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FATHERS' LEVEL OF INVOLVEMENT IN THE LIVES

OF THEIR SPECIAL NEEDS CHILDREN

A Project

Presented to the

Faculty of

California State University,

San Bernardino

o _____

In Partial Fulfillment

. of the Requirements for the Degree

Master of Social Work

by

Lorraine Jimenez

June 2010

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June 2010

Approved by:



Date

Dr. Carolyn McAllister, Faculty Supervisor Social Work

Dr./Janet C. Chang, M.S.W. Research Coordinator

ABSTRACT

Although parents of developmentally disabled children have been examined in a number of studies, there is limited research on fathers of developmentally disabled children. This project reports the results of a study, which explored the level of father involvement in the upbringing of their special needs child. The results indicated the fathers who participated in this study were highly involved in the every day life of their special needs child. One of the limitations of this study included the small, homogenous sample of father participants, which was not representative of the population. Some of the recommendations as a result of this study include further research in this area in order to find representative data. In addition, professionals and parents may benefit from further studies such as this one in efforts to bridge the gaps between services offered to the special needs community and the impact this has on the families.

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ACKNOWLEDGMENTS

I deeply owe the accomplishment of this thesis to my field advisor, Dr. Carolyn McAllister whose enthusiasm, guidance, support, patience, and encouragement from the initial to the final stages of this project helped me to develop an understanding of the research process. I am grateful for the guidance and support of Dr. Rosemary McCaslin who helped me see this project was not as "big of a monster" as I had anticipated.

I also owe this achievement to David Gama for pushing me to pursue the masters program and keeping me company on the late nights, the "crisis" situations and helping me out with the tables. Henry Jimenez for keeping me grounded and motivating me when I needed it the most. Janet Mendez for your strength, honesty, unconditional love, support, and validation.

It is a pleasure to thank all those involved in this process and who have made this accomplishment possible; Enrique & Socorro Jimenez, Carmen Jimenez, Ray Liles DSW, Sjoekje Sasbone LCSW, Rachel Strydom LCSW, Linda Helsper LCSW, Danielle Buckland, Michael Sweitzer, Carlos LaMadrid, Marleni Gonzalez, Lupe Cruz, Mona Landeros, Olivia Anguiano, Victor Phipps, Jose Rodas, Rocio Mendoza

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Ma.Ed, Orfa Torres MPP, Alfredo Castaneda, the fathers of this study, the Wyley Center, Jacqueline Blanco, the CSUSB MSW class of 2010 cohort, friends and family and Tim Thelander. I could not have done it without all your support, guidance, help and most importantly your encouragement and humor!

DEDICATION

Esta tesis es dedicada a mis padres, Enrique y Socorro Jimenez. A mi mama por su apoyo incondicional y por inculcar en mi que todo en esta vida se puede, hechandole ganas, y mientras "no se me cierre el mundo". A mi papa por su apoyo y su guia que me ha permitido sobresalir y derrotar obstaculos que no se comparan con los obstaculos que ellos han vivido. Gracias a ustedes, sus esfuerzos, desveladas, y sacrificios que yo soy lo que soy ahora. Que dios me los bendiga siempre.

This thesis is also dedicated to all the fathers who choose to raise their children despite the hardships.

In addition, I dedicate this thesis to all those I have lost but continue to watch over me; abuelos Arturo y Soledad Martinez, abuelos Ramon y Carmen Jimenez, abuelos Jose y Amelia Cardenas.

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CHAPTER ONE

INTRODUCTION

The first chapter discusses the presenting problem regarding the level of father involvement in the upbringing of their special needs child. An explanation of why this topic is worth studying as well as the implications for social work practice and related fields will be addressed. The purpose of the study, needs, and issues will also be discussed, along with the social work implications rooted in studies such as this one. Social work roles in the family unit as well as on the macro level will be addressed.

Problem Statement

For most parents, raising children is filled with great moments, milestones and achievements as well as being highly stressful and overwhelming, especially if the upbringing involves a special needs child. The levels of stress involved in the upbringing of a developmentally disabled child are intense and can often times hinder the healthy growth and development of the family unit. While services geared towards the improvement of quality of care for the special needs individual have been and

continue to be developed, most of these services are a result of what professionals have observed when working with special needs families or from the mothers' perspective on what services are needed. The social work field and other related fields have continuously forgotten to take into account the fathers' perspective and his unique needs. This is evident in the limited resources available and offered, specifically for the fathers.

Most research regarding the impact the family experiences when given the news and diagnosis of their special needs child addresses the child or the mother, but rarely the needs or perspective of the fathers. Social workers and other researchers would benefit from studies addressing paternal needs and perspectives in order to develop services to better meet the needs of the entire family unit. Social workers would be better skilled and equipped to advocate for the family if the body of research included the fathers of the special needs child.

With a growing number of children diagnosed with special needs such as the diagnosis of autistic spectrum disorder (ASD), it is important for the social work field

and other related fields to acknowledge paternal needs at this point in time in order to help the family unit transition to the different stages of development in a healthy manner. Quinn (1999), found in Marsiglio (1995) that

if the school and child care centers welcome fathers, if the hospitals and doctors schedule appointments and present information for both parents, and if the workplace truly accommodates and encourages the schedule necessary for his involvement, the father will have a much higher likelihood of successfully managing each transition...The social policies affecting programs, services, health care access and education are part

of the context in which transitions occur. (p. 449) Even if services do exist such as, parent support groups, research shows the jargon and environment may intimidate the fathers resulting in their withdrawal from participating in the group or even benefiting from it (Quinn, 1999, p. 445).

Purpose of the Study

The aim of this study was to explore the level of father involvement in the upbringing of their special needs child. Although, there is research addressing the fathers' role with their special needs child, the research appears to be limited as it mostly focuses on the stress the couples often face when raising a developmentally disabled child. Most of the research is also limited due to the variations of the definition of a father. When the research does address fathers it mainly focuses on the lack of involvement they have with their typical child. Research specifically addressing the needs of fathers when it comes to the special needs child is limited and scarce. This study hopes to analyze whether previous findings are in fact accurate in determining whether or not fathers are less involved in the upbringing of their developmentally disabled child or if this is simply a common misconception and fathers are not receiving the credit for taking part in the upbringing of their special needs child. In addition, this study aims at encouraging further studies focusing on the needs of the fathers from the fathers' perspectives and identifying the social work implications of such

findings. Quinn, (1999) states; "encouraging paternal involvement in families of children with disabilities is congruent with social work values of focusing on strengths and supporting client participation" (p. 440).

The knowledge social workers gain from studies such as this one, will allow families of special needs children, service providers, medical personnel, teachers law enforcement and other professionals to learn about the level of father involvement as well as determine what types of other studies are needed in order to assess the needs of the fathers. This may lead to appropriate services and supports for the often-ignored parental figure-the father. Resources, father support groups, and other services addressing paternal needs as well as further research may be a direct result of studies such as this one. The mental health field, medical professionals, social service agencies working with the special needs population, teachers, law enforcement, students and other members of society may also be interested in learning more about what implications of living with a developmentally disabled individual involve, in order to continue to work towards identifying needed services and supports for such families,

specifically for fathers. It is important to identify the existing gaps by collecting data in order to help minimize this gap and develop future services that do meet the needs of the father so fathers will want to be directly involved in the upbringing of their special needs child and their family. This study entails a questionnaire specifically asking the fathers to identify the level and types of involvement they have with their special needs child.

