A study on the children of the developmentally disabled

Nahid Anna Bahrami
Pamela Lynne Shiner

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A STUDY ON THE CHILDREN OF THE DEVELOPMENTALLY DISABLED

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

In Partial Fulfillment of the Requirements for the Degree Master of Social Work

by
Nahid Anna Bahrami and Pamela Lynne Shiner
June 1994
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Presented to the Faculty of
California State University, San Bernardino

by
Nahid Anna Bahrami
and
Pamela Lynne Shiner

June 1994

Approved by:

Dr. Morley Glidden, Project Advisor

Dr. Teresa Morris, Chair, Research Sequence Committee
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INTRODUCTION

Individuals diagnosed with developmental disabilities live in communities along with other members of society. They exercise the same rights as all citizens and function within the laws of our society (Macklin, 1981; Copeland, 1989). Because developmentally disabled persons have the right to grow up in a normal environment, many professionals advocate marriage as long as appropriate community supports are available. However, parenthood among the developmentally disabled is not often viewed in such a positive and supportive manor (Copeland, 1989). Thus, social workers often have conflicting emotions and professional views about whether or not to advocate for the developmentally disabled person's right to experience parenthood. This research project focuses on the children of the developmentally disabled and on their level of functioning in the society when additional supports from extended families and/or social service professionals are provided.
PURPOSE OF THE STUDY

A developmentally disabled person, as defined in this paper, is an individual whose intelligence level (IQ) is at or below the norm of seventy (70). Many developmentally disabled persons, with IQ's of 70 or less, have become parents. The role of being a parent is difficult enough for normal persons. However, the challenge of successful parenting is infinitely greater for the developmentally disabled person. The intellectual limitations of the developmentally disabled parent is often a factor in successfully performing the many assigned responsibilities of parenthood. Because of such limitations, some writers believe that children of developmentally disabled parents are often deprived of having a more normalized environment.

Exploring the environment of the children of the developmentally disabled's rearing may reveal their emotional, cognitive, and social status. Questions raised in the issue of the developmentally disabled parents competency to parent adequately are: what effect does the parents' intellectual functioning have on their children? What are
the emotional and intellectual needs of these children? Would the environment in which these children grow up in and the rearing they receive have any effect on their development? Would the involvement of their extended families or professionals affect the child’s development? How would the parenting skills of the parents affect these children? Responses to these questions could have an important impact on the way our society deals with the developmentally disabled parent and his/her children.
A great deal of opposition to sexual expression and marriage for developmentally disabled people was caused by the eugenic fear that "defectives" would beget more inferior babies and, thus, genetically contaminate society (Evans, 1983). According to Evans (1983), in 1911, researcher Charles B. Davenport stood firm in his perception that all children of two "feebleminded" parents would, under all certainty, be defective. Accordingly, Hall (Evans, 1983) presented findings of thirty-one inquiries into the likelihood of developmentally disabled parents having retarded offspring. Evans reported that the figures range from 2.5 percent of all children of retarded parents being retarded to 83 percent.

Before the 1950s, the developmentally disabled were placed in institutions indefinitely. It was believed that mental retardation was genetic, therefore, laws were introduced enforcing involuntary sterilization of the developmentally disabled (Stroman, 1989; Macklin, 1981). As scientists discovered more about the nature of developmental
disabilities, the negative attitudes toward the developmentally disabled began to change. Research indicated that intelligence was determined as much by upbringing and environment as it was by heredity (McManis, 1989). With the prevalence of such research findings, procreative rights became fundamental to society. During the 1960 and 1970s, the idea of mainstreaming of the mentally retarded into society was introduced. Mainstreaming and normalization refers to a philosophy of treatment and services that attempt to make the lives of retarded people as much like the lives of everyone else as possible (Stroman, 1989; Copeland 1989). Laws were introduced to protect the rights of these individuals. The concept of “developmental disability” replaced “mental retardation.”

Currently, many of the developmentally disabled live independently in their own homes and have families. According to Evans (1983), data shows an absence of positive correlation between the developmentally disabled parents’ IQ and parental capabilities. Also, Scally (1973) reported that one-third of all developmentally disabled parents reared children in a satisfactory way. The remaining two-thirds had
better success with other provisions and support. However, Bergman (1969) contends that developmentally disabled parents whose IQs are less than 55 or 60 (moderate) were seldom capable of providing the proper care for their children. He reported that, in most cases, mothers with IQ’s less than 60, were inadequate parents. Herber (1970) found that 20% of children of less than 6 years, and more than 90% over 13 years had IQ’s below 80 when parents’ IQ was also less than 80. Finally, Polansky (1972) found that 9 of 11 mothers with IQ’s less than 71 provided below average child care.

