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Parenting With Special Needs

Parents Who Are Mentally Retarded and Their Children

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

July 1993



Parenting With Special Needs: Parents Who Are Mentally Retarded and Their Children

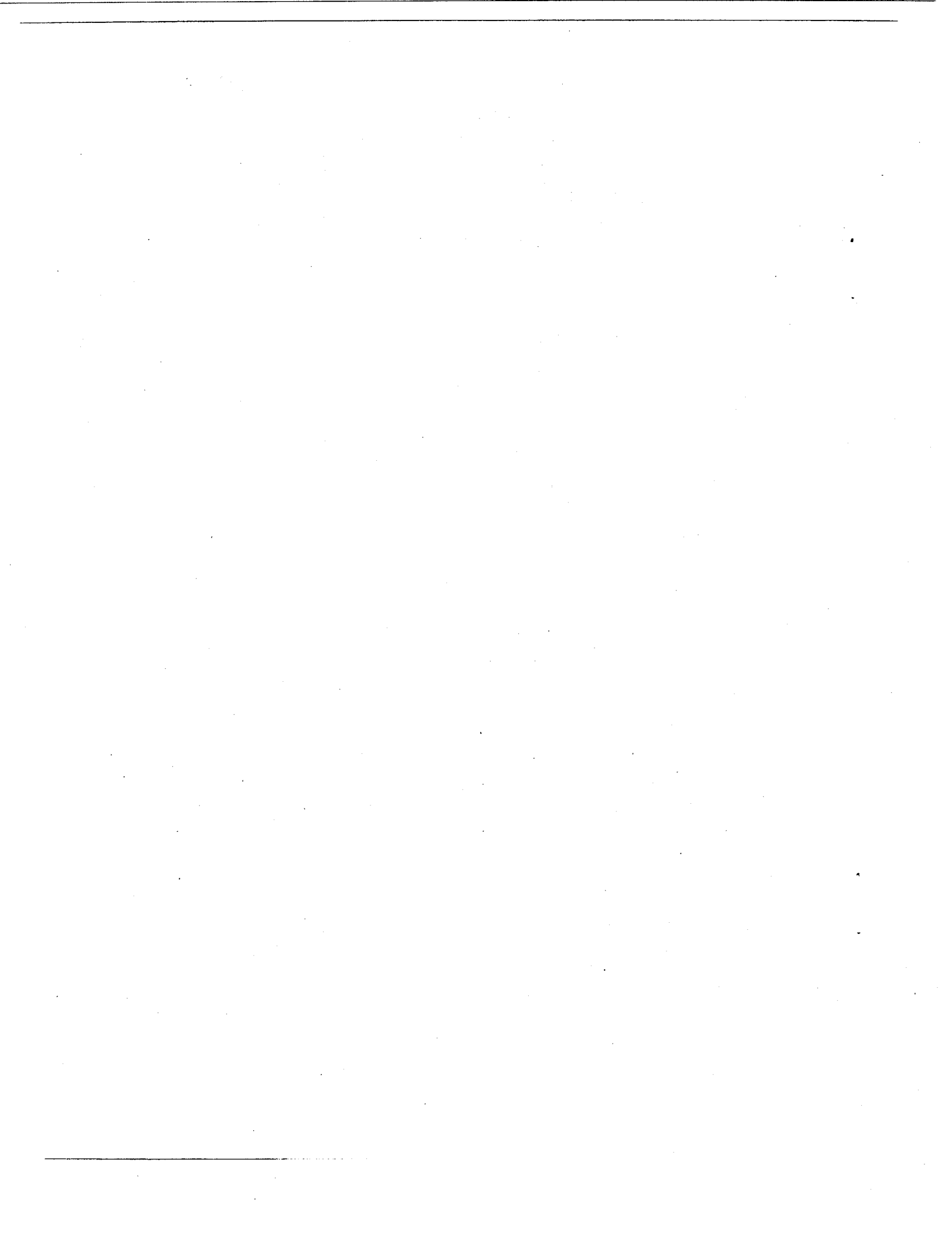
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COMMISSIONERS

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NYS COMMISSION
ON QUALITY OF CARE
FOR THE MENTALLY DISABLED



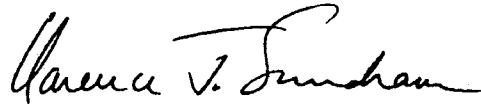
Acknowledgments

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.