Significance of the Project for Social Work Studies such as this one are necessary for the sake of healthy family development for the special needs population. The more social workers are aware of the "forgotten parent's" needs, the more likely the social worker will be a better advocate and will be better able to meet and consider the needs of the entire family, not just the needs of the special needs child and/or the mother. Social workers would also be better equipped when negotiating services with outside entities and identifying needed services. In addition, social workers would learn how to develop and tailor existing services to match the specific needs of the father. If studies

such as this one continue to explore the paternal role in the lives of their special needs child, social workers would be able to provide further education for the fathers and families about the diagnosis, how to navigate the system for services and supports, developing coping strategies, ways to manage time and stress as well as educating the families on ways to adapt to their new life and transitions.

Hartley, Ojwang, Baguwemu, Ddamulira, and Chavuta (2004) found in Porter and Mckenzie (2000) "...the way families respond to and cope with disability depends on four issues, internal and external resources...External resources include support from the extended family and community and government programmes" (p. 169). Part of social work roles include advocating and participating in policy changing strategies. Trute (1990) suggests; "the strengthening of the parental subsystem should be a primary concern to those professionals who wish to assist the family to maintain a stable and nurturing home environment for their disabled child" (p. 296). In order to obtain a clear understanding of the needs of the family with a special needs child, it is important to consider what the paternal role is and their level of

involvement in the upbringing of their developmentally disabled child.

CHAPTER TWO

LITERATURE REVIEW

Introduction

Chapter two focuses on a critical review of previous literature addressing the paternal role of the special needs child. This section identified conflicting findings, methods used, and theoretical perspectives guiding the research. The literature review also identified the need for further studies in this specific area as the current body of research seems to be limited and special needs fathers continue to lack adequate professional supports and resources. This study builds on previous research as well as helps expand the information for future research studies to include fathers of special needs children when assessing quality and availability of services and the needs of the family.

Developmental Disabilities and Father Involvement

Several studies attempt to define the terms: developmental disability and father involvement in efforts to have a consistent framework. Hughes and Rycus (1999) define the meaning of developmental disability as

chronic and severe conditions; that the disabling condition must occur before the age of 22; that it is caused by a mental or physical impairment; that it may last a long time; and that it makes it difficult to engage in one or more basic life activities. (p. 317)

Quinn, (1999) found in Pleck (1997), "the three components of father involvement include engagement, accessibility, and responsibility for care of the child...". Quinn, (1999) also found in Pleck (1997) his, "proposed four-factor model for contributing factors of father involvement: motivation, skills and self-confidence, social supports, and institutional practices" (p. 440). This study relied on the above definitions when exploring the level of father involvement in the upbringing of their developmentally disabled child.

There is a large body of research analyzing the gender roles and differences between the parental roles and caretaking responsibilities of mothers and fathers (Levy-Shiff, 1999, p. 55). However, the results of these studies tend to primarily end up addressing the needs of the mothers, often times neglecting the fathers' views

and opinions about their level of involvement in the lives of their special needs child. Studies addressing the level of paternal involvement in the upbringing of their special needs child are rare and the information we do have has been from the maternal perspective (Kersh, Hedvat, Hauser-Cram, and Warfield, 2006; Levy-Shiff, 1999; Quinn, 1999).

The research that does exist mainly focuses on the parental stress experienced by the parents of special needs children as compared to the parental stress of those with typical children. Numerous studies have found parents of the special needs population experience approximately the same stress as families without special needs when it comes to the parental duties (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). The few studies that have addressed and considered the paternal perspective have found fathers value and often rely on social and external supports to help them cope with their special needs child and for their adjustment to their new life (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Levy-Shiff, 1999). However, research has also shown the strong influence societal stereotypes and the common beliefs of traditional gender roles play in the level of

father involvement in the upbringing of their special needs child. Trute (1990) found in Darling, 1979 and Kazak, 1986;

...family instability is often seen as inevitable consequences of having a developmentally disabled child in the family. Although this negative stereotype is widely held by human service professionals serving disabled children and their families, research evidence in this regard is inconclusive. (p. 292)

inconcracive. (p. 202)

Societal stereotypes and traditional gender roles may be one of the contributing factors for the perceived low paternal involvement as compared to maternal involvement.

Some studies suggest fathers are often "indirectly involved" and mainly serve as a source of support for their wife, focusing on decision making regarding services and financial planning and are less involved in things such as changing diapers and functions of the child's daily living (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Levy-Shiff, 1999; Trute, 1990). Other studies suggest the parents' educational level will affect the way in which families are able to cope and adjust with the special needs, seek services and follow

through with identifying services and therapies. Trute (1990) found "when paternal education is then added...higher educational levels predict heightened overall family functioning" (p. 295). Data indicating educational levels predict family functioning may suggest social workers role is to continue to educate parents in areas such as, learning about their child's diagnosis, navigating the system to obtain adequate services and 'encouraging parents to participate in support groups, among other related fields.

Father's Perceptions on Societal/Gender Roles and Expectations

While there is growing research addressing the special needs population, one important element of the family that seems to often get overlooked is the father's role in the upbringing of the special needs child. The limited body of research conducted that addressing the paternal role has concluded some of the barriers for father involvement are directly a result of societal roles and expectations. This includes the fathers' own upbringing, their lack of exposure to caring for babies or siblings, the influence of gender roles and their pressure to secure financial stability (Quinn, 1999;

Trute, 1990). Fathers who have participated in previous studies have reported the shared activities they had with their special needs child resulted in them feeling emotionally connected and having increased sensitivity to the needs of their child as well as recognizing their type of involvement included playing, discipline, nurturing and making decisions on services (Quinn, 1999; Simmerman & Blacher, 2001).

In addition, studies have found a correlation between the father's marital relationship and father-child relationship; "fathers who were involved in cohesive marital relationships were also involved in cohesive father-child relationships. Conversely, fathers who were disengaged from their wives were likely to be disengaged from their children as well" (Martin & Cole, 1993, p. 192). The field of research and social workers should take into account the fathers' perceptions when assessing the needs of the special needs family as well as consider what current social supports look like and aim at developing further social supports for the fathers.

Social Supports for Fathers

Studies on parent involvement have focused on the parents' belief in their ability to fulfill parenting roles (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006, p. 884). However, data suggest fathers often times feel excluded, confused, and insecure about their ability to raise a special needs child. Fathers often times get information second-hand and feel "like idiots" when they do join medical or educational meetings (Ramaglio, Romeo, Viri, Lodi, Sacchi, & Cioffi, 2007, p. 23). Previous studies involving father's perceptions indicate fathers believe they are often ignored by professionals, have a difficult time meeting with professionals alone, do not feel strong, rather they feel vulnerable and just a "spare part", (Ramaglio et al., 2007; Quinn, 1999). The lack of services tailored to the specific needs of the fathers discourages their involvement as fathers continue to feel excluded and "intimidated by the jargon and the atmosphere" (Quinn, 1999, p. 445).

