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The family support services study

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THE FAMILY SUPPORT SERVICES STUDY

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts
in
Special Major

by
Patricia Ann Hodge
April 1989
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ABSTRACT

The ability to provide services that will allow children with developmental disabilities to live at home, whenever possible, requires the planning of support services to families. To provide family support services requires the coordination of an organized, efficient, cost effective state wide system. This paper details a brief history of the family support service system from a state and regional perspective. It explains the evaluation tool, "The Family Support Services Study", which examined the family support system in California from both the perspective of the regional centers and from that of the family of the developmentally disabled child. This paper provides some preliminary results from research data that identifies the characteristics of the family most likely to place their developmentally disabled child in out of home placement. Such placement is one in which the mother works, is single, has little help, has some college, indicates high work stress, money spent on the child is high, income is medium, age of child is 9, the child's functions are high, and burden of care is low. Finally, The paper presents a collaborative grant proposal to develop a program which will ameliorate the parenting skills of developmentally disabled parents and prevent developmental delay in their children.
Table of Contents

ABSTRACT .................................................................iii
INTRODUCTION ..........................................................1
  THE NEED FOR RESPITE CARE ......................................2
  THE FAMILY SUPPORT STUDY .......................................3
RESEARCH QUESTIONS ASKED .........................................6
  HYPOTHESIS DEVELOPED ............................................7
LITERATURE REVIEW ..................................................10
HISTORY OF FAMILY SUPPORT SERVICES ..........................18
INLAND COUNTIES REGIONAL CENTER ..............................24
FINANCE .................................................................28
FAMILY SUPPORT SERVICES STUDY ..................................31
UNIVERSITY OF CALIFORNIA, RIVERSIDE ..........................32
  DATA COLLECTION PROCESS ......................................33
  METHODOLOGY ......................................................34
  PERSONAL INTERVIEW .............................................36
  METHODOLOGY ......................................................36
  RESULTS ..............................................................38
OFFICE OF PLANNING AND POLICY DEVELOPMENT ..................43
  DATA COLLECTION PROCESS ......................................43
  METHODOLOGY ......................................................45
  RESULTS ..............................................................47
DISCUSSION ............................................................49
RECOMMENDATIONS ..................................................54
REFERENCES ............................................................59
THE FAMILY SUPPORT SERVICES STUDY

INTRODUCTION

A developmentally disabled person is one who has a disability which originates before the individual attained age eighteen, continues or can be expected to continue indefinitely, and constitutes a substantial handicap for the individual. This term includes mental retardation, cerebral palsy, epilepsy, autism, and handicapping conditions found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals. It does not include handicaps that are solely physical in nature (Brochure).

In the state of California special organizations have been developed to specifically meet the needs of the developmentally disabled child. These organizations are called Regional Centers. There are 21 Regional Centers throughout the state of California. The primary objective of the centers is to assure the provision of services which will allow persons with developmental disabilities to live in situations as close to normal as possible. The agencies serve as an advocate for the developmentally disabled person to help them obtain necessary services such as medical care, living arrangements, education and work training. When these services are not available through generic agencies such as medi-cal, insurance, schools, California Childrens Services, agencies may purchase services from approved vendors.
One of the goals of the regional centers is to remove developmentally disabled individuals from state hospitals and move them into more suitable living situations that promote a lifestyle as close to normal as possible. To do this, involves encouraging families to maintain the disabled family member at home whenever possible.

Families are supported in maintaining the disabled family member at home through periodic respite care. Respite care, the provision of temporary relief to families, can be provided in a variety of ways. Some of the ways respite care is provided include: group day care, private in-home care, community residences, residential treatment facilities, nursing home, group residential care, respite placement agencies, camperships and funding conduit, and state institutions (Upshur, 1979).

Apollini & Triest's (1983) parent survey reported of the population receiving respite 79% were in the 0-20 age range, with an emphasis on early childhood years (0-5; 31%) and late teens (16-20 yrs; 20%). They were largely multi-handicapped (82%), rated moderately (31%) or severely mentally retarded (47%), and were drawn from two parent natural homes (75%).

THE NEED FOR RESPITE CARE

The primary reasons cited in Apollini & Triest's (1983) study by both parents (84%) and Regional Centers (100%) for the use of respite care was relief from the emotional stress
of caring for a child/adult with a developmental disability. It appeared that sheer relief for overworked family members was the foremost reason for respite, with practical needs coming next, i.e.: care during emergencies and illness. More supplemental respite care and recreational needs came last, i.e.: permit parents to take vacations away from their disabled child.

Respite services are purchased by the regional centers from approximately two hundred respite provider agencies throughout the state. Apollini & Triest (1983) found that respite services in California have several critical problems. Fundamentally there is a lack of consensus regarding what respite care is, and what it is not. Parents have insufficient input regarding the nature and quality of the respite that is available. Respite services are not consistently available across the state. The management information system in place does not permit state and regional planning. Planning and evaluation procedures are inconsistent. Lastly, there is no career development model for respite workers.

THE FAMILY SUPPORT STUDY

The Family Support Services Study had a threefold purpose. First, the study was to describe the characteristics of the family support system for families with developmentally disabled members as it now functions in the State of California. Secondly, the extent to which
California is meeting the needs of persons with developmental disabilities as these needs are perceived by the families.

The third purpose was to determine the impact of the family support system on the family and its member with developmental disabilities, with special reference to those factors which influence the family's ability to retain its child at home rather than seeking out-of-home placement.

Family support services regardless of how they are defined cost money. Proposition 13 froze property tax at 1978 rates. This decreased revenue resources and encouraged all government agencies to seek other sources of revenue and to form coalitions to monitor overlapping services.

State and local governments are all reacting to economic stresses and demands of their constituents for more accessible and acceptable programs by reorganizing and regrouping existing services. However, "organizing and reorganizing are not effective substitutes for careful deliberation about where we are going and how we are going to get there." (Hanlon & Pickett, 1984, p.187).

As recent as February 1989 Regional Center operation budget funds were reallocated to another source because the state felt that a portion of the Regional Center operations could be charged to the Federal Government. When the Federal Government denied liability, operations at the Regional Centers were to discontinue until July 1. At the last minute
funds were designated to continue operations. The prospects of this occurring on an annual basis are possible in today's climate of financial crunch.

Results of the Family Support Study will no doubt identify many services that families would like to receive to maintain their developmentally disabled child at home. The state has limited resources for these services. The Regional Centers are provided a budget that must be spent on many client services, only one of which is respite care. Other support services may be seen as more important on a personal level of need.

With dwindling budgets and increased service costs it is timely that the Department of Developmental Disabilities conduct this study. Efforts to minimize costs and maximize services that families will actually use is essential to better utilize resources available to the internal environment.
RESEARCH QUESTIONS ASKED

1. Does help from family members who live in the home of the target group differ significantly from relatives and friends not in the home?

2. Does assistance from the regional center differ from region to region?

3. Do agencies other than regional center provide accessible and satisfactory services to families of the target group?

4. Is there a difference in the amount of physical care required by the target group?

5. Is there a relationship between hours spent out of the home by the target group and family caretaker stress level?

6. Does the age of the target group show a statistical difference on the family stress level?

7. Does the number of people living in the home of the target group differ significantly to the families ability to retain the target group at home?

8. Does the education of the major family caretaker of the target group show a significant difference to the families ability to retain the target group at home?

9. Does the level of developmental disability of the target group make it more difficult to work outside of the home?

10. Does the level of developmental disability affect any working adult in the households' work performance or
promotion/transfer abilities?

11. Has the family seriously considered placing the child with developmental disabilities outside out of the home? If so how seriously?

12. Is there a relationship between the level of disability and the families decision to place?

13. Do families perceive a support service they are not receiving to be more helpful in retaining their child in their home?

14. Do families find one support service they are receiving more helpful to retain their child in their home?

HYPOTHESIS DEVELOPED

1. Null hypothesis states there is no association between physical care required by the client and family stress level.
   Alternate hypothesis states that there is an association between physical care required by the client and family stress level.

2. Null hypothesis states that there is no association between hours spent away from home by the client and stress level of the family care provider.
   Alternate hypothesis states that there is an association between hours spent away from home by the client and stress level of the family care provider.

3. Null hypothesis states that there is no association between age of the child and family stress level.
Alternate hypothesis states there is an association between age of the child and family stress level.

4. Null hypothesis states there is no association between the number of people living in the home of the client and the families ability to retain the client in the home. Alternate hypothesis states there is an association between the number of people living in the home of the client and the families ability to retain the client in the home.

5. Null hypothesis states there is no association between family stress level and family decision to place the child out of the home temporarily or permanently. Alternate hypothesis states that there is an association between family stress level and family decision to place the child out of the home.

6. Null hypothesis states there is no association between services families are receiving and those they are not receiving that families perceive would be most helpful in retaining the client in their home. Alternate hypothesis states that there is an association between services families are receiving and those they are not receiving that families perceive would be most helpful in retaining the client in their home.

7. Null hypothesis states there is no association between services delivered from regional centers from region to region
Alternate hypothesis states there is an association between services delivered from regional centers from region to region.
LITERATURE REVIEW

Society's rules of conduct for its members are interpreted through the family. Many health and social services which the family needs for its members, other than affectional, have been transferred to outside agencies with the advent of industrialization and urbanization (Winch, 1971), especially when it comes to ill and disabled family members for example. Farber (1978) hypothesized that performance of nurturance and control functions is adapted according to the amount of time and energy demanded by the retarded child, the extent of family resources, and prior loyalties and commitments.

Kazak & Marvin (1984) studied three types of stress: individual, marital, and parenting. They found that rather than affecting marital satisfaction, the stress related directly to parenting issues with the mother experiencing more personal stress. Many mothers presented as suffering from parental "burnout". Mothers perceived their disabled child as more demanding and less adaptable to changes in their physical and social environment thus, less adequately fulfilling mothers own expectations for her children. Mothers experienced more depression around parenting issues and felt less competent as mothers. Mothers spent significantly greater amount of time caring for their children at bedtime, smaller percentage of time with themselves and spouses. Significantly more of mothers
leisure time was spent with extended family than in the comparison group and they tended to have smaller social networks.

Wilcox (1981) found that larger networks were predictive of more positive adjustments than were smaller networks. He described network size by how many friends outside the family who were not friends of other family members as a larger network versus a small network of only family and interrelated friends. He also found fathers spent significantly less time with their disabled child at bedtime and reported higher levels of disagreement with their spouses over child discipline than the comparison fathers of normal children.

This study reaffirms the finding in the present Family Support Service Study that reports the single mother with a small social family network is more likely to place her disabled child even if the child is only mildly retarded. The family functions as a role model in which individuals learn and practice roles appropriate for life-cycle development. As maintenance functions are fulfilled, family members are enabled to participate in the usual activities of their relevant social networks.

Suelzle & Keenen (1981) studied changes in family support networks over the life cycle of mentally retarded persons. These findings have implications in family support planning. They found utilization of personal support
networks declined over the life cycle in contrast to utilization of health-care professionals and school personnel. Significant declines over the life course were found in the utilization of family members or friends as baby sitters. Utilization of "rap sessions" with other parents and parent counseling and guidance also declined over the life cycle.

Suelzle & Keenan (1981) also discovered that attitudes toward mainstreaming, the concept of a continuum providing retarded children with an increasing amount of contact with other children, are based upon judgments about both the educational and social needs of retarded children. Discrepancies with average rates of development became much greater over the life cycle. At the same time, parents became more appreciative of the efforts of special educators and have had a longer exposure to the rationale for special education.

Whatever the attitudinal sources, parents of older children were significantly less supportive of mainstreaming and reported a greater need for special education than did parents of younger children. Parents felt that their children would have difficulty socially if all other children were non-retarded, and that their children would not benefit from meeting more non-retarded children. Parents of older children also were more likely to perceive neighbors as less likely to accept their children in age-
appropriate social roles. Parents were more likely to plan for more restricted residential and occupational alternatives for their children. This finding was supported by Wolfensberger's (1980) study that found as discrepancies with average rates of development became more apparent with age, parents became resistant to applications of the normalization concept.

The highest unmet needs for living alternatives were reported by parents of elementary-aged children and young adults. At these stages, families were experiencing transitional crises, first when their children left home for school and then again when their children left school. Parents of young adults were most aware of the lack of availability of many types of living alternatives within their communities, indicating that extra familial environmental factors are important considerations in understanding families with retarded children. Suelzle & Keenen (1981) concluded that the life cycle of children is a stronger correlate to service utilization than are other demographic characteristics.