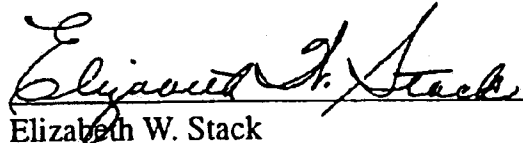
This report would also not have been possible without the gracious assistance of the program directors, parenting aides, and volunteers of the eight parenting programs reviewed. The dedication of these women and men in helping parents who are mentally retarded and in many cases in extending their workdays 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.

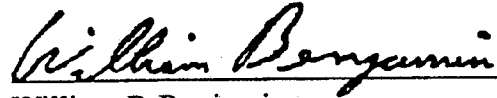
The findings, conclusions, and recommendations expressed in the report reflect the unanimous opinion of the Commission.



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Chairman



Elizabeth W. Stack
Commissioner



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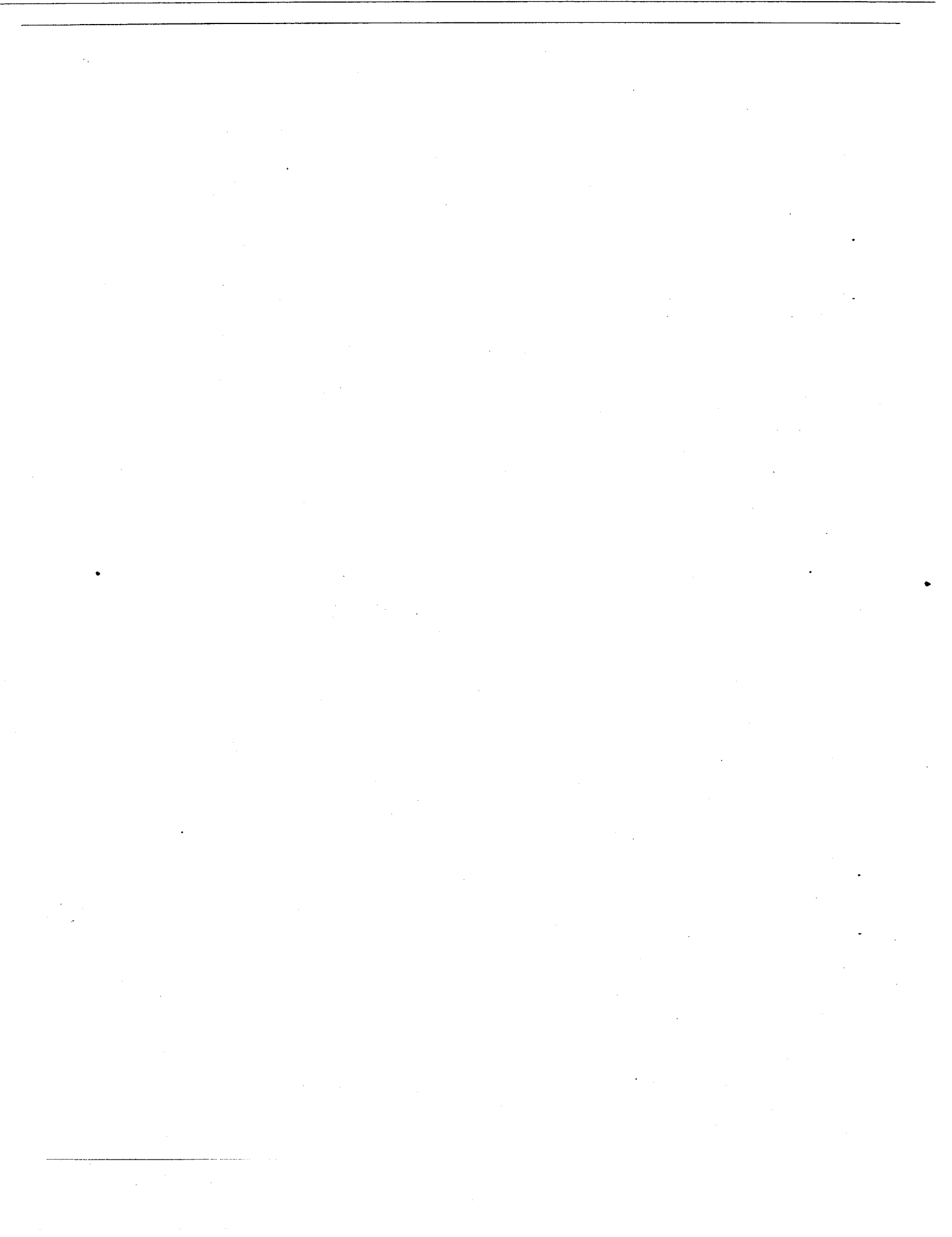


