection and advocacy system for developmentally disabled citizens of New York State:

1. New York's current plan for advocacy services submitted pursuant to Public Law 94-103 should be modified to establish an administrative framework for developing a comprehensive and cost efficient advocacy system.
2. The designated protection and advocacy agency should be responsible for strengthening the capability of existing independent advocacy agencies and for directly providing advocacy services in order to ensure that a full range of remedies are available to developmentally disabled persons throughout the State.

(x)

3. The designated statewide agency should contract regionally with certain advocacy agencies delegating to such agencies the responsibility to perform intake and referral services for the region, to coordinate the establishment of effective local and regional advocacy networks, and to promote the development of critically needed services unavailable within the region.

Chapter I - Background to the Study

The human services field has been undergoing dramatic change in recent years with the recognition and evolving understanding of the human and legal rights of the clients being served. Governments at all levels have responded in redressing the problems of disadvantaged groups through such means as the enactment of legislation and initiation of special programs.

With the passage of the Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103), national recognition of the rights of the developmentally disabled was achieved. This legislation not only spelled out the rights of these persons, but a special effort was made to ensure that these rights were protected.

Section 113 of P.L. 94-103 authorizes states to develop "Protection and Advocacy" (P and A) systems which are responsible for pursuing legal, administrative and other appropriate remedies for developmentally disabled persons. Under this Act, each Governor may designate a "P and A" agency which must be independent of any State agency providing "treatment, services or habilitation" to the developmentally disabled.¹ As noted in a Senate report to this legislation, the "inherent conflict in the role a State must play in delivering services and administering programs . . . and in protecting the legal and human rights" of developmentally disabled persons requires that the P and A system be independent from the service delivery system.²

In order to implement this new program, financial assistance was authorized for the designated P and A agencies.

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1. "Developmentally Disabled Assistance and Bill of Rights Act", P.L. 94-103, Section 113.
 2. Senate Report 94-160, page 37, from Advocacy Under the Developmental Disabilities Act, by Stanley Herr, B.A., J.D., page 15.

In addition to providing fiscal assistance, two other features of the Act further ensured the likelihood of states developing a protection and advocacy system. The Act also stipulates that continued receipt of aid for direct service grants for the developmentally disabled, authorized under this legislation, is contingent upon the establishment of a P and A agency. A second feature required that the designated P and A agency ensure that a statewide system of advocacy services for the developmentally disabled evolve. More clearly, under the Act, the P and A agency is responsible not only for its own operations but for administering a protection and advocacy system in accordance with a State plan approved by the Governor. In sum, these features of the Act encourage states both to establish a P and A agency and to plan and develop a comprehensive advocacy system.

Under pending regulations, the intent that the designated agency serve as a coordinating mechanism to ensure statewide coverage is further strengthened. If adopted as currently proposed, the P and A agency would be required to report on other protective and advocacy agencies in the State and describe the cooperative relationships that have been developed with these other agencies.³

The development of a statewide P and A system, as envisioned in P.L. 94-103, has been one of the major variables included in national evaluations of the program's effectiveness. These studies have indicated that no single state yet has been able to establish a comprehensive statewide advocacy system.⁴ In one of the most recent studies

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3. Proposed regulations, "Developmental Disabilities Program", Department of Health, Education and Welfare, Office of Human Development Services, Rehabilitation Services Administration, published in the Federal Register, Vol. 45, No. 92, May 9, 1980.
 4. Susan Weisberg, Statewide Advocacy Systems for the Developmentally Disabled - Profiles in Innovation, DD Protection and Advocacy Review Project, American Bar Association Commission on the Developmentally Disabled, and An Evaluation of the Implementation of the Systems for the Protection of the Individual Rights of and Advocacy for Individuals with Developmental Disabilities and the Development of Performance Standards for the Systems, Harold Russell Associates, Inc.

of the program it was found that all the designated agencies visited had made "serious efforts to provide statewide services" but that even the highest funded state visited had not established a comprehensive system.⁵ This same report further noted potential for achieving statewide effect, given the limited funding provided under the federal P and A program, was best accomplished in those states which had developed working relationships with other advocacy organizations to form a state network of advocacy services.⁶

Purpose of the Study

In seeking to establish a truly comprehensive protection and advocacy system for the developmentally disabled in New York State, the Governor requested that the NYS Commission on Quality of Care for the Mentally Disabled undertake a study of New York's advocacy network for the developmentally disabled with the ultimate goal of identifying the most cost-effective manner of establishing a coordinated system. Four objectives for this study were identified:

- (1) to provide a descriptive profile of those agencies providing protective and advocacy services to the developmentally disabled;
- (2) to analyze the level and types of coordination among agencies providing P and A services;
- (3) to assess the adequacy of protective and advocacy services throughout the State and to identify critical gaps in the availability of these services; and
- (4) to develop recommendations, for establishing a comprehensive and cost effective protection and advocacy system.

5. Ibid, page 31.

6. Ibid, page 34.

Methodology

The methodology utilized to conduct the study is discussed in three sections: (1) sample selection; (2) survey instrument design; and (3) phases of the study.

° Sample Selection

In accordance with the major purpose of the study, to identify a means for establishing a comprehensive system of protection and advocacy by maximizing available P and A type agencies, criteria were developed to identify those agencies or organizations which could serve as components of such an advocacy system. These criteria included:

- (1) the agency must be currently operating and be composed of more than one person;
- (2) the focus of the agency's advocacy services must be within New York State;
- (3) the agency must be independent of direct care service providers in conformance with the Federal P and A standards;
- (4) the agency must offer at least one of the following types of advocacy services:
 - information and referral
 - systems advocacy
 - legal advocacy
 - individual case advocacy
 - community education; and
- (5) the agency must provide advocacy services to the developmentally disabled as follows:
 - by serving the developmentally disabled exclusively, or
 - by serving the general population, the disabled or mentally disabled persons, including the developmentally disabled as a client or group, or
 - by serving special population groups, e.g., the low income, the deaf or blind, and including the developmentally disabled with such special characteristics/needs as part of the agency's focus.

These criteria were based on the federal law and guidelines governing the federal protection and advocacy program. Based on these standards, agencies which provide direct care or habilitative services were excluded from the sample for the survey. The Commission does, however, recognize that significant advocacy services are provided for the developmentally disabled by agencies in the service delivery network. Indeed many of these organizations have assumed roles of service providers out of their very commitment to advocate on behalf of the developmentally disabled. Advocacy provided through this system, commonly referred to as internal advocacy, is indeed a vital component of a truly comprehensive advocacy system which recognizes the necessity for both internal and independent advocacy efforts.

• Survey Instrument Design

A survey instrument was designed to provide a descriptive profile of advocacy agencies in the sample. The survey instrument, relying primarily upon close-ended questions, assessed several aspects of an agency's operations and its perception of the advocacy network, including:

- (1) staffing patterns;
- (2) types of advocacy services provided;
- (3) types of clients served;
- (4) catchment area of the agency;
- (5) critical gaps in the advocacy network and clients most unserved or underserved;
- (6) financing of advocacy services; and
- (7) level of coordination among advocacy agencies.

The survey instrument is included in the appendix.

Due to both the time limitations and scope of the study, and the nature of the survey items, a telephone survey was determined to be the most practical means of

gathering the data. Prior to initiating the telephone survey, the survey instrument was pretested on advocacy groups, independent of the Commission on Quality of Care for the Mentally Disabled. Based on this pretest, the survey instrument was revised to ensure the reliability and validity of the data to be gathered in the study.

° Phases of the Study

(1) Development of an Inventory of External Advocacy Agencies

The first step in the Commission's study was to develop an inventory of New York State external advocacy agencies. Prior to this study, no such listing was available on a statewide basis. The inventory was developed through two means.

Mailing lists of state agencies and voluntary organizations concerned with the care and treatment of the developmentally disabled were reviewed first to identify potential external advocacy agencies. After this process, Commission staff then contacted many State and local agencies by telephone to solicit the names of other possible external advocacy agencies. This alone involved contacting over 200 organizations including, but not limited to:

- a. The Boards of Visitors of State Developmental Centers;
- b. Developmental Center Facility Directors, also generally including the Supervising Social Workers;
- c. New York State Association for Retarded Children;
- d. New York State Cerebral Palsy Association;
- e. New York State Epilepsy Foundation;
- f. New York State Society for Autistic Children;
- g. New York State Association for the Learning Disabled;
- h. New York State Association of Community Residence Administrators;

- i. Center on Human Policy;
- j. Mental Health Information Service;
- k. Office of Mental Retardation and Developmental Disabilities County Service Group Directors;
- l. County Mental Hygiene Directors;
- m. Representatives to the County Mental Retardation and Developmental Disabilities Advisory groups; and
- n. County Information and Referral agencies.

Developing the inventory took approximately three weeks beginning April 24 and ending May 9. Two temporary surveyors and three members of the Commission participated in this stage of the study.

(2) Surveying External Advocacy Agencies

Those external advocacy agencies identified in the inventory were then surveyed over the telephone using the developed instrument. (See appendix.) In conducting these telephone interviews, which required between 20-30 minutes each, every attempt was made to contact the person most knowledgeable and qualified (e.g., agency director).

In general, all agencies identified in the inventory listing were surveyed. The only significant departure from this procedure was when a statewide and/or regional organization existed which oversaw the operations of local chapters. In these cases, the statewide and regional organizations were surveyed and, in addition, a small number of local chapters were surveyed. This method enabled the Commission to collect information on the entire agency's operation while at the same time limiting the number of contacts which would have otherwise been required if all local chapters were to have been surveyed.

Over 300 agencies were surveyed by telephone. Based on the findings of the telephone survey, those agencies which did not meet the sample criteria of the study were deleted. A total of 265 agencies constituted the study's final sample.

While these agencies represent the vast majority of existing independent advocacy agencies in the State, it should be emphasized that the study's time constraints did not permit an exhaustive search to identify all such agencies. As such, the 265 agencies surveyed are a representative sample, but may not constitute the totality of the State's independent protection and advocacy network.

(3) Data Analysis

In order to accurately process the amount of information obtained in a timely fashion, all information was coded for computer analysis. A coding system was devised, with the consultation of a computer programmer, which permitted the information on the survey forms to be easily transcribed onto computer forms.

Once coded, the data were analyzed through a computer program. Statistical tabulations of the data, including frequency counts of the responses to the survey questions and cross tabulations, were made. The data tabulations were analyzed further by Commission staff focusing on the study's objectives. Based upon this analysis, the conclusions and recommendations made in this report were formulated.