The most commonly reported benefit to families receiving respite services is a substantial reduction in family tension, burnout, and strain (Wikler & Hanusa, 1980). Joyce, Singer & Isralowitz (1983) studied families' perception of the impact of respite care and increase in quality of life. This included family relations, social
activities, and emotional and physical strains. They found the overall perception was it had a positive impact upon their lives. 96% said respite allowed them to make social plans ahead of time. 76% stated they could now do things that were not possible prior to receiving respite. Interestingly enough, only 27% agreed they felt less tired from caring for their child since receiving respite.

Parents with younger children viewed respite services as more helpful than parents with older disabled children. It appears that parents who have had to cope for longer periods of time have already developed resources to care for their child. For this group respite does not seem to have as great an impact as they do for families with younger children who have yet to develop care options (Joyce et al., 1983).

Respite may also help young adults with developmental disabilities to gradually achieve independence from the constant care and supervision of family members (Boggs, 1979). Respite experiences may motivate people with disabilities to live independently, test their readiness to go out into the world, and give them confidence in their ability to survive there (United Cerebral Palsy Association, 1981).

Blacher, Nihira & Meyers, (1987) data indicated that parents with severely retarded children report a greater impact of the child on family adjustment, but also their
own greater involvement in parenting and greater orientation toward the child then do families with children who are less retarded.

Wikler (1986) looked at periodic stresses of families with older retarded children and found that if periods of increased stress can be anticipated, clinical and policy strategies can be developed to aid families.

Castellani, Downey & Tausig (1986) findings suggest that policies that encourage the extension of family support services to families who may only need a minimal array of these services may stabilize a family environment and assist in keeping a member with developmental disabilities from placement in more restrictive settings.

Over the last decade, the major focus of attention and resources in the de-institutional process has been on establishing community-based residential and vocational/habilitative day programs. Family support services, defined as services other than those basic residential and vocational habilitative services that people with developmental disabilities require for normal community living, were expected to be in place to augment core services. However, the absence of or inability to gain access to such services as information and referral, transportation, and recreation has been identified as being related to re-institutionalization and lack of success in community living.
It also became apparent that services are required for individuals with developmental disabilities living in family settings in order to support and enhance the quality of care families provide to members with developmental disabilities and to prevent undue out-of-home placement (Perlman & Giele, 1983). This group of services, which has been linked to re-institutionalization and the enhanced capacity to provide quality care, have become known as family support services. A wide range of services have been included within this framework. The need to develop policies and programs to stabilize and enhance family support services requires a base of information on the delivery of these services and the factors affecting their availability and accessibility.

Castellani et al (1986) found that several factors affected the availability and accessibility of family support services. Castellani et al (1986) conclude that these factors must be taken into account in moving from an acknowledgement of need for services to actually designing and implementing them. The variations in availability by location and program type, auspice, and size indicate that family support services are closely linked to their community contexts.

These findings indicate that these variations should be taken into account in designing and implementing programs in this area.

The results of these studies suggest that professionals
in the field of developmental disabilities should not hesitate to promote respite care services use among families with a developmentally disabled child. Particularly families with younger children who have just begun to form social networks. Fostering the development of these services in communities where they are not available should also be the professionals objective.
HISTORY OF FAMILY SUPPORT SERVICES

To understand the Family Services Support Study a review of the regional center and legislation that led to its formation may be helpful. Keeping in mind that before the system came into being, it was up to the parents of mentally handicapped children to find services for their children. Generic services such as schools, the Department of Rehabilitation, and transportation agencies provided little in the way of accommodating for their children's needs.

Parents often did not know their child was retarded for two or three years, as diagnostic services were not available. Physicians were reluctant to tell a parent to early and then when they did the only alternative suggested was to place their child in a state hospital. The last state hospital in California was dedicated in 1956.

It was during the 1950's that parents began to ban together and to create services for their mentally handicapped children. The parent movement came alive and local associations for the retarded were established. These associations offered the only services that were available to the handicapped at the time. They were both school and workshop. Parents became active through these associations and frequently traveled to Sacramento to catch the ear of their legislator.

Legislators soon were traveling to the parents
communities to attend town hall type political meetings and listening to the needs of their constituents. The move toward more state supported services on behalf of their children was where their sights were aimed. Parents wanted a future for their developmentally disabled child and institutionalization as a last resort rather than a normal course of events.

In 1962 President Kennedy's panel on mental retardation published it's report. In 1963 President Kennedy gave a message to Congress requesting action to combat mental retardation. California had 13,500 mentally retarded patients residing in four overcrowded State Hospitals with a maximum of 50 square feet per individual by 1965. Waiting lists for State Hospital admissions contained 3,000 people's names who would wait 2 to 3 years for admission (Clark, 1988).

The Assembly Interim Committee on Ways and Means, Sub-Committee on Mental Health studied the care for retarded people in California. They criticized the state's existing system and recommended that the state accept responsibility for persons entering state hospitals. There was no help for families except state hospitals. They recommended community based medical agencies to provide regional services including diagnosis, counseling and continuing services (Clark, 1988).

In 1965 Governor Brown signed Assembly Bill 691,
authorizing establishment of regional centers for the mentally retarded under the jurisdiction of the State Department of Public Health. This Bill shifted state responsibility for the mentally retarded from the point of entering a state hospital, to the point where a diagnosis of mental retardation is made (Clark, 1988).

The following year the first two regional centers were established. The State Department of Public Health negotiated a contract with two private agencies. Children's Hospital in Los Angeles and San Francisco Aid to Retarded Citizens. In 1969 Assemblyman Frank Lanterman introduced Assembly Bill 225 which extended the regional center network of services throughout the State of California. The purpose of this legislation was to meet the needs of each retarded person, regardless of age or degree of handicap, and at each stage of his life's development (Clark, 1988).

The Lanterman Mental Retardation Services Act went into effect on July 1, 1971. By 1972 regional centers were serving 7,500 families and clients. Few remained on waiting lists at State Hospitals for the mentally retarded. The State Hospital population was 11,000. In 1973 Assemblyman Lanterman authorized Assembly Bill 846 which mandated regional centers to serve persons with other developmental disabilities in addition to mental retardation, including cerebral palsy, epilepsy, autism and other neurologically handicapping conditions closely related to mental
The current Lanterman Developmental Disability Services Act was created in 1976. This Act resulted from legislative hearings in 1975 regarding the condition of the developmental disability delivery system. All parts of the system came under severe scrutiny during these hearings, including the State's administration of the delivery system and regional center deficits. The Act also established the right to treatment and habilitation services to persons with developmental disabilities. With the establishment of the East Bay Regional Center there were 21 regional centers across the State (Clark, 1988).