The developmentally disabled person has been afforded civil rights, but the risk of failure to thrive and developmental delays in the children of these parents are considered to be quite high (Goldstein, 1964). The State of California under Welfare and Institution Code 16509.2, awards individuals who are developmentally disabled the right to become parents. But the safety and basic well-being of the child are also mandated (Prevention Committee, 1990). Thus, agencies have been created such as California’s “regional centers” to provide case management services to
address the needs of the developmentally disabled. These services include: appropriate housing, education and training, employment, counseling, resources, and referrals.

Historically, it was a given that children who were born to a developmentally disabled parent would become the responsibility of either the mother’s family or the welfare system. However, the current emphasis on community integration for persons with developmental disabilities introduces the opportunity for autonomous living (Whitman, 1990). Today, more persons with developmental disabilities are residing in community settings and are exercising the rights accorded to all citizens. Consequently, there is not only a considerable increase in the number of developmentally disabled parents but a very large percentage of these parents who are also choosing to keep and raise their children (Whitman, 1990).

"Protection and Advocacy, Incorporated" (1985-1986) has represented several developmentally disabled women in asserting their parental rights. In many situations, the mothers did not maintain an independent living situation, lacked the skills to do so, and displayed little knowledge
of child rearing. Because of these limited skills, a child protection service agency would quickly seek to remove the child from the mother’s custody and care, alleging that the parent was developmentally disabled, and consequently, incapable of parenting or developing parenting skills. The tension between the limitations of developmentally disabled parents and their civil rights raises several questions: does the developmentally disabled parent have a chance of retaining a parental relationship with their child(ren), should the developmentally disabled parent have the same rights afforded to them as non disabled parents to raise their children? For the general population, parenting and family relationships are a fundamental and constitutional right. The parents are entitled to custody, companionship, and the right to guide their child(ren)’s developmental process. It is only when the child or children are at risk of physical and psychological harm that the state has the right and the responsibly to intervene. However, when confronted with the developmentally disabled parent, the state typically assumes that the developmentally disabled are inherently incompetent to provide the love, care, and
guidance necessary for the child's physical safety or intellectual and emotional development. Thus, children of developmentally disabled parents are removed from their custody with termination of parental rights. Recently, however, the state has come to believe that the developmentally disabled parents have a vast range of parental abilities and that the parent's IQ is not a good predictor of parental capabilities. Furthermore, it was found that with parental training, and supportive services tailored to the parents' special needs, many developmentally disabled parents show strong capacity to love and care for their child(ren). They also demonstrate the capacity to cope with the routine day to day demands of raising their children (Protection & Advocacy, INC., 1985-1986).

Due to the increasing number of developmentally disabled parents, educational systems have been developed to help improve parenting skills of these individuals. Project Esprit developed in 1981, believes in early intervention strategies to successfully influence parenting skills and interaction between developmentally disabled parents and their children. Bakley (1986) developed a manual for
professionals who work with developmentally disabled parents. She notes that the developmentally disabled individuals are used to daily routines and are protected from everyday problems faced by most of us. Therefore, developmentally disabled parents have limitations that effect their reactions to change or to problems. Living outside of institutions has brought new challenges for this population. Schilling (1982) suggests a correlation between the developmentally disabled parent’s intelligence and maltreatment of their children. Some of the factors mentioned are the developmentally disabled parents’ difficulty with concrete thinking, inability to generalize learning, and display of communication deficits. Other indirect evidence that links the parents’ developmental delays with child abuse and neglect are the parents’ socioeconomic status and stress-related problems that arise from social and cognitive limitations and functioning. Other situations that link the parents’ developmental delay with child abuse and neglect are the parents responsibilities to meet the medical, educational, and emotional needs of their children (Schillings, 1982).
Bakely (1986) believes that the developmentally disabled often suffer from low self-esteem which affects their child rearing abilities. Consequently, developmentally disabled parents often provide a low stimulus environment for their children. To improve this situation, developmentally disabled parents often need help in increasing their motivation to parent. The involvement of extended families and other agencies might also assist them in their parental roles (Bakley, 1986).

Lynch (1989) notes that the developmentally disabled have difficulties “learning, remembering, reasoning, and solving problems” (p. 44). She believes that this, in turn, makes it difficult for the developmentally disabled to parent. Often, she reports, finding the correct form of discipline is a problem, and that developmentally disabled parents’ discipline methods are often “punitive, controlling, inappropriate for the child’s age, and ineffectual.” (p.44) She concludes that these individuals need support from others to be able to parent. Robinson (1978) found that developmentally disabled mothers are more likely to hold more protective controlling and punitive
attitudes toward their children than mothers without developmental disabilities. Feldman (1985) studied twelve (12) two year old children of the developmentally disabled. Her findings indicated that the children exhibited developmental delays as early as age two. The study also indicated that when mothers of these babies were closely involved with their child, that their babies did better. Feldman cautions that when children have been taken away earlier in the parents' contact with the child, the probability of failing again is high.