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Chapter I

Introduction

This report looks at lives of a special group of New York families—families with one or both parents known to have significant intellectual impairments and/or developmental disabilities. The Commission came to know more about these families through the conduct of an evaluation study, requested and funded by the New York State Developmental Disabilities Planning Council, which examined eight demonstration programs the Council had funded to serve parents with developmental disabilities.

Over the years, the Commission, and especially its regional Protection and Advocacy Offices, had intervened on behalf of a small number of parents with developmental disabilities. Through this study, the Commission has come to appreciate that parents with intellectual impairments and/or developmental disabilities are a diverse group of individuals. While many of the families share some common struggles in parenting their children, and especially in coping with incomes less than the established poverty level, as a group, they are characterized by their heterogeneity.

Most importantly, it did not usually appear that the parents' specific intellectual and developmental limitation was the only significant

The Commission has come to appreciate that parents with intellectual impairments and/or developmental disabilities are a diverse group of individuals.

factor influencing their capacity to parent their children. Like all parents, their motivation to parent, the training and experience they had with

parenting tasks and responsibilities, their other strengths and needs, and the presence of specific formal and informal supports in their lives were often equally, if not more, important factors influencing their ability to nurture and care for their children. At the same time, through the conduct of this study, the Commission has also

It did not usually appear that the parents' specific intellectual and developmental limitation was the only significant factor influencing their capacity to parent their children.

come to appreciate that intellectual impairments and other disabilities were often substantial handicaps for the parents studied as they attempted to fulfill their parenting responsibilities.

Over the course of this study, we were able to become acquainted with 54 of these families, and 25 of these families invited us into their homes for a visit. Yet, there is still much that we do not know about the quality of life for these parents and their children, particularly over the long term, as their children grow into adolescence and adulthood. Similarly, there is still much to learn about the support services from which these parents and their children will most benefit, and how these services should be provided and funded.

Thus, this is a preliminary report introducing some basic information about parents with significant intellectual impairments and/or developmental disabilities and the programs and services in their communities designed to assist

them and their children. What we have learned, however, has clearly indicated that providers of social programs serving families and children can no longer overlook the special needs of this significant and growing population of parents who require services in their communities.

It became apparent that most of the available literature was anecdotal in nature and that empirical studies focusing on the number of families headed by one or two parents with developmental disabilities have not been reported.

Literature Review

The Commission began its evaluation by studying available research and literature focusing on parents with developmental disabilities. As we pursued this objective, it became apparent that most of the available literature was anecdotal in nature and that empirical studies focusing on the number of families headed by one or two parents with developmental disabilities have not been reported. Although several articles have been published in recent years tracing parenting training programs for these families or the problems parents with mental retardation encounter in parenting, empirical needs assessment studies on significant samples of these families were sorely lacking.