Proposition 13, a landmark initiative limiting the State's ability to realize property tax revenues, was approved by California voters in 1978. This provided, a climate that precipitated the formation in 1979 of The Association of Regional Center Agencies to incorporate as a non-profit organization comprised of regional center board volunteers and executive directors for the purpose of promoting statewide regional center action, advocacy and coordination. It is generally referred to as ARCA (Clark, 1988).

California was confronted with a $1 billion deficit with the prospect of issuing promissory notes, carrying a huge deficit into Fiscal Year 1983-84 and making deep cuts in state supported programs. Legislation to provide
emergency regional center funding, authored by Assemblyman Margolin, passed after intense negotiations. AB 40X also provided the Department of Developmental Services with emergency authority, through regulations, to directly control regional center expenditures. Service reductions were authorized at 10 regional centers (Clark, 1988).

AB 40X also carried with it many restrictions that brought about a law suit by the Association of Retarded Citizens of California against the Department of Developmental Disabilities. The California Supreme Court handed down the decision that the state is obligated to fund the necessary services or to amend the Lanterman act. Services to the developmentally disabled are an entitlement and the 40X restrictions were lifted.

By 1984 regional centers were serving over 70,000 clients and their families. They were confronted with the effects of significant reductions in funds for staff, inadequate rates of reimbursement for providers of service and insufficient Purchase of Service funds. Their budget funds are divided into two groups: 1. for operations and 2. for client services. Operation funds are never taken from client services funds.

A number of legislative and budget initiatives were being proposed to deal with these problems in Fiscal Year 1984-85. SB 1513 was signed into law by Governor Deukmejian on April 22, 1988. This legislation increased rates paid to
residential care providers (Clark, 1988).

October 8, 1986 Congress enacted and the president signed into law PL 99-457; amendments to the education of the Handicapped Act. These amendments include:

1. Handicapped infants and toddlers. It creates a discretionary program to assist states to plan, develop, and implement a statewide agency system of comprehensive, coordinated, multi-disciplinary, interagency programs for all young handicapped children, birth to three years.

2. The Preschool section amends a previous portion of the Education of the Handicapped Act. It creates enhanced incentives so that all states will provide a free and appropriate public education to all eligible three through five year old handicapped children by school year 1990-91 or 1991-92 depending on availability of federal funds.

In California the Department of Developmental Services became the lead agency for coordinating this legislation. Services for family support of developmentally disabled children have come a long way since the 1950's to assist each child to develop to his/her potential. The creation of new and innovative services in the future are only limited by the creativity of tomorrow's planners.
INLAND COUNTIES REGIONAL CENTER

On August 12, 1971 Inland Counties Regional Center, Inc was formed and the first Board of Trustees organized. January 1, 1972 Inland Counties Regional Center began accepting clients. It was the thirteenth regional center to open its doors. San Bernardino, Riverside, Inyo and Mono counties comprise the Inland Counties it is responsible to serve.

The regional centers are a unique service system. They are private, non-profit corporations operating under state contract designed to be distinctively different, offering services that are unique to the needs of the clients in the area. They were designed to provide services from birth to death and they brought something very new into the arena of social services: the purchase of service capability, the ability to buy services. In addition to purchase of services, the regional centers offer diagnosis, evaluation, counseling and identification of unmet needs.

Some of the philosophical tenants of Inland Regional Center include that the person with mental retardation is the client and is the person for whom the regional center will advocate. The Board is committed to being fiscally sound. There is and was a strong commitment to the concept of normalization. To the idea that clients should be assisted in leading as normal a life as possible, enjoying
many of the routine rhythms, challenges, rights and responsibilities as the population at large. The clients served are people first and mental retardation is an ambiguous adjective (Clark, 1988).

There is a commitment to facilitate services for their clients that are given to other members of the public by utilizing generic services from the established agencies in the community expecting them to serve people with mental retardation and serve them well, making the necessary accommodations. Occasionally this has taken the form of using legal action on behalf of its clients.

The challenges from the first were enormous. Changing peoples minds about what the mentally retarded needed and what they could do. Most people with mental retardation in the community stayed home during the day. Few were in any school or workshop program. Working with education programs clients are provided an appropriate education.

Today both education and the regional center are on the threshold of a new concept of integration and transition, preparing the client from infancy to be an adult in this world. Today adult clients have jobs where they earn money, they have the opportunity to learn independent living skills so that they can manage on their own. They are no longer sitting at home. They are involved in Special Olympics, workshop training, enjoying opportunities only limited by the individuals ability.
Raising the consciousness of generic agencies, and the people in the community in general, about their clients needs and capabilities, has advanced the concept of normalization and has given them a whole new way of looking at people with handicaps.

Inland Regional Center has been in the forefront of depopulating large congregate facilities and to seeing that people they serve have the opportunity to reside in small facilities where they can realize their individual potential. They have been instrumental in developing new types of facilities for people with severe behavior problems, facilities for people with medical problems and for medically fragile infants.

On the horizon, new types of facilities for people with more medical needs than can currently be served by existing vendors need to be developed. Such as a sub-acute unit which has been identified as a real need as a result of strides made in medical technology.

The Inland Regional Center is committed to working together with the family and to support the family's desire to keep their developmentally disabled child or family member at home. This has been accomplished in many ways and one way often identified as accomplishing this is through purchase of services that are not otherwise provided by generic services.

Purchase of service is accomplished through regional
center authorizing a vendor to provide the service and regional center paying the vendor after the service has been rendered. Vendors have been used since Inland Regional Center opened its door, however respite service as we now know it was first vendoed July 1, 1979.

