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AN EXPLORATORY STUDY OF SINGLE PARENTS RAISING
A CHILD WITH DEVELOPMENTAL DISABILITIES

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
Marlena La Nae Graves
Tracy Ann Schroeder

June 2001

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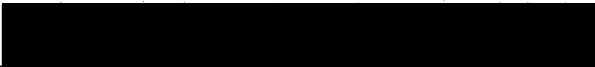
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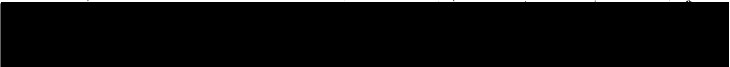
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ABSTRACT

The study gathered information from parents raising a developmentally disabled child. The data were gathered by utilizing the Questionnaire on Resources and Stress-Short Form, and two open-ended questionnaires developed by the researchers that were used as guides to conduct semistructured interviews. The participants received services from a community agency and/or support group designed to benefit parents raising developmentally disabled children. The purpose of this study was to explore the unique experiences and specific needs of single parent families while assessing their level of stress raising a developmentally disabled child.

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The researchers would like to acknowledge our friends and family for their love and support during our search to achieve at a study that is considered more difficult. You shared your love and emotional support when needed.

The researchers would like to acknowledge each other's efforts in working very arduously as a team to complete the project. We yearn for the desire to work with disabled citizens and this project was our first step in committing ourselves as social workers to make a difference in their lives.

We would like to express our deep appreciation to Dawn Anderson with the Pediatric Diagnostic Center and other public agencies for your support and assistance with identifying participants to conduct our research project.

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CHAPTER ONE

INTRODUCTION



Problem Statement

The Developmental Disabilities Assistance and Bill of Rights Act, and Public Law 95-603 (Slater & Wikler, 1986), defined a developmentally disabled person as having a "severe, chronic disability that results in substantial functional limitations in three or more of the following major areas: capacity for self-care, receptivity to language and use of language, learning ability, mobility, self-direction, capacity for independent living, and economic self-sufficiency" (p. 385). This includes persons with mental retardation, cerebral palsy, epilepsy, autism, and other disabling conditions that require treatment similar to that for individuals who are developmentally disabled (American Association of Mental Retardation, 1992).

Prior to the 1960's, children with developmental disabilities were often placed outside the home. According to Slater and Wikler (1986), "there were two criteria why children were placed out of their homes: 1) The child's family was unable to provide a supportive

environment, and 2) the family would have a difficult time staying together" (p. 385). However, with changes in the awareness of psychotropic medication, and legislation reforms (PL 94-142, PL 99-457) developmentally disabled children are able to remain in the home.

In today's society divorce rates are high and many parents find themselves raising their developmentally disabled child alone. However, there is not much research on parents raising children with developmental disabilities. Mothers have been included in many studies that evaluated their feelings as caregiver of a disabled child. However, single mothers were not the main emphasis in many studies.

Fathers were minimally included in studies as a parent needing support services and assistance adapting to their disabled child. One reason is that mothers are typically responsible for overseeing the duties of their child's education and development, whereas men are generally looked upon as the provider for their families. Single fathers, however, are responsible for the same duties as mothers, which includes being solely responsible for their child's upbringing. Nonetheless, society has stereotyped fathers to believe that only

certain duties are applicable to their role as father and provider for their family.

With the increase in single fathers due to divorce, and more cohabiting and nonmarital relationships, more fathers will have an opportunity to be custodial parent for their disabled child. Single fathers and single mothers are not looked upon as providing a reciprocal family environment compared to that of a marital relationship. Fathers, however, are looked at as providing a steady, nurturing, disciplined environment for their child because they set limitations and establish rules (Cummings, 1976). Fathers who have a higher educational level are known to provide a better stable environment economically for their child (Eggebean & Snyder, 1996). Unfortunately, the accountability of good fathers is misunderstood due to the lack of research and even less so for single fathers raising a developmentally disabled child. Therefore, meeting support services needs for this population may be limited.

There is a need for support services for single parent families rearing children with developmental disabilities. Karp and Bradley (1991), defined family

support services as, "an array of practical supports that are determined by individual family needs. Ideally, family support is flexible, focused on the entire family, changes as family needs change, encourages families to use natural community supports, and provides a convenient and central access to services and resources" (p. 2). Support services, therefore can also be respite, family counseling, case management, adaptive equipment, medical care, support groups, recreational services, and transportation. The purpose of these services is to reduce family stress and keep children with developmental disabilities living at home with their families as long as possible.

Single parents need quality support services to assist them with the struggles of raising a child with developmental disabilities (Freedman & Boyer, 2000). According to Freedman and Boyer (2000), little research has been done on the effectiveness of such services. Studying single parents who care for a developmentally disabled child has become important because in the years to come these families will be more common.

Traditionally, women have been the dominant caregiver in the home for their children. However, this

trend is subsiding with more men becoming single fathers and taking the responsibility of raising a developmentally disabled child. As more single parents begin caring for their developmentally disabled child, there is a need for more internal and external supports. The support must include instrumental, informational, and emotional support. As defined by Gottlieb (1983) instrumental support provides monetary support, informational support provides resources, and emotional support entails providing empathy and concern.

Previous research studied single mothers with handicapped children as different from their married counterparts (Schilling, Kirkham, Snow, & Schinke, 1986). This study found no significant differences between the two types of mothers when rearing a disabled child. Another study assessed mothers perceived level of support when caring for a developmentally disabled child (Marcenko & Meyers, 1992). The referenced study only assessed mothers as caregivers, by incorporating single mothers into the study.

A study done with fathers assessed the impact of the disabled child on the father (Cummings, 1976), and fathers as intervention agents for their developmentally

disabled child (Russell & Matson, 1998). These studies were done to measure the father's stress level and their feelings about their handicapped child. However, research is needed exclusively on single parents and their reactions and feelings about their disabled child, and what support services would suit the families.

There is a need to look at the factors that affect single parent families such as role conflict, emotional impact, support system, ecetera. Support may be a family member or nonhandicapped sibling; however, family members may be financially incapable of providing support or live too far away to be utilized as a resource. Siblings sometimes may be too young or resent the developmentally disabled child. Consequently, single parents need support services and human service professionals have to know how to assist these families. This study hopes to fill the gap in research conducted on behalf of single parents raising children with developmental disabilities and their available support resources.

This exploratory study will also examine the stress levels of single mothers and fathers raising children with developmental disabilities, and from their

perspective, what support services they feel are necessary.



Problem Focus

Since the early 1980's, families have been encouraged to care for their disabled child in the home. Parents accepted the responsibility without fully knowing the implications it would have on their family. The emergence of single parenting currently includes more fathers accepting the role as caregiver. Simultaneously, more mothers are becoming single parents solely caring for their disabled and nondisabled children. Mothers have been programmed to be a caregiver and nurturer from their up bringing. However, most single mothers and fathers face many challenges caring for a disabled child. Practitioners can have a great influence on parents who are learning to cope with a child with developmental disabilities.

The completion of this study is expected to provide practitioners with the knowledge to identify single parents' needs. Generally, practitioners focus on the child's needs. But, the challenge is to also identify the needs of the family. Each family member's role has to be

assessed to determine what ways the single parent can receive support with child care responsibilities. Social workers have to go beyond linking parents to resources and analyze the single parent as the sole provider for their child. Thus they can assess what informal and formal supports they need, so they are able to function independently. Hopefully, this research will guide practitioners when assessing a family and linking them to the appropriate services.

Single parents have to make up for the loss of a missing parent, which requires professionals to be even more sensitive to their families needs as a whole. There are limited studies on single parents with a disabled child. With the increasing pattern of single parent homes caused by separation, divorce, death, or nonmarital relationships, the goal of this research is to develop an understanding of their needs. This study will attempt to answer the following questions about single parents raising children with developmental disabilities:

- What stress do single parents experience raising a child with a developmental disability?

- What ways can support services better assist single parents with a developmentally disabled child?

CHAPTER TWO

REVIEW OF THE LITERATURE

At the beginning of the 20th century, families often felt ashamed of their children with developmental disabilities and were advised by their physicians to place them in institutions (Mackelprang & Salsgiver, 1996). During the second half of the 20th century, the medical model was used to treat people with developmental disabilities. Physicians made the decisions and informed patients and their parents about their decisions regarding treatment and services. If the family or the individual disagreed with the physician, they were withdrawn from services (Mackelprang & Salsgiver, 1996; Mary, 1998).

