TRANSITION FROM PARENTAL COPING TO PARENTAL EFFICACY:
WHAT FACTORS SUPPORT PARENTAL EFFICACY DEVELOPMENT
FOR PARENