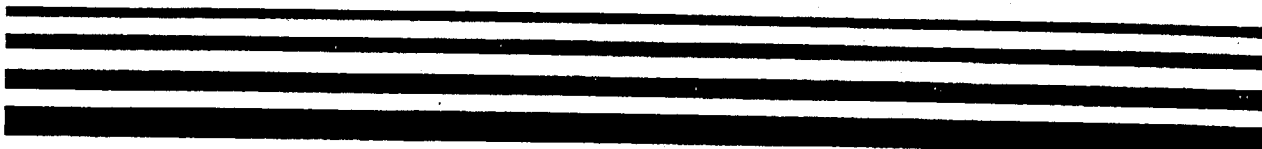
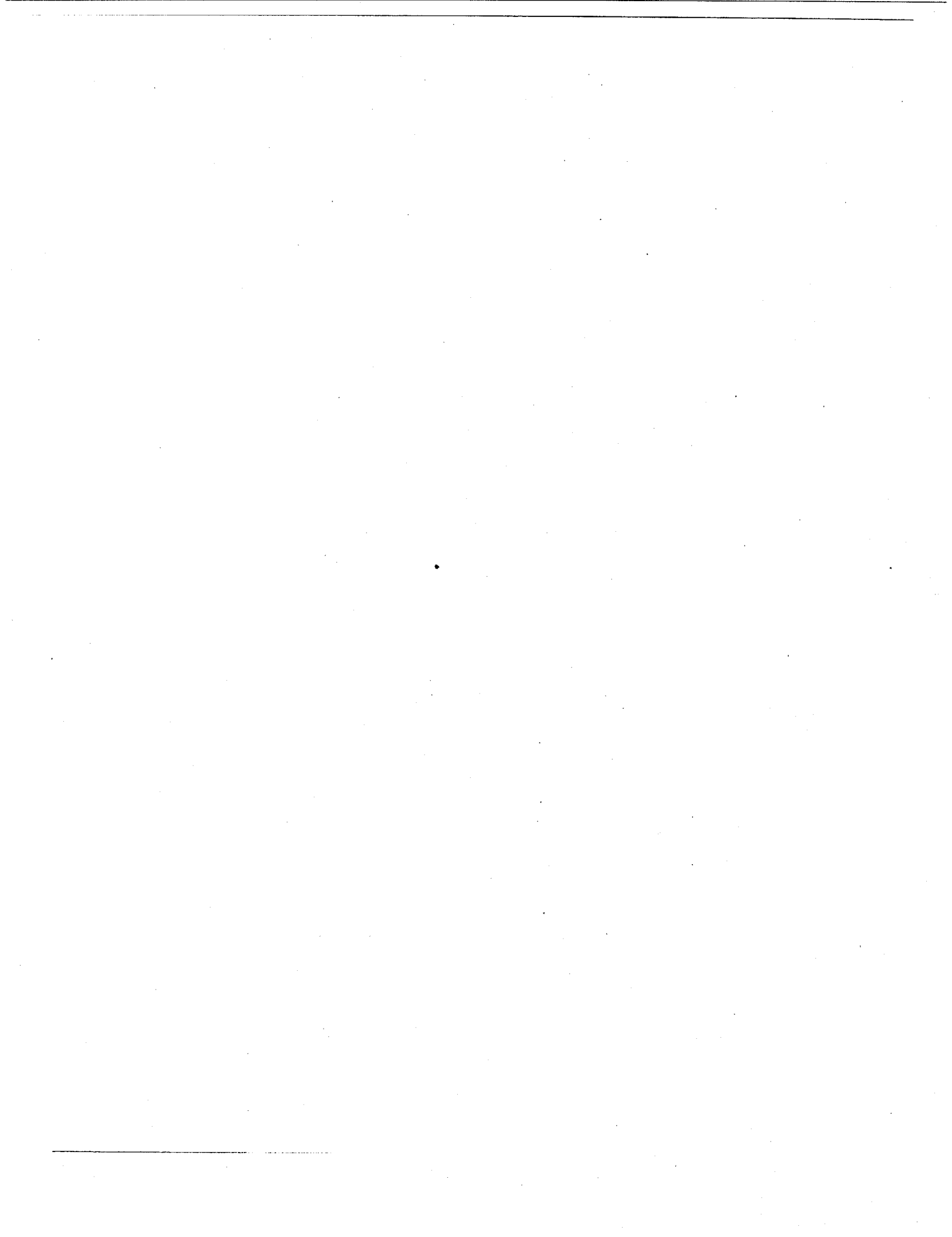


# Serving Parents Who Are Mentally Retarded: A Review of Eight Parenting Programs in New York State

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

July 1993





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# Serving Parents Who Are Mentally Retarded: A Review of Eight Parenting Programs in New York State

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Clarence J. Sundram  
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COMMISSIONERS

July 1993



NYS COMMISSION  
ON QUALITY OF CARE  
FOR THE MENTALLY DISABLED



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# Acknowledgments

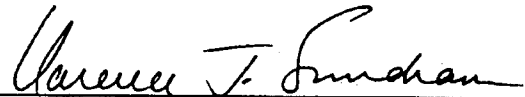
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The Commission wants to express its deep gratitude to the families served by the eight parenting programs reviewed. Through their stories and experiences, recast and retold to protect their confidentiality in the vignettes in this report, the Commission was able to obtain a first-hand perspective of parenting with special needs that it would never have been able to construct from an empirical data base alone. The Commission is especially appreciative of the 25 families who invited Commission staff into their homes to meet their children and to learn more directly about their daily lives.

This report would also not have been possible without the gracious assistance of the program directors, parenting aides, and volunteers of the eight parenting programs reviewed. The dedication of these women and men in helping parents who are mentally retarded and in many cases in extending their workdays far into the night and weekends was remarkable across the programs. At each of the eight parenting programs, these individuals devoted considerable time from their busy schedules to accommodate our site visits and to share with us what they had learned about serving parents who were mentally retarded.

This evaluation study was funded by a grant from the New York State Developmental Disabilities Planning Council. Throughout the conduct of the review, the Commission has benefited from a discussion of the issues presented with the members of the Council.

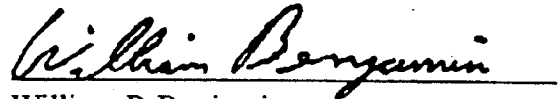
The findings, conclusions, and recommendations expressed in the report reflect the unanimous opinion of the Commission.



