



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

Clarence J. Sundram, Chairman
Mildred B. Shapiro
Joseph Harris, Commissioners

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Funded by the New York State
Advisory Council on Mental
Retardation and Developmental
Disabilities

Staff:

Nancy Ray, Director, Policy Analysis
and Development Bureau

Robert Melby, Assistant Director,
Policy Analysis and Development Bureau

Jane Murphy, Training and Staff
Development Evaluation Specialist

Patricia Fennell, Project Assistant

Arliene Boochever, Project Assistant

Mary Ann Penner, Project Assistant

Lorraine Benson, Project Assistant

Timothy Watters, Project Assistant

Fred Goodman, Project Assistant

Connie VanValkenburg, Secretary to the
Chairman

Geraldine Kirpens, Secretarial Stenographer

Barbara Berry, Senior Stenographer

Sandy Sheedy, Senior Stenographer

Marianne Grant, Stenographer

Acknowledgements

The Commission is deeply grateful to the many persons, dedicated to the enhancement of the lives of New York State's developmentally disabled citizens, who have helped us complete this project. Without the cooperation of the independent advocates who, often on short notice, took time from their busy schedules to answer questions concerning their agencies' operations and the advocacy needs of the developmentally disabled, this study would not have been possible.

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

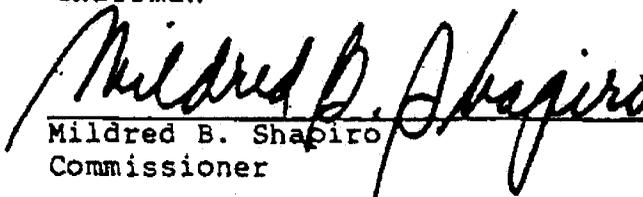
At the request of the Governor, the Commission was asked to undertake a study of New York State's independent advocacy services for the developmentally disabled to assess the means for establishing a comprehensive and cost effective statewide advocacy system. The conduct of this study involved identifying 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.

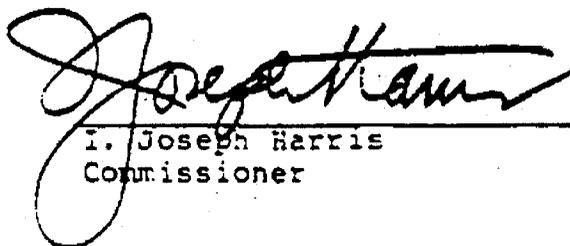
Through this report and its recommendations, the Commission hopes to assist in the establishment of a comprehensive statewide system to promote and protect the rights of all persons with developmental disabilities.



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.

Chapter II - Profile of NYS Protection and Advocacy Agencies

Protection and advocacy agencies serving the developmentally disabled in New York State include a wide range of agencies and organizations. The profile of NYS protection and advocacy agencies presented in this chapter describes these agencies across five major variables:

- (1) Geographical location and catchment area;
- (2) Organizational characteristics;
- (3) Client populations served;
- (4) Types of advocacy services provided; and
- (5) Funding.

This profile was developed based on the data derived from telephone interviews with 265 independent advocacy agencies located in the State which provide services to the developmentally disabled. Although the agencies vary in their focus, e.g., from serving the developmentally disabled exclusively to serving the general population, all agencies surveyed share a major service orientation to individuals with developmental disabilities.

Geographical Location and Catchment Area of Agencies

Geographically, the 265 agencies surveyed are located across the State, with greater concentrations of agencies in large metropolitan areas and the greatest concentration of agencies in the New York City area. The catchment areas of the agencies vary in size, with the majority of agencies serving a county or multi-county areas. There were 33 municipal agencies, 111 county agencies, 101 regional (two or more counties) agencies, and 20 statewide agencies among the agencies surveyed.

The data show that all of the State's 62 counties are served by at least 4 advocacy agencies. The majority of counties (32) are served by 4-9 agencies; 21 counties are served by 10-20 agencies, and 9 counties, including the 5 boroughs of New York City, are served by 21-35 agencies. The New York State map, shown in Figure 1, identifies the number of agencies in the sample in each county.⁷

Advocacy agencies in the sample were also identified by the county service group⁸ in which they were located. The Western and Northern County Service Groups were most highly represented by advocacy agencies, with 61 and 60 agencies, respectively. The Southeastern and New York City County Service Groups were also heavily represented, with 52 and 50 agencies, respectively. The Long Island County Service Group was least represented with only 22 agencies. In addition, 20 statewide agencies, serving all 5 county service groups, were included in the sample. Table 1 indicates, more comprehensively, the distribution of advocacy agencies by county service groups and catchment area served.

Organization Characteristics of Advocacy Agencies

Organizationally, the advocacy agencies surveyed are a heterogeneous group. They range from long-established organizations to groups which have been operating less than two years. Some agencies have a formal organizational structure; many others are informal groups of individuals, operating without by-laws, incorporation status, or even a budget.

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7. It should be noted that advocacy agencies serving more than one county were multiply counted in each county they served. Therefore, the total number of agencies, shown in Figure 1, (750) exceeds the number of agencies surveyed (265). This method of tabulating the data also accounts, in part, for the large number of agencies serving the boroughs of New York City. A total of 50 agencies serve the New York City area, but many of these agencies serve two or more boroughs.
 8. The NYS Office of Mental Retardation and Developmental Disabilities (OMRDD) program operations are divided into five regions or county service groups: Western, Northern, Southeastern, New York City, and Long Island.

Table 1: NUMBER OF ADVOCACY AGENCIES IN THE SAMPLE
BY CATCHMENT AREA AND COUNTY SERVICE GROUP

Catchment Area	Total	County service group					
		Western	Northern	South-eastern	NYC	Long Island	State-wide
Total	265	60	61	52	50	22	20
Local	33	4	4	6	16	2	1
County	111	32	27	32	9	11	0
Regional (two or more counties or boroughs)	101	24	29	14	25	9	0
State-wide	20	0	1	0	0	0	19

They range in nature from parent groups to self-help groups to broadly-based community efforts. Some employ broad outreach strategies to ensure that the rights of individuals with developmental disabilities within their catchment area are protected; others only serve individuals with developmental disabilities who come to them.

Although the sample included both public agencies and private not-for-profit advocacy agencies, it is clear that the New York State advocacy network for the developmentally disabled is predominantly composed of agencies in the private sector. Nearly 80 percent (211) of the agencies surveyed indicated their auspices as private not-for-profit. No agencies in the sample identified themselves as private-for-profit.

The 47 public advocacy agencies surveyed are fairly evenly distributed among the Western, Northern, Southeastern, and New York City County Service Groups. Only one public advocacy agency in the sample was located in the Long Island County Service Group. The auspices of the agencies surveyed by county service groups are identified in Table 2.

The staffing arrangements of agencies also vary. The advocacy agencies in the sample rely heavily on volunteer part-time staff. At the same time, a simple majority of the agencies (53 percent) do employ paid staff and they generally do so on a full-time basis.

The vast majority of agencies surveyed (214 or 81 percent) utilize volunteer staff. Of these 214 agencies, 88 agencies employ more than 20 volunteers, including 21 agencies which employ over 100 volunteers. Over 90 percent of the agencies utilizing volunteers do so on a part-time basis.

Only 142 of the 265 agencies surveyed stated that they employ paid staff and most of these agencies (86) indicated that they employ fewer than 10 paid staff. However, unlike the volunteer staff of agencies who are largely part-time, paid staff of advocacy agencies tend to be full-time. One hundred six (106) of the 142 agencies which utilize paid staff do so on a full-time basis. (See Tables 3 and 4.)

Table 2: NUMBER OF ADVOCACY AGENCIES IN THE SAMPLE
BY AUSPICES AND COUNTY SERVICE GROUP

Auspices	Total	County service group					
		Western	Northern	South- eastern	NYC	Long Island	State- wide
Total	265	60	61	52	50	22	20
Private/not for profit	211	51	50	39	38	20	13
Private/for profit	0	0	0	0	0	0	0
Public	47	8	9	11	11	1	7
Other	7	1	2	2	1	1	0

Tables 3 and 4 display the study's findings relating to size and status of the agencies paid and volunteer staffs.

The study's data also revealed that most advocacy agencies provide training for their staff. Over two-thirds of the agencies surveyed (69 percent) provide their staff with some training for their advocacy duties. Seventy (70) of the 182 agencies which provide training offer both orientation and in-service training; 39 offer only orientation training; and 68 offer only in-service training. In addition, many agencies indicated that their staff come with substantial professional training as lawyers, clinicians, program consultants, etc.

Most of the agencies offering training do so using their own staff as trainers, however, about one-third of the agencies providing training use both their own staff and outside consultants. Only 43 of the 182 agencies providing training use only outside consultants.

Table 5 summarizes the study's data pertaining to the training provided by advocacy agencies for their staff.

Clients Served

In order to provide an accurate profile of the clients served by advocacy agencies surveyed, the telephone survey instrument included several questions related to the agency's client population. First, agencies were asked to identify the general population group they serve: the general population; only persons with low incomes; or only persons with disabilities. Secondly, agencies were asked what specific developmental disability populations (mental retardation, epilepsy, cerebral palsy, autism, other) they serve. In addition, agencies were asked to describe their clients by place of residence (community, institution, or both) and by age (children and adolescents, adults, elderly, all age groups). Finally, agencies were asked to indicate the types of clients they predominately serve for these categories, as well as the orientation of the agency (individual, family, group).

Table 3: NUMBER OF ADVOCACY AGENCIES IN THE SAMPLE
BY SIZE OF PAID/VOLUNTEER STAFF
AND COUNTY SERVICE GROUP

Staff size	Total	County service group					
		Western	Northern	South- eastern	NYC	Long Island	State- wide
PAID STAFF							
Total	265	60	61	52	50	22	20
0	124	33	34	24	22	9	2
1 - 10	96	22	19	19	17	10	9
11 - 20	23	3	5	5	4	2	4
21 - 30	9	1	2	1	2	0	3
31 - 50	9	1	1	2	4	0	1
51 - 100	3	0	0	1	1	1	0
101+	1	0	0	0	0	0	1
VOLUNTEER STAFF							
Total	265	60	61	52	50	22	20
0	51	14	7	7	13	2	8
1 - 10	77	15	22	12	14	9	5
11 - 20	49	16	11	12	6	2	2
21 - 30	31	5	5	9	9	1	2
31 - 50	18	5	4	4	3	2	0
51 - 100	18	4	6	4	2	1	1
100+	21	1	6	4	3	5	2

Table 4. NUMBER OF ADVOCACY AGENCIES IN SAMPLE
 BY STAFF STATUS (FULL-TIME/PART-TIME)
 AND COUNTY SERVICE GROUP

Staff size	Total	County service group					
		Western	Northern	South- eastern	NYC	Long Island	State- wide
PAID STAFF							
Total	141	28	28	28	28	12	17
Full-time	106	23	17	20	23	9	14
Part-time	17	1	6	2	3	2	3
Both	18	4	5	6	2	1	0
VOLUNTEER STAFF							
Total	219	47	54	45	38	21	14
Full-time	10	0	4	5	0	0	1
Part-time	204	45	49	39	37	21	13
Both	5	2	1	1	1	0	0

Table 5. NUMBER OF ADVOCACY AGENCIES IN THE SAMPLE
BY STAFF TRAINING STATUS, TYPE, SPONSORSHIP
AND COUNTY SERVICE GROUP

Staff training characteristics	Total	County service group					
		Western	Northern	South-eastern	NYC	Long Island	State-wide
TRAINING STATUS							
Total	265	60	61	52	50	22	20
Provide staff training	182	39	42	39	29	17	16
Do not provide staff training	83	21	19	13	21	5	4
TYPE OF TRAINING							
Total	182	39	42	39	29	17	16
Orientation	39	7	4	16	7	5	0
In-service	68	18	15	10	13	5	7
Both orientation and in-service	70	12	20	13	9	7	9
Other	5	2	3	0	0	0	0
TRAINING SPONSORSHIP							
Total	182	39	42	39	29	17	16
Own agency	80	20	18	12	11	10	9
Outside consultants	43	11	13	10	4	4	1
Both own agency and outside consultants	59	8	11	17	14	3	6

The survey data relating to the clients served by advocacy agencies reveal that over 40 percent of the agencies surveyed dedicate their advocacy services to individuals with disabilities. The remaining agencies tend to serve the general population or persons with low incomes, but have a major advocacy service provision focus on the developmentally disabled. The survey data also indicate that each of the commonly identified developmental disability populations (mental retardation, epilepsy, cerebral palsy, and autism) is served by at least 70 percent of the agencies surveyed.