Other findings have confirmed fathers of special needs children display high parental stress "related to incompetence, which was also strongly negatively related to their overall life satisfaction" (Deilve, Samuelsson,

Tallborn, Fasth, & Hallberg, 2005, p. 399). However, conflicting research has found fathers evaluated parenting as less stressful as compared to mothers, are less directly involved in the parenting role and mainly serve as "gatekeepers" controlling and making the decisions about services (Hartley, Ojwang, Baguwemu, Ddamulira, & Chuvuta, 2004; Levy-Shiff, 1999; Ramaglia, Romeo, Viri, Lodi, Sacchi, & Cioffi, 2007). On the other hand, Kersh, Hedvat, Hauser-Cram, and Warfield (2006), found in Hadadian and Merbler (1995), Lillie (1993), and May (1996) that "many fathers want greater involvement with their children with special needs but they may feel like outsiders, even when included in intervention efforts" (p. 890). The purpose of this study is to shed light on the level of paternal involvement in the upbringing of their special needs child from the fathers' perspectives. The following addresses the theories applied in previous research and the theories used for the purpose of this study.

Theories Guiding Conceptualization The literature review had limited information regarding the theories applied to the studies, however,

some of the theories discussed included "Kazak and Christakis' (1994) systems and social-ecological model, which is a synthesis of family systems theory, and Bronfenbrenner's (1979) model of the ecology of human development" (O'Brien, 2001, p. 14). The rationale for using the social ecological model in assessing family experiences with special needs children is due to the "microsystem of the family, whereas the category of negotiating with outside entities relates primarily to the ecosystem" (O'Brien, 2001, p. 17). O'Brien suggests families with special needs children try to make sense of their lives, change their priorities, manage daily life and work towards maintaining a functioning family system (p. 17). The theory guiding this study is Bowen's family systems theory (1950s) as it considers the thoughts and feelings of each family member and the larger system of family relationships that shapes the life of the family (Trivette, Dunst & Hamby, 2010). Family systems theory suggests individuals cannot be understood in isolation from one another, but rather as part of their family, as the family is an emotional unit (Trivette, Dunst & Hamby, 2010). In this case, although, fathers will be the main focus, it is important the entire family unit be

considered as each individual affects each other's interactions and perceptions. Research shows social support is correlated with marital satisfaction, which also leads to parents' overall satisfaction of their family unit (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006, p. 889).

Summary

The literature review has defined the meaning of what constitutes a developmental disability and father involvement in order to have a common framework. This chapter has also discussed the limited research addressing the fathers of special needs children, the societal expectations and gender roles influencing paternal involvement and the fathers' own perceptions regarding social supports, services and professionals. Research also indicated conflicting results regarding paternal stress and paternal involvement. The chapter concludes with a discussion of the theories guiding previous and current research with a specific focus on the family systems theory.

CHAPTER THREE

METHODS

Introduction

Chapter Three will address the study design with an overview of the specific purpose of this study. Research methods will be discussed as well as practical methodological implications and limitations of the study. In addition, the sample from which data is obtained, the selection criteria and the instrument used to gather and measure the data will be addressed. Finally, the procedures and logistics, the protection of human subjects used in this study and data analysis will be addressed.

Study Design

The specific focus of this study was to explore the level of father involvement in the childrearing of their special needs child. The research design used to explore this issue was a questionnaire using a purposive sample of families. Galvan (2004) defines a purposive samples as "sample of individuals who are selected on purpose based on the careful judgment of the researchers regarding what types of individuals would be specially good sources of

data for a particular research topic" (p. 57). The rationale for using this approach is the need for the fathers who are surveyed to have a special needs child in order to specifically address and meet the focus of this study, which is to explore the level of father involvement in the upbringing of their developmentally disabled child.

The research design includes a questionnaire developed by Dawson and Chitty, (personal communication, March 5, 2009) for a self-help style-book they plan to develop for parents who have a child with an additional need. Their survey's main focus was to address the impact a special needs child has on the couple and surveyed both mothers and fathers. The information borrowed from their survey for the purpose of this study included demographics, relationship status, the child's diagnosis, the needs of the child, behavioral concerns, father's perceptions of professionals in the field, finances and social supports.

Dawson and Chitty's survey was modified and tailored to fit this study. The modified survey allowed this study to also focus and include the following additional areas; the level of education and employment status. The

modified survey specifically targets the type of involvement the father has with his child as well as explored the types of supports fathers would like to have offered that are specifically tailored for paternal needs and interests.

The main limitation of this study is the specific focus on the fathers and their perspectives. This study is only addressing the father and his perceptions of his level of involvement, the type of involvement, his specific needs influencing that involvement and his expectations from professionals, services and supports. Other limitations included the low turn out of fathers to parent support groups and the limited resources to reach out to the fathers who do not attend parent support groups. This study was also conducted in one language, English, which limited the participation size. The focus of this project is to explore the level of father involvement in the upbringing of their special needs child.

Sampling

The sample from which data was obtained was from a parent support group in the Inland Empire. The

participants were selected based on geographic location and willingness of the parent support group to participate in this study. Due to the small father turn out to parent support groups, the data was gathered from The Wiley Center parent support group via online questionnaire. The questionnaire was sent to the parent support group coordinator via electronic mail (email), who then disseminated the questionnaire to the support group participants.

The selection criteria were automatically determined via the decision to gather data from parent support groups. The fathers included in this study were asked to participate on a voluntary basis. Upon selecting the sample of fathers, the data was obtained through a confidential and anonymous questionnaire. The questionnaires were returned completed by the fathers via electronic mail (email), faxed or through the main contact from the Wiley Center parent support group. Due to the expected and reported (from support group facilitators) low turn out, the total number of participants was 17 fathers with special needs children. The rationale supporting the decision to approach fathers is due to the nature of this study and its purpose to

explore the fathers' level of involvement in the upbringing of their special needs child, as well as to focus on the fathers since little research has been done with this population.

Data Collection and Instruments

The level of father involvement is the dependent variable. It is the level that this study aims at answering. What is the fathers' level of involvement in the upbringing of their special needs child? The dependent variable shaped the study in exploring the level of involvement. The reason for that level of involvement (why the father demonstrates that level of involvement) is the independent variable. The result will help guide the social work implications of such findings.

Defining the level of involvement includes looking at the father-child interaction and whether or not the fathers spent time playing with their special needs child, as well as, whether or not the fathers help with the daily living needs of changing diapers, administering medications, feeding, etc. The questionnaire developed measured the level of involvement from the father's perspectives. The questions comprised of the above

factors (i.e. caretaker/nurturer, teacher, role model, making decisions about child rearing, amount of time devoted to fathering, etc) with the option of ranking some of the questions: yes, no, sometimes, choose not to answer. There are a total of thirty-six questions aiming at measuring level of paternal involvement in the questionnaire (Appendix A). Out of those thirty-six, ten questions are specifically measuring the type of father-child interactions.