In 1987, Whitman surveyed a sample of developmentally disabled parents in a community. Her sample consisted of four hundred and two (402) parents who had one thousand ninety-six (1096) children. Fifty-five percent or six hundred and one (601) of these children lived with their parents. The remainder were removed or had grown up and moved out of the parents' homes. This study had difficulty determining the strengths and weaknesses of the parents. Whitman concluded that the developmentally disabled parents noted problems in raising their children but could not identify these problems. The professionals could better
identify weaknesses and strengths of these individuals' parenting skills.

Concern regarding the ability of people with developmental disabilities to care for their child or children is appropriate. It is unclear, however, whether circumstances or the ability of parents affects the child rearing of these individuals. Many believe that children of persons with developmental disabilities experience developmental delays. More systematic studies have shown that the incidence of organic etiologies among children of the mentally handicapped equals that of general population (Tymchuk, 1987). A large number of studies have been done on the amount of care that these parents provide, but, there are limited definitions of what constitutes adequate care. Tymchuk (1987) suggests that the adequacy of care is related to the number of children per family, to marital harmony, to additional problems such as: alcoholism or drug abuse, and to adequacy of income. However, Tymchuk (1987) believes that persons with developmental disabilities can learn to be adequate parents with help of parenting training programs.
Tymchuk (1990) defines adequate parenting skill as the ability to plan for and respond to the needs of children throughout their developmental process. He examined the decision making ability of developmentally disabled mothers versus mothers with the same socioeconomic background. He states that the developmentally disabled mothers made decisions that were as good as those made by the other group. Furthermore, this study showed that mothers with developmental disabilities had appropriate decision making abilities given the appropriate training (Tymchuk, 1990).

Wayne (1986) argues that the developmentally disabled have had limited exposure to parenthood. Most of them have led a sheltered life and are in need of community support to be able to problem solve their everyday life problems. A parenting group was developed by social workers in Cambridge, Massachusetts (Wayne, 1986). The focus of the group included: nutrition, grooming and hygiene, sex education, and advocacy on behalf of the members of the group. The social workers provided information and advice. The group was held for two years and revealed that the group members were complex human beings with a wide range of
feelings and strengths, but these mothers were also experiencing problems. The group process proved beneficial and helpful in guiding the developmental disabled mothers' experiences toward more fruitful outcomes.
To address the issue of parenting effectiveness among the developmentally disabled, a post positivist approach was taken. The data abstract and interview questions were an integral part of this study and were utilized to answer the following research questions:

1- What are some of the significant problems that the developmentally disabled parents’ face?
2- What are some of the problems that children of developmentally disabled parents experience?
3- Have the developmentally disabled parents parenting skills affected the developmental milestones of their children?
4- What services might stimulate better parental functioning in developmentally disabled parents?
5- What is the Regional Center’s level of involvement in helping developmentally disabled parents?
6- What involvement does the extended family have in enhancing parenting skills of developmentally disabled parents?
SAMPLING

To answer the research questions, a sample of families headed by a developmentally disabled person(s) was selected. The sample population was identified and selected from two Regional Centers' clientele. The sampling consisted of twenty-five cases selected randomly from two Regional Centers in the greater Los Angeles area. A family unit was considered a case. The child(ren) of these individual(s) who were not born with disabilities were identified. The child and her/his parent(s) were called a family unit, and considered for this case study.

INSTRUMENTS

The data for this project was gathered through case records at two Regional Centers. The protocol that guided the data collection is in appendix D. When the cases were selected, the service coordinator of each case was identified. These counselors were then interviewed after the data was gathered by completing the data abstraction form.
for each case. The questions posed to these counselors were a set of previously prepared open-ended questions that are included in appendix A.

PROTECTION OF HUMAN SUBJECTS

The names of the families selected for this sample as well as the names of the regional centers’ counselors that were interviewed were kept anonymous for purposes of confidentiality. The data, for this research project was gathered through case studies and interviews. Therefore, none of the developmentally disabled parents or their children were contacted in person. Informed consent was obtained from each Regional Center and from each counselor interviewed. A debriefing statement was given to each counselor. A copy of the informed consent and debriefing statement is in the appendix B and C.
DATA ANALYSIS

The data gathered for this research was derived through the review of case files and open-ended interviews with counselors responsible for each case. The use of open-ended interviews resulted in a large range of information. The most frequently used words and phrases were chosen and organized into different categories and headings. From the data abstract form, the following demographics were obtained: parents' age, ethnicity, marital status, the parents' psychological diagnosis, the child(ren)’s age and gender, and the extent of involvement of extended families and agencies. Table 1 illustrates these demographics for each of the 50 cases.
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Min. 21  Mean 30.19  Max. 46  5  61.06  1.8  3.5  0  0  6  4

Legends:
- b) d) 70–84 = Borderline Intellectual
- c) 50/55–70 = Mild Mental Retention
- e) 35/40–50/55 = Moderate Mental Retention
- g) 1= Caucasian
- h) 2= Mexican American
- i) 3= African American
- j) 4= Asian American
- k) 5= Other Hispanic
- l) 6= Other
- m) 1= Department of Children Services(DCS)
- n) 2= Regional Center
- o) 3= Children Protective Services(CPS)
- p) 4= Other (Independent Living Services)
- q) 5= Other
- r) 6= Other
- s) 71–84 = Borderline Intellectual
- t) 50/55–70 = Mild Mental Retention
- u) 35/40–50/55 = Moderate Mental Retention
- v) 1= Caucasian
- w) 2= Mexican American
- x) 3= African American
- y) 4= Asian American
- z) 5= Other Hispanic
- A) 6= Other
- B) 7= Other
- C) 8= Other
- D) 9= Other
- E) 10= Other
- F) 11= Other
- G) 12= Other
- H) 13= Other
- I) 14= Other
- J) 15= Other
- K) 16= Other
- L) 17= Other
- M) 18= Other
- N) 19= Other
- O) 20= Other
- P) 21= Other
- Q) 22= Other
- R) 23= Other
- S) 24= Other
- T) 25= Other
- U) 26= Other
- V) 27= Other
- W) 28= Other
- X) 29= Other
- Y) 30= Other
- Z) 31= Other
Since demographics such as parents' age, number of children per family, children's age, and mental test scores (the IQ), are simple and numeric, they were used for recording and for calculations. The mental test scores, principally the IQ, have been the single most widely employed indicator for charting developmental change in mental growth in children and adults. It is used in this research, to study parent-child resemblance in intelligence and to estimate the extent of heredity. However, after the data was gathered from each of the Regional Centers, it became clear that IQ data for the children was not complete. Most of the children studied in this sample did not have an IQ score recorded in their charts. This was because the children of the developmentally disabled parents were not necessarily Regional Center clients. The mental IQ scores, then, were utilized to determine the parents' level of intelligence. In most of the fifty cases studied, mothers' IQ were higher than fifty (50), placing them in the range of mild mental retardation. The mean score for mother's IQ was 61.06.
Table 2: IQ of Mothers

Table 3: Distribution of IQ of Mothers
The data also showed that information was missing on the fathers of these children. Out of the cases studied, charted data had information only on five fathers.

Many extended families are involved in the everyday lives of the developmentally disabled. There was an interest to determine what this level of involvement was and if it had a bearing on the parenting skills of the developmentally disabled parents.

Of the 50 cases studied, developmentally disabled parents' extended family involvement was predominantly maternal with a high level of involvement in child rearing.

Table 4: Family Involvement with Children
Because of the limited chart recordings, the role of the extended family members in the lives of the target families became clear through the interviews with the Regional Center counselors. Also, because of the involvement of Regional Centers, it became necessary to identify the specific agencies that were involved with each family.

Table 6: Number of Agencies Involved with Each Case
Tables 6 and 7 show the level of professional intervention by various agencies.

It was discovered that numerous agencies other than Regional Centers were involved with each family. These agencies were the Department of Children Services, Child Protective Services, and vendors of Regional Centers that provide independent living skills and parenting skills to the developmentally disabled parents.

The mean score of parents' age, children's age, and agencies involved were calculated. Table 8, 9, 10, and 11 illustrate parents' age.
Table 8: Mothers Age

Table 9: Distribution of Mothers Age
Table 10: Fathers Age

Table 11: Distribution of Fathers Age
Out of the 50 cases studied, the average mother's age was 30.19 and father's age was 35.6. The age of children of each family was recorded, and information was gathered about the number of children that each family had. The following table shows that families studied in this research had mostly one (24 out of 50 families), or two children (18 families).

Table 12: Number of Children per Family

![Table 12: Number of Children per Family](image)

Table 13: Distribution of Number of Children per Family

![Table 13: Distribution of Number of Children per Family](image)
The demographics reflect that 25 of the 50 cases studied were single parents, 11 of them were married, 7 were divorced, and 3 were separated.

Table 15: Distribution of Marital Status
The ethnic distribution of the random sample illustrated that a large number of parents were Caucasian and of other Hispanic ethnicity.

Table 16: Ethnicity of Sample Population

Table 17: Distribution of Ethnicity of Sample Population
FINDINGS

The sample families chosen included mothers and/or fathers who lived with their child(ren). The data abstract form and interviews revealed that predominantly mothers were involved in the rearing of their children. In specific, 25 of the cases studied were single mothers. It was also discovered through the same analysis, that biological fathers had little or no involvement with the children. In fact, it soon became clear that most of these children had little contact with their biological fathers. The case records primarily had information regarding the mothers but lacked necessary information regarding the children and fathers and/or partners. There was only one case in which the developmentally disabled father had the custody of his children.