The total clients case managed in 1988 were 5894. Their living arrangements were: 3568 or 60.54% lived in their own home or lived independently; 191 or 3.24% lived in a state developmental center; 1415 or 24.01% lived in community care facilities; 595 or 10.10% lived in Intermediate Care Facilities for Developmentally Disabled; 105 or 1.78% lived in Skilled Nursing Facilities. (Operations Manual, 1988)

One of the goals for the 1988-1989 annual planning effort used as the center's focus is to coordinate early intervention services in the two county area of San Bernardino and Riverside in accord with the mandate of PL 99-457. One of the objectives to meet that goal is to identify in-home family support service needs by surveying all of the families of clients 0-5 years who are placed out of home. (Operation Manual, 1988)
FINANCING RESPITE CARE

Regional Center budget funds are divided into separate budgets, one for operations and the other for client services. Those client services include a purchase of service budget. Respite care is paid for through the purchase of service budget. The Inland Regional Center's annual budget in Fiscal Year 1971-72 was only $217,244 compared to the 1987-88 budget of $27,425,546. A little less than 3% of the purchase of service budget of $12,972,910 or $384,000 was allocated for respite services, however families utilized only $209,792 or 55% of their allocation. These figures are close to the 59% utilization level reported as the consensus among regional centers by Apolloni & Triest (1982).

The most impressive trend in financing of public institutions during 1977 through 1984 according to Braddock, Hemp, & Howes (1986) was the absence of real economic growth in total spending. Important trends identified were: a plateau in adjusted total nationwide spending for institutional operations; a decline in adjusted nationwide spending for institutions from state revenue sources; and the emergence of the Federal Government as equal partner with the states in the financing of state institutions.

Braddock, Hemp, & Howes (1986) also confirmed, through June 30, 1984, the continuing annual reduction in the institutional census and the steady climb in per diem. The
nationwide per diem exceeds $100 for the first time. Given the average annual rate of decline since 1977, the nation's institutional census will fall below 100,000 in Fiscal Year 1986.

The Inland Regional Center annual budget report for average cost per year per client including Social Security Insurance was $2,871.60 and operational costs per client was $1158.02. In comparing this figure with the $100 per diem for institutionalization it is clearly cost effective for government to spend funds to develop alternate living situations in less restrictive environments not only for the financial benefits but the humane benefit.

Until the mid 70's the Federal Governments role in financing state institutions was very limited. In fiscal year 1972 the two largest federal programs impacting on institutions were PL 92-223, which authorized Intermediate Care Facilities/Mentally Retarded Programs (ICF/MR) and PL 89-313 which authorized educational aid. Subsequent expansion of the ICF/MR Program to include tens of thousands of institutional residents brought with it a major federal financial presence in the fiscal structure of state institutions.

In the past decade, Mentally Retarded/Developmental Disability programs have gained increasing visibility in administrative and budgetary structures of state governments everywhere. This visibility makes studies feasible and
replicable in the future. Because such studies employ official state government budgetary information as the basic unit of analysis, the data are especially useful for state planning and program development and public policy forums (Braddock et al, 1986).
FAMILY SUPPORT SERVICES STUDY

In October 1987 the Department of Developmental Services Office of Planning and Policy Development began a complete study of all phases of the statewide family support system. The study titled "Family Support Services Study", is still under way. All the data has been collected. However, the data is still being analyzed and a final report has not been written.

The study was conducted jointly by the Office of Planning and Policy Development of the Department of Developmental Services and the Department of Sociology of the University of California, Riverside, Jane R. Mercer Ph.D., Principal Investigator. University of California Riverside's portion of the study was funded through a Program Development Fund contract for $64,921.

As this was a joint study, for the purpose of this paper it will be discussed as a two part study and will be explained as to design and responsibility separately. Each study and data collecting was done simultaneously.
The first study relates to the University of California Riverside's two part study, the questionnaire and then the personal interview describing the characteristics of the Family Support System from the families perspective.

Data collection requested:
1. to collect a description from the parent perspective of the perceived burden of care, need for supervision, and developmental level and progress.

2. Demographic and structural characteristics of families. Including ages, relationships of persons in the household, employment status of adult members, income, ethnicity, type and size of family housing arrangements, presence of other physically handicapped or developmentally disabled family member.

3. Analyze types and amounts of regional center purchase of service expenditures for children and families from data provided by OPPD.

4. Direct service and assistance provided by regional centers to families with in-home children including family counseling, family training, giving information, helping families develop support networks, referring families to generic services, and similar activities.
5. Generic services received by families, the kinds and amounts.

6. Privately-funded agencies and organizations.

7. Kinship, neighborhoods, and friendship networks and the functions these groups fulfill.

8. Family satisfaction with all the components of support system including ease or difficulty of obtaining services and the availability and adequacy of all components of the system.

DATA COLLECTION PROCESS

A questionnaire was developed that consisted of ten pages of thirty multiple choice questions that addressed all the data requested above plus three open-ended questions. The open-ended questions allowed the care provider the opportunity to write in the support service the family was receiving and felt was the most helpful; the support service they were not receiving that they thought would be the most helpful; and anything else they would care to tell about the available support services.

Management of the process began. Management is defined as:

Getting things done through people. Generally consists of the activities of planning, organizing, controlling, and directing work utilizing people, ideas, resources, and objectives. Using a systems approach, the process of allocating an organization's inputs (human and economic resources) by planning, organizing, directing, and controlling for the purpose of producing outputs (goods and services) desired by its customers so that organization objectives are accomplished. In the process, work is performed with and through
It was important to provide the necessary resources without interrupting regular business.

METHODOLOGY

OPPD randomly selected 300 clients from each regional center, age 0-18 and who lived in their family home, through Universal Client Identifier (UCI) numbers. (These are numbers assigned to each client at the time of intake at each regional center, and used for reporting purposes to the state so that the state can obtain information on each client but the identity of the client remains confidential, as required by law). The list of UCI numbers were sent to Jane Mercer Ph.D. UCR. She was not to know the identity of the client to protect client confidentiality.

Dr. Mercer then mailed a packet to each regional center that included the UCI numbers relating to clients of that regional center, a letter explaining how she wished the mailing to be conducted and dates the questionnaires were to be mailed. The questionnaires, in English and Spanish, with two envelopes, one to be used to mail the questionnaire and one for the family to return the completed questionnaire to Dr. Mercer. A post card and a sample letter in English and in Spanish were also included.

The Inland Regional Center identified the names of the clients through the UCI numbers and a computer printout was
provided with the names and addresses of the clients. It was then necessary to identify the counselor responsible for the client and verify that the child was still in the home, address, and any reason they might not think the family would not be suitable for receiving the questionnaire ie: client deceased.