According to the California Department of Developmental Services (DDS, 2000), approximately 42,401 children between the age of 0 to 13 are diagnosed with a developmental disability. There are approximately 4,759 children age 0 to 13 going through an assessment and intake that might have a developmental disability. Approximately 13,361 children under the age of 2, are served by Regional Centers in California for being at

risk of a developmental disability or developmentally delayed (DDS, 2000). Approximately 85% to 90% of people with developmental disabilities live at home with their families (Karp & Bradley, 1991; Freedman & Boyer, 2000). As the number of children with developmental disabilities living at home increases, many researchers have sought to study maternal parents and their relationship with their developmentally disabled child (Wikler & Haack, 1994).

There is extensive literature that pertains to families with children with disabilities in general, families raising a disabled child in the home, and mothers raising children with disabilities and their stress level. But, very few studies have assessed fathers raising children with disabilities and their stress level. This section will include research literature pertaining to the emotions that parents experience raising a child with a developmental disability, the parents predictors of stress, background information on single mothers and single fathers, and support services currently available to parents with a disabled child.

Emotions Raising Children with Developmental Disabilities

Reportedly, the first phase of dealing with the reality of having a disabled child is denial (Mallow & Bechtel, 1999). Both parents are upset, heart broken, and often blame themselves for their child's disability. At times parents also blame each other. A study conducted by Mallow and Bechtel (1999) examined the chronic sorrow perceived by mothers and fathers of developmentally disabled children. According to Mallow and Bethel (1999), chronic sorrow is defined as "the intense recurrent feelings of sadness, which vary from time to time for the same persons, from situation to situation, and from one family to another" (p. 31). The mothers will immediately express chronic sorrow after the diagnosis, whereas the father's emotions turn to frustration and resignation (Mallow & Bethel, 1999). A study by Farber (1970) indicated many "family upsets" in families with a disabled child with an IQ of 55 or less.

When a child is diagnosed with a disability, the marital relationship becomes strained. The mother's and father's traditional roles clash which causes a strain on both. Parents noted having doubts, fears, guilt, and

maladjustment problems (Farber, 1970). The fathers feel excluded and inferior to the mothers because she is the nurturer, whereas his traditional role is to be the provider (Fathers Network, 2000). Accepting the fact that the child they dreamed of is different from other children is hard. Most often mothers are able to deal with their grief and start caring for their child as if they were not disabled. This may be how they learn to deal with any anger, grief, or resentment. On the other hand, men seem to deal with their grief in a passive way. They tend not to take their grief as hard as the woman does, but they deal with it in a more quiet way.

Fathers can experience depression, weakness, anger, guilt, and feelings of powerless, and their feelings may be seen instead through addictive behaviors such as drinking, substance abuse, or becoming a workaholic. However, the cases of men turning to destructive behavior are rare (Fathers Network, 2000). As noted by a case manager with Inland Regional Center, men do tend to move on with their lives and have the same responsibilities as they did if they had a nondisabled child. But, the mother still continues to take on most of the caregiving while the man resumes the provider role (Case Manager, 2000).

Understandably, a father as the provider for their family will have worries that include increased child-rearing cost, finances, stigmatized identity, social incapacities, and lack of knowledge about their child's disability. What is now available to help men deal with their pain are support groups designed for fathers. In the Southern California area, several support groups are available that focus on helping fathers that have children with special needs. One specific support group is the Fathers Network.

The Fathers Network helps bring to light that fathers are used to being a playmate to their child rather than caregiver. In most instances, this has to be adjusted and men have to learn new ways to include their child in activities. They may not be able to play football or other games; however, they can learn adaptive ways to be an intervention agent for their child. Men can make a difference in their child's cognitive, motivational, and motor skills (Lamb, 1981). Just like a nondisabled child looks up to their father, a disabled child can do the same.

Predictors of Stress

Parents face many stressors throughout their life. They worry about their children, work, and paying their bills. Parents of children with developmental disabilities face even more stress than parents with "normal" children. Stressors that families face include childcare, financial burdens, lack of information, isolation from the community, childhood milestone, education decisions (Dyson, 1997), and long-term care (Slater & Wikler, 1986). Additional stressors include school administrators, Medi-Cal, and Regional Centers (Blancher & Baker, 1994).

Families have a hard time finding quality childcare for their developmentally disabled child because they require specialized care. The specialized care may include expensive adaptive equipment that medical insurance does not cover.

Parents experiencing isolation from the community, suffer additional stress. Their child's behavior may prevent them from going to public places because of the embarrassment (Karp & Bradley, 1997). Moreover, a study done by Slater and Wikler (1986), showed that parents stress tends to increase as the child's level of

dependency and basic needs for care increases. Parents became frustrated with their child's regression in health, and other child related problems, which also increased their stress (Blancher & Baker, 1994). Other research showed that when children with developmental disabilities go through transitional childhood stages, parents experience more stress trying to care for their child (Dyson, 1997; Flynt & Wood, 1989).

Dyson (1997) showed that fathers of school age children with developmental disabilities experienced as much stress as mothers. Fathers also display more stress than mothers when their sons are developmentally disabled because fathers have difficulties adjusting to their expectations of their sons (Frey, Greenberg, & Fewell, 1989). Also, research shows that marital factors could affect stress levels among parents. Flynt and Wood (1989) showed that single mothers reported more stress than married mothers did, but found no significant difference in the stress levels among different socioeconomic statuses.

Blancher and Baker (1994) examined the reasons parents decided to place their child in out of home care. The primary caregiver for the child answered the

questions; these were 59 mothers, and three (3) fathers. The respondents indicated that the decision was not easy, but caring for their developmentally disabled child became overwhelming. It became a strain on them to care for their child because they were always tired. The parents believed that they could never do enough for their child and did not see progress. Furthermore, their child's mood would change and at times their child would attack them.

As well, the McBride and Darragh (1995) study revealed that parents with rocky marriages have problems with family integration and the added stress further impacts the marriage when a developmentally disabled child is in the home. However, mothers who place higher expectations on their spouses tend to receive better support with caregiving and have better marital satisfaction.

Single Mothers

Single mothers who are raising a child with a developmental disability are not much different from single mothers who are raising a nondisabled child (Schilling, et al., 1986). However, literature on single

mothers who are raising a disabled child is limited. A study by Marcenko and Meyers (1991) assessed stress and compared coping skills between single mothers and married mothers. The study indicated there was not a significant difference in the support sought for their disabled child. The main difference was the perceived support of married mothers by their husbands, whereas single mothers expected little support from their child's father and his family.

Another study assessed issues faced by divorced mothers raising a developmentally disabled child. The study showed that the demands of caregiving along with lack of social support and the child's temperament add to the stress of being a single mother.

Working single mothers generally take on dual responsibilities as caregiver and income provider. Their income is more likely to be less than married mothers; therefore, single mothers may receive more financial support from agencies. However, single mothers report not to be as satisfied with their families in terms of financial stability, job satisfaction, living space, and neighborhood (Schilling, et al., 1986). Finances would play a detrimental role for a single mother considering

she is the sole provider for her family. She does not have anyone with whom to share the expenses of medical care, equipment, special classes, special foods, and therapy cost (Schilling, et al., 1986).

Single and married mothers report having less emotional support networks because most mothers are at home caring for their disabled child. Relief from caregiving is not shared with a spouse, and emotional support, advice, and motivation is limited to family and friends (Schilling, et al., 1986). Usually, family members provide babysitting regularly or in emergency cases if the mother works. Evidently, single mothers experience more emotional despair from their caregiving considering their support system is limited. Single mothers must become a major focus in more social service agencies because they need emotional, financial, internal, and external support.

Single Fathers

In the past two decades, single fathers as the primary caregiver has increased. In 1970, the United States Census Bureau showed 350,000 fewer single father families than in 1960, and an increase to 1.4 million by

1989. By 1993, single father households were 15.5% of families (Eggebean & Snyder, 1996). The reasons are due to post-war changes with more families cohabitating, higher rates of divorce, less childbearing, and more women with a commitment to their career. Single fathers sacrifice their personal life and some, their jobs, to spend more time with their children (Eggebean & Snyder, 1996). They are usually younger than married fathers, but not as young as single mothers.