It was found, through interviews with fourteen (14) counselors of the two Regional Centers, that some of these children, with the involvement of professionals, were not evidencing any developmental delays at the time of entrance into school. One of the counselors mentioned that a few of
these children were considered witty, above average and even bilingual. Through case studies, 11 children were found to be developmentally delayed and even diagnosed with mental retardation by age three. Nine Counselors reported that there were some children who were evidencing mild developmental delays and needed more intervention. Seven counselors indicated that some school aged children experienced multiple difficulties: feeling overwhelmed, not comprehending school's expectations of them, acting out, truancy, becoming withdrawn, and lacking social skills. Some of the factors that contributed to the difficulties that these children were experiencing in school, according to the seven counselors, were due to the parents limitations. According to five of the counselors interviewed, the majority of the developmentally disabled parents did not feel that their child's education was their responsibility. They believed that it was up to school and teachers to stimulate their children's educational growth. Parents did not help their children with their homework assignments, and even the parents who were eager to help, could not because of their own intellectual limitations. These counselors
reported that most of these parents could not read higher than third or fourth grade level.

In this study, the children's socialization surfaced as an area impacted by the disabled parenting experience. In very few cases, according to eighteen of the counselors that were interviewed, the child functioned appropriately and had positive social experiences. These interviews conveyed that the children were socially deprived and lacked actual experiences in the community. There was no home stimulation, and parents did not know how to expose their children to social and community activities. An example given by one counselor was that during an outing at a pizza parlor, parents mostly played at the arcades and the children were left to be cared for and fed by professionals. In another interview, a parent left her children of 3 and 5 years old outside a movie theater because she could not afford to pay for their tickets. Six counselors reported that the older children often cared for the developmentally disabled parents and their younger siblings. The children often did not have their own social experiences, in terms of having
friends, and doing age appropriate social activities such as movies, “hanging out” at malls, and playing.

These children, from information the counselors received from the children, reportedly faced a variety of predicaments. Some began to take on the roles of parenting for and of their parents. Six counselors believed that these children then realized that their parents were different, and eventually, they resented and became embarrassed by their parents. The counselors observed these children to often lack self-esteem. From information received from two counselors, in three specific cases, children found themselves explaining differences in their parents to their peers, and underwent criticism and teasing by peers. Eventually they started protecting the privacy of their homes by not allowing their peers to visit and interact with their parents. These 3 children were found to say that they wished they had a “normal” mother to drive them to school or take them shopping. Nine counselors reported that 60% of school-aged children in their case loads had difficulties with completing homework assignments, and some were ashamed to confide in their teachers that their parents were unable
to assist them. Consequently, some had difficulties excelling academically.

There were varied findings in the developmentally disabled parents’ parenting capabilities. In a few cases, counselors conveyed that parents displayed good basic parenting skills and had no negative impact on their children. However, the majority of the developmentally disabled parents displayed many difficulties, according to 18 of the counselors interviewed. These parents were reported to have difficulty bonding with their children and assuming a nurturing role. Ten of the counselors observed and reported that parents just coexisted with their children and had no positive interactions with them. Their parenting styles were poor or they had no concept of the parameters of parenting. Some parents had difficulty giving guidance, setting limits, and giving structure to their children’s environment. Again ten counselors observed that 40% of the parents in their case load were not consistent in their discipline, and were often too lenient or too strict. Same counselors reported that parents were not able to identify problems or the needs of their children. These parents
encountered difficulties with the basic care of their children. They could not identify their children's health issues, nutritional needs, and grooming and hygiene needs. As the children grew older, the parents were unable to discuss the developmental changes of their children with them, such as their son or daughter going through puberty, starting male-female relationships, and future aspirations. Four of the counselors interviewed mentioned that some of these children had unlimited freedom due to parents' not being conscientious about their children's whereabouts. They could not understand, be supportive, or counsel their children regarding these issues.

Through the analysis of the data abstract, the study found that the developmentally disabled parents lived in their own apartment settings, with their extended families, or with their current partners that were not necessarily the biological father of their child(ren). Twenty-five of the parents who lived independently received support services such as independent living skills training. These services allowed the parents to maintain a stable and functional environment. These services included: money management,
housekeeping, menu planning, grocery shopping, securing medical resources, and parenting skills. Five of the interviews revealed that the developmentally disabled parents that resided with their extended families, and had a maternal figure, had more positive parenting techniques as they modeled the behavior of this person. Also, it was reported by three counselors that the extended family member assumed most of the parenting responsibilities. A few of the two parent families experienced greater success in their parenting roles because they were able to share the responsibilities of parenting, according to two of the counselors interviewed.