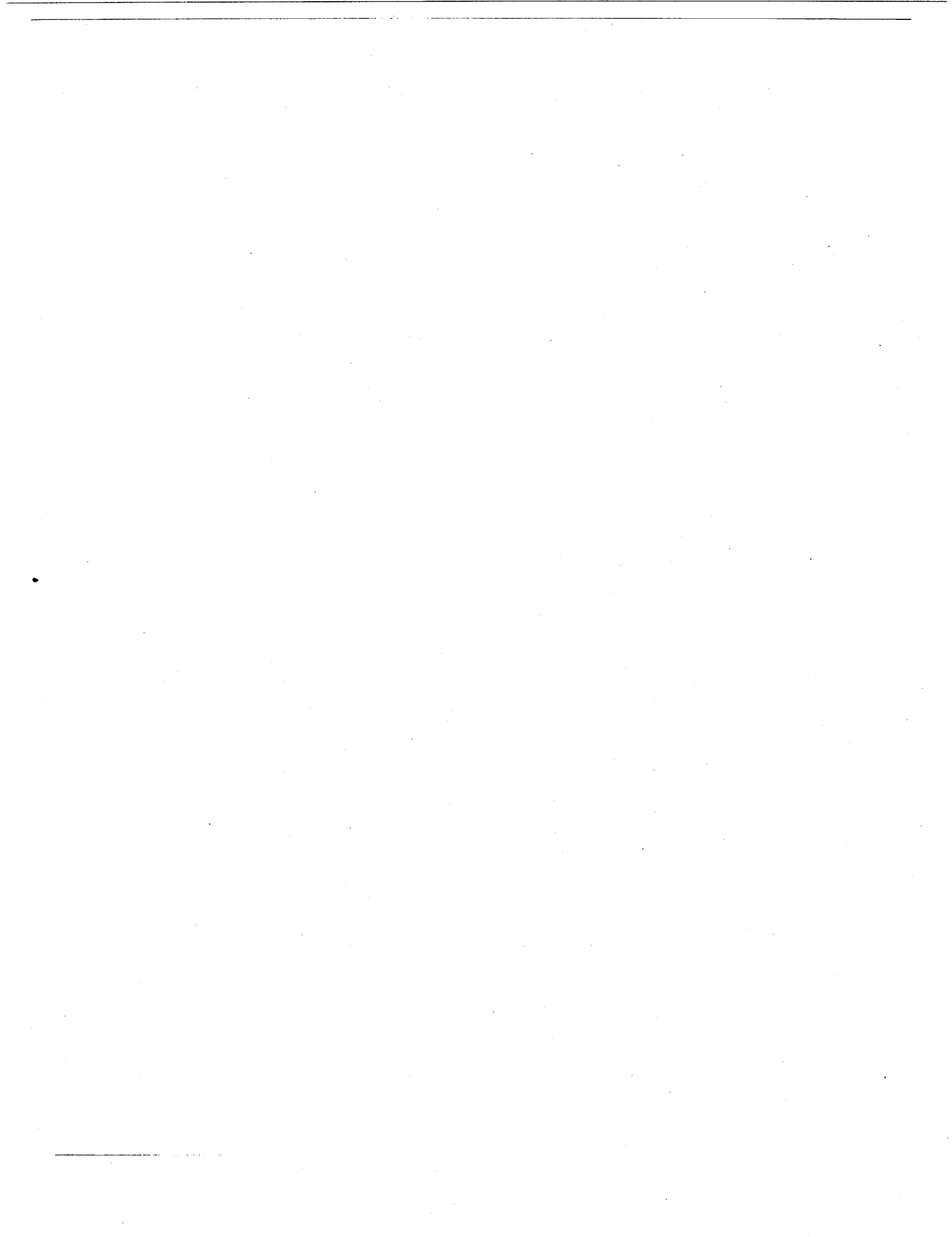
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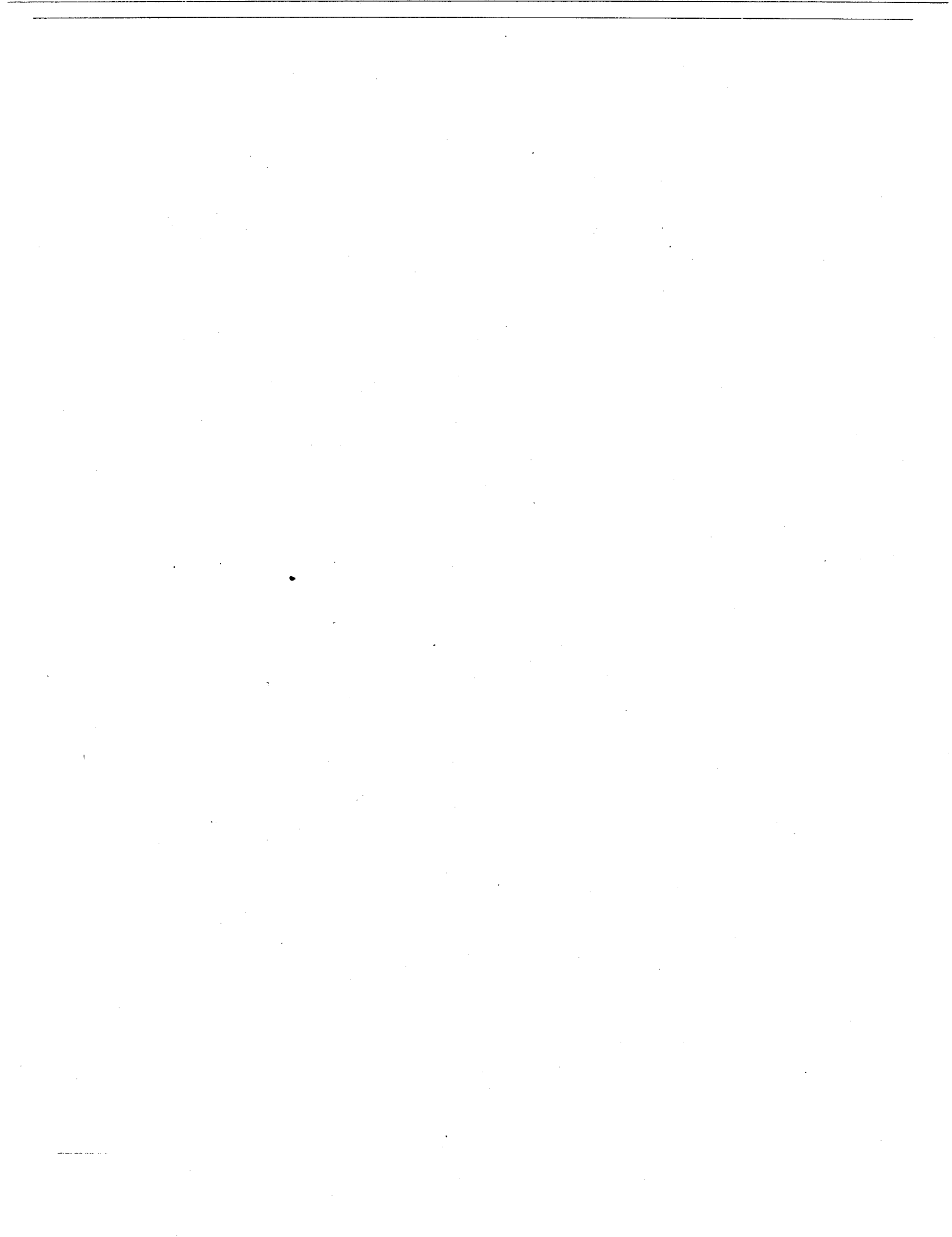


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# Table of Contents

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Chapter I:	Introduction .....	1
Chapter II:	Programs and Sponsoring Agencies .....	5
Chapter III:	Getting Started and Serving Families .....	13
Chapter IV:	Program Standards .....	29
Chapter V:	Measuring Program Success .....	41
Chapter VI:	Conclusions and Recommendations .....	53
• Appendix A:	Responses to Draft Report From:	
	■ New York State Office of Mental Retardation and Developmental Disabilities	
	■ New York State Department of Social Services	
	■ New York State Office of Advocate for the Disabled	