The increase in single fatherhood can be attributed to more fathers obtaining custody after divorce (Eggebean & Snyder, 1996). The court is no longer interested in routinely granting custody to the mother. Now the parent that can better provide a stable living environment for the child is considered first. Among single fathers, diversity exists within their own group. Single fathers can have different educational levels, living arrangements, and income levels. Moreover, they experience fewer problems with caregiving and have more support from their family in caring for their child. However, what is not accounted for in many studies and by the Census Bureau, is the number of fathers labeled as single fathers, who are really cohabiting or have

occasional help from a girlfriend. The same could hold true for single mothers as well. Nonetheless, compared to married fathers, children in single father families are not better off financially, but are better off than being in a single mother home.

Fathers are looked at as providing a steady, nurturing, disciplined environment for their child because they set limitations and establish rules (Cummings, 1976). In fact, single fathers who have a higher educational level are known to provide a better stable environment economically for their child (Eggebean & Snyder, 1996). Unfortunately, the accountability of good fathers is misunderstood due to the lack of research and even less so for fathers with developmentally disabled children.

A study conducted by Russell and Matson (1998), evaluated fathers as their disabled child's intervention agent in which they learned that fathers can respond to specific behaviors which set limits for their child. Another study assessed the impact of the child's deficiency on their father (Cummings, 1976). This study assessed each father's mood, self-esteem, interpersonal satisfactions, and child rearing attitudes and found that

fathers of developmentally disabled children do experience psychological stress. Frey, Greenberg, and Fewell (1989) suggested future research and interventions need to include fathers more frequently than is currently done.

Men lack formal and informal support networks compared to women. Agencies seem to offer fewer services to fathers compared to mothers which limits their social participation in their child's life (Cummings, 1976). To alleviate the imbalance in the struggle for fathers to meet the expectations of fatherhood, parenting programs for fathers is recommended (McBride & Darragh, 1995).

The Fathers Network, headquartered in Seattle, Washington, is a support group for fathers of children with special needs. They concur that fathers are wonderful men that enjoy playing with their children more than being caretakers. And, they provide fathers with the support they need to express their emotions about their disabled child. As more research is conducted and support resources become available for fathers with developmentally disabled children, fathers will be given more opportunities to express their feelings in a

supportive environment and build a better relationship with their child.

Support Services

Many public laws made it possible for families and individuals with developmental disabilities to receive support services and live productive lives. The Education of All Handicapped Children Act (PL 94-142) now called the Individual with Disability Education Act (IDEA), made it possible for disabled children to be mainstreamed in schools and assist families with support services (Karp & Bradley, 1991; Mary, 1998). Under this law, the school districts provide special education and related services for children.

According to the Individuals with Disability Education Act (IDEA), the school is responsible for providing services to children with developmental disabilities. Some services include physical and occupational therapy, language and speech development, instruction in the home or hospital, adapted physical education, counseling and guidance, parent counseling and training, social worker services, and health services. Support services can reduce stress (Flynt & Wood, 1989),

and benefit parents and children emotionally, educationally, and financially (Freedman & Boyer, 2000). Services have improved over the last thirty years, but there is still a need for more effective and constant services.

In 1970, deinstitutionalization of people with developmental disabilities called for a need for community services and support services for families and individuals. The Lanterman Developmental Disabilities Service Act of 1973, gave individuals with developmental disabilities and their families the basic right to live productive and normal lives. The Lanterman Act focused on support services for individuals, so they are able to live in the community. In 1970, Regional Center expanded their services to provide support services to individuals and their families. In 1992, an amendment was added to the Lanterman Act stating that support services should be person-centered-services should meet the needs of the individual and their families (Mary, 1998).

From 1970 to 1980, family support services consisted primarily of respite care. Support services were limited to individuals with severe disabilities that were at high risk for institutionalization (Freed & Boyer, 2000).

During the 1990's, many states expanded their scope of family support services (Freedman & Boyer, 2000; Mary, 1998). The main goal for family support services is to keep individuals with developmental disabilities at home with their families. Family support services include, but are not limited to respite care, health care, medical assistance, adaptive equipment, financial assistance, family counseling, recreational activities, family education, and training (Freedman & Boyer, 2000; Karp & Bradley, 1991; Mary, 1998; Slater & Wikler, 1986).

A study completed by Freedman and Boyer (2000), states that many parents face barriers when trying to get services for their children. Some of these barriers are lack of information and outreach, restrictive eligibility criteria, administrating regulations, and inflexibly of services. Parents would like to be more involved in choosing support services and they would like more consistent workers. Families would like to have support services that assist the whole family instead of just focusing on the developmentally disabled child (Freedman & Boyer, 2000; Karp & Bradley, 1991; Wyngarden & Krauss, 1997; Slater & Wikler, 1986). As well, parents are concerned that support services are still not meeting

their child's needs in terms of socialization opportunities and community inclusion (Freedman & Boyer, 2000).

Furthermore, parents are disturbed about how services for their child are coordinated. Some services are pieced together and many agencies do not work together to provide the best support services for families. Families would like more information about programs and resources to make effective decisions regarding their child's future.

As well, parents desire more education and advocacy-training opportunities regarding their child's disability, and support services to be proactive and preventive in focus. Support services should also not stop in the summer. The school district provides many services, but does not offer services in the summer, which leaves families without support services. Support services that are cut in the summer are OT/PT, behavior modification, and speech therapy (Freedman & Boyer, 2000).

Summary

The literature assessed thus far studied mothers and fathers raising a developmentally disabled child as a family unit. The authors have concluded that parents' emotions about their normal newborn disabled child would be different from parents with a nondisabled child. The authors assessed their first reaction, feelings, family impact, stress, and support services. This study will build upon previous studies by focusing on single parents.

The needs of single parents may be different from their married counterparts. Therefore, this study will assess what is needed to help single parents function independently. Support for single parents with a developmentally disabled child can be unveiled by asking these questions:

- What stress do single parents experience raising a child with a development disability?
- What ways can support services better assist single parents with a developmentally disabled child?

CHAPTER THREE

METHODOLOGY

Study Design

Quantitative and qualitative measures were used to examine the stress among single parents and their satisfaction with the support services received. The research method/design used to collect data for this study were questionnaires and semistructured interviews. An open-ended questionnaire was developed by the researchers to assess parents support services and stress; but, also used as a guide for interviews. The Questionnaire on Resources and Stress Short Form (QRS-F) was used to measure stress (Friedrich, Greenberg, & Crnic, 1983).

A questionnaire with open-ended questions was the most suitable design method to use for identifying the needs of single parents. Single parents raising a developmentally disabled child is a difficult population to acquire and the objective was to acquire an adequate sample to better understand their needs. According to Rubin and Babbie (1997), open-ended questions could be

used in interview schedules to allow participants to provide their answers to questions.

Semistructured interviews was a viable means of obtaining further information about the unique needs of single parents. Single parents have needs that may be different from their married counterparts and may experience stress from factors that cannot be identified through a stress instrument. Grinnell (1997) states semistructured interviews allow the researcher to use interviews to follow up on certain questions that may differentiate between participants.

The QRS-F questionnaire is a short questionnaire that would meet the need of this study to explore the stressors of single parents. The questions were close-ended, true/false answers. Close-ended questions as indicated by Grinnell (1997), keep answers uniform and is a better means to compare data.

Sampling

The method of sampling for this project was convenience sampling. Among the many sampling methods available, convenience sampling is a popular means of sampling when conducting interviews with a smaller

population (Grinnell, 1997). Convenience sampling is also the most suitable because access to the population being studied could only come about through their association with an agency that provides supportive services.

Supportive services are designed to meet the specific needs of parents that have developmentally disabled children. Their goal is to support, educate, and revitalize parents by assuring them of their indispensable role in their family.

The criterion for inclusion in the study was single parents 18 years of age, solely caring for a developmentally disabled child in their home; and the child must be newborn to age 21. For the purpose of this study, developmentally disabled is defined by The Developmental Disabilities Assistance and Bill of Rights Act, and The Public Law 95-603, as a person having "a severe, chronic disability that results in substantial functional limitations in three or more of the following major areas: capacity for self-care, receptivity to language and use of language, learning ability, mobility, self-direction, capacity for independent living, and economic self-sufficiency" (Slater & Wikler, 1986, p. 385). A single parent for this study is defined as

separated, divorced, widowed, or never married, and noncohabiting.

Participants selected for the study included single and married parents who reside in Southern California and one out of state participant. Out of possible 75 questionnaires distributed, there were eleven returned questionnaires by single parents and nine by married parents. The single parents sample yielded an inadequate amount of participants, therefore the nine married parents were added to the study.

The single and married participants, who willingly participated, have at least one developmentally disabled child. The single parents selected for follow up interviews was based upon their willingness to be interviewed by providing their name and telephone number on the questionnaire.

Instrumentation

The researchers formulated a self-administered questionnaire and a questionnaire utilized to guide the interviews. Both questionnaires included open-ended questions which were designed with an ex-post facto premise that is not intended to show a cause and effect

relationship, but a relationship between two variables. Thus, the questionnaires were used to assess the respondent's current stressors and its relationship with received support services to anticipate future behavior.

The self-administered questionnaire contained two open-ended questions and a rank ordering system in which respondents were expected to rank, in the order of importance, their informal and formal support services. Informal support services included family, friends, neighbors, etcetera. Formal support services included Regional Center, Medi-Cal, respite care, school, etceteras. Based on the respondent's answers, feedback was requested about their number one and two choices.

The independent variables for the questionnaire was the basic family background characteristics such as parent's age, gender, ethnicity, social economics, educational level, and the child's age, gender, ethnicity, number of siblings and ages, nature of child's disability, and the support services received for the family.

The questionnaire developed for the interviews focused on the family's needs caring for a developmentally disabled child, and suggestion on better

ways to provide services. This questionnaire contained a total of seven questions.

Along with the self-administered open-ended questionnaire, the Questionnaire on Resources and Stress-Short Form (QRS-F) developed by Friedrich, et al (1983) was administered. The questionnaire contains (52) true and false questions that measure family stress. The QRS-F measures four independent factors, which include Parent and Family Problems, Pessimism, Child Characteristics, and Physical Incapacitation.

According to Friedrich, et al (1983), each of the four factors is designed to measure a specific aspect of stress. For instance, the first factor, Parent and Family Problems includes 20 questions that are meant to assess the participants perceived notion of problems or measure a specific aspect of stress. For instance, the participants perceived notion about their family members, family as a unit, or themselves are measured. The second factor, Pessimism, includes 11 questions about the pessimism of their child's current and future self-sufficiency needs. For example, "I worry about what will happen to...when I can no longer take care of him/her." The factor Child Characteristics includes 15 questions

that seek to understand the difficulties of the participant's behavior or attitude concerning their child's disability, "Sometimes I avoid taking...out in public." Lastly, the factor Physical Incapacitation contains six questions that measure the participant's perceptions about their disabled child's limited physical abilities and self-help skills.

According to Dyson (1997), The Kuder-Richardson-20 reliability coefficient for the questionnaire is .95, with item total correlation's ranging from .15 to .63 and a mean interterm correlation of .26. According to Scott, Sexton, Thompson, & Thompson (1989), the QRS-F was found highly reliable ($\alpha = 0.92$). The strength of the QRS-F is that it has been used in many research projects (Dyson, 1997, Hayden & Goldman, 1996, Scott et al., 1989), and no better scale has been developed.

Procedure

Participants were recruited from the Kaiser Permanente and Fathers Network support groups, and Pediatric Diagnostic Center and Abilities First which are public agencies. Participants at support groups were given background information about the study and invited

to participate. If they agreed, participants (15) were given a self-administered questionnaire and self-addressed stamped envelope. Participants (60) recruited through agencies were explained about the study by the agency's director, and also given a self-administered questionnaire and self-addressed stamped envelope if they chose to participate.

After the questionnaires were returned, interviews were conducted with single parent participants who provided their name and number. Three in-home interviews were conducted with participants who live in the San Bernardino County area, and their preference to be interviewed in their home. Five phone interviews were conducted with participants who lived outside of the San Bernardino County area and/or preferred to be interviewed by phone.

Prior to the three in-home interviews, participants were handed an informed consent, and a debriefing statement was given after the interview. The five phone interviewees were read the informed consent and approval given to participate before the interview questions were asked. After the interview, they were read the debriefing statement and asked if they wanted a copy mailed to them.

The researchers used a questionnaire as an interview guide to ask parents questions. The questions focused on two topic areas, which included the following: 1) the needs of their family caring for a developmentally disabled child, and 2) suggestions on better ways to deliver services.

Data Analysis

Data was collected over the course of four months. Once all the questionnaires were collected and interviews completed, the researchers began their analysis of data.

First, a descriptive analysis was completed which included univariate statistics such as frequency distribution, measure of central tendency, and dispersion to describe the parent's characteristics. Secondly, a t-test was used to compare the measures between two variables. The Statistical Package for the Social Sciences (SPSS), was used to examine the relationship between the QRS-F total scores and the independent variables, and link the factors of resources and stress levels together.

Each question for the QRS-F was hand scored using the direction of the true or false response of the

respondents. Two points were given to each item in which the answer selection indicates stress. For example, "...doesn't communicate with others of his/her age group". If the respondents answer true, it was given a value of two. The higher the total score, the more stress indicated. A total stress score was then computed.

A coding design was used to analyze the responses to the self-administered open-ended questions and data from the interviews. Coding designs help to extract the important issues into categories for easier analysis (Santos, Mitchell, Pope, 1999). The most frequently used words and responses were coded and organized into categories corresponding to the ten major topic areas: (1) support services, (2) monetary support, (3) companion support, (4) public assistance, (5) education, (6) developmental/disability, (7) delivery of services, (8) social acceptance, (9) childcare/activities, and (10) pessimism. The coding system table includes the following: identification, question, category, and comments.

The identification field signifies the respondent. The question field identifies the question number while the category field pre-classifies the response for better

analysis. And, the comments field details the respondent's responses. To illustrate, a barrier identified was social acceptance of the child. The identification number assigned was (01), question number is 5, category number is 8, and comment, "people stare at her." Appendix H contains this table.

CHAPTER FOUR

RESULTS

Characteristics of Sample

There were 20 parents included in the study. Eighty-five percent (17) of the participants were female and 15% (3) were males. The mean age of parents was 36. The age range of the sample was 19 to 48. Forty-five percent (9) were white, 40% (8) Hispanic, 10% (2) African-American, and 5% (1) other. Twenty-five percent (5) of parents reported some college, 20% (4) completed graduate or professional school, 20% (4) high school graduates, 20% (4) had less than a high school education, and 15% (3) were college graduates. Forty percent (8) of the parents reported a yearly income below \$20,000, 5% (1) made between \$20,001 to \$30,000, 20% (4) made between \$40,001 to \$50,000, and 35% (7) were above \$50,000. Over 50% (11) were sole caregivers, 40% (8) shared caregiving responsibilities, and one (1) participant did not answer the question.

Three-fourths (15) of the children were female and one-fourth (5) were male. Children ranged in age from 1 to 21 years ($M = 9.5$). The children had multiple

diagnoses reported. Appendix H illustrates the children's background information for each of the 20 respondents. Seventy percent (14) of the children have siblings, 25% (5) had no siblings and one participant did not answer the question.

Factors Related to Stress

Analysis of the total scores for the QRS-F showed possible scores could range from 52 to 104. The range was from 53 to 85 ($\underline{M} = 70.6$). The majority scored 66.

Fifty-five percent (11) of the participants scored 68 and below and 45% (9) scored over 69 and higher.

Unfortunately, some participants left some questions blank which caused lower stress scores. The participant who scored 53 on the QRS-F left 18 questions blank causing her score to show more stress than other participants. Another participant left six (6) questions blank causing her total score to be 66.

An independent sample t-test was done to examine relationships between variables. The independent sample t-test revealed that single parents ($\underline{M} = 70.64$, $\underline{SD} = 10.31$) showed no significant difference on their stress score than married parents ($\underline{M} = 70.56$, $\underline{SD} = 7.92$)

raising children with developmental disabilities ($t = -.020, df = 17.954, p = .984$). There was no significant difference between parents ($M = 70.11, SD = 10.86$) that earned below \$30,000 a year, and ones that earn above \$40,000 ($M = 71, SD = 7.86$) a year on the stress score ($t = -.205, df = 14.240, p = .840$). There was no significant difference between sole caregiving ($M = 71, SD = 10.73$) and shared caregiving ($M = 70.63, SD = 7.46$) responsibilities on the stress scores ($t = .090, df = 16.989, p = .929$). The t-test revealed no significant difference in stress between parents with an only child ($M = 71.60, SD = 13.63$) in the family and parents with siblings ($M = 70.57, SD = 7.82$), ($t = -.160, df = 4.975, p = .879$).

A one tailed Pearson correlation was done to examine parent's age and the total QRS-F score. Parent's age and the QRS-F score ($r = -.219, N = 20, p = .177$). The correlation between child's age and QRS-F score ($r = -.047, N = 20, p = .843$). There was no significant correlation between parents or child's age and stress scores.

Open-Ended Questions

Question #1: Prioritize the informal support you receive?

A total of 13 out of 20 parents prioritized their informal support for this question. There were seven (7) married parents and six (6) single parents. Majority (6) of the married parents responded that their number one informal support is received by their significant other. One married parent selected their family as their number one means of informal support. Their number two choice for informal support is family (3), friends (2), family-in-laws (1), and neighbors (1). Fifty-percent (3) of the single parents responded that their number one choice of informal support was from their family. One single parent reported that the father of their child was supportive. One single parent answered that they receive support from their friends. Their number two form of informal support are friends (4), father (1), and family (1). One parent did not provide an answer for their number two form of informal support.

Question #2: Discuss the kind of informal support that is given by your number one and two choices above?

The majority (6) of married parents who selected the father/mother of the child for support commented that

they provide direct care and emotional support. They also commented that they provide encouragement and a listening ear. Other comments were that their in-laws were supportive and family was involved.

Single parents (9) commented that their family provides emotional support, baby-sitting, and help them to relieve stress, and their friends provide them with emotional support, baby-sitting, friendship, and recreation.

Question #3: Prioritize the formal support you receive?

A total of 13 parents prioritized their formal support for question #3. There were seven (7) married parents and six (6) single parents. The number one form of formal support received by married parents was school (2), respite (2), regional center (1), SSI (1), and CCS (1). Their number two form of formal support was school (2), SSI (1), Medi-Cal (1), and respite (1). Two parents did not select a second form of formal support.

The number one form of formal support received by single parents was school (2), regional center (1), support groups (1), SSI (1), and CCS (1). Their number two form of formal support was school (2), regional center (2), SSI (1), and Medi-Cal (1).

Question #4: Discuss the kind of formal support that is given by your number one and two choices above?

As their number one and two choices for formal support, parents (4) reported that regional center provides them with education, respite, school advocacy, information, networking, direction, and pays for recreation services. One parent reported that support groups provide support by sharing information and providing a listening ear. Four parents reported that SSI provides them with monetary support. Two parents replied that Medi-Cal provides them with medical supplies and resources. Two parents reported that CCS provides them with donations and also medical supplies. Parents (3) commented that respite provides time to themselves at home and work.

A total of eight (8) out of 20 parents receive support and services from their child's school. The school promotes a supportive environment by providing feedback, emotional support, help, education, guidance, and suggestions for activities. The school provides services for their child such as special day classes, speech therapy, and teacher aides.

Question #5: What are your major barriers or challenges in raising a child with developmental disabilities?

Parents (18) made 33 comments about their barriers/challenges: developmental/disability (8), social acceptance (7), childcare (6), pessimism (4), support services (3), monetary support (2), companion support (1), and education (1). First, the trend in answers dealt with their child's developmental and disability needs. The parents mentioned that the constant attention, behavior problems, physical constraints, time strains, and meeting their child's developmental needs are a challenge. The second trend in answers dealt with the parent's worry about their child's social acceptance, health and safety, and not knowing their future medical incapacities. Third, the parents made comments regarding support services which include support groups for the child and family, not receiving information on services needed, trying to get services needed such as before and afterschool childcare, and consistency with services especially speech and respite. Lastly, one parent was concerned about having a companion that will love their child as much as they do.

When question #5 was asked in the interviews, "ignorance of society" was a significant issue identified by five mothers. Their children being developmentally disabled has not been well received by society. Mothers reported that people stare at their child, and responses have included, "other children call my child stupid", "they are mean to her", "they try to avoid her." A young mother struggling to care for her child that is blind indicated, "I put sun shades on my daughter to keep people from staring at her." The mother's understand their child is growing older and realizing they are not normal. But, it hurts when people do or say mean things to them.

Another barrier/challenge identified was the lack of education about their child's developmental needs. Three mothers stated they need some form of education to help meet the needs of their maturing female disabled child. Mothers are finding it difficult to teach their daughters how to care for their hygiene needs. One mother stated, "I wish I could take a class to teach me so I can teach her." As girls advance through puberty their mothers are becoming overwhelmed with the responsibility for ensuring their daughters maturing needs are met.

Question #6: If you could have one resource and/or service to give you additional support and to help eliminate stress in raising your child, what would it be?

Parents (19) made 12 comments concerning resources and services: childcare/activities (3), support services (3), monetary support (2), and delivery of services (2), companionship (1), and pessimism (1). Eight parents replied that in-home services would help them, such as respite with qualified people, physical therapy, tutoring, and nursing. One mother stated, "Services should not be based on your income, there is too much red tape to just get respite care and then I have to appeal to people who don't even know my daughter." Another popular request by seven parents was providing outside-home services such as a multidisciplinary team of doctors that work together to cut down on office appointments, transportation, after-school activities, social skill training, peer groups, and camps. The final need identified was resources for the family that would provide for more monetary support, free time, and sibling support services.

When asked question #6, during the interviews only two out of eight mothers provided additional feedback.

The first mother felt that housing assistance should be provided for disabled children and their families, while the second mother requested outings twice a month with other families of children with the same disabilities.

Question #7: What is a typical day in your home like?

This question is the first of the interview questionnaire. In the category of developmental/disability needs, two comments were made for this question; "50/50, she sometimes dresses herself and sometimes not", "depends on how lazy she is, she will get dressed, other days she won't." Among the mothers with children that were ambulatory and age appropriate, a typical day in the home was consistent with the children able to shower and feed themselves with minimal assistance.

Question #8: Do you feel your day and needs are different from married parents raising a child with a developmental disability?

A total of eight comments were made in response to this question. Six mothers feel strongly about their limitations without having a mate in the home. The daily routine of coping with their child's needs can take its toll, causing more stress. The mothers reported, "I live

by myself, I have no help", "No one to share responsibilities and decisions with", "I get no relief, at least if his father could help", "What I would give for five minutes", "I just can't pick up and go somewhere right quick." The fathers of these mothers children do not provide any form of support for the mothers.

Question #9: Do you receive any support from community members?

A total of five comments were made that were in the category of support services. One mother indicated, "At church meetings members baby-sit." Another mother stated, "I am active in church and if I need help they would be right over." But, one mother replied, "I don't go to church. . . I have to work, and take care of my daughter, I am too tired." One mother has received outreach support services that have provided food and assisted in paying her utility bills.

Question 10: Does your family receive any other type of support services?

For this question, in the category of support, one mother commented, "My other source of support is my family, but they live too far away."

Question #11: What do you feel your family's needs are caring for a disabled child?

Two mothers made five comments in the categories of childcare/activities (2), education (1), monetary support (1), childcare/activities (1), and delivery of services (1). One mother felt that her family could benefit more if she could locate transitional housing for her daughter that is not a facility for older adults, and the mother needs help understanding what to expect from the different developmental stages her child goes through. The other mother felt that her family could benefit from more monetary support, qualified people to answer questions, and when her child is sick, someone to baby-sit so she can go and pick up medical equipment.

Question #12: What services are you not receiving that you feel that will benefit your child's life?

In the category of support, only one comment was made in which the mother stated, "More respite, to spend more time with my other children."

Question 13: What is your suggestion on better ways to deliver services to single parents caring for a developmentally disabled child?

In the category of delivery of services, this question rendered the highest feedback from all eight interviewees. To provide a better delivery of services, a few statements were as follows: "More education and research about my child's disability", "Flexibility when scheduling appointments." Other statements included, "Respite care paid to in-home family members - I only trust my older daughter and they won't pay her for providing respite care because she lives with us." Another mother said, "Stop overloading social workers so I can keep the same one for awhile. Once my child becomes acquainted with their social worker and I share my child's life history, the social worker changes."

Another concern was the way services are provided. A mother reported, "Don't treat people like it's their fault their child is disabled." The mother who made this statement is concerned about a trust account for her son with a minimal balance, and when she applied for social security services, the representatives made it clear, "You are receiving free money and you can't have money in the bank above a certain amount." This mother's annual income is below \$20,000 and feels she cannot have

anything without jeopardizing the services she receives for her son.

Lastly, mothers felt there is not enough child care services offered before and afterschool. One mother was forced to accept a lowering paying position based on the time her child attends school, which has limited her professional goals.

Discussion

The instruments applied yielded separate results, but gave the researchers an idea of what single parents raising a developmentally disabled child encounter and their satisfaction in their role as caregiver.

This study set out to identify the stressors of single parents and support services needed to function independently in their role as caregiver. The findings of the eight interviews conveyed the following results: single parents interviewed, for the most part, are pleased with their supportive services and only minimal barriers were identified. And, as revealed in the statistical analysis of the QRS-F, a significant amount of stress was not identified being single and caring for a developmentally disabled child. However, it appears

variables such as income, support from fathers and church members have an effect on their perception of stress.

The independent sample t-test results were insignificant. According to Weinbach & Grinnell (1998), a sample size of 30 or more is best for running an independent sample t-test. Unfortunately, the researchers were unable to obtain a sample size of thirty parents. Thus, the QRS-F score identified no differences between married and single parents. Moreover, most parents had a moderate score; there are several reasons for this outcome. One is the sample size was not large enough to do an independent sample t-test. Another reason is the QRS-F questionnaire had no measurement for the severity of disability.

The correlations also did not show any significant differences between single and married parents in relation to the QRS-F questions. This may be a result of the small sample size and the QRS-F was not designed to specifically measure single parents stress of being sole care provider. The QRS-F is strictly designed to measure factors of stress related to caring for a disabled child. To adequately assess single parents stress and emotions about raising their child, another instrument would have

to be used. Nonetheless, neither the open-ended questions on the self-administered questionnaire or the interviews with single parents revealed any extra stress caring for a developmentally disabled child, compared to that of married which does not support the findings of Flynt and Woods (1989).

According to the comments concerning support services, families seem to receive adequate services for their child if they meet specific income criteria. Parents who receive more support services have less stress than those who do not, based on the comments made by parents with incomes above \$50,000. However, it appears that parents with higher incomes do not receive their preferred amount of support services which may mean their family is not better off than a lower income family struggling financially to meet for their child's medical needs as well. Parents with higher incomes just have to go through more red tape as one parent commented to receive more services such as in-home respite care which is unfair. Hence, this information attest to the study done by Freedman and Boyer (2000), in which they also found that parents do face difficulties when trying to receive services such as respite for their child.

Out of all the services received by parents, it appears that schools provide the most useful services. During the interviews mothers commented that the delivery of services could be better, but no comments were made about the quality of school services. The only mention about schools is their desire for them to provide services during the summer.

Two mothers were noted as receiving support from their children's father in terms of child support and weekend visits every two weeks. As well, these mothers are active in their church. Surprisingly, these mothers seem to experience less stress and have adjusted in their role as mother to their developmentally disabled child. No negative connotation was made about the lack of support by their child's father. When one mother was asked about a typical day in her home, she stated, "I take my children with me wherever I go because I won't always have them with me and I will miss them when they move out." This statement is opposite to the single parents with no paternal support and would like to have their support so they may leave their child with them to run errands.

The six mothers that have limited or no support from their child's father, and/or church affiliation seem to face anguish and pain. Mothers stated they used to wish for help from their fathers, but now they have accepted his absence. These are the same results identified in Marcenko and Meyers (1991) study. Their study showed that married women received support from their husbands, whereas single women did not expect any help from their child's father or his family. Surprisingly, these mothers with no paternal support appear to desire companionship, but only to help with caregiving responsibilities.

According to the interviews, the most notable barrier in this study was the parent's concern about the ignorance of society. As a disabled child grows older, the parents began to realize that their children are not like other children. As commented by several mothers, they have to defend their child in public when people allow their children to treat them like they have a disease. However, they cannot help but to worry about their child when they grow up and on their own in some cases. They will not only have to worry about their child's developmental and medical needs, but how people will receive them in public. Karp and Bradley (1997) also

noted in their study that parent's stress about social settings and what society might think. Unfortunately, the stigma they receive from society should be their least concern.

In multiple interviews, mothers seem to want more for their children, but they are limited. Some parents desire more monetary support, a home, and/or better paying jobs. However, support services are usually granted if their income is not above a specific amount. Thus, lower income single parents will either have to sacrifice certain services to have a higher income, buy homes, and/or have sizable monetary assets. The study performed by Schilling, et al. (1986) documented these same results in which single mothers were not as happy about their families in terms of financial stability, living space, and job satisfaction.

Limitations

This research study had several limitations. A significant limitation was the cost and time required to complete the study. The researchers began the study with the intent to obtain participants through support groups. However, many phone calls were made to agencies across

the Southern California area about their support groups, and either phone numbers were disconnected, or they did not have single parent attendees. When the researchers did attend a support group, members were motivated to participate, but they did not return the questionnaires. For instance, 15 questionnaires with self-addressed stamped envelopes were handed out, and only three questionnaires were returned. The same attempt was made with public agencies to have their clients return questionnaires, but there was also a low response rate. Between two agencies, approximately 60 questionnaires and stamped envelopes were circulated. Yet, only 17 questionnaires were returned. According to Grinnell (1997) a low response rate should be expected when using questionnaires because it is not uncommon for a study using questionnaires to yield a 10 to 20 percent rate of return.

The most apparent limitation relates to the sample of eight interviews for the study. The study was exploratory and was expected to yield a small sample. But, since the sample was small, caution must be maintained in drawing conclusions and generalizing them

to the entire population of single parents raising a developmentally disabled child.

Another limitation to the study was related to a bias in the sample selection. Given that the mothers interviewed are receiving services, the information obtained only reflects the opinion and experiences of those already in the service system. The responses that were given regarding delivery of services were greatly influenced by the fact that the mothers already had knowledge and familiarity with social services. The essential element is to understand the experiences of single parents who receive services and those who do not.

This project may be difficult to replicate as well. The study utilized questionnaires to prevent time constraints among single parents; however, there were five pages to read and respond to: informed consent, demographics data for child and parent, open-ended questions, and debriefing statement. Many single parents have jobs outside the home, caregiving responsibilities for other children in the home beyond their disabled child, and they have time limitations. Therefore, to minimize limitations, a shorter questionnaire should have

been used to ensure greater participation of busy parents.

A weakness identified in this study was the inability to control for all variables while attempting to show a relationship between variables. For instance, follow up interviews showed a significant relationship between agency support services and a healthy family system. Yet, this may not be correct because internally, the family may have learned how to function in their appropriate roles over the course of four months. As well, externally, influences outside the family such as support from family, friends, or neighbors could have increased which led to a healthier functioning family. All variables in the study could not be controlled, but research was necessary to begin gathering data on single parents raising a developmentally disabled child.

Implications for Practice

Practitioners experience many challenges providing services to families, even more for those caring for a developmentally disabled child. It has become very hard to diagnose developmentally disabled children with the changes in theories and medical diagnosis. Practitioners

have to rely solely on a chart at times to diagnose clients. However, when providing services to single parent families, diagnosis must go beyond the child. Practitioners must assess the family's system and seek ways to alleviate the burden of not having at least two providers and caregivers in the home.

Practitioners must also be willing to evaluate the single parents entire family system and assess the role of each family member. Where the system is short, be willing to alleviate the gap through support services. This may not be always possible depending on funding, but they must assess and reassess to make sure the system is working. For instance, a mother prefers if services are received at one building because she lacks transportation. This being the case, support services should depend on the mother's ecological environment and ease of community support with helping to meet her child's needs.

In addition, intervention strategies must include finding ways parents can associate with parents with like disabilities. These parents research and knowledge about their child's disability can help another parent. If cross-referencing is not feasible, follow up with the

parent to see if they are involved in a support group. Some single parents are too busy to attend a support group. But, some are not. If they do not have an informal support system that can give them relief from caregiving responsibilities, then referral to a support group should be made. Not only are the parents learning more about their child's disability, they are also given the opportunity to get out and socialize.

Finally, when social service agencies deliver services to clients, they must remember to treat parents the way they would want to be treated. The parents have enough to deal with going home to cater to their child's needs. But, when they seek services, they are not to be treated like they are a number. Understandably, delivery of services to the public is overwhelming at times, but it is not the parent's fault. The more social services does up front, the less problem society will have with the increasing cases of child neglect and abuse.

CHAPTER FIVE

RECOMMENDATIONS AND CONCLUSIONS

Recommendations

Utilizing a quantitative and qualitative design to conduct the study proved to be beneficial in terms of gathering more information from single parents rearing a developmentally disabled child. The open-ended questions and interviews shed light on many aspects of what single parents encounter caring for their disabled children. However, possibly due to sample size, no significant factors were identified to that of married parents.

To enhance future research efforts, consideration should be given to using an agency in which participants are identified through case analysis. The clients should be contacted and the questionnaires completed in the office to alleviate lost questionnaires and/or return. This would possibly increase the sample size and enrich SPSS analysis of the QRS-F.