Case reviews revealed that parents were often in the lower socioeconomic levels. The average income of the developmentally disabled parents was reported to be $800.00. Most of these parents were recipients of Supplemental Security Income (SSI), Social Security (SSA), and Aid to Families with Dependent Children (AFDC). Fourteen counselors reported that due to their financial limitations, developmentally disabled parents, in most cases, were just able to meet their children’s basic financial needs. These
included: shelter, food, and clothing. According to three counselors, many of the children of the developmentally disabled parents were dependent on charity contributions for their toys, books, and other supplies. Counselors stated that this was more evident when there was no extended family involvement.

Eleven of the interviews revealed that 40% of the developmentally disabled mothers in their case loads often made poor choices regarding their relationships, which directly or indirectly affected their children. Counselors reported that a few of the developmentally disabled mothers were attracted to men who were psychologically diagnosed with mental illness. These men were often abusive, alcoholic, or drug abusers. Often mothers were physically and emotionally abused, and consequently, in some cases, their children were also physically, emotionally, and sexually abused. Eleven counselors mentioned that these mothers often negated their children’s experiences and did not report the abuse to authorities. Accordingly, the abuse was reported, in these cases, by counselors and other individuals involved. Seven counselors revealed that in some
of their cases, due to the developmentally disabled mothers' relationships, the mothers did not attend or follow through with independent living training and parenting classes. In their cases, developmentally disabled mothers experienced instability in their relationships, therefore, their children did not have an opportunity to establish a healthy and solid relationship with a father figure.

The analysis of the data abstract showed that all the families studied in this research, received services from Regional Centers. Services included case management services, independent living training services that included parenting classes and aids with the children. When the above mentioned services were lacking, fifteen counselors reported that the home environment was less than adequate: the homes were not kept properly, the parents lacked good parenting skills, and often the living environment was hazardous to the well-being of the child. Due to lack of parenting skills and training, twelve of the counselors interviewed believed that developmentally disabled parents lacked the necessary coping skills to handle problems. For example, these parents did not know how to handle their children when
they cried. In these cases, parents lacked basic awareness to care for children's tangible needs such as food, personal hygiene and grooming, and experienced difficulty judging the level of illness in their child(ren). According to nine counselors, Regional Centers' level of involvement decreased as the extended family involvement increased. It was the consensus of all the counselors interviewed that with professional interventions, parents' parenting skills increased and the children did better.
RECOMMENDATIONS

It is our belief that further research is needed to study the longitudinal affect of the developmentally disabled parents’ parenting skills. A study is needed on the social and emotional outcome of these children in their later years. Also, it would be beneficial to know what percentage of these children are diagnosed with developmental disabilities and/or delays in their adult years. Are they, themselves as adults, going to become part of the Regional Center system? How successful will these children be as parents? Are they reflecting their own experiences into their children? Or have they made concerted efforts to be more effective parents and give to their children what they possibly lacked when they were growing up? Are they going to continue being part of their parents’ life?

It was found that a large number of these children were not being followed by the Regional Center system, and the data regarding their developmental milestone were minimal. It was frequently necessary to rely on the observations and
interactions of the Regional Center counselors with these children to obtain the information necessary for this project. It was found that although these children were not part of the Regional Center system, the developmentally disabled parents’ counselors were very influential and involved with the families. The counselors intervened and collaborated with these parents in regards to necessary resources and services for their children. These services included referrals to health care agencies (immunizations, doctor’s appointments, and pharmaceuticals), educational programs (enrollment in day care, preschool, and school districts), and other services. We believe that all these children (whether psychologically diagnosed for developmental disability or not) should become part of the Regional Center system until they are at least eighteen. This is due to the parents’ limitations and the amount of interventions and support that these children may require.
CONCLUSION

There were many controversial views regarding the developmentally disabled parents and their children. Many believe that no one could morally remove the choice of being a parent from the developmentally disabled persons. Others feel strongly about these individuals becoming parents, and yet many others had mixed emotions regarding this issue. Nine of the counselors interviewed commented that they did not feel that the developmentally disabled should become parents since it would be like children raising children. These counselors said that the developmentally disabled individuals could not care for themselves, therefore, how could they then care for their children? Many counselors felt that the child most likely would be raised and cared for by others. Six counselors positively commented in support of the developmentally disabled becoming parents with the contingency that they have maximum supports from friends, extended family members, and professionals.

The parents’ intellectual functioning, overall, had an adverse affect on their children, based upon counselors’
observations. Often children lacked social stimulation and opportunities. They were emotionally fragile and needed consistency in their lives. Their environment was often unsafe, unstable, and chaotic, according to seven of the interviews.