The independent variables may include the child's specific diagnosis and the types of behaviors that may accompany it. Parents will be asked to identify the diagnosis as well as whether or not their child presents with behavioral challenges (nominal measurement). Another independent variable may be the fathers' educational background. If a gap in the fathers' knowledge exists between typical child development and child behavior deficits in a special needs child, the father's level of involvement may be affected (Quinn, 1999). Paternal involvement may also be influenced by the fathers' acceptance of their child's condition (yes or no/nominal measurement).

Procedures

The initial step was to contact potential support groups in the Inland Empire Area and introduce the study's purpose and goals in order to solicit father volunteers. The data collection was gathered via online questionnaires (emailed to the support group coordinator at the Wiley Center). Some of the fathers chose to return the questionnaires via fax, others mailed them via standard mail, while the majority emailed them back to their parent support group coordinator who forwarded the questionnaires to the researcher. The allotted time to complete the questionnaires was one-two months. All information remained confidential and anonymous.

Protection of Human Subjects

In efforts to protect the individuals who participate in this study, an informed consent (Appendix B) and debriefing statement (Appendix C) were provided to each father prior to their participation. The fathers were informed their participation was on a voluntary basis. Fathers were asked to take the questionnaire home to complete (once they agreed to participate in the study) and return within the next one-two months.

Participants were given the choice to send the questionnaires via email, standard mail or fax.

Data Analysis

This study is both qualitative and quantitative in nature. For the qualitative data, a constant qualitative analysis (Boeije, 2002) was used for the open-ended questions. Patterns and themes were identified by comparing all the open-ended responses. In addition, descriptive statistics including, frequencies and ANOVAs were done on several of the research questions to examine the data (Grinell & Unrau, 2008).

Summary

Chapter three covered the study design, sampling, data collection and instruments used as well as the specifics of how the data was gathered. It also discussed the protection of human subjects and how confidentiality was maintained as well as the data analysis describing the quantitative and qualitative procedures that were used to explore the research question, What is the level of father involvement in the life of their special needs child?

CHAPTER FOUR

RESULTS

Introduction

This study explored the fathers' perspectives of their type of involvement in the upbringing of their special needs child. There were a total of seventeen participants from the Inland Empire who belonged to local parent support groups with fourteen of the participants belonging to the Wiley Center parent support group and the other three participants were from the Inland Empire community who received the questionnaire via email from the Wiley Center support group members. The seventeen participants were asked to describe their level of involvement in the every day activities of their special needs child as well as to identify any additional services that would help meet their family's needs, specifically the father's needs. Chapter Four will describe the demographics of the participants as well as illustrate the quantitative and qualitative data this study gathered. The gualitative data was guided by the following questions on the survey: Have your relationships with friends changed from being a parent of

a special needs child? Are your friends and/or extended family supportive of your situation? Provide examples of when professionals did or did not understand your needs, What types of supports/services/activities would you like to have offered that are specifically tailored to father's needs and interests? How have your finances been affected by having your special needs child? Have you found additional financial pressures due to your child's needs? In this chapter the results of the study will be presented.

Demographics

This study included seventeen males who are the fathers of a special needs child. All seventeen participants were over the age of eighteen. The ages of the fathers ranged from 22 to over 60. The three primary languages reported by the participants included English (60%), Spanish (10%), and Arabic (5%) and 25% of the participants chose not to answer this question. The ethnicity of the fathers included White (35%), African-American (5%), Latino/Chicano/Mexican/Hispanic (30%), Asian Pacific Islander (10%), Other (5%), and 15% chose not to answer. The level of education ranged from

high school graduates to professional degrees. Ten percent of the fathers were high school graduates, 15% had some college education, 15% had a two year college degree, 25% had a four year college degree, 5% had a masters level degree, 10% had a doctoral degree, and 5% had a professional degree with 15% choosing not to answer. Eighty percent of the fathers reported being employed, 5% were unemployed, and 15% did not answer. Of those fathers who were employed, 30% reported working 31-40 hours per week, and 50% reported working more than 40 hours per week. The annual income level of the fathers ranged from \$20,000 to \$100,000 or higher with 25% of the fathers choosing not to answer. With regards to the father's marital status, 85% percent reported being married to the mother of their special needs child, 15% chose not to answer, but all reported living or still being in a relationship with the mother of their special needs child (refer to Table 1. Demographics for an illustration of the above information).

Category	Response	Percent
Language		
	English	60%
	Spanish	10%
	Arabic	5%
	No Answer	25%
Age		
	22-29	5%
	30-39	15%
	40-49	40%
	50-59	20%
	Over 60	5%
	No Answer	15%
Ethnicity		
	White	35%
	African American	5%
	Latino/Chicano/Mexican/Hispanic	30%
	Asian Pacific Islander	10%
	Other	5%
	No Answer	15%
Level of Education		
	High School/GED	10%
	Some College	15%
	2 Year College Degree	15%
	4 Year College Degree	25%
	Masters Degree	5%
	Doctoral	10%
	Professional	.5%
	No Answer	15%
Currently Employed		
	Yes	80%
	No	5%
	No Answer	15%
Number of Hours		
Worked Per Week	31-40 Hours	30%
	More than 40	50%
	Not Currently Working	5%
	No Answer	15%

Table 1. Demographics

Category	Response	Percent
Income Per Year	· · · · · · · · · · · · · · · · · · ·	-
	20,000-29,999	10%
	30,000-39,999	10%
	40,000-49,999	5%
	50,000-59,999	10%
	60,000-69,999	10%
	70,000-79,999	5%
	90,000-99,999	5%
	100,000 or Higher	20%
	No Answer	25%
Marital Status		
	Married	85%
	No Answer	15%
Child's Diagnosis	·	
	Autism	70%
	Down Syndrome	6%
•	Lissencephaly	6%
	Fragile X Syndrome	6%
	Mental Retardation	6%
	Deletion of long arm of #1 Chromosome Q43 Q44	68

Presentation of the Findings

Based on the qualitative questions of the survey, there were five common themes amongst the fathers that emerged. These included relationships, professionals, desired supports, finances, and insurance coverage. The qualitative questions were used to obtain the fathers' perspectives on the above five subjects in order to explore whether or not these affected their level of involvement in the activities of everyday living of their

special needs child. These five subjects are illustrated in tables 2 through 6 and represent the perspectives of the fathers.

Table 2. Relationships

Types of relationships	Number of fathers
Making & maintaining <u>new</u> friendships have been negatively impacted as a result of my special needs child	7
Family and friends they had <u>prior</u> to their child being born have continued to remain supportive of their new family needs	14
Family and friends distancing themselves after the birth of their special needs child	2

In Table 2. Relationships, seven fathers reported the needs of their developmentally delayed child had negatively impacted their ability to make and maintain new friendships. This response implies the fathers not only have a difficult time making new friendships but their circle of support is limited. For 14 fathers, their circle of support appears to include the family and friends they had prior to the birth of their special needs child, while two fathers reported losing family and

friends after the birth of their developmentally delayed child.

Table 3. Professionals

Problems with professionals	Number of fathers
School or their child's doctor ignored their questions and/or suggestions for services	6
Parents were denied additional services from the school district to meet their child's special needs	14
Their doctor did not understand the needs of their special needs child and accused them of "bad parenting"	3
Doctors using terms too difficult to understand, mislabeling their child & forcing the parents to seek their own knowledge on the disability instead of educating the parents	8

The second common theme found among the fathers' responses is illustrated in Table 3. Professionals, where six of the fathers reported their child's school and/or doctor ignored their questions and/or suggestions for needed services, 14 fathers were denied additional services to meet their child's needs from the school district, three fathers reported their child's doctor did not understand their child's condition and accused them

of "bad parenting", while eight fathers disclosed the terms the doctors often use are too difficult for them to understand, their doctors had mislabeled their child, did not take the time to educate the parents on the actual disability and resulted in the fathers feeling forced to seek their own knowledge on their child's disability.

Table 4. Desired Supports

Types of desired supports	Number of fathers
Support classes/groups specifically tailored to the needs of the fathers	5
Behavior modification classes that accommodate to the working schedule of the father	2
Sibling support in order for the entire family to learn about their loved one's needs	1
Respite to be able to spend time with their wife and time alone	2
Vocational training & education for their special needs child to prepare them to adulthood	7
Educational workshops tailored to working fathers	3

One of the aims of this study was to identify the types of services fathers of special needs children felt

they needed. In Table 4. Desired Supports, five fathers desire parent support groups specifically tailored to the needs of the fathers, two fathers would like behavior modification classes that accommodate to the working schedules of the fathers, one father would like access to sibling support in order for his entire family to learn about their loved one's special needs, two would like respite in order to spend time with their wife and take a break from their child's care, seven would like vocational training programs for their special needs child in efforts to prepare them for meaningful activity when they become adults and three fathers would like educational workshops tailored to working fathers.

Table 5. Finances

Extra expenses due to the needs of their developmentally delayed child	Number of fathers	
Finances have been affected by their special needs child	13	
Out of pocket costs include conferences, buying supplements, special foods, private evaluations, dental services, doctor visits and speech therapies	17	

Parents of developmentally delayed children tend to have additional costs as compared to parents of typical children due to their child's special needs. In Table 5. Finances, 13 fathers reported their finances have been affected due to their special needs child, while all 17 fathers reported additional out of pocket expenses in attending conferences to educate themselves in the condition of their child, buying supplements due to dietary restrictions, buying special foods, paying for private evaluations, paying for dental services, doctor visits and therapies such as, speech pathology.

Table	6.	Insurance	Coverage
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Types of services not covered through insurances	Number of fathers
Therapies; occupational, physical	7
Vitamin supplements	1
Holistic medicine	2
Dental services (i.e. general anesthesia for their child)	12
Multiple surgeries & doctor visits add to co-payments	2
Special diets and/or foods	9
Some medications not covered	4

Along with fathers reporting additional out of pocket expenses, Table 6. Insurance Coverage, illustrates the final common theme found among the fathers. Seven fathers reported their private insurance did not cover therapies such as occupational or physical therapy, one father reported his insurance did not fund for vitamin supplements, two fathers indicated their insurance does not fund for holistic medicine practices, 12 fathers reported their insurance does not cover general anesthesia for dental care of their special needs child, two fathers reported multiple surgeries and the numerous doctor visits result in additional co-payments, nine fathers indicated their insurance does not cover special diets and/or food supplements, while four fathers reported some medications are not covered through their private insurance.

In addition to obtaining the answers to the open-ended questions and learning about the experiences these 17 fathers have shared, this study also explored the type of involvement they have with their special needs child. The following table (Table. 7) illustrates the specific areas of everyday living activities. These areas include father involvement in being a part of

financial decisions regarding their child's care, scheduling, transporting and following up with medical appointments, their direct involvement in participating in therapy services (i.e. behavioral modification services, participating in Individualized Educational Plans, etc.), changing diapers, feeding, dressing, bathing their child, administering medications, helping their child with homework, playing with their child outdoors and/or indoors, taking their child to family events, recreational activities/social gatherings and the amount of leisure time fathers spend with their child were explored.

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Table 7. Level of Father Involvement

Daily living activity	Number of fathers involved	Percentage
Financial decisions relating to services, equipment, therapies, etc.	14	82%
Scheduling, transporting, medical appointments or therapy sessions	14	82%
Direct services: speech therapy, behavior modification services, IEPs, etc.	1.4	82%
Administer medications	9	53%
Changing diapers	14	82%
Help feed, dress & bathe their child on a regular basis	13	77%
Help with homework	11	65%
Play indoor and/or outdoors with their child	15	88%
Participate in family events, social / recreational activities	15	88%
Average time spent watching		
Τ.V.	> 1 hr. per week: 4	248
	1-2 hrs. per week: 10	59%
	3-4 hrs. per week: 3	17%

Table 7 shows 82% of fathers are part of the financial decisions made in relation to their child's special needs such as, equipment and therapies, as well

as scheduling, transporting and following up with medical appointments or therapy sessions and are part of participating in direct services such as, speech therapy, behavior modification services and individualized education planning team meetings (IEPs). 53% are involved in administering daily medications, 82% change their child's diapers, 77% help feed, dress and bathe their child, 65% help their child with homework, 88% play with their child either, indoors and/or outdoors, as well as, have their child participate in family events and social and recreational activities, 24% of the fathers spend less than one hour per week watching television with their child, 59% spend 1-2 hours per week and 17% of the fathers spend 3-4 hours per week watching television with their developmentally delayed child.

The following research questions were tested utilizing the ANOVA test in efforts to identify if there were any significant correlations between the level of father involvement and the following variables; amount of work, level of education, social economic status, age of the father, maladaptive behaviors and, diagnosis of their child. After analyzing the quantitative data, this study

found no significant correlations between these variables.

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Summary

Chapter four discussed the data results, the demographics of this study's participants, the answers to the questionnaire on both the qualitative and quantitative data and finally the significant correlation findings identified in this study. The following and final chapter is a discussion of the data found.

CHAPTER FIVE

DISCUSSION

Introduction

The following will be a discussion of some of the challenges experienced throughout the course of the study as well as the limitations of this study, recommendations for social work practice, policy and research and finally, a conclusion of this study.