One subset of studies reports on efforts to identify parents with developmental disabilities and to determine the well-being of their usually very young children. Feldman et. al. (1985), for example, reported on a small case study of 12 mothers who were mentally retarded and their two-year-old children. Although none of the children were diagnosed with disabilities at birth, the study found that the two-year-old children raised by the mothers were at high risk for developmen-

tal delays, especially in language. The research also found that the inability of a mother to care for an older child, as determined by child protective services, as well as the passivity of mothers, significantly correlated with the presence of developmental delays in the children.

Whitman et. al. (1987) reported on a community survey of parents who were mentally retarded. Relying on community agencies, they identified 280 families with one or more parents who were mentally retarded. These families had a total of 1,096 children. Their study, found that fewer than 15% of the parents had received help from schools or other agencies with child-rearing and parenting skills, although over one-fourth of the parents had at least one child removed from their custody.

One of the more interesting studies in this area was conducted by O'Neill (1985), who studied a small cohort of 19 children with normal or above-average intelligence who had a mentally retarded parent. Over half of the children studied displayed negative adaptations and behavior, including open rebellion, social adjustment problems, and impulse control problems. Another one-fourth of the children had taken over the parental role in the family with a subsequent lack of adult fulfillment.

Reports of parenting training programs generally assert positive outcomes for families participating in the training, but empirical evaluation data are not presented.

Reports of parenting training programs for mothers and fathers who are mentally retarded are more common in the literature. These reports focus on describing the curriculum of the

parenting programs with some information of the teaching interventions used. The reports generally assert positive outcomes for families participating in the training, but empirical evaluation data are not presented.

For example, Nanis and Scheer (1984) reported on a home-based training program, Project P.A.L.S. (Parents Are Learning Skills), sponsored by a local voluntary mental retardation agency in California since 1978. The project found that four problems characterized the families served: (1) lack of basic parenting skills; (2) parental social/emotional instability; (3) social isolation; and (4) inability to access available government entitlements and community resources. Based on their work with parents with developmental disabilities, the authors offered specific parenting training guidelines, including keeping verbal instructions simple, avoiding questions that only have yes/no answers, modeling the performance of tasks, and treating parents with respect and dignity.

Whitman et. al. (1989) reported on an alternative service delivery model for parents with mental retardation, which relied most heavily on interactional instruction for parents and children in a four-day-a-week early intervention school setting. Although the sponsors reported anecdotal successes, they noted that despite the provision of transportation, attendance was sporadic and fluctuated around 50%.

The Commission's review surfaced only one article which dealt with the ethical questions involved in serving parents who are mentally retarded.

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In another report, Heighway et. al. (1988) discussed the Positive Parenting Project in Brown County, Wisconsin. Opened in 1985, this pro-

gram provides in-home, individualized, and intensive case management services for families. In their report, they acknowledged the impediments of the parents' cognitive limitations in generalizing parenting concepts and skills, and they cited the limited social and "play" skills of the parents. The article concluded with a report of positive outcomes for children and parents who participated in the program, but empirical evaluation data were not presented.

One of the more useful parenting training guides was prepared by Bakley of San Diego University (1986). This guide provides a listing of 20 problems typically encountered in these families and offers successful teaching approaches. For example, in working with parents who may appear as unresponsive or as having a flat affect, the guide recommends activities that have high interactive potential. For helping mothers who misinterpret a baby's cries, the guide recommends a checklist of common reasons why babies cry, which mothers can reference.

Graves et. al. (1990) reported on a similar didactic teaching curriculum for parents with mental retardation. The curriculum includes eight basic goal areas (e. g., child development, addressing the child's basic needs, daily routines, etc.) and, in each area, specific behaviorally stated objectives are listed. For example, one objective under the goal area of daily routines is "to keep a housekeeping schedule with 90% accuracy."

The Commission's literature review surfaced only one article, Dennis Brodeur's "Parents with Mental Retardation and Developmental Disabilities: Ethical Issues in Parenting" (1990), which dealt comprehensively with the ethical questions involved in serving parents who are mentally retarded. While endorsing the strong legal and ethical presumption that biological parents should care for their own children, he cautioned that there are some indications that,

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)

even in the best of circumstances, some parents with mental retardation will not be able to meet the child's long-range adolescent needs. Brodeur supported enriched early intervention programs for parents who are mentally retarded (before problems surface), but he qualified, "Children's long-term needs cannot be sacrificed for adults' short-term gains."

Methodology

Data collection for this study took many turns. As noted above, the Commission began by studying the relevant literature. Next, Commission staff met with the directors of the eight demonstration programs, funded by the New York State Developmental Disabilities Plan-

ning Council, to discuss their programs, their accomplishments, and the problems they have encountered. Of note, at the time of this meeting, most of the programs were funded for approximately one year, but most had been operational (i.e., serving families) for only about six months. Early telephone interviews with each of the program directors further helped the Commission to acquaint itself with the programs and their operations.

-Program Site Visits

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 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.¹ 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.

¹ 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 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.

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

-Other Activities

The Commission also visited three other agencies with special experience and expertise related to the needs of families with parents who are significantly intellectually limited or developmentally disabled. Two of these agencies, the Herkimer Association for Retarded Children and the Huntington Family Center, had been serving a significant group of families headed by parents with these disabilities for more than five years. The Commission also made a site visit to the Westchester Institute for Human Development (formerly called the Westchester Mental Retardation Institute). In the past several years, staff at the Institute had worked with local agencies serving parents with developmental disabilities, and they had prepared a video tape of several of these families in their homes.

Finally, the Commission requested written expenditure and budget information from the eight demonstration programs. In the summer of 1992, we also conducted structured telephone interviews with the directors of the seven operating demonstration programs to obtain a better understanding of their current funding sources and their plans and prospects for continued funding when their demonstration project grants from the New York State Developmental Disabilities Planning Council expired in 1993.

Limitations

Although these activities helped the Commission to learn much about families with parents who are significantly intellectually limited and/or developmentally disabled, they were not without their limitations. In particular, for many of the families studied and/or visited, there were

significant historical gaps in the program staff's clinical knowledge and records. Formal psychological assessments of the parents were conducted uniformly by only a few programs, and structured assessments of the parents' adaptive functioning in daily living and parenting skills were not regularly completed by any of the programs.

Social histories of the families were similarly incomplete, and in most cases, little was known of the parents' childhoods or historical encounters with child protective or preventive

Historical service profiles of the parents were so fragmentary that it was impossible to make any judgments about whether early intervention services had made a difference.

services (as children or as parents). At the time of the Commission's visits to the programs, nearly half of the families studied had one or more children who were living out of their homes due to allegations of neglect or abuse.² Staff at most of the programs visited knew little of these children or the incidents that had led to their removal.

Similarly, most of the programs had little information about the services that the families had accessed in the past, either as children or as adults, and as parents. With the notable exception of some parents who had been clients of the local mental retardation agency since they were youngsters, historical service profiles of the parents were so fragmentary that it was impossible to make any judgments about whether early intervention services had made a difference in their parenting abilities.

² Historically, almost half of the 54 families studied or visited (49%) had one or more children removed from their homes temporarily, due to allegations of abuse or neglect.

Finally, good recordkeeping and regular and descriptive progress notes were not strong features of the majority of the eight programs. Much of what was known about the families was not documented in charts, but verbally shared by paid staff and volunteers. These individuals had usually established close and personal relation-

ships with the families, and their accounts had the credibility of real life stories, with plentiful examples from their personal encounters. Nonetheless, the reader is advised to bear in mind that these reports were also subject to the vagaries of personal recollections and impressions.