It is a given that the developmentally disabled individual has a fundamental right to parent, however, it is observed by all of the counselors interviewed that many developmentally parents need support and assistance. It is noted that these individuals also need guidance that would allow them to make informed and conscious decisions regarding becoming a parent. Even though some of these parents continue to have difficulties with parenting skills, Regional Center involvement allows them to be more successful in their efforts.

The findings indicated in this report reflect only the 50 cases reviewed. It should be noted that these findings can not be generalized to the overall developmentally disabled population who parent. The information gathered reflects only the views and perceptions of the few
counselors who were interviewed and may not represent the entire Regional Center system.
Appendix A

Interview Questions
INTERVIEW QUESTIONS

1. Are the children of the developmentally disabled parents compatible in terms of grades and social functioning, with other children their age? How?

2. Are these children able to function in the community as any other child does (i.e.; use buses, skills in purchasing items, etc.)? Please expand on your answer.

3. Has the developmentally disabled parent's intellectual functioning level affected the developmental milestones of their child(ren)? Please explain fully.

4. Has the developmentally disabled parent's parenting skills affected the developmental milestones of their child(ren)?

5. Does the living situation (housing, area, etc.) of the developmentally disabled parent's have a bearing on their parenting skills? Please provide details.

6. What are some of significant problems the developmentally disabled parent(s) face? Please expand on your answer.

7. Describe some of the problems their children face?

8. Explain Regional Center's involvement with the developmentally disabled parent(s) and their child(ren)?

9. In your view, what impact do developmentally disabled parents have on their children?

10. Are Regional Centers effective in terms of their work with developmentally disabled parents and children?
Appendix B

Informed Consent
INFORMED CONSENT

The study in which you are about to participate is designed to investigate the developmental status of children who are being raised by parent(s) who are psychologically diagnosed with developmental disabilities. The study also includes the involvement of the family's support systems, such as extended family or professional supports.

This study is being conducted by Anna Bahrami and Pamela Shiner, MSW students, under the supervision of Dr. Morley D. Glicken, Professor at Social Work of California State University, San Bernardino. The study has been reviewed and approved by the Institutional Review Board of California State University, San Bernardino.

In this study, the case files of 30 individuals, who are randomly selected, will be reviewed and studied. Also, service coordinators who are familiar with these chosen cases will be interviewed. The information obtained through your agency for this study will be confidential. The names of the individuals involved will not be reported, and all responses will be destroyed upon completion of the research.

At the conclusion of this study (June 15, 1994), your agency may request a copy of relevant findings directly from Dr. Glicken at 909-880-5557.

Please understand that participation in this study is totally voluntary and anyone who wishes to withdraw from it, may do so at any time.

Participant/s Date: 

Researchers Date: 

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Appendix C

Data Abstraction Form
DATA ABSTRACTION FORM

Identifying Information:

1. Case Number: ______

2. Mother's Age: _____ Father's Age: _____

3. 1st Child's Gender: _____ 2nd Child's Gender: _____
   3rd Child's Gender: _____ 4th Child's Gender: _____

4. 1st Child's Age: _____ 2nd Child's Age: _____
   3rd Child's Age: _____ 4th Child's Age: _____

5. Ethnicity:
   1= Caucasian 2= Mexican American
   3= African American 4= Asian American
   5= other Hispanic 6= Other

6. Marital Status of Parent/s:
   1= Single 2= Married
   3= Divorced 4= Separated 5= other

7. Mother's IQ level:
   1= Borderline Intellectual Functioning: Ranging: 71 to 84
   2= Mild Mental Retardation: Ranging: 50-55 to 70
   3= Moderate Mental Retardation: Ranging: 35-40 to 50-55
   4= Not Applicable: Ranging: 84 and higher
8. Father's IQ level:
   1= Borderline Intellectual Functioning: Ranging: 71 to 84
   2= Mild Mental Retardation Ranging: 50-55 to 70
   3= Moderate Mental Retardation Ranging: 35-40 to 50-55
   4= Not Applicable:

9. Medical problems at birth:
   1st Child ___ 2nd Child ___ 
   3rd Child ___ 4th Child ___ 

10. Denver Development Test of child(ren) at under 3 months:
    1st Child ___ 2nd Child ___ 
    3rd Child ___ 4th Child ___ 

11. Bayley Scale of Infant Development of Child(ren) between 3-6 months:
    1st Child ___ 2nd Child ___ 
    3rd Child ___ 4th Child ___ 

12. Bayley Scale of Infant Development of Child(ren) at age 1:
    1st Child ___ 2nd Child ___ 
    3rd Child ___ 4th Child ___ 

13. Bayley Scale of Infant Development of Child(ren) at Age 2:
    1st Child ___ 2nd Child ___ 

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3rd Child ___ 4th Child ___

14. Psychological Diagnosis of Child(ren) at Age 3:
   1st Child ___ 2nd Child ___
   3rd Child ___ 4th Child ___

15. Developmental Milestone of Child(ren) at Age 6 (School):
   1st Child ___ 2nd Child ___
   3rd Child ___ 4th Child ___