Discussion

The aim of this study was to explore the level of father involvement in the life of his special needs child from the fathers' perspective. The results of this study outline a few common themes among the fathers that would otherwise not be considered if the fathers had not brought to our attention since there is a limited amount of research in this area obtained from the fathers directly. One of the common threads found among these participants is feeling pressured to keep a job and work fulltime in order to be able to provide for the additional expenses typical fathers do not otherwise have. For example, the costs of dental services, therapies, private evaluations, attending conferences in

efforts to educate themselves on their child's disability and special needs, etc. The participants of this study reported wanting to spend more time with their families, however, due to the financial burden of having a developmentally delayed child, these fathers feel they are forced to work and as a result, spend less time in the childrearing of their child. One father stated; "I feel I need to provide for my family which gives me a little pressure that I should always have a job", (participant two, personal interview, August, 2009). Another father stated; "With SSI decreasing it has had a great impact on my finances as I am the only bread winner with a sick wife too", (participant eleven, personal interview, August, 2009). Therapies are often needed in order for the developmentally delayed child to gain functional skills. One father shares his thoughts;

therapies not covered by school or insurance and the special diet costs me an arm and a leg. Vitamin supplements to keep him off of drugs are not reimbursed by anyone and I have guardianship to protect him and that's a financial hardship too. (participant eight, personal interview, August, 2009).

Along with therapies, another common additional expense fathers of special needs face are the dental costs. Many children with conditions such as Autism have a difficult time sitting on a dentists chair for dental check ups, often times these children tend to display emotional outbursts or temper tantrums requiring general anesthesia for dental care. One father reported;

I think at this point in my child's development, the main challenge is dentistry. That is very expensive, but again it is something that needs to be done, I just need to get the extra money doing other jobs on the side, meanwhile I still drive my beat up Nissan. The last anesthesia cost me \$800. (participant three, personal interview, August, 2009)

This study did not identify any significant correlations, however, it did gather important and useful information for not only the special needs community, but for professionals as well. Part of why this study may not have found significant correlations in the types of variables affecting father involvement is that the number of participants was low and the parent variation was limited resulting in a homogenous sample. This sample involved highly involved fathers as evidenced by both

their level of involvement and their willingness to volunteer in this study. The fathers in this study are much more involved in the life of their special needs child than anticipated at the initiation of this study. These are significant findings that may counter societal misconceptions and previous research findings of fathers being under involved, particularly within the special needs population.

This study raises a few guestions stemming from the demographics of the sample. For example, all of the participants had a minimum of a high school diploma, suggesting fathers without a high school diploma are less likely to participate in studies such as this one or become members of parent support groups. This study also resulted in all 17 of the fathers still in a relationship with their special needs' child's mother, also raising the question of the reasons why single fathers may not be part of support groups, or may not be reached out to by professionals nor seek help or support on their own. Out of the 17 fathers, 71% reported their child had a condition of Autism, while the rest of the participants' special needs child varied in developmental disability. The developmental disabilities included in this study

were; 71% Autism, 6% Down Syndrome, 6% Lissencephaly, 6% Fragile X Syndrome, 6% Mental Retardation, and 6% Deletion of long arm of #1 chromosome Q43 Q44, (please refer to Table 1 Demographics for an illustration). Despite most of the children in this study having Autism, this exploratory study did not find a significant relationship between father involvement and the type of disability their child was born with. Based on this researcher's professional background with the special needs community, the original hypothesis was that the fathers of children with Autism would have less involvement in the life of their child due to challenging maladaptive behaviors people with Autism often display, coupled with the time restraints fathers often are faced with due to employment circumstances. However, this study indicates the level of father involvement remained consistent among the different disabilities. There was also no significance in the level of father involvement and the type or amount of work they do, no significance in the level of father involvement and the level of education, socio-economic status or age of the fathers. This study does, however, outline the concerns of the fathers and the reasons for their type and level of

involvement with their special needs child and hopes to shed light on the needs of the fathers for professionals to help bridge the gap between services and fathers' participation in the life of his developmentally disabled child. Some studies suggest fathers are often 'indirectly involved' and mainly serve as a source of support for their wife, focusing on decision making regarding services and financial planning and are less involved in things such as changing diapers and functions of the child's daily living (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2005; Levy-Shiff, 1999; Trute, 1990). This is inconsistent with the results found in this study. Fathers in this study are directly involved and not only serve as a support for their wife but also change diapers, administer medications, attend Individualized Education Plans (IEP), help with homework and play with their child. Other studies suggest the parents' educational level will affect the way in which families are able to cope and adjust with the special needs, seek services and follow through with identifying services and therapies. Trute (1990) found, "when paternal education is then added...higher educational levels predict heightened overall family functioning"

(p. 295). This is consistent with my findings. All participants had at least a high school diploma with 25% of the fathers holding a bachelors' degree, 5% a masters degree, 10% a doctoral degree and 5% a professional degree. In addition, there is a correlation between the father's marital relationship and father-child relationship, indicating those fathers who have healthy marriages tend to also have healthy and involved lifestyles with their developmentally delayed child as evidenced by 85% of the fathers in this study being married and reporting a healthy relationship with their spouse and are also actively involved with the caretaking of their special needs child.

Limitations

One of the main limitations of this study was recruiting the fathers to participate in the study. There were approximately 10 different parent support groups in the Inland Empire that were approached for possible participation, but the common response from the parent support group coordinators was that either they had "very few fathers that come" or "we don't have any fathers coming to our meetings". In the process of looking for

participants, this researcher found local parent support groups have little to no direct father involvement. This observation further supported the purpose of this study to try to identify the level of father involvement with their special needs child, as well as to identify the reasons for the low turn out in parent support groups. As this study found, fathers feel they have to work in order to financially provide for their families and the parent support group times and dates may not be accommodating to the fathers' schedules. But this does not indicate fathers do not want to be a part of the childrearing process. How this researcher was able to obtain the 17 participants was due to the help of a parent support group coordinator who suggested the guestionnaire be made available via electronic mail (email). The questionnaire was emailed to the Wiley Center support group coordinator, who then disseminated the questionnaire via a mass email to her support group members as well as other fathers of special needs children and thus, the 17 participants. Due to the small sample size of this study, the results are not representative nor cannot be generalized to the larger special needs population.

Another limitation of this study was that the study only included fathers who spoke English and the questionnaire was not made available in other languages. The results may have varied had this study included other language speaking populations. In addition to the above limitations, time was of concern. The time constraints limited the efforts to pursue a larger sample size as well as the possibility of translating the questionnaire into other languages. It is also worth noting, the fathers who participated in this study are already highly involved in the child rearing of their special needs child and thus, open to participate in this study versus the fathers who are not actively attending nor have attended parent support groups. Another observation is that the participants all have at least a high school degree with the majority of them at a bachelor's level education, which may not be representative of the general population of fathers with special needs children. Future studies may vary if the participants' ethnicity, language, education, and socio-economic status are different than those of this sample. The type of questions asked may also be tailored in efforts to obtain significant correlations and relationships between common

themes. The results of this study cannot be generalized due to the small sample size and the limited demographics (i.e. income, level of education) of this study, however, inferences can be made and open the door for further research in this specific area.