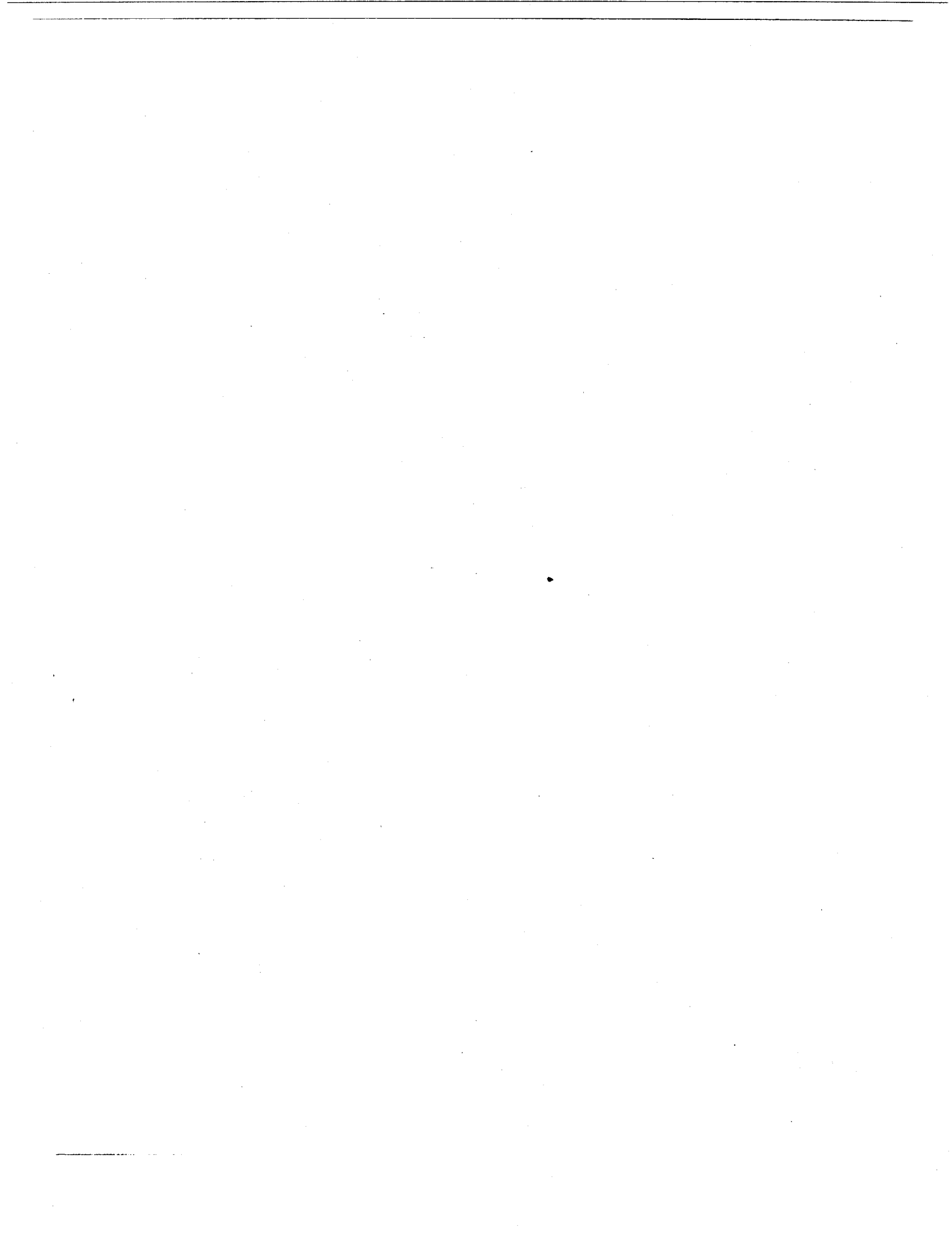


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# List of Figures

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Figure 1: Funded Parenting Programs .....	1
Figure 2: Program Reliance on Paid Staff Versus Volunteers .....	2
Figure 3: Review Methods .....	3
Figure 4: Sponsoring Agency Budgets .....	5
Figure 5: Total and Per Family Funding by Parenting Program .....	7
Figure 6: Staffing Issues .....	8
Figure 7: Parenting Aides and Volunteers Talk About Their Work Experience .....	9
Figure 8: Training Topics for Parenting Aides and Volunteers .....	11
Figure 9: Snapshot of Parents .....	15
Figure 10: Social Histories of the Parents .....	16
Figure 11: Level of Parenting Skills .....	16
Figure 12: Disabilities of Children at Home .....	19
Figure 13: Difficulties of the Children .....	21
Figure 14: Annual Discharge Rates/Why Families Dropped Out .....	22
Figure 15: Service Provision by Program .....	24
Figure 16: Safety and Well-Being of Children in Families Visited .....	29
Figure 17: Estimated Program Graduation Time Frames for Families .....	31
Figure 18: Service Plans and Progress Reviews .....	33
Figure 19: Parenting Aide/Volunteer Satisfaction with Local Child Protective/Preventive Services .....	37
Figure 20: Ratings of Program Effectiveness .....	42
Figure 21: Ratings of Program Effectiveness for Individual Families .....	44
Figure 22: Volunteers/Parenting Aides Share Their Difficulties in Working with Families .....	47
Figure 23: Limitations of Programs .....	48
Figure 24: Trouble Spots for Programs .....	51



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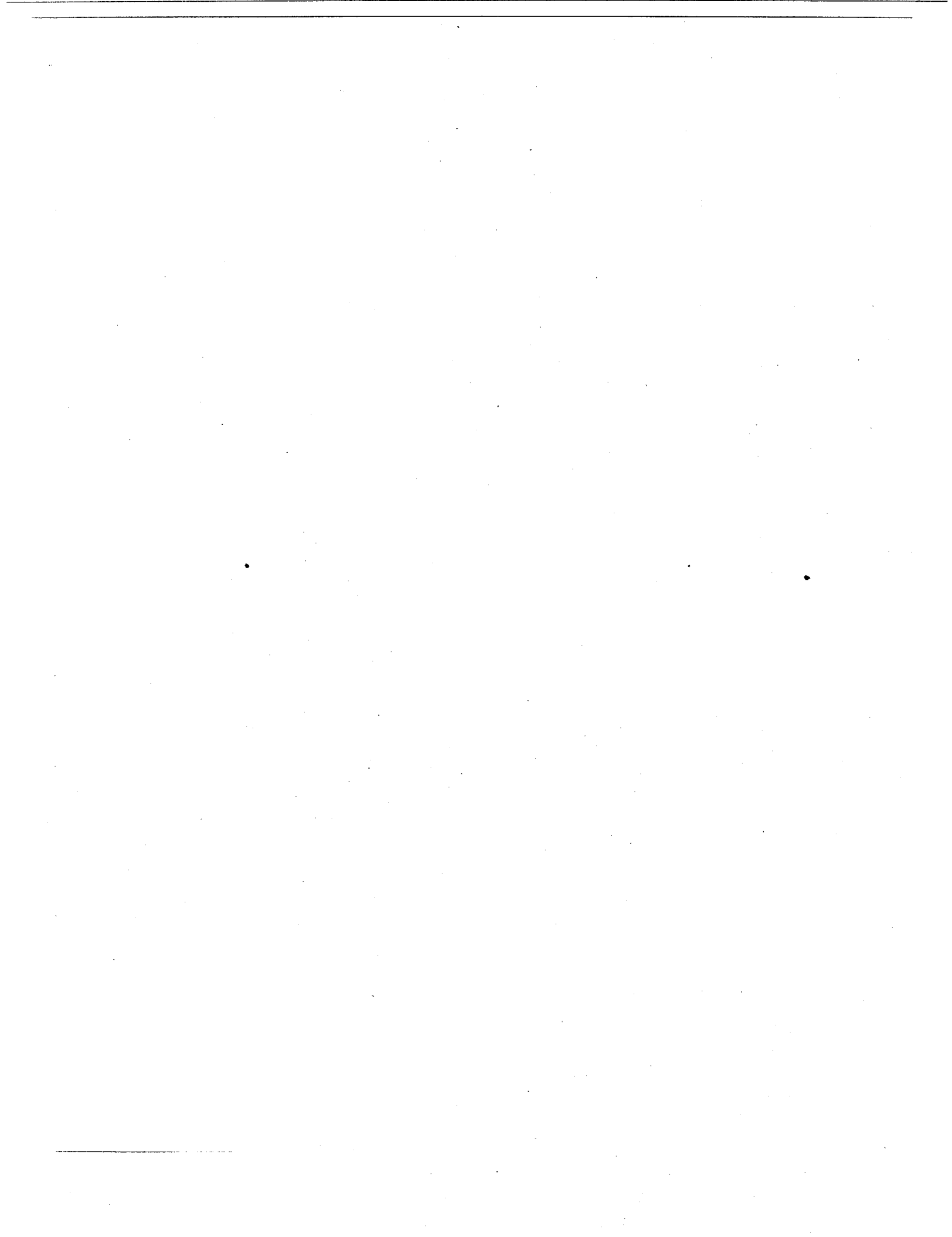
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# Chapter I

## Introduction

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This report discusses eight programs, funded by the New York State Developmental Disabilities Council (DDPC), to provide training and assistance to parents who are developmentally disabled (Figure 1). The Council had initially requested that the Commission conduct a formal evaluation of these eight programs, all of which were originally proposed to rely on a common service delivery model, heavily reliant on "companions"—older persons volunteering as parent trainers for parents with developmental disabilities. The Commission's study of these programs, however, has taken a broader descriptive focus, as the Commission discovered that, within months of receiving their funding grants from the Council, each of the eight demonstration programs had tailored and substantially altered the initially proposed service delivery model.

In the conduct of this evaluation, the Commission also gathered substantial data on 54 families with one or more parents with significant cognitive limitations and/or developmental disabilities. Although this report presents a brief profile of these families, the Commission also prepared a more comprehensive report on the families studied, *Parenting with Special Needs: Parents Who Are Mentally Retarded and Their Children*.

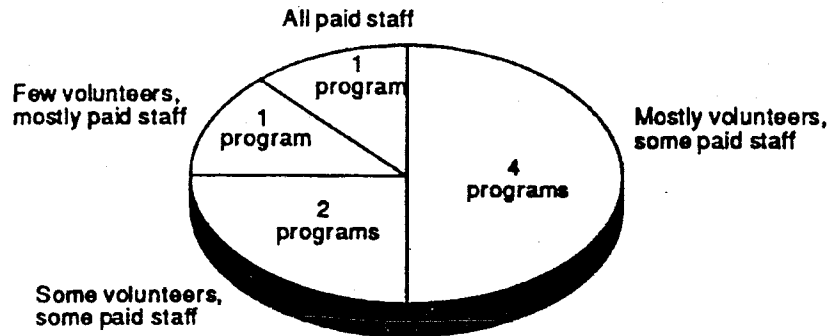
### A Medley of Program Models

Although seven of the eight programs did use volunteers to assist in their work with families, only four relied primarily on volunteers, and one of these programs served only five families (Figure 2). Another one of these programs closed within the first year of operation. One program entirely abandoned the concept of utilizing volunteers before it even started delivering services; one other program used volun-

Figure 1: Funded Parenting Programs

- Parents with Special Needs  
Young Adult Institute  
New York City
- Parent Training Program  
Sinergia, Inc.  
New York City
- Special Needs Parenting Project  
The Task Force for Child Protection, Inc.  
Dutchess County
- Senior Companion Program  
Ulster County ARC
- Senior Companions/Parents with  
Developmental Disabilities Project  
Orleans County ARC
- Senior Companion Program  
Chautauqua County ARC
- In-Home Parenting Training Program  
Community Services for the  
Developmentally Disabled, Inc.  
Erie County
- Senior Companion Parent Training  
Program  
Heritage Centers  
Erie County

Figure 2: Program Reliance on Paid Staff Versus Volunteers  
(N = 8 Programs)



teers in only a very limited capacity, and usually not in the families' homes. Another two programs relied primarily on paid parenting aides, but had recruited several very capable volunteers who played integral service roles with some of the families enrolled.

Programs also differed substantially in the extent to which their families were served exclusively by the DDPC-funded parenting program or also referred to other services sponsored by their agency, including sheltered workshops, supportive apartments, early childhood programs, and Department of Social Services (DSS) funded case management. Similarly, some programs provided many more service referrals to other agencies in their community. Intensity of service provision from the demonstration programs themselves also varied extensively, ranging from only a few hours a week to a regular on-site home presence of 15 or more hours a week.

Finally, most of the programs were learning by doing, and as their programs moved forward, they continued to make changes in their service

delivery model. These changes were often substantial, and they often directly affected the services the families received. Program directors were candid in acknowledging that in the first year they made many false starts; most had thoroughly redesigned many key aspects of their programs, from their parenting training sessions, to the training and direction they provided their paid parenting aides and volunteers. Thus, to a large degree, the individual service delivery models of each of the programs were also continually evolving.

### A Descriptive Study

It soon became apparent that a formal evaluation was not well-suited to the heterogeneity evident in the eight demonstration programs, or to the changing nature of the programs' distinctive service models over their relatively brief two years of operation.

A formal evaluation study was also short-circuited by the absence of strong recordkeeping by the majority of the eight programs. None of

the eight programs had maintained good records of specific program accomplishments or the achievements and difficulties of the families they had served. Thus, programs could not report how many families, through their intervention, had obtained more appropriate housing, or conversely how many families, despite their intervention, had been evicted from their homes or apartments.

Programs also did not have records to substantiate the number of families which had graduated from the surveillance of local child protective or preventive services programs or which had been the subject of additional child abuse or neglect reports subsequent to their intervention. Indeed, directors of three of the eight programs intentionally shunned these hard measures of program success or failure, as they believed these measures would inaccurately overshadow the positive, if less quantifiable, day-to-day benefits of their programs for the families served.

With these limitations in mind, the Commission chose instead to provide a descriptive profile of the eight programs and the specific services that they offered to the families studied. This profile also includes self-assessment ratings of the programs' effectiveness provided by the program staff and volunteers and the families themselves. Additionally, reflective of a central mission of the programs to enhance the self-esteem of the parents, especially as related to their parenting, this descriptive profile includes a discussion of the parents' perceptions of the best and worst parts of being parents.

## Methods

The Commission had the opportunity to access information about the programs from many sources (Figure 3). From the outset, the Commission was able to review the programs' initial grant proposals, and Commission staff were invited to attend two cluster meetings of senior staff of the eight programs sponsored by the Developmental Disabilities Planning Council. The Commission also reviewed fiscal re-

Figure 3: Review Methods

- ✓ Meetings with program directors
- ✓ Review of program proposals
- ✓ Review of program funding and staffing
- ✓ Two site visits to each program
- ✓ Record reviews and staff interviews for 41 enrolled families (initial sample)
- ✓ Modified Developmental Disability Profile of parents in 41 enrolled families (initial sample)
- ✓ Home visits to 25 enrolled families (second sample)

ports prepared by the program staff, and later followed up with telephone interviews to obtain more detailed program funding information.

Commission staff also made two on-site visits to programs, one in the fall of 1991 and one in the spring and summer of 1992. Both visits focused on obtaining a front-line perspective of the day-to-day operations of the programs and the families they served. On the initial visit, Commission staff spent several hours speaking with program staff and reviewing the program records of a sample of 41 of the 86 families enrolled in the eight programs. Program staff were also asked to complete a slightly modified version of the Developmental Disability Profile (DDP), the official needs assessment of the New York State Office of Mental Retardation and Developmental Disabilities, for each of the parents in the 41 families.

On the second visit, Commission staff visited the homes of 25 enrolled families, accompanied by the parenting aide/volunteer assigned to the family. These 25 families included 12 families in the initial sample, plus 13 new families.<sup>1</sup> During the second site visit, Commission staff also met with the staff of the local departments of social services to obtain an understanding of how the programs interfaced with local child protective and preventive services.

Interview data with program staff and families, as well as record review and fiscal data, were collected on structured instruments.

## Organization of the Report

A basic descriptive profile of the programs and their sponsoring agencies is presented in Chapter II. This chapter provides information related to the size and budget of the sponsoring agencies, the funding of the parenting programs, and the programs' staffing. Chapter III focuses on the families served by the programs and the

services offered by the eight programs. Chapter IV focuses on specific operational aspects of the programs, ranging from their admission and discharge criteria to their assessment and treatment planning practices to their relationships with local child protective and preventive services in their counties/boroughs.

Chapter V, entitled "Measuring Program Success," provides a summary of the directors', staff's, and recipients' self-assessments of the programs' effectiveness, as well as Commission staff observations of their strengths and weaknesses.

Finally, in Chapter VI, the Commission attempts to distill some of the lessons learned as a result of this evaluation in an effort to assist the Developmental Disabilities Planning Council and the relevant state agencies and service providers in addressing the future needs of parents with developmental disabilities and the complex programmatic and funding issues inherent in doing so.

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<sup>1</sup> Although the Commission had hoped to make home visits to all 41 of the families in the initial sample, this was not possible. At the time of the follow-up visits, one of the eight programs had closed down operations, and staff of one other program steadfastly refused to allow any home visits. At the remaining six programs, there were also other sampling changes, as some of the initial families had dropped out of the program, and some families did not want the Commission staff to visit.



# Chapter II

## Programs and Sponsoring Agencies

As discussed in the introduction, the eight programs were more characterized by their variability than by their similarity. Not only did each of the eight programs make significant changes along the way in their operation, they also started with significantly different visions of what services they would provide and how they would serve families. The programs also ranged from small, informal operations to relatively large programs which received substantial agency and community resource support, apart from their funding grant from the Developmental Disabilities Planning Council.

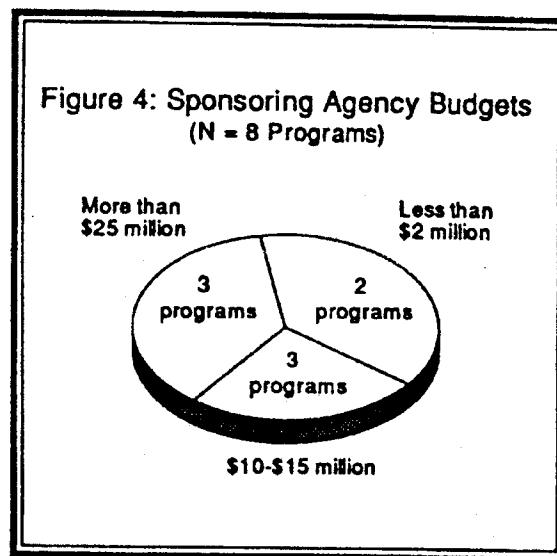
The purpose of this chapter is to highlight the marked heterogeneity among the sponsoring agencies of the programs, as well as the funding and staffing of the eight parenting programs themselves. Although these resource differences alone did not shape the variability among the eight programs, the Commission did find that the size, experience, and resources of the sponsoring agencies did have a fundamental influence on the parenting programs.

### The Sponsoring Agencies

All eight of the sponsoring agencies were established not-for-profit agencies, and seven (88%) were primarily focused on service provision to persons with developmental disabilities. Five of the eight agencies (63%) exclusively served persons with developmental disabilities.

The agencies also reflected a combination of smaller and larger agencies. One of the agencies sponsored only two other service programs in addition to the DDPC-funded parenting program, whereas three sponsored three to five other programs, and four were large agencies

with six or more other programs. Total annual budgets of the sponsoring agencies of the eight programs also varied widely from \$240,000 to \$45,000,000. Three agencies had total annual operating budgets of more than \$25,000,000; three had budgets between \$10,000,000 and \$15,000,000; and two had budgets under \$2,000,000. (Figure 4).



The sponsoring agencies also differed significantly in terms of their tenure as service providers in their communities and the strength of their relationships with other community service providers. Whereas all of the eight agencies had been operating for at least five years, four of the eight agencies' tenures in their communities had spanned more than three decades. Reflective, in part, of the size of their budgets and their tenure in their communities, several of the sponsoring agencies were also seen as critical service providers in their communities by others.

The Commission did not assess the relationship of these intangible experience and expertise variables to program success. It was apparent, however, that the manifold needs of many of the families often required many different types of services. Sponsoring agencies which could easily meet these needs, either through their own programs or through well-orchestrated referrals to other agencies in their communities, clearly had an initial advantage over smaller and younger organizations.

## Program Funding

Commission site visits to the eight programs clarified that there was considerable variability in the funding bases of the eight programs. Differences in resources available for the parenting program were due, in part, to differences in the funding for the individual programs. More critically, however, a program's resources were dependent on what services it could readily access or share from its sponsoring agency.

For example, four programs had successfully accessed Department of Social Services Medicaid case management funds to cover many of these service costs for all or some of their families. Many programs also accessed some home health aide services for enrolled families, and one program had been able to access DSS-funded home health aides to assist several of its enrolled families for up to 40 hours weekly.

Three of the programs had also integrated their services to parents with developmental disabilities with the agencies' preexisting supportive housing and enriched foster care programs. In addition, at five programs, enrolled parents had easy access to the sponsoring agencies' supported work and sheltered work programs, and at two programs, many of the young children of the enrolled families had easy access to the sponsoring agency's early intervention preschool program. Most of the programs also shared transportation services with their parent agency.