16. Developmental Milestone of Child(ren) at age 9 (school):
   1st Child___ 2nd Child____
   3rd Child___ 4th Child____

17. Developmental Milestone of Child(ren) at age 12 (school):
   1st Child____ 2nd Child _____
   3rd Child____ 4th Child _____

18. Medical Diagnosis of Child(ren):
   1st Child ___ 2nd Child ___
   3rd Child ___ 4th Child ___

19. Extended Family Member(s) involvement:
   1= none   2= low    3= some    4= ave    5= good    6= high
   1= Maternal Grandmother    2= Maternal Grandfather
   3= Maternal Other     4= Paternal Grandmother
5 = Paternal Grandfather       6 = Paternal Other

20. Agencies Involved:

  1 = DCS    2 = Regional Center    3 = CPS    4 = other

21. School Grades (For Q 21 & 22):

  1 = low    2 = ave    3 = good    4 = very good    5 = exceptional

     1st Child _____ 2nd Child ___

     3rd Child _____ 4th Child ___

22. School Conduct:

     1st Child _____ 2nd Child ___

     3rd Child _____ 4th Child ___
Appendix D

Protocol and Debriefing Statement
This research project will investigate the developmental status of children who are being raised by parent(s) who are psychologically and/or medically diagnosed with developmental disabilities.

The sample population will be identified and selected from two Regional Centers' clientele. The researchers will circulate a memorandum to the service coordinators that have developmentally disabled parents in their case loads, requesting identification of cases of children that were not born with any disabilities at birth. The sampling will consist of randomly selected 30 case files from each Regional Center. A family unit will be considered a case.

Developmentally disabled individual(s) who are living with their child(ren) will be focused on. The child(ren) of these individual(s) whose milestone were within the normal range at birth will be identified, the child and her/his parent(s) will be called a family unit, and considered for this case study. Each family unit or case will be numbered from 1 to the highest number of cases that will be identified. The final sampling population will be randomly selected by choosing case numbers (UCI#) whose least significant number is an even digit (0,2,4,6,8) until 30 cases have been selected from each Regional Center.

When the cases are being selected, the service coordinator of each case will be identified. After the 30 cases are selected, then three to five service coordinators will also be randomly selected by their case load number, using the same procedure explained earlier. These counselors will then be interviewed after the data is gathered by completing the data abstraction form for each case. The questions asked from these service coordinators are going to be the same set of previously prepared open ended questions.

A copy of the data abstraction form and interview questions are included.
DEBRIEFING STATEMENT

The study you have participated in was designed to investigate the developmental status of children who are raised by developmentally disabled parents. The research data was collected through evaluation of case material, and interviews with selected service coordinators. All data collected was and will be kept confidential. You may receive the final findings by contacting Dr. Morley Glicken, Professor of Social Work and project advisor at 909-880-5557.

If you have any questions or concerns regarding this research, please contact students Anna Bahrami or Pamela Shiner through the CSUSB Social Work office at 909-880-5501.
MEMORANDUM

DATE: March 8, 1994

TO: Anna Bahrami
   Service Coordinator

FROM: Edward Kutik
      Chief, Case Management Services

RE: Research Proposal for M.S.W. Degree Under the Supervision of California State University, San Bernardino

This is to confirm our conversation that San Gabriel/Pomona Regional Center will authorize you to review case records and interview regional center staff. The purpose of this is for you to conduct a research project on the children of consumers with developmental disabilities.

This authorization is contingent upon your assurances of the following:

1. All information you access will be kept strictly confidential.
2. The research will only collect data which will not identify any individual.
3. The research has received final approval by the Human Subjects Review Committee at California State University, San Bernardino.

Please coordinate the selection of records and interviews with Letha Sellars, Clinical Services Manager.

cc: R. Keith Penman, Executive Director
    Letha Sellars, Clinical Services Manager
    Luke Franck, Program Manager
March 28, 1994

Dr. Morley Glickien
Social Work Department
California State University
San Bernardino
5500 University Parkway
San Bernardino, CA 92407

RE: Pamela Shiner - Proposal for Research Project

I am writing in support of Pamela Shiner’s proposal for a research project relating to developmentally disabled parents and their children.

Please be advised that our agency will assist Pamela to insure the success of her research project. This will allow access to client files and other statistical data that may be required.

Sincerely,

Verlin Woolley
Director

VW:tm
IRC
3-28-94

cc: Mary Lynn Clark, Client Services Programmer
    Mary Gutierrez-Biedebach, Chief, Case Management Services
    Gina Gregory, Program Manager
REFERENCES