As well, research should seek to include single fathers with a disabled child in interviews. Two questionnaires received were single fathers, but they were not interviewed. However, their comments on the

questionnaires were important because the researchers understood them to have the same needs as single mothers.

Conclusions

In the past decade, the culture of our society has changed. More parents are caring for their disabled child solely, with minimal support from their family members. As these changes occur, more research on their stance about caring for their disabled child has been limited and this study hoped to add to the wealth of information about single parents raising a disabled child. Similar studies were conducted in which single parents were grouped together with married parents.

This study was exploratory and the sample size for interviews was eight single mothers. The sample size was small, but expected. The researchers recognized that single parents raising a disabled child may have different needs and those needs should be explored. For example, single parents have to solely respond to duties such as caregiving and decision making for their disabled child.

Tending to their disabled child's needs may be overwhelming if they are faced with dilemmas concerning

their child's health and welfare. Many single parents make sacrifices of themselves to ensure the emotional and physical needs of their disabled children. Key factors such as feeling lonely, needing more monetary support, and desiring support from their child's father are not as important as the attention they give to their child. Single parents with a developmentally disabled child may appear to be like other single parents caring for a nondisabled child. But, they are not.

This study did not identify any differences between married and single parents in terms of their stress caring for their disabled child besides needing a companion with whom to share caregiving responsibilities. As well, desiring a home versus apartment to raise their child in. But, meeting their needs with ample support services are needed.

Over the years more research will be tended to about single parents with disabled children. During that time, it is hoped that a larger sample size is captured and the results will make a significant change in the lives of developmentally disabled children with single parents.

APPENDIX A
INFORMED CONSENT

INFORMED CONSENT

The interview in which you are about to participate is designed to measure stress levels and supportive resources among single parents with a developmentally disabled child. The interview will assess the perspective of parents regarding raising a disabled child and the support services they receive. The project is being conducted by Marlena Graves and Tracy Schroeder and has been approved by the Department of Social Work Sub-Committee of the California State University San Bernardino Institutional Review Board.

In this interview you will be asked to respond to several questions about your feelings and your child that is developmentally disabled. Some of these questions might be sensitive and personal. The interview should take about 25 to 30 minutes. All of your responses will remain confidential. Your name will not be reported with your responses, but reported in-group form only.

Your participation in this interview is completely voluntary. You are free to withdraw at any time during the interview without penalty. Your decision to participate or not to participate in this study will not affect the services you receive. When you complete the interview you will receive a debriefing statement describing the study in more detail.

If you wish to talk to someone about issues raised in the interview, please contact your Regional Center, or contact our office for a referral at (909) 880-5560. If you have any questions about the study please do not hesitate to contact Dr. Nancy Mary at (909) 880-5560. The results of this study will be available as of June 2001, and you may contact your participating agency for the results.

By placing a check mark in the box below, I acknowledge that I have been informed of and understand:

1. The nature and purpose of this interview.
2. I freely consent to participate and may withdraw my participation without penalty.
3. My decision to participate or not to participate will not affect the services I receive.
4. I understand that no foreseeable long-range risk is involved in participation.
5. I acknowledge that I am at least 18 years of age.

Place a check mark here

Today's Date _____

APPENDIX B
DEBRIEFING STATEMENT

Debriefing Statement

The interview you have just completed was designed to measure resources and stress levels among parents of developmentally disabled children. The intent of this interview was to assess parents' stresses, their role as a parent to their family with a developmentally disabled child in the home, the parents' support system, and their satisfaction with the current efforts made by agency personnel to provide necessary services. Specifically, the goal is to identify what are the needs of single parents to increase empowerment and self-sufficiency.

Thank you for your participation in this interview. If you have any concerns, please feel free to contact Dr. Nancy Mary at (909) 880-5560. If you would like to obtain a copy of the group results of this study, please contact your participating agency for the results beginning June 2001.

APPENDIX C
SHORT FORM OF THE
QUESTIONNAIRE ON
RESOURCES AND
STRESS

Short Form of The Questionnaire on Resources and Stress

This questionnaire deals with your feelings about a disabled child in your family. There are many blanks on the questionnaire. Imagine the child's name filled in on each blank. Give your honest feelings and opinions. Please answer all of the questions, even if they do not seem to apply. If it is difficult to decide True (T) or False (F), answer in terms of what you or your family feel or do most of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False, even then. Please begin. Remember to answer all of the following questions.

- | | | |
|---|---|---|
| 1. _____ doesn't communicate with others of his/her age group. | T | F |
| 2. Other members of the family have to do without things because of _____. | T | F |
| 3. Our family agrees on important matters. | T | F |
| 4. I worry about what will happen to _____ when I can no longer take care of him/her. | T | F |
| 5. The constant demands for care for _____ limit growth and development of someone else in our family. | T | F |
| 6. _____ is limited in the kind of work he/she can do to make a living. | T | F |
| 7. I have accepted the fact that _____ might have to live out his/her life in some special setting (e.g., institution or group home). | T | F |
| 8. _____ can feed himself/herself. | T | F |
| 9. I have given up things I have really wanted to do in order to care for _____. | T | F |
| 10. _____ is able to fit into the family social group. | T | F |
| 11. Sometimes I avoid taking _____ out in public. | T | F |
| 12. In the future, our family's social life will suffer because of increased responsibilities and financial stress. | T | F |
| 13. It bothers me that _____ will always be this way. | T | F |
| 14. I feel tense whenever I take _____ out in the public. | T | F |
| 15. I can go visit with friends whenever I want. | T | F |
| 16. Taking _____ on vacation spoils pleasure for the whole family. | T | F |
| 17. _____ knows his/her own address. | T | F |
| 18. The family does as many things together now as we ever did. | T | F |
| 19. _____ is aware who he/she is. | T | F |
| 20. I get upset with the way my life is going. | T | F |
| 21. Sometimes I feel very embarrassed because of _____. | T | F |
| 22. _____ doesn't do as much as he/she should be able to do. | T | F |

- | | | |
|--|---|---|
| 23. It is difficult to communicate with _____ because he/she has difficulty understanding what is being said to him/her. | T | F |
| 24. There are many places where we can enjoy ourselves as a family when _____ comes along. | T | F |
| 25. _____ is over-protected. | T | F |
| 26. _____ is able to take part in sports and games. | T | F |
| 27. _____ has too much time on his/her hands. | T | F |
| 28. I am disappointed that _____ does not lead a normal life. | T | F |
| 29. Time drags for _____, especially free time. | T | F |
| 30. _____ can't pay attention for very long. | T | F |
| 31. It is easy for me to relax. | T | F |
| 32. I worry about what will be done with _____ when he/she gets older. | T | F |
| 33. I almost get too tired to enjoy myself. | T | F |
| 34. One of the things I appreciate about _____ is his/her confidence. | T | F |
| 35. There is a lot of anger and resentment in our family. | T | F |
| 36. _____ is able to go to the bathroom alone. | T | F |
| 37. _____ cannot remember what he/she says from one moment to the next. | T | F |
| 38. _____ can ride a bus. | T | F |
| 39. It is easy to communicate with _____. | T | F |
| 40. The constant demands to care for _____ limit my growth and development. | T | F |
| 41. _____ accepts himself/herself as a person. | T | F |
| 42. I feel sad when I think of _____. | T | F |
| 43. I often worry about what will happen to _____ when I no longer can take care of him/her. | T | F |
| 44. People can't understand what _____ tries to say. | T | F |
| 45. Caring for _____ puts a strain on me. | T | F |
| 46. Members of our family get to do the same kinds of things other families do. | T | F |
| 47. _____ will always be a problem to us. | T | F |
| 48. _____ is able to express his/her feelings to others. | T | F |
| 49. _____ has to use a bedpan or a diaper. | T | F |
| 50. I rarely feel blue. | T | F |
| 51. I am worried much of the time. | T | F |
| 52. _____ can walk without help. | T | F |

APPENDIX D
BACKGROUND INFORMATION
ON CHILD WITH
DEVELOPMENTAL
DISABILITY

Background Information on Child with Developmental Disability

1. What is his/her gender? 1. Male 2. Female

2. What is his/her age? _____

3. Does he/she have any siblings? 1. Yes 2. No

3. If Yes, what is their gender and ages?

4. What is the nature of your child's developmental disability?

1. Mental Retardation 2. Autism 3. Cerebral Palsy 4. Epilepsy 5. Other _____

Please answer the following questions. There is a blank piece a paper attached, if you need more room for additional comments.