Even from the narrow perspective of their direct parenting training and assistance service, *only one of the programs operated exclusively on its funding grant from the Council.* Several programs had received supplemental funding grants (usually under \$25,000) from the New York State Office of Mental Retardation and Developmental Disabilities. These included grants under the Office's traditional family support services program, as well as other assorted purchase of service contracts for intensive parent training and individual support services. One program had received a small grant (\$15,143) from the local United Way, and five of the seven operating programs reported making in-kind contributions to the parenting program ranging from \$1,000 to \$21,000.

Program grants from the Council also varied across the eight programs, ranging from \$40,000 to \$59,000 for the federal fiscal year 1992. In the spring of 1992, three of the programs also solicited and received a \$25,000 supplement for crisis services.

As shown in Figure 5, the total funding for the programs did not always correlate to the number of families served or the intensity of services provided. In 1992, per family funding across the programs ranged from \$4,670 to \$10,710.

## Future Funding Sources

All seven programs which continued operation after the first two years of funding from the Developmental Disabilities Planning Council hoped to find alternate funding sources to maintain their programs subsequent to the end of their third year of demonstration funding from the Council. The seven programs pinned their hopes on a variety of different funding sources, with most programs counting on putting together a funding package from several sources.

**Figure 5: Total and Per Family Funding  
by Parenting Program\***

<i>Program</i>	<i>Total Parenting Program Funding</i>	<i>DDPC Grant Award</i>	<i>Total Families Enrolled</i>	<i>Per Family Funding</i>
Orleans County ARC	\$126,180	\$70,000	27	\$ 4,670
Sinergia, Inc.	\$104,000	\$84,000	18	\$ 5,770
Young Adult Institute	\$ 96,429	\$75,000	9	\$10,710
Heritage Centers	\$ 55,555	\$50,000	5	\$ 8,890
Community Services for the Developmentally Disabled	\$ 71,429	\$50,000	11	\$ 6,490
Chautauqua ARC	\$ 71,000	\$50,000	10	\$ 7,100
The Task Force for Child Protection, Inc.	\$ 56,143	\$40,000	10	\$ 5,610

\* All funding information is based on program self-reports for fiscal year 1991-92, with the exception of Heritage Centers, which is based on a 15-month period. Enrollment information is based on self-reports of enrolled families as of fall 1991. Funding information for Ulster County ARC is not included, as this program closed in December 1991.

Two programs hoped to continue funding the services to their enrolled families by integrating the services of their parenting program with other agency family support, residential, and/or early intervention programs. Four programs indicated that they would look to the Office of Mental Retardation and Developmental Disabilities' various ongoing grant programs for continued funding, including its family support program and its newly established individual support services program. Three programs also spoke of seeking funding from their local departments of social services as a preventive service program, while three mentioned that they were seeking private funding sources, including private foundation funding and funding

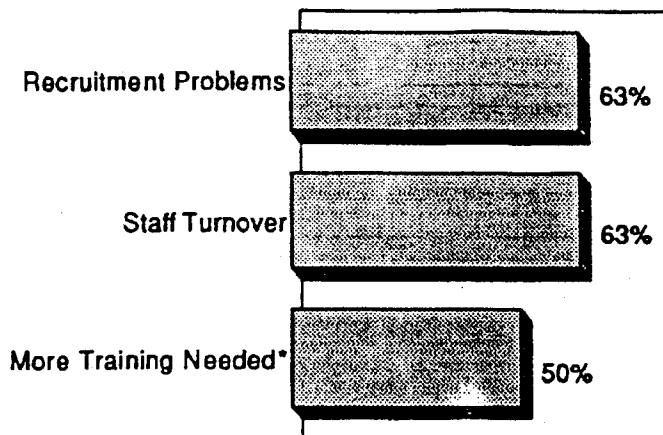
from the recently established Self-Advocacy Association.

At the time of the Commission's interviews with the program directors in the fall of 1992, however, none of the seven programs were clear on the availability of continued funding, and only a couple of the programs had formally pursued the potential future funding sources that they had identified.

### Program Staffing

At the time of the Commission's fall 1991 visits, all but one of the programs had only one or two paid full-time equivalent staff persons. As a matter of practice, this meant that most of the

Figure 6: Staffing Issues



\*Although half of the parenting program directors cited staff training needs, 78% of the 18 paid aides and volunteers who traveled with Commission staff to visit families requested additional training.

programs were staffed with a program director and either one or two part-time or full-time parenting aides.<sup>2</sup> One program, which relied extensively on additional funding sources, stood apart from the other programs with seven paid staff persons.

As noted above, in the spring of 1992, three of the programs requested and received additional funding (\$25,000) from the DDPC to augment their staffing with either a part-time or a full-time paid crisis worker. These programs presented a coordinated request to the Council, stating that so many of their families were in periodic crisis that they required a special staff person to cope with these recurring situations.

With the exception of one program, all programs reported having at least one volunteer at the time of the Commission's fall 1991 visit.

Two of the programs had only one volunteer; two had two volunteers; and three had four volunteers. The latter programs relied primarily on volunteers to provide direct services to families. One of these three programs served only five families, and one other program, although relying heavily on volunteers to provide in-home support and training, also placed approximately half of its enrolled families in enriched family foster care homes.<sup>3</sup>

## Staff Qualifications and Recruitment

Five of the eight programs (63%) reported encountering some problems in recruiting paid staff or volunteers, and four of these programs (50%) reported that recruitment problems were frequent (Figure 6). Part of this problem was

<sup>2</sup> All paid staff figures reflect full-time equivalent staff positions. Volunteers, on the other hand, usually work 10-20 hours a week.

<sup>3</sup> Through these foster family placements, this program had essentially ensured round-the-clock supervision and support for half of its families, thus obviating some of the more serious flaws of the volunteer service delivery model cited by other programs choosing not to rely so heavily on volunteers in serving families.

clearly linked to the wages the programs were paying. In accordance with the federal guidelines, volunteers earn only \$2.35 an hour, and to enroll in the program, volunteers also needed to meet certain low income qualifications. The paid parenting aides were also not usually well paid. At some programs, hourly wages only slightly exceeded the minimum wage, and at none of the programs did paid parenting aides earn more than \$6.50 an hour.

More than money, however, program directors reported that recruitment was difficult because this job was not for just anyone. When

asked what qualities they looked for in their paid staff and volunteers, program directors were remarkably consistent. Across the programs, three factors—acceptance of persons with developmental disabilities; receptiveness to new ideas; and interest, knowledge, and confidence in childcare and parenting activities—were cited as the most important staff qualifications. When asked to select adjectives that more broadly described their most effective staff and volunteers, program directors offered “responsible,” “self-confident,” “compassionate,” “motivated,” “nonthreatening,” “accepting,” “flexible,” and “patient.”