Three sets of name and address labels were generated. The Chief, Case Management Services rewrote, in Spanish and English, the model letter requesting the family to participate in the study and the family member who provided most of the care taking of their developmentally disabled child to answer the questions in the booklet and she then signed it. These were xeroxed on regional center letterhead stationary. Each questionnaire, post card and address label had to have a matching UCI number, manually entered, so that Dr. Mercer could identify who was to receive a follow-up letter when their questionnaire was not returned. The letter, questionnaire and return envelope were stamped and mailed on February 2, 1988. The post cards reminding the family to complete the questionnaire were sent to all families February 8, 1988.

Inland Regional Center was requested to do a second mailing with new letter, questionnaire, and repeat of the process followed in the first mailings. This time to only the families who did not return their questionnaire and were identified only by UCI numbers. This mailing was done March
7, 1988. It was again necessary to identify and compare UCI lists to determine who needed to receive the second questionnaire enter the UCI number on the questionnaire and rewrite the letter.

PERSONAL INTERVIEW

The second part of the UCR study related to factors influencing families' retention of children at home rather than seeking out-of-home placement for their child. The purpose was to examine a whole range of factors that could have an influence on placement decisions and make it possible to determine interrelationships among these variables.

METHODOLOGY

The sample consisted of 200 children who had been placed out of their home since July 1986. The information source was The Client Development Evaluation Report (CDER). The 200 were selected from among all of the placed children (about 900 as of July 1986) and were "sorted" into categories by age (0-9, 10-18), maladaptive behavior (high, low), and level of retardation (none, mild, moderate, severe, profound, unknown); these categories result in 24 "cells"; the percent of all clients placed in each cell was determined; the 200 sample clients selected randomly from each cell to represent the same percentage figures as the total group for each subgroup. A comparison group of another 200 children who still live in family homes were selected
using the same technique: after sorting the in-home population (25,000 children as of July 1987) into the same 24 categories, the 200 in-home clients were selected randomly from each cell in proportions equal to the proportions of the placed sample.

Again, Dr. Mercer mailed a set of the UCI numbers, postcards and a sample letter in Spanish and English. 48 were English speaking and 8 were Spanish speaking. The process of generating address labels and revising the letter was repeated. On April 6, 1988 letters on Inland Regional Center letterhead signed by Chief, Case Management Services informing the family about the interview and assuring them that the responses from the interview would be confidential, no one at the regional center would see them, and all reports would discuss groups of people and no individual families would be identified. Postcards addressed to UCR were included with the letter. The family was to return, if agreeable to being interviewed and fill in their name address and phone number, as the only identification on the postcards that Dr. Mercer would have was the UCI.

About this time The contact person was requested to help in identifying persons familiar with and sensitive to the regional center who could be used as interviewers. These persons could not be presently employed but may have been a past employee. Bi-lingual interviewers were needed as well. The interviewer would be trained and paid $30 per interview.
The interview would take 1 hour. Names were provided after a personal call and the person relating a willingness to be retained as an interviewer.

Although a one time only personal interview letter was to be sent. The researchers wanted to have a 50% rate of return. In early June they had a 30% rate of return. The regional center was again asked to send a second letter and post card. Again, a list of UCI numbers she had not received responses from were sent. The process was repeated. A new letter and mailing on June 14, 1988 was sent.

Many of the same variables were examined however, this portion of the study was a personal interview with the family member most responsible for the caretaking of their retarded child. It was expected that variables of a sensitive nature having to do with family dynamics would be included. Family stress, the families' reaction to and ways of coping with the child with disabilities, the child's impact upon other members of the family, perceptions of the child as both a joy and a burden were among the variables.

RESULTS

Data is still being analyzed by Dr. Mercer and a completion date for her report to the state is uncertain. All the information from the questionnaire has been entered into the computer and some has been analyzed. The personal interview data is entered on the computer but the analysis will take some time and a projected date of a report is fall
of 1989. Dr. Mercer is presently working full time on the analysis of the questionnaire.

Some interesting data from the questionnaire was available however and permission to share it for the purposes of this paper was granted. Keep in mind that this data is only a partial portion of a very extensive study.

Questionnaire survey response rate and sample frame:
client pool 25100
sample size 6300
mailed 5025
received 2652
percent 52.8%
useable 2540
percent 50.5%

The personal interview study response rate:
postcards sent 429
postcards returned 230 living in home 130
placed out of home 100
Interviewed living in home 108
Interviewed placed out of home 77

At least half of the families reported they never received the following kinds of services from their regional center: parent meetings, educational programs for parents, referrals to community agencies, diagnostic services, and crisis intervention. At least half of the families reported receiving the following kinds of services from the regional
center: talking to a case worker, receiving written information, meeting to develop the Individual Program Plan. one third received counseling and advice, one forth reported receiving help with school problems or receiving diagnostic services on a yearly basis.

Stress related questions indicated: 67.2% of the respondents reported frequently worrying about the future; 56% give up outside activities because of family responsibility; 52.4% are tired in the middle of the day and 53.3% look forward to the end of the day. Only 4.3% reported having to quit a job because of stress. Of those working 26.6% reported frequently experiencing more stress on the job.

In regard to receiving vendored services: 63.1% reported never receiving respite care; 81% never receive recreation; 89.3% never receive residential or day camp; 73.9% never receive school vacation/extended day services and 89.1% never receive after school extended day services.

Respondents reported the most helpful service they are receiving is respite/baby sitting followed by counseling services. Services not being received that the parents perceived would be the most helpful to receive were first; recreational (day camp, after school program, special olympics, summer camp, dance lessons, and school vacation programs) followed by respite services (such as respite outside the home and baby sitting).
Data provided by the Department of Developmental Services indicates the average per client purchase of services for recreation is $37.77 however, 96.0% of the sample report not receiving this service. Average per year spent by the department per client on respite is $377.54 of the sample 71.8% report not receiving the service.

In studying the relationship between family structure, child characteristics and plans to place: In families where mom does work, has some college, is a single parent, indicates high work stress, burden of care is low, child functions high on MR level and on the CDER, family is small, income is medium, Money spent on the child is high, help is low, and child is 9 years old, plans for placement is high.

The next likely family to have high placement plans: mom does not work, has some college, is single parent, burden of care is high, work stress is low, CDER is low, MR level is medium, child is less than 8 years old, income is low, family is small, a low amount of money is spent on child, and help is low.