Of the 265 agencies surveyed, 122 serve only individuals with disabilities, 90 serve the general population, and 53 dedicate their advocacy services to persons with low incomes. Thirty (30) of the 53 agencies serving persons with low incomes are legal advocacy agencies, primarily legal aid societies. Table 6 shows the data findings relevant to the general type of population served by county service groups.

When asked to identify the developmental disability population or populations they serve, many agencies indicated that they serve more than one of the groups identified in the survey instrument (mental retardation, epilepsy, cerebral palsy, autism, other).⁹ Three-fourths of the agencies surveyed indicated that they serve individuals with mental retardation, epilepsy, and/or cerebral palsy, and nearly 70 percent of the agencies indicated that they serve individuals with other developmental disabilities, primarily identified as individuals with neurological impairment and/or learning disabilities. This distribution of specific developmental disability populations served by advocacy agencies statewide was also consistent within the five county service groups.

9. It is important to note in interpreting the data findings on specific developmental disability population served/predominantly served, that agencies indicated all the specific populations they served; therefore, the total count of agencies shown exceeds the 265 agencies in the study's sample.

Table 6. NUMBER OF ADVOCACY AGENCIES IN THE
SAMPLE BY TYPE OF POPULATION SERVED

Population served	Total	County service group					
		Western	Northern	South-eastern	NYC	Long Island	State-wide
Total	265	60	61	62	50	22	20
General population	90	23	11	30	16	5	5
Persons with low incomes	53	14	12	13	12	2	0
Persons with disabilities	122	23	38	19	22	15	15

The agencies' indications of the developmental disabilities populations they predominantly serve similarly show that many agencies predominantly serve more than one disability population (see Footnote 9 on previous page). Over half of the agencies surveyed (143) indicated that they predominantly serve individuals with mental retardation, while 37 percent, 40 percent, and 34 percent of the agencies stated that they predominantly serve individuals with epilepsy, cerebral palsy, and autism, respectively. Interestingly, 42 percent of the agencies surveyed indicated that they predominantly serve "other" developmental disability populations.

Table 7 indicates the developmental disability populations served and predominately served by agencies surveyed by county service groups.

The relationship between the developmental disability populations served and predominately served by individual agencies further clarified the major client populations of agencies surveyed. This analysis revealed that of the 221 agencies which serve individuals with mental retardation, 64 percent predominantly serve this population. Nearly half of the agencies serving individuals with epilepsy, cerebral palsy, and autism also predominantly serve these populations. The higher percentage of agencies serving and predominately serving the mentally retarded is probably attributable to the fact that individuals with mental retardation constitute the largest single population group of the developmentally disabled and that many individuals with other developmental disabilities also are mentally retarded.

The group of agencies serving other developmental disability populations (primarily identified as neurologically impaired and learning disabled) who also predominantly served these populations was, however, unexpectedly high. Over two-thirds of these agencies both serve and predominately serve these populations. This finding indicates

Table 7. NUMBER OF ADVOCACY AGENCIES IN THE SAMPLE BY DEVELOPMENTAL DISABILITY POPULATIONS SERVED AND PREDOMINANTLY SERVED AND COUNTY SERVICE GROUP

Developmental disability populations	Total	County service group					State-wide
		Western	Northern	South-eastern	NYC	Long Island	
MENTAL RETARDATION							
Served	221	52	50	44	44	16	15
Predominantly served	143	39	27	32	28	9	8
EPILEPSY							
Served	198	50	44	41	34	15	14
Predominantly served	99	31	10	26	16	9	7
CEREBRAL PALSY							
Served	200	49	48	39	37	14	13
Predominantly served	107	30	12	25	23	8	9
AUTISM							
Served	182	43	41	36	33	14	15
Predominantly served	91	29	8	23	16	7	8
OTHER							
Served	135	25	32	30	24	12	12
Predominantly served	112	27	20	26	20	12	7

advocacy agencies serving the neurologically impaired and learning disabled in the study's sample tend, more so than other agencies surveyed, to offer their services primarily to these populations. This finding suggests that advocacy services for the neurologically impaired and learning disabled are more specialized in service delivery.