### Figure 7: Parenting Aides and Volunteers Talk About Their Work Experiences

#### Best Part

*Watching a mom learn something we've been working on and seeing her actually do the task.*

*Seeing parents accomplish tasks and be happy with themselves. Seeing real bonding occur between mom and child.*

*Seeing her child progress with his speech and the progress the mother has made to get custody of her son.*

*When I first met the 18-month-old child, she had no affect and needed affection. It was a great joy to see her running into her mother's arms to be picked up and watching her grow to become responsive.*

*Seeing the parents hit the children less and talk with them more.*

*[Knowing] the mom is able to shop better and make better choices.*

#### Worst Part

*Not being able to help the children and protect them from harm, particularly with parents who should not have custody of their children.*

*Adolescent problems, since the child goes beyond parents intellectually.*

*Parents' mismanagement of money, domestic violence, and poor housekeeping skills.*

*Families not following through with suggestions, hard to see if I make any difference. Many times I want to throw my hands up in the air.*

*When a parent was charged with child abuse/neglect.*

*Parents need to interact more with their children; they don't follow up and complete assigned tasks.*

As suggested by the above, program directors had high expectations of their volunteers and paid aides. At the same time, relatively few of the paid staff or volunteers had any formal education or training in the field of developmental disabilities, and very few had actually worked with persons with developmental disabilities in the past. It seemed to be more important that the individuals be people who saw themselves as having something both to give and to learn and who had a genuine commitment to and interest in working with adults with developmental disabilities as they strived to parent their children.

## Staffing Turnover

Although each of the programs reported spending considerable time recruiting and screening potential job candidates, most had also experienced significant paid staff and volunteer turnover. Volunteer retention, especially, appeared to be a problem for most programs. At the time of the Commission's fall 1991 visit, the seven programs using volunteers had a total of 17 volunteers on their staff. Only two of these programs reported no volunteer turnover in the past year, while five others reported having lost a total of 12 volunteers in the past year. Although most of the volunteer turnover was due to voluntary resignations, two of the programs had terminated a volunteer in the past year.

When Commission staff visited families in their homes with the parenting aides and volunteers, they came to appreciate more fully the difficult and stressful jobs aides and volunteers had undertaken. At many programs, paid aides and volunteers had given families their home phone numbers, and after-hours crisis calls for assistance were frequent.

Most paid staff and volunteers also had at least one family on their caseload which was resistant to suggestions for parenting or simply unable to carry them out consistently. These families and their frequent crises placed enormous stress on paid staff and volunteers who worried about the well-being of the children and/or the parents. And, despite the deep gratitude of many of the families for the services of the parenting program, paid aides and volunteers recognized that there were many pressing needs of the families that they were unable to meet.

As shown in Figure 7, interview comments of paid staff and volunteers vividly portrayed the ups and downs of their jobs. Their comments reinforced that these were not jobs for men or women who expected quick rewards and few disappointments. At the same time, they also reinforced the substantial and invaluable rewards that these jobs could offer.

## Training and Supervision

All eight programs reported having an ongoing in-service training program, and all but one of the programs reported having a formal orientation program for new volunteers and paid parenting aides. As shown in Figure 8, these programs covered an array of topics. Some focused specifically on the needs of persons with developmental disabilities, but more centered on basic skills and information about childcare, health, and nutrition.

Weekly direct supervision of volunteers and paid staff was also the general rule, although one program, which relied heavily on students and persons with other day jobs, reported that face-to-face supervision sessions were sometimes held only on a monthly basis.<sup>4</sup> Most of the

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<sup>4</sup> Subsequent to the Commission's on-site visit and report to this program, its director reported that supervision of paid parenting aides has been enhanced.

**Figure 8: Training Topics for Parenting Aides and Volunteers**

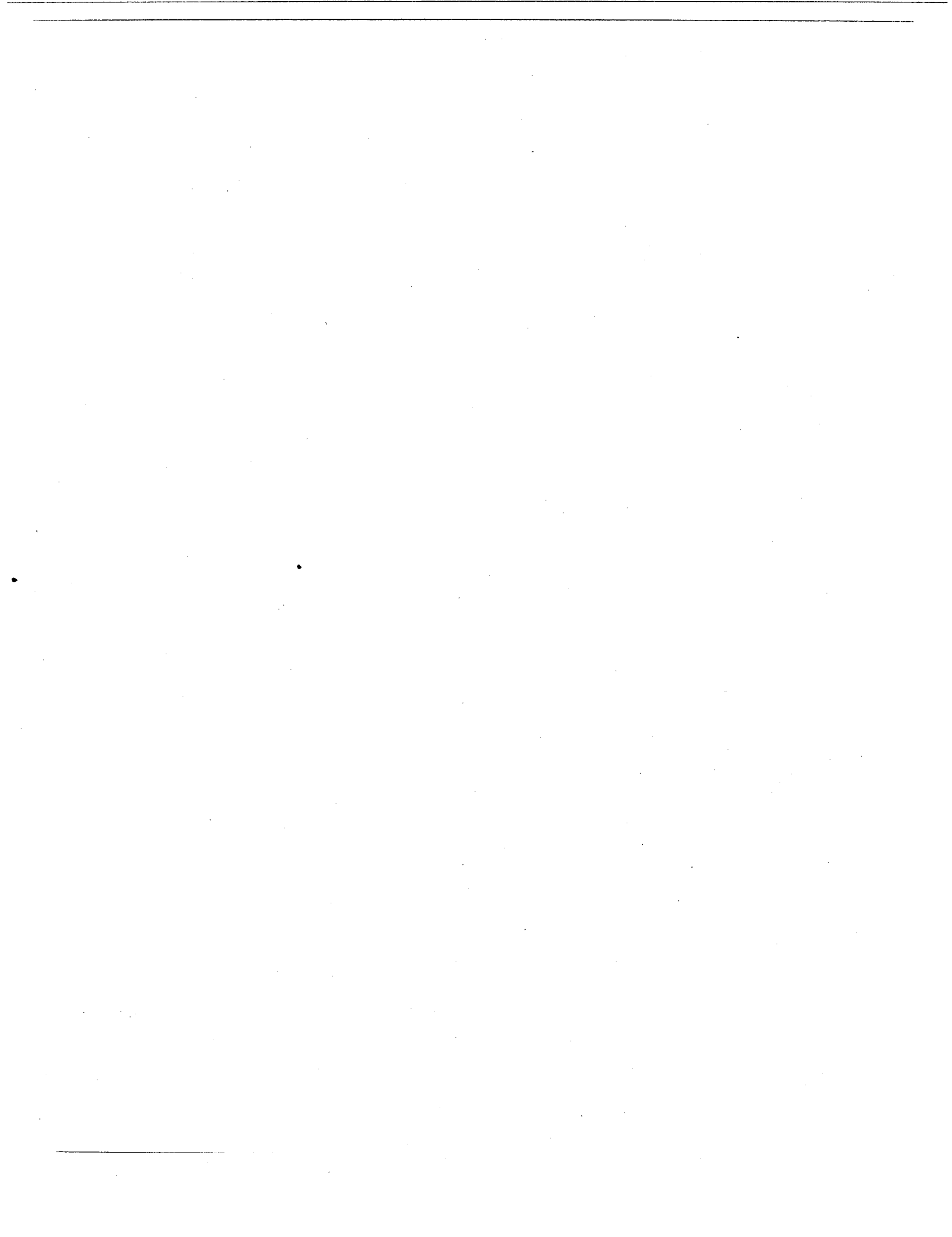
- Specific parenting skills
  - infant care
  - nutrition
  - budgeting
- How to engage and interact with the families
- How to detect abuse, neglect, and domestic violence
- How to handle specific situations

programs, however, scheduled one full or half-day each week when all volunteers and paid staff met to discuss the families served, the problems encountered, and needed revisions in the families' services. At several programs, these sessions were also regularly coupled with an in-service training presentation.