Recommendations for Social Work Practice, Policy and Research

This study and its findings have important implications for the social work field and other disciplines. The most obvious implication is the need for services and support groups to be made available around the schedules of the fathers. The domino effect of the expensive treatment options, therapies, medical and dental expenses require the fathers to work longer hours or extra jobs to make ends meet, which in turn, results in less time spent with their special needs child. However, as this study has found, there are many fathers who are actively involved in the every day care taking of their developmentally delayed child, despite having to work full time or odd hours. As social workers, part of our ethical obligations is to take the family unit into consideration when attempting to identify appropriate services and supports. It is in my professional

experience when working with the special needs population that social workers automatically make efforts to communicate with the mothers first, and more often than not assume the fathers are not actively and equally involved. This study has proven these assumptions are inaccurate and these 17 fathers want to be actively involved and included just as much as the mothers do. A recommendation worth considering is also the value of helping maintain healthy marriages and provide opportunity for the couples to obtain respite and take a break from their child's care. Simmerman and Blacher (2001) found in Gadivia-Payne and Stoneman, 1997; Krauss, 1993, Trute, 1995, that a healthy marriage results in quality family dynamics and the family is typically able to cope with the everyday challenges and burden of caring for their special needs child. Professionals may want to consider the limited social supports fathers often are faced with and make active and genuine efforts to promote social/recreational activities tailored to the fathers to promote social supports. Professionals may also want to enhance or make a conscious effort to promote individual, couple and/or family counseling so these families can openly discuss their feelings and thoughts about their

family's circumstances in order to promote positive mental health, avoid burn out, and explore both natural resources and professional resources available to them so the family unit can remain healthy and together. On a macro level, policy and funding for the special needs community may want to consider studies such as this one to properly allocate funding for the development of services and supports for the developmentally disabled population. Further studies pertaining to the special needs population, the fathers, mothers, and siblings may benefit the families and professionals in bridging the gap between services and the family unit. In addition, future studies may benefit from exploring the specific needs of the fathers as reported by the fathers in order to build on this study and obtain a fuller understanding of the fathers' needs.

Conclusions

The level of father involvement in the life of their special needs child from the father's perspective has shed light on the type of childrearing activities these fathers take part in. This study of 17 fathers exposed the concerns these fathers have causing them additional

stressors and caretaker burden due to a lack of connection with professionals (i.e. doctors, teachers, social workers), a lack of insurance coverage, limited social supports and limited resources specifically tailored to the needs of the fathers. The results of this exploratory study also indicate these 17 fathers embrace their special needs child and want to be actively involved in the daily living activities of their child and family. Professionals would benefit from taking this into consideration when working with families and decrease the automatic approach to only address the mothers under the false assumption that fathers want little to no involvement. These findings suggests a need for future policies pertaining to the families with special needs children, interventions to improve and/or develop programs tailored to the families and fathers since at this time, there are limited resources currently available for the fathers and their families. The services and supports for the fathers of special needs children will need to increase if these parents are to have the same opportunity for a quality of life as those parents with typical children.

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APPENDIX A

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QUESTIONNAIRE

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Level of father involvement in the lives of his special needs child - Survey

Please select the best answer:

1) What is your primary language?

Choose not to answer

- 2) What is your age? ______18-21 yrs. ______22-29 yrs.
 - _____ 30-39 yrs.
 - _____ 40-49 yrs.
 - _____ 50-59 yrs. over 60
 - Choose not to answer
- 3) What is your ethnicity?
 - White
 - White/Non-hispanic
 - _____ African-American
 - _____ Latino/Chicano/Mexican/
 - Hispanic
 - _____ Asian Pacific Islander
 - _____ Native American
 - Other (please specify):
 - Choose not to answer
- 4) What is the highest level of education you have?
 - _____ Less than High School
 - _____ High School / GED
 - _____ Some College
 - 2 yr. College Degree
 - _____4 yr. College Degree
 - _____ Masters Degree
 - _____ Doctoral Degree
 - Professional Degree
 - _____ Choose not to answer
- 5) Are you currently employed?
 - ____ Yes
 - _____No
 - _____ Choose not to answer

- 6) If you are employed, are you working
 - _____ Less than 10 hrs. per week
 - _____ 11 hrs 20 hrs. per week
 - _____ 21 hrs 30 hrs. per week
 - _____ 31 hrs 40 hrs. per week
 - _____ More than 40 hrs.per week
 - _____ currently not working
 - Choose not to answer
- 7) What is your yearly income?
 - $\begin{array}{c|c} Less than 10,000 \\ \hline 10,000 19,999 \\ \hline 20,000 29,999 \\ \hline 30,000 39,999 \\ \hline 40,000 49,999 \\ \hline 50,000 59,999 \\ \hline 60,000 69,999 \\ \hline 70,000 79,999 \\ \hline 80,000 89,999 \\ \hline 90,000 99,999 \\ \hline 100,000 \text{ or more} \end{array}$
 - _____ Choose not to answer

Relationships/Social Supports:

- 8) What is your current marital status? Single, Never Married
 - _____ Single, Never IV.
 - _____ Married
 - _____ Separated
 - _____ Divorced
 - _____ Widowed
 - _____ Choose not to answer
- 9) If you are NO LONGER in a relationship with your child's mother, was the cause of the separation due to your special needs child?
 - ____ Yes
 - _____No
 - _____ Somewhat
 - _____ Choose not to answer
 - _____ Am still in a relationship with child's mother

10) Does your child's special needs affect your employment status?

Yes No Choose not to answer

- 11) Have your relationships with friends changed from being a parent of a special needs child? How so?
- 12) Are your friends and/or extended family supportive of your situation? Tell me about how they have helped or hindered you.
- 13) Do you discuss the impact your special needs child has had on your life with anyone?
 - Yes
 - No
 - Choose not to answer

Your Child's Diagnosis

- 14) What is your child's diagnosis?
- 15) At what age was your child diagnosed?

____ at birth

- before the age of one
- _____ between the age of 1-2
- _____ between the age of 2-3
- _____ between the age of 3-4
 - _____ after the age of 5
- 16) Were you present when doctors diagnosed your child? _____Yes
 - No
- 17) Did the medical professionals directly speak with you or was most of the contact and explanations provided to the mother?
 - _____ Spoke with me
 - _____ Spoke to mom

_____ Equally spoke to both

_____ Choose not to answer

- 18) Do you accept your child has special needs?
 - ____ I accept it
 - _____I do not accept it
 - ____ Not sure
 - _____ Choose not to answer
- 19) Does your child sleep well?

____Yes

- ____No
- ____ Sometimes
- _____ Choose not to answer
- 20) Does your child have challenging behaviors?
 - ____Yes
 - ____ No
 - _____ Sometimes
 - _____ Choose not to answer
- 21) Does your child require prescription medications?
 - ____Yes
 - ____ No
 - ____ Sometimes

Types of involvement Please choose the best appropriate answer:

22) Are you part of the financial decisions made relating to services, equipment, therapies, etc. your child requires?

____Yes

- ____ No
- _____ Sometimes

____ Choose not to answer

23) Are you part of scheduling, transporting, following up with medical appointments or therapy sessions directly involving your child on a regular basis?

____Yes

- _____ No
- _____ Sometimes
- _____ Choose not to answer
- 24) Are you directly a part of any services received in efforts to learn strategies on how to work with your child? (i.e. behavioral intervention services, speech, participating in IEPs, etc.)