In response to the questions pertaining to the place of residence of clients served, 52 percent of the agencies indicated that they serve both community-based and institutionalized (e.g., State developmental center) clients. Forty-two (42) percent of the agencies indicated that they serve only community-based clients, while only 5 percent (14 agencies) indicated that they serve only institutionalized clients. This distribution of clients served by place of residence was generally consistent across county service groups, with the exception of the New York City County Service Group where a disproportionately high number of agencies serve clients residing both in the community and in institutions. This New York City finding is probably attributable to the relatively greater emphasis on deinstitutionalization and the development of a community residential network in the New York City area resulting from the mandates of the Willowbrook Consent Decree.

When agencies were asked to elaborate further on the place of residence of the clients they serve by indicating the place of residence of clients they predominantly serve, the data indicated that many of the agencies serving both community-based and institutionalized clients, tend to predominantly serve community clients. Fifty-one (51) of the 139 agencies, which indicated that they serve both community-based and institutionalized clients, stated that they predominantly serve community-based clients. Of the remaining 88 agencies serving both populations, 79 indicated that they predominantly serve both populations and only 9 stated that they predominantly serve institutionalized clients.

This finding suggests that institutionalized developmentally disabled clients may be more underserved by the advocacy system than the frequency count of agencies serving this population indicates.

The data, displayed in Table 8, indicates the place of residence of clients served and predominantly served by agencies surveyed and county service group.

A majority of agencies surveyed (52 percent) serve clients of all ages, however, many agencies can be differentiated by the age group of the clients they serve. Eighty-seven (87) percent of the agencies surveyed, or 231 agencies, serve children and adolescents, while 77 percent, or 204 agencies, serve adults. Only 58 percent of the agencies serve the elderly.

The age groups of clients predominantly served by the advocacy agencies surveyed closely correlated with the age groups generally served. Again, most agencies (200) predominantly serve children and adolescents, with the number of agencies (172) predominantly serving adults running a close second. However, only 105 agencies predominantly serve the elderly, compared with the 155 agencies indicating that they serve the elderly. This data finding indicates that while nearly 60 percent of the agencies surveyed indicated that they have a capability of serving the elderly, fewer than 40 percent predominantly serve senior citizens.

Table 9 displays the study's findings related to the age groups of clients served and predominantly served by advocacy agencies.

The survey instrument also solicited information pertaining to whether the agency serves individuals, families and/or a special group or class. Three-fourths of the agencies replied that they serve individuals; 62 percent indicated that they serve families; and 26 percent indicated that they serve a special group or class. This latter category, special group or class, comprised a variety of special groups ranging from single parents to clients of a particular State developmental center to Willowbrook Class members.

Table 8. NUMBER OF ADVOCACY AGENCIES IN THE SAMPLE BY PLACE OF RESIDENCE OF CLIENTS SERVED AND PREDOMINANTLY SERVED BY COUNTY SERVICE GROUP

Clients place of residence	Total	County service group					
		Western	Northern	South- eastern	NYC	Long Island	State- wide
COMMUNITY BASED							
Served	112	31	29	26	15	8	3
Predominantly served	163	34	45	32	33	14	5
INSTITUTIONAL							
Served	14	1	5	1	5	2	0
Predominantly served	23	4	9	1	7	2	0
BOTH COMMUNITY BASED AND INSTITUTIONAL							
Served	139	28	27	25	30	12	17
Predominantly served	79	22	7	19	10	6	15

Table 9. NUMBER OF ADVOCACY AGENCIES IN THE SAMPLE BY
AGE GROUP(S) OF CLIENTS SERVED AND PREDOMINANTLY
SERVED AND COUNTY SERVICE GROUP