Notably, despite the regularity of in-service training, program directors at half of the programs reported that more training would be helpful. Subsequently, when the Commission staff travelled with the 18 parenting aides/volunteers to visit the 25 families in their homes, an even more striking 78% of the aides/volunteers stated that they would benefit from additional training.<sup>5</sup>

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<sup>5</sup> These 18 individuals included 12 volunteers and 6 paid parenting aides.





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# Chapter III

## Getting Started and Serving Families

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With the exception of one program which had been providing training and assistance to parents with developmental disabilities for at least five years, none of the programs found smooth sailing in their early months of operations. From finding good staff and volunteers to keeping parents motivated to designing (and redesigning) their service delivery to meet the families' needs and interests, start-up problems were the rule, not the exception, across programs.

Most programs also came to find their enrolled families more needy, and often less trusting, than they had initially anticipated. In particular, many families had serious difficulties related to poverty, family dysfunction, alcohol abuse, and domestic violence, as well as their cognitive impairments. Maintaining the trust and confidence of parents, as well as their interest and commitment to making fundamental changes in their lives, surfaced as paramount issues for many programs.

Finally, within weeks, programs learned that their responsibilities for many of their enrolled families would span far beyond providing parenting training and assistance. For many families, programs had to start with the basics of finding appropriate housing, ensuring that the food supply was adequate, and meeting basic medical care needs. Parenting aides and volunteers also became far more than teachers and role models for many families where they became the family's one true friend and the family's vital ambassador with social services caseworkers, teachers, doctors, and public health nurses.

### Start-Up Delays

Although each of the eight demonstration programs officially received its first funding

grant from the New York State Developmental Disabilities Planning Council in September 1990, actual start-up dates and family service initiation dates for the eight programs varied substantially. While some of the agencies had historically served some of these families, as the parents and/or children had been served in one of their other sponsored programs, with the exception of one agency, the Council grant marked the initiation of the agency's focused attention in serving this population. Not surprisingly, some agencies experienced more difficulties and delays in getting this new venture started than others.

Six of the eight programs (75%) reported that they did not begin serving families until four months after the program had opened its doors, and two of these programs reported that they did not begin serving families until more than six months after they opened.

Delays in beginning service delivery were attributed to different problems. One program had problems identifying families in need of its services, while all had some problems maintaining families in their programs. Five programs also reported that they initially struggled to recruit volunteers, and three determined after several months to rely more intensively on paid parenting aides. Several programs also encountered some initial problems in matching families and parenting aides/volunteers. And, while all programs had some problems in retaining families in services, for two programs, this issue had a substantial impact on their early operations.

### Families Served

In the fall of 1991, a total of 86 families were being served by the eight programs. The re-

### *Edward and Charlene G.*

*Mr. and Mrs. G. met each other at the state institution where they both lived until they were 22. They have two children, Patrice, age 4, and Gerald, age 2. Mrs. G. also has a 20-year-old daughter from a previous marriage, who visits often and helps around the house.*

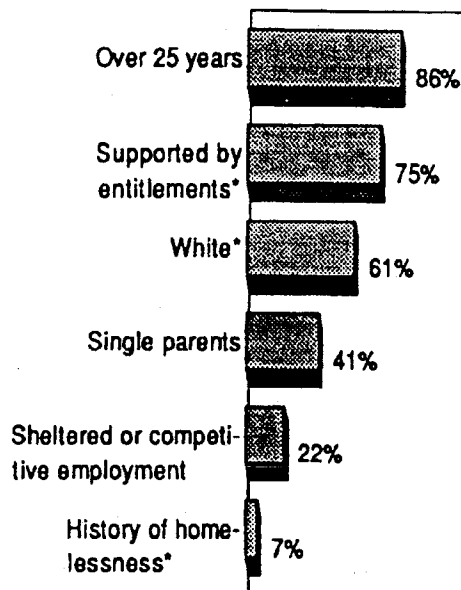
*This family lives in a residential neighborhood in a very clean three-bedroom apartment. They have all the modern conveniences, including a microwave, several television sets, a VCR, a dishwasher, and a coffee maker.*

*Both Mr. and Mrs. G. are mildly mentally retarded, and Mr. G. has an ambulation problem and uses a cane. Mrs. G. works full-time at a nursing home, where Mr. G. also volunteers two mornings a week. They are very supportive of one another and share in caregiving for their children and in all the household chores. They can become easily overwhelmed, especially when one parent has to care for both children at the same time. In the evenings, Mr. G. prepares dinner for the family, and the family often visits other extended family members who live in the community and provide considerable support.*

*Mr. and Mrs. G. have been enrolled in the parenting program for slightly more than one year, and the volunteer, who spends about eight hours a week in their home, reported that the family is doing well. Although Patrice is learning disabled, the volunteer stated that she is a smart and outgoing child who enjoys painting and drawing and likes to be the center of attention. Her younger brother, Gerald, has been diagnosed as mildly mentally retarded, with a slight speech impediment, but he is reportedly doing very well at the preschool program that he is attending. The volunteer described Gerald as a happy, well-adjusted boy.*

*The volunteer told the Commission that Mr. and Mrs. G. can well manage most of the household chores, cooking balanced meals, and attending to the children's medical and dental needs. He is focusing his time with the parents in encouraging them to be comfortable with and a little less protective of the children, particularly in allowing the children to play with appropriate toys, crayons, coloring books, etc. This is very difficult for Mr. and Mrs. G. who fear that if something happened, their children would be taken away.*

**Figure 9: Snapshot of Parents  
(N = 41 Families)**



\*"Yes" ratings were given to two-parent families if one or both parents met the indicator. There were no interracial families in the sample.

ported capacity of the eight programs ranged from 5 to almost 30 families. Six of the eight programs, however, were quite small, serving fewer than 15 families. Half of the programs reported being capable of serving 5-10 families; two reported capability to serve 11-15 families; and two reported capability to serve 16-27 families.

Despite their start-up problems, by the fall of 1991, six of the eight programs were also full, and five of these programs (63%) had at least one family referral pending. One program, which had experienced especially difficult start-up problems, was serving only two families (capacity five families); one other program which had made the decision to close in a few months was also serving only two families.

In the fall of 1991, the Commission visited the eight programs and obtained demographic, clinical, and social history data on 41 enrolled families. These data allowed us to develop a snapshot profile of the families served. A brief summary of this profile is provided here, but readers are referred to a more comprehensive description of the families in the Commission's companion report, *Parenting with Special Needs: Parents Who Are Mentally Retarded and Their Children*.

## The Parents

Parents ranged in age from 19 to 54, but three-fourths were between the ages of 25 and 40. Most of the families were headed by two parents, but 41% were single-parent families. Over half of the families had only one or two children, but 17% of the families had four or more children (Figure 9).

The families served by the eight programs were also largely poor; almost all families (regardless of size) subsisted on less than \$900 per month. Many of the families had lived or now live in substandard housing. Although the parenting programs had helped many of the families move to more suitable apartments or homes, most families continued to live in cramped arrangements or in housing that was difficult to heat or that needed some maintenance work.

For many of the parents, their own childhoods had been marked by abuse or neglect and/or out-of-home placements and, unfortunately, these histories followed many of the parents into adulthood. Almost half of the families had had at least one child removed from their custody, at least temporarily, due to allegations of abuse or neglect, and histories of domestic violence and trouble with the law were common to approximately one-fourth of the families (Figure 10).