The third group most likely to place their child: mom works, does not have some college, is single parent, burden of care is medium, work stress is medium, CDER is high, MR level is medium, child is over 9 years old, income is low, family is small, a medium amount of money is spent on the child, and help is medium.

The least likely family to place their child: mom does
not work, has no college, two parent family, burden of care is high, CDER is low, MR level is low, child is under 8 years of age, income is medium, family is large, income is low, and help is medium.
The second study was conducted by the Office of Planning and Policy Development that looked at the regional centers individually and then collectively. Some of this data was provided by on site interviews, record reviews, and Client Development Evaluation Reports (CDER) files. (These files are initiated at each regional center on each client and sent to the Department of Developmental Services and entered into a Master File following the initial intake process and updated on each client annually by the regional center).

DATA COLLECTION PROCESS:

1. Characteristics of Clients Living at Home. This included the demographic, diagnostic, behavioral and medical characteristics of clients 0-18 years of age living with their families. Sex, ethnic group, level of mental retardation, diagnostic category, specific medical conditions, and behavioral characteristics such as independent living skills, social skills, motor skills, cognitive skills and maladaptive behavior.

2. Types and amounts of regional center purchase of service expenditures for children and families. (Generate from CDER).

3. Department and regional center policies. The family support system is expected to vary across the state.
therefore a description will require both a statewide and regional focus. The Department as well as the regional centers policies regarding family support services will be examined. (Review records and interview on site.)

4. Direct service and assistance provided by regional centers with in-home children including family counseling, family training, giving information, helping families develop support networks, referring families to generic services, and similar activities. (Interview regional centers regarding general policy and practices).

5. Regional center organization for and support of family support services. This included the way family support activities fit into the regional center's organizational structure, case management ratios for family support, the frequency of contact between case managers and clients and their families, frequency and nature of Individual Program Planning (IPP) monitoring, focus on family support in informational material and staff training, planning and budgeting practices for family support. (Record reviews and interviews).

6. Decision making for family support and processes used by regional centers to make decisions about services needed by in-home clients and their
families. These processes included areas such as when services should be purchased and when the client should be referred for services; what families and the children need from regional centers at what stage of the clients' life-cycle; criteria that are used in devising IPP's. (Interview)

7. Strengths and weaknesses of the family support system from the perceptions of the regional center. Including issues such as the comprehensiveness and adequacy of generic services, vendored services, and regional center activities to support families. Departmental policies and budgeting practices that affect this area. Barriers that exist will be examined and methods that could be used to improve the system at any level, local or state, will be explored. (Interview).

METHODOLOGY

From January 13 - 15, 1988 two staff members from Sacramento conducted several interviews at Inland Regional Center. These included Chief, Case Management Services, Ten counselors who case manage 0-18 year old clients, one board member, and one supervisor. Appointment times were set up that were convenient to all involved. They were interested in each persons knowledge of regional center policy regarding family support services, Supports their families needed, what was available to them and frustrations
In addition to personal interviews, document reviews were requested. These included some they wished to review while at the regional center and some they wished to take copies of back to Sacramento. Documents requested were:

1. Board meeting agendas for the past 12 months. Their policies relating to services for families who care for their child with developmental disabilities at home. Board meeting minutes where part of the meeting specifically related to family support. Any special Board reports related to the needs of families who care for their children at home.

2. A current regional center organizational chart.

3. A list of committees regional center staff belong or assigned to.

4. Outlines of in-service training curricula including staff orientation material. In-service training outlines specifically related to family support services.

5. Any evaluations of studies of family support services or related issues prepared by regional center staff or consultants.

6. Information materials given to the parents whose children are clients of the regional center (this could be brochures, orientation outlines or other).

7. Public service announcements in last 12 months.
8. Policies, procedures and guidelines related to purchase of service for children living at home or for their families.

9. Policies, procedures and guidelines related to use of generic services for children living with their families.

10. List of generic service agencies to which clients and their families are referred.

11. Any eligibility criteria used by the generic service agencies to which clients are referred.

12. Specific policies, procedures and guidelines governing follow-up of referrals to generic agencies.

13. Any recent planning documents which show how the regional center is planning to meet the needs of the families who care for their child at home.

14. Service standards that apply to services delivered to families and children when the children live at home.

RESULTS

The results of this portion of the study have not been released as yet. The original letter regarding the complete study report indicated that the results from this portion would be released simultaneously with the UCR questionnaire data. UCR's protocol is to complete the data and send the results to the Department of Developmental Services who will
then release all the results to the directors of the regional centers.
DISCUSSION

With dwindling budgets and increased service costs it is timely that the Department of Developmental Disabilities conduct this study. Efforts to minimize costs and maximize services that families will actually use is essential to better utilize resources available by controlling the internal environment.

It is also essential that resources in the external environment be organized and utilized in a cooperative effort. To be coordinated in such a way that services are provided in the most efficient and cost effective manner. To do this will optimize results.

As resources available for human services decline, it is essential that providers, especially at the local level with commitment to the effort at the state and national level, acquire the resources needed to do the job by negotiating and coalition building with other provider organizations. Whatever shape the integrative effort takes, it is necessary for the organizations to look to each other for shared resources (Hanlon & Pickett, 1984).

Planning is more important than ever. It is important to define the objective once the goal has been stated. According to Hanlon & Pickett (1984), the effect of planning is to clarify the difference between alternatives, and in important decisions, its the clarification that narrows the superficial differences and exposes the value differences as the principal issue. They suggest that when two or more people have to make a choice involving values, the process
of decision making is political.

There are limiting conditions in any planning that decreases the rationality of planning. Value determination regarding goals and objectives, clarification and conflict; data and information accumulation; and formal and informal organizational conditions. Planners must use different measures to clarify goals than they use to clarify objectives or measures (Spiegel & Hyman, 1978).

Certainly the decreased availability of budget funds is going to make that value determination much more difficult to reach the mission of the regional center. Planning for future support services will have to be prioritized.

Spiegel & Hyman (1978) describe the decision process as occurring through two components. The first component for setting priorities is the input component: this is information or data given to the group for decision making, to identify specific elements and list decision criteria; the second component is the output component: lists of goals or objectives the decision-making group agree upon. The decision making process refers to all the goals and objectives that are prioritized.