Age group	Total	County service group					
		Western	Northern	South- eastern	NYC	Long Island	Statewide
CHILDREN AND ADOLESCENTS							
Served	231	54	49	48	42	21	17
Predominantly served	200	49	39	47	31	19	15
ADULTS							
Served	204	45	52	38	36	18	15
Predominantly served	172	38	44	33	30	15	12
ELDERLY							
Served	155	32	39	32	26	10	16
Predominantly served	105	24	21	30	11	10	9

These findings on the service orientation of the agencies indicate that a relatively large number of the advocacy agencies surveyed recognize and address both the developmentally disabled individual's advocacy needs and those of his/her family. In addition, the minority of agencies (26 percent or 70 agencies) serving a special group or class indicates that while the majority of advocacy agencies in the network tend to avoid focusing their services on a narrowly defined group, a significant percentage of agencies can be described as serving a dedicated population. The service orientation of advocacy agencies is shown in Table 10.

The client profile of the agencies indicates that while many advocacy agencies (40 percent) tend to exclusively serve individuals with disabilities, a majority of the agencies (60 percent) which provide advocacy services for the developmentally disabled serve the general population or persons with low incomes. This finding suggests that the developmentally disabled are substantially "mainstreamed" in their receipt of advocacy services. The client profile also reveals that each of the specific developmental disability populations (mental retardation, epilepsy, cerebral palsy, and autism) is served by at least 70 percent of the agencies surveyed. In addition, each of the specific developmental disability populations is predominantly served by at least 91 agencies statewide, with individuals with mental retardation being predominantly served by 143 agencies.

Finally, the client profile indicates that the advocacy agencies tend to focus their services on children, adolescents, and adults living in the community. The elderly and institutionalized clients tend to be served by significantly fewer agencies. And, the service orientation of advocacy agencies tends to be on individuals and their families.

Table 10. NUMBER OF ADVOCACY AGENCIES IN THE SAMPLE BY
SERVICE ORIENTATION AND COUNTY SERVICE GROUP

Service orientation	Total	County service group					
		Western	Northern	South- eastern	NYC	Long Island	Statewide
Individuals	200	42	47	43	35	17	16
Families	164	39	36	43	26	8	12
Special groups/ class	70	10	19	8	16	9	8

Types of Advocacy Services Provided

In addition to describing the types of clients served by the agencies, the study's survey instrument also solicited information relevant to the types of advocacy services provided. More specifically, agency representatives were asked if they provided one or more of the following advocacy services: (1) information and referral; (2) individual (case) advocacy; (3) legal advocacy; (4) systems advocacy; (5) community education and/or training; and (6) other advocacy services.¹⁰ Similarly to the survey's inquiries about the clients served, agencies were asked to indicate the advocacy services they generally provided and those services they predominantly provided.

The study's data revealed that the majority of advocacy agencies provide a variety of advocacy services or remedies. Information and referral is provided by nearly all agencies, while individual (case) advocacy, systems advocacy, and community education and training are provided by at least two-thirds of the agencies. Legal advocacy is the least frequently provided advocacy service, with only 38 percent of the agencies providing this service.

Ninety percent, or 239 of 265 agencies surveyed, indicated that they provide information and referral. Community education and training, individual (case) advocacy and systems advocacy are also commonly offered, with 82 percent, 75 percent and 69 percent of the agencies surveyed offering these services, respectively. Legal advocacy is provided by significantly fewer agencies (38 percent) than the other types of advocacy services. Forty (40) of the 100 agencies providing legal advocacy are legal aid societies or other similar legal agencies. This statewide profile of the types

10. These categories of advocacy services were derived from the categories of advocacy services identified by the federal guidelines for state designated protection and advocacy agencies. Community education and training, not identified in the federal guidelines, was included in the survey instrument due to the Commission's awareness that many New York State advocacy agencies provide this service.

of advocacy services provided by agencies is generally consistent within each county service group.

The types of advocacy services provided by agencies surveyed correlated generally with the types of services predominantly provided. Information and referral, the service most frequently provided by agencies, was also the most frequently cited advocacy service predominantly provided. Forty-three (43) percent, or 114 agencies, indicated that they predominantly provide information and referral. Individual (case) advocacy and systems advocacy were cited as predominantly offered next most frequently, with 35 percent and 31 percent of the agencies indicating that they predominantly offer these services, respectively. Significantly, community education and training, which is provided by 217 agencies, was cited as being predominantly provided by only 81 agencies.