There are two types of support: informal support, which consists of family, relatives, friends, and neighbors, and formal support, which consist of agencies, support groups, and other services.

1. Please prioritize the informal support from one to five. Number (1) will be the person whom gives you the most support and (5) is the least support. Place a (0) if the person is not involved or non-applicable.

- a) Father/mother of the child. _____ d) Other Relatives _____
b) Family _____ e) Friends _____
c) Family-in-laws _____ f) Neighbors _____
g) Other (specify) _____

2. Discuss the kind of informal support that is given by your number one and two choices above?

3. Please prioritize the formal support that you receive from one to eight. Number (1) will be the agency (or group) gives you the most support and (8) is the least support. Place a (0) if the agency (or group) is not involved.

- a) Regional Center _____
- b) Support Group _____
- c) Recreational Services _____
- d) SSI _____
- e) Medi-Cal _____
- f) Respite _____
- g) School _____
- h) Other (specify) _____

4. Discuss the kind of formal support given by your number one and two choices above?

5. What are your major barriers or challenges in raising a child with developmental disabilities?

6. If you could have one resource/service to give you additional support and to help eliminate stress in raising your child, what would it be?

Will you be willing to participant in an interview? Yes _____ No _____

If yes, Please provide your name and phone number.

Name _____

Phone Number _____

Additional Comments:

APPENDIX E
DEMOGRAPHIC INFORMATION

Demographic Information

Please circle your answer.

A. What is your gender? 1. Male 2. Female

B. What is your age? _____

C. What is your ethnicity?

1. White 2. African-American 3. Hispanic/Latino 4. Asian-American 5. Other ____

D. What is your marital status?

1. Married Parent 2. Single Parent (Never Married) 3. Separated Parent

4. Divorced Parent 5. Widowed Parent 6. Other _____

E. What is your highest level of education completed?

1. Less than high School 2. High School Graduate 3. Some College

4. College Graduate 5. Graduate or professional school

J. What is your estimated yearly income for last year?

1. Below 20,000 2. 20,001 to 30,000 3. 30,001 to 40,000

4. 40,001 to 50,000 5. 50,001 or more

K. Caregiving Responsibility

1. Sole caregiver
2. Shared caregiving, if so shared with _____

APPENDIX F
INTERVIEW QUESTIONS

Interview Questions

Name _____ Date _____

7. What is a typical day in your home like?

8. Do you feel that your day and needs are different from married couples raising a child with a development disability? If so, how?

9. Do you receive any support from community members? If so, what type of support do you receive?

10. Does your family receive any other type of support services?

11. What do you feel your family's needs are in caring for a disabled child?

12. What services are you not receiving that you feel that will benefit your child's life?

13. What is your suggestion on better ways to deliver services to single parents caring for a developmentally disabled child?

APPENDIX G
CHILDREN'S BACKGROUND
INFORMATION

Children's Background Information

Questionnaire #	Child's Gender	Child's Age	Disability
1	Female	1	Developmentally Delayed, Blind
2	Female	11 ½	Spina Bifida
3	Male	9	Developmentally Delayed
4	Female	21	Mental Retardation
5	Female	10	Agensis of Corpus Collusa
6	Female	17	Mental Retardation, Down Syndrome
7	Female	11	Mental Retardation
8	Female	11	Cerebral Palsy
9	Male	5	Down Syndrome
10	Female	7	Congenital Myopathy
11	Female	6	Mental Retardation
12	Female	5	Cerebral Palsy
13	Male	5	Autistic
14	Female	6	Cerebral Palsy
15	Female	10	Cerebral Palsy
16	Female	7	Autism
17	Female	17	Mental Retardation, Cerebral Palsy
18	Male	11	Cerebral Palsy
19	Female	14	Spina Bifida
20	Female	13	Muscular Atrophy

APPENDIX H
CODING SYSTEM

CODING SYSTEM

IDENTIFICATION	QUESTION	CATEGORY	COMMENTS
01	5	3	I am stressed being single.
No paternal support,	5	10	She's not normal.
below 20,000.	5	8	People stare at her.
	6	7	Multidisciplinary team.
	6	1	Respite care.
	8	3	Live by self-no help.
	8	3	Make decisions by myself.
	8	3	More stressed than married parent.
	13	1	Support group for mothers.
	13	1	Help with transportation to appointments.
02	5	6	Developmental changes such as puberty.
Paternal support	5	6	Mood swings.
Sometimes, church	5	6	Self-help skills are inconsistent.
support, below	9	1	Church meetings-members baby-sit.
20,000.	13	7	More education and research about disability.
03	5	6	He's getting heavier to carry, its dead weight.
No paternal support,	5	10	Not certain about his future.
Below 20,000.	8	3	No one to help make decisions.
	9	1	Food banks.
	9	1	Outreach-help pay for utilities.
	12	2	More monetary funds for child.
	12	4	Housing benefits.
	13	7	Don't treat parent like it's their fault.
04	5	8	She realizes she's different.
No paternal support,	5	8	People stare.
Above 50,000.	5	8	Ignorance of society.
	5	9	More age appropriate activities for disability.
	5	9	Programs during hours need them, after 3 pm.
	5	9	No childcare.
	5	6	Have more needs and less time to access them.
	6	9	Childcare.
	8	3	No one to share responsibilities and decisions with.
	10	1	Family lives too far away.
	11	9	Transitional housing, adult day care vs. adult home.
	11	5	Help with educating about her developmental changes.
	13	7	Flexibility of time for appointments, and visit programs.
	13	7	Sick time to use for daughter.
	13	7	Allow respite pay to in home relative.
05	5	10	Future unknown about development
No maternal support,	5	8	Society acceptance
above 50,000	5	5	Finding a balance of love and empathy vs discipline and direction.
	6	3	Companionship
06	5	10	Health and safety concerns.
Paternal and church	5	8	Ignorance of public.
support, 20-30,000.	6	2	Additional monetary funds.

IDENTIFICATION	QUESTION	CATEGORY	COMMENTS
	6	7	Qualified people for respite care.
	6	1	Peer group outings.
	7	6	Inconsistent with self-help.
	8	3	It's only me, a companion could help me.
	8	3	What I would give for five (5) minutes.
	9	1	Active in church, need help right over.
	11	2	Money.
	11	7	Qualified people to answer questions.
	11	9	Someone to babysit when she's sick, I have to leave to go get her equipment.
	13	7	Cross reference families with same disabilities.
	13	7	Stop overloading social workers so I keep the same one for awhile.
07	5	8	Other children are mean, they call her stupid, kids try to avoid her.
No paternal support,	5	9	Someone besides my mother to depend on for care.
Less than 20,000.	5	6	She's going through puberty and I need help learning to teach her how to put on sanitary napkins.
	5	2	I know my daughter and I will always have to live someone else because I can't afford housing.
	5	9	Missed promotions because I would have to be at work at 5 am and bus comes at 7:30 am.
	5	2	No money to pay a baby sitter.
	5	9	Don't trust anyone to care for my daughter besides my mother.
	6	9	Afterschool activities that drop off and pick up.
	7	6	Self-help inconsistent
	9	1	I don't go to church, too tired.
08	5	6	Not enough time to spend with my other children.
No paternal support,	5	1	More time to recharge.
below 20,000.	6	10	Worry about him.
	8	3	I get no relief, at least if his father could help.
	12	1	More respite to spend time with other children.
	13	7	Provide respite care for fathers to encourage them to spend time with their children.
09	5	6	Meeting his goals.
	6	1	Have sports activities for parents.
10	6	2	Money, I can't work because I have to care for my daughter.
17	5	1	The services we ask for is always "No".
	5	1	Have to appeal decisions to people who don't even know my daughter, too much red tape.
	6	9	Camp twice a year in June, I only get to rest seven (7) days out of 365 days.

Category Codes: 1) Support Services, 2) Monetary Support, 3) Companion Support, 4) Public Assistance, 5) Education, 6) Developmental/Disability, 7) Delivery of Services, 8) Social Acceptance, 9) Childcare/Activities, 10) Pessimism

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ASSIGNED RESPONSIBILITIES

Introduction

Marlena Graves and Tracy Schroeder

Literature Review

Marlena Graves and Tracy Schroeder

Methodology

Interviews

Marlena Graves

Statistical Analysis of Data

Tracy Schroeder

Procedures

Marlena Graves

Results

Marlena Graves and Tracy Schroeder

Discussion

Marlena Graves and Tracy Schroeder

Summary, Conclusions, and Recommendations

Marlena Graves and Tracy Schroeder