In this case, the parent questionnaire and the study of the regional centers by the Office of Planning and Policy Development are the vehicles that will provide the data. It will be up to the directors of the regional center and the
Department of Developmental Disabilities to prioritize and list the goals and objectives within budgetary constraints.

Following this prioritization of support services, planning follows. This includes developing clear, concise, and measurable goals and objectives. Next, consideration of various alternative action in resolving a particular problem. This may include involving generic coalitions. The cost and benefits of each alternative must be examined by the group. Once the service has been determined, implementation follows. It is during this phase that all of the materials, methods and resources will be utilized, designation of tasks to be completed within a given time frame will be specified, and individuals and agencies responsible for a specific segment of the program will be indicated (Spiegel & Hyman, 1978).

Evaluation is the last step in planning. It should be done along the way and be instituted early on in the planning process. Evaluation includes identification of the goals to be evaluated, analysis of the problem the activity must come from, description and standardization of the activity, measurement of the change that takes place, determining whether the change was due to the activity or some other force, and if the effects or change will continue. Alterations in the plan can then be made along the way thus, conserving resources.

Families have indicated in several studies that they
did not know where to obtain respite services when they needed them. One might assume that the demand for respite services would outweigh the supply once this information was learned. However, both families and agencies reported reluctance to leave their child with strangers. Apparently it is not enough merely to have care available but families must know where to call (Upshur, 1982)

Communicating the nature, benefits and methods of securing specific services from particular organizations is a marketing strategy. While the term marketing is not often used in government agencies, as many of these agencies become more cost effective through need and begin using strategic planning as a sound basis for meeting budgetary constraints, marketing should become a familiar term to all.

Spiegel & Hyman (1978) suggest that the use of precise words help planners to direct activities into clearly defined channels. In other words, as government agencies begin using more processes developed in the private sector it should use the same terms as they do to clarify intent.

There are several types of communication the state can and does use. Public service announcements through the media, educational films, brochures, newspapers, personal contact from regional center employees, Associations of Retarded Citizens groups, and association with other community groups, to name a few.

Whatever approach taken to communicate and promote, the
results of organizational efforts should be evaluated in order to identify results, justify efforts, and determine the most effective techniques. The results of such evaluations should be used to adjust communications and alter the organizations service delivery where appropriate (MacStravic, 1977). In this day of multi media there should never be a lack of access to information. It is the responsibility of the service provider to furnish this access.
RECOMMENDATIONS

A personal goal from the beginning as coordinator for Inland Regional Center of the Family Support Services Study, had been to identify a service that would realistically support a families' desire to maintain their child in their home. This study was a needs assessment to identify assets and deficits in the system. Personal experience indicated that respite care would be high on the list of need request. However, the budgetary constraints on this service is in the hands of a higher authority.

Incomplete results indicate the family most likely to place their child, is the single mother who has a small support system and spends a large portion of her income on her developmentally delayed child who has high functions and is physically capable of self-help skills.

Personal experience also shows that licenced day care for developmentally handicapped is non existent for the working mother. This has been a concern for many of us in early intervention. Often these children look a little different and its perceived that they require special care, while this is often not true. In keeping with the regional center philosophy of encouraging generic agencies to expand the skills of their service providers to meet our clients' needs, a meeting of the director of a county wide child care
agency and a county employed pediatric nurse practitioner was arranged to discuss a training program we could present at the child care agency's annual workshop.

The goal would be to have a few providers encouraged to take one high functioning child and the nurse practitioner would provide in-service and be a resource person for the provider. It was felt that success with one disabled child would travel the grapevine and encourage other providers to include at least one of this group in their cliental. As their experience and success increased perhaps training to care for the fragile infant whose mother must work would be considered.

However, after several meetings it was clear that the liability issue was clouding success of this plan. This issue of liability in our society often hampers success of the small provider who cannot afford insurance beyond that which day care licencing requires. Assisting in the solving of the liability problem is one recommendation.

One of Inland Regional Centers goals for this year as mentioned earlier, is to survey in-home family support service needs of clients 0-5 years who are placed out of home. More contact and information sharing with this group to encourage generic agencies to develop programs that will assist these families is recommended.
One of the problems of a survey of the magnitude of the Family Support Services Study is that there is a possibility that local needs will not be identified. With the advent of normalization, equal rights for retarded persons in the areas of equality and marriage are being advocated. Involuntary sterilization is banned in many jurisdictions. These events suggest that many more retarded people will be marrying and bearing children. Concerns about the ability of retarded persons to raise non-retarded children have been expressed. Feldman et al (1985) study of development and nurturance of children of mentally retarded parents found that the children were at risk for developmental delay, particularly in language.

Personal experience with this group of parents has indicated it takes the joint efforts of the regional center and many generic agencies to support these parents to learn appropriate skills for parenting. Transferring information and their ability to retain the information are very difficult barriers to hurdle. Foxx, McMarrow, & Schloss describe success in teaching social skills and Foxx, McMarrow, & Mennemeier (1984) describe success in teaching vocational skills to retarded adults by using a commercially available table game "Sorry" with modifications. Clearly, with innovation and creativity barriers can be hurdled. We need something like this on the local level.
As a need request from Inland Regional Center a joint grant application with the San Bernardino College District and The San Bernardino County Superintendent of Schools submitted for funds to implement a program for 20 children in an all-day, 4 day a week program with parent participation happening at least three times a week in the classroom and parent training classes.

The children will be from ages 18-36 months who do not currently qualify for special educational services in existing infant or early childhood programs, yet these children are still at risk of physical and cognitive deprivation because of parent neglect and depressed parent developmental functioning level.

The grant was submitted March 3, 1989. Should it be accepted the project will begin in June on the San Bernardino Valley College campus. It will utilize many of the college resources for the parents including recreational, and provide a vocational training ground for students. For the toddlers it will provided appropriate social outlets with peers and an opportunity to reach their potential.

Parenting is stressful for all of us. To parent a child with developmental disabilities, as the literature review in this paper attests to, is full of many stresses most of us do not have in our lives. These families are bonded to their
child as we all are. It is a herculean emotional task for most of them to place their child. It is just as devastating to the child.

As a society we have a responsibility to support these families in their effort to maintain their child at home as long as possible. On the other hand when these children reach adulthood and begin to enjoy the normal every day rhythms of society we also have a responsibility to provide support services to insure their children have the same opportunity to reach their developmental potential that their parents were granted.
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