Also significant is the fact that the distribution of the types of advocacy services predominantly offered statewide by agencies does not correspond closely with the distribution of services predominantly offered by agencies within individual county service groups. For example, while systems advocacy is the least frequently cited service predominantly offered by agencies in the Western and Northern County Service Groups, it is the most frequently and the second most frequently cited service in the New York City and Long Island County Service Groups, respectively. Furthermore, the data revealed no consistent pattern to the variance of advocacy services predominantly provided by agencies within each county service group. Table 11 displays the study's data pertaining to the types of advocacy services provided and predominantly provided by advocacy agencies surveyed.

Funding Level and Sources of Income

A major concern of states in establishing a comprehensive advocacy system for the developmentally disabled is to

Table 11. NUMBER OF ADVOCACY AGENCIES IN THE SAMPLE BY TYPE OF ADVOCACY SERVICES PROVIDED AND PREDOMINANTLY PROVIDED AND COUNTY SERVICE GROUP

Advocacy services	Total	County service group					
		Western	Northern	South-eastern	NYC	Long Island	Statewide
INFORMATION AND REFERRAL							
Provided	239	55	51	51	45	18	19
Predominantly provided	114	28	28	29	15	7	7
INDIVIDUAL (CASE) ADVOCACY							
Provided	199	42	54	42	30	18	13
Predominantly provided	93	23	26	18	15	4	7
LEGAL ADVOCACY							
Provided	100	26	23	17	19	8	7
Predominantly provided	54	16	13	8	10	3	4
SYSTEMS ADVOCACY							
Provided	183	37	33	39	40	18	16
Predominantly provided	62	10	10	10	17	8	7
COMMUNITY EDUCATION/ TRAINING							
Provided	217	48	44	44	43	20	18
Predominantly provided	81	14	13	20	13	12	9
OTHER							
Provided	32	4	8	8	4	3	5
Predominantly provided	13	2	3	2	2	1	3

ensure the cost-effectiveness of this system. However, at the present time little descriptive information relevant to the financing of advocacy agencies is available, and virtually no comparative studies of the cost-effectiveness of alternative models of protection and advocacy systems exist.

Data are available indicating that over 80 percent of the operating budgets of state designated protection and advocacy agencies are funded with federal monies under the Developmental Disabilities Act (PL 94-103) and other federal aid programs. Yet, there is no comparable data base on the financing of the vast majority of other independent advocacy agencies in the nation which provide services to the developmentally disabled, but which are not funded as the state designated protection and advocacy agency.

Preliminary information to assist New York State in establishing a cost effective comprehensive advocacy system for the developmentally disabled was obtained by asking the advocacy agency representatives interviewed to indicate the amount of their agency's annual operating costs and the sources of their funding. While recognizing this data would not reveal how cost-effectively the agencies spend their available monies, it was anticipated that it would provide basic information pertaining to the level and type of funding of the agencies surveyed.

In gathering this information on the funding characteristics of agencies, it was apparent that a significant minority of the agencies surveyed were reluctant and/or unable to share this information. Twenty-nine (29) of the agencies surveyed, or only 11 percent, did not provide any information regarding their annual operating costs.¹¹

In addition, a review of the data collected revealed some obvious contradictions in the funding information individual agencies provided. For example, while 20 agencies stated that they operate at no cost, only six (6)

11. Ten (10) of the 29 agencies which did not provide information concerning their total operating costs are located in the New York City County Service Group.

agencies indicated that they had no funding sources. In view of these limitations, the funding data about the agencies surveyed should be interpreted cautiously.

In general, the study's data revealed that most independent advocacy agencies in New York State are small-scale financial operations which rely on a combination of funding sources. Almost two-thirds of the agencies surveyed have annual operating costs of less than \$50,000. And, the funding sources of advocacy agencies include client fees, public funds, foundation grants, private contributions, membership dues, and fund raising.

Of the 236 agencies surveyed which provided information concerning their annual operating costs, 8 percent indicated that they operate at no cost and another 56 percent have annual operating costs of less than \$50,000. Only 36 percent of the agencies responding have annual operating costs over \$50,000, and only 5 percent have annual operating costs over \$500,000. As would be expected statewide agencies tend to have larger annual operating costs than regional, county, and local agencies. Of the 14 agencies reporting annual operating costs over \$500,000, six (6), or 43 percent, are statewide agencies.

Table 12 relates the annual operating costs of agencies by county service group.

Forty (40) percent of the 259 agencies reporting funding sources indicated that they rely on public funds and private contributions. Of the 106 agencies indicating that they receive public funds, 55 receive federal aid, 47 receive State aid, and 34 receive local aid.¹²

Only 15 percent of the agencies indicated that they receive foundation grants, while fewer than 3 percent of the agencies receive funds from client fees. A large group of agencies, 114 or 44 percent, indicated that they receive

12. Since several agencies receive a combination of federal, State, and/or local aid, the sum of the number of agencies receiving each type of public aid exceeds the 106 agencies receiving public funds.

Table 12. NUMBER OF ADVOCACY AGENCIES IN THE SAMPLE BY
ANNUAL OPERATING COSTS AND COUNTY SERVICE GROUP

Annual Operating Costs	Total	County service group					
		Western	Northern	South- eastern	NYC	Long Island	Statewide
Total	265	60	61	52	50	22	20
\$0-50,000	151	39	43	35	19	12	3
\$50,001- \$100,000	26	7	7	2	6	2	2
\$100,001- \$500,000	45	8	8	6	13	4	6
\$500,001- \$1,000,000	10	1	2	2	1	0	4
\$1,000,000+	4	0	0	1	1	0	2
No informa- tion given	29	5	1	6	10	4	3

funds from "other" sources, often identified as membership dues and/or fund raising (e.g., bake sales, car washes, benefit dances, etc.).

Agencies within different county service groups are not differentiable by the types of funding sources they utilize with one exception. Proportionately fewer agencies within the Long Island County Service Group than in other county service groups rely on public funds. Table 13 indicates the types of funding sources utilized by advocacy agencies surveyed.

Some agencies surveyed also identified their specific funding sources. Among the State agencies and departments most commonly cited as funding advocacy agencies were the Office of Vocational Rehabilitation, the State Education Department, and the Office of Mental Retardation and Developmental Disabilities. Most agencies receiving county funds received them from county departments of mental hygiene, while CETA (Comprehensive Education and Training Act) and the Legal Services Corporation were the most frequently identified federal sources.

Many private funding sources were identified, but several private sources surfaced as the primary funders of advocacy agencies. These included the United Way, the Elks Club, unions, universities, and church groups. Generally, a large number of different specific funding sources were identified by agencies, indicating that the funding base for advocacy services is very diversified.

Summary Profile of NYS Protection Advocacy Agencies

The above discussion highlights the heterogeneity of the New York State advocacy service delivery system serving the developmentally disabled. At the same time, the study's data also reveal some significant trends which contribute to an understanding of the nature of advocacy agencies serving this population. These trends, or general descriptor statements, are listed below.

Table 13. NUMBER OF ADVOCACY AGENCIES IN THE SAMPLE
BY FUNDING SOURCES AND COUNTY SERVICE GROUP

Funding Sources	Total	County service group					
		Western	Northern	South-eastern	NYC	Long Island	Statewide
Total	259	58	59	52	48	22	20
Client fees	7	1	0	2	1	1	2
Public funds	106	23	26	24	19	6	8
Federal	55	8	13	12	12	4	6
State	47	8	10	15	6	3	5
Local	34	8	10	10	3	1	2
Foundation grants	38	6	2	6	13	4	7
Contributions	108	22	24	23	16	13	10
Other*	114	24	23	20	22	14	11

*"Other" sources of funding cited frequently included membership dues and fund raising (e.g. bake sales, car washes, benefit dinners, dances, etc).

° 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.

° Organization characteristics

1. Organizationally, New York State'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 State'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.
4. A majority of agencies (69 percent) recognize and attempt to address their staff's training needs pursuant to their advocacy duties.

° 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 services 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 (26 percent) 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 than \$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 procedures. These agencies often arrange financing on an as-needed basis.