____ Yes

____ No

- ____ Sometimes
- _____ Choose not to answer
- 25) Do (or did) you change your child's diapers on a regular basis?

____Yes

- ____ No
- ____ Sometimes
- _____ Choose not to answer
- 26) Do you help feed/dress/bathe your child on a regular basis?

____ Yes

- ____No
- _____ Sometimes
- _____ Choose not to answer

- 27) If your child takes prescription medication, do you help administer the medication on a regular basis (daily)? Yes
 - ____ res No
 - Sometimes
 - _____ Sometimes
 - My child does not take prescription medication
- 28) Do you help your child with his/her homework?
 - _____Yes
 - _____No
 - _____ Sometimes
 - _____ Choose not to answer
- 29) Do you play (indoor and/or outdoor) with your child?
 - Yes
 - No
 - Sometimes
 - _____ Choose not to answer
- 30) Do you and your child participate in family events/social gatherings/recreational activities on a regular basis?
 - _____Yes
 - ____ No
 - _____ Sometimes
 - ____ Choose not to answer
- On an average day, how much time do you spend with your child during leisure time? (i.e. watching T.V. unstructured play, etc.)
 - Less than 1 hr.
 - _____1-2 hrs.
 - _____ 3-4 hrs.
 - _____ More than 5 hrs.

Professionals

- 32) Do you think professionals understand your needs?
 - ____Yes
 - ____ No
 - _____ Sometimes
 - _____ Choose not to answer

- 33) Please give some examples of when professionals did or did not understand your needs.
- 34) What types of supports/services/activities would you like to have offered that are specifically tailored to father's needs and interests?

Finances

- 35) How have your finances been affected by having your child?
- 36) Have you found additional financial pressures due to your child's needs? Can you give some examples?

Thank you for answering this questionnaire. You may return this questionnaire to your parent support group facilitator or e-mail to: jimel303@csusb.edu

APPENDIX B

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INFORMED CONSENT

Informed Consent

The study in which you are being asked to participate is designed to explore the level of father involvement in the lives of their special needs child. This study is being conducted by Masters in Social Work student Lorraine Jimenez under the supervision of Dr. Carolyn McAllister, MSW, PhD. This study has been approved by the School of Social Work Sub Committee of the Institutional Review Board at California State University, San Bernardino.

Fathers of special needs children will be asked to share their level of involvement in the lives of their developmentally disabled child. In this study you will be asked to respond to several questions exploring the type of diagnosis your child has and the father's perceptions of how it has impacted your life. The questionnaire should take about 15 to 30 minutes to complete. All of your responses will be held in the strictest of confidence by the researcher. Your name will not be reported with your responses. All data will be reported in group form only. You may receive the group results of this study upon completion in September, 2010 at the following location: California State University, San Bernardino Pfau Library and with your parent support group facilitator.

Your participation in this study is totally voluntary. You are free not to answer any questions and withdraw at any time during this study without penalty. When you have completed the questionnaire, you will receive a debriefing statement describing the study in more detail. There are no foreseeable risks, discomforts or benefits to you for participating in this study.

If you have any questions or concerns about this study, please feel free to contact my faculty supervisor Dr. McAllister, MSW, PhD at (909) 537-5559 or email; cmcallis@csusb.edu. Should you have any questions or comments about the findings of this study, you may contact me directly at; jimel303@csusb.edu.

By placing a check mark in the box below, I acknowledge that I have been informed of, and that I understand, the nature and purpose of this study, and I freely consent to participate. I also acknowledge that I am at least 18 years of age.

Place a check mark here:

Today's date:_____

APPENDIX C

DEBRIEFING STATEMENT

Father involvement in the lives of their special needs child DEBRIEFING STATEMENT

Dear Parent,

Thank you for taking the time to take part in this survey. I am working on my thesis project at California State University, San Bernardino School of Social Work. The focus is to explore the level of father involvement in the lives of their special needs child and identify the gap between professional services and supports and the fathers. The ultimate goal is to identify the needs of the fathers of special needs children. It would be really helpful if you could share your experiences of parenting a child with special needs and how it impacts your level of involvement with him/her.

Respectfully,

Lorraine Jimenez

REFERENCES

- Boije, H. (2002). A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality & Quantity*, 36, 391-409.
- Dellve, L., Samuelsson, L., Tallborn, A., Fasth, A., & Hallberg, L. (2005). Stress and well-being among parents of children with rare diseases: A prospective intervention study. Journal of Advanced Nursing, 53(4), 392-402.
- Galvan, J. L. (2004). Writing literature reviews: A guide for students of the social and behavioral sciences (2nd ed.). Glendalae, CA: Pyrczak.
- Grinnell, R. M. Jr., & Unrau, Y. A. (2008). Social work research and evaluation: Quantitative and qualitative approaches (8th ed.). Itasca, IL: F.E. Peacock.
- Hartley, S., Ojwang, P., Baguwemo, A., Ddamulira, M., & Chavuta, A. (2004). How do carers of disabled children cope? The Ugandan perspecitive. Journal of Child: Care, Health & Development, 31(2), 167-180.
- Hughes, R. C., & Rycus, J. S. (1999). Developmental disabilities and child welfare. Book review. Child and Adolescent Social Work Journal, 16(4), 317-320.
- Kersh, J., Hedvat, T. T., Hauser-Cram, P., & Warfield, M. E. (2006). The contribution of marital quality to the well-being of parents of children with developmental disabilities. *Journal of Intellectual Disability Research*, 50(12), 883-893.
- Levy-Shiff, R. (1999). Fathers' Cognitive Appraisals, Coping Strategies, and Support Resources as Correlates of Adjustment to Parenthood. Journal of Family Psychology, 13(4), 554-567.
- Martin, J. M., & Cole, D. A. (1993). Adaptability and cohesion of dyadic relationships in families with developmentally disabled children. Journal of Family Psychology, 7(2), 186-196.

- O'Brien, M. E. (2001). Living in a house of cards: Family experiences with long-term childhood technology dependence. Journal of Pediatric Nursing, 16(1), 13-22.
- Quinn, P. (1999). Supporting and encouraging father involvement in families of children who have a disability. Child and Adolescent Social Work Journal, 16(6), 439-454.
- Ramaglio, G., Romeo, A., Viri, M., Lodi, M., Sacchi, S., & Cioffi, G. (2007). Impact of idiopathic epilepsy on mothers and fathers: Strain, burden of care, worries and perception of vulnerability. *Epilepsia*, 48(9), 1810-1813.
- Simmerman, S., & Blacher, J. (2001). Fathers' and . mothers' perceptions of father involvement in families with young children with a disability. Journal of Intellectual & Developmental Disability, 26(4), 325-338.
- Trivette, C., Dunst, C.J., Hamby, D.W. (2010). Influences
 of family systems intervention practices on parent child interactions and development. Topics in Early
 Childhood Special Education, 30(1), 3-19.
- Trute, B. (1990). Child and parent predictors of family adjustment in households containing young developmentally disabled children. Family Relations, 39(3), 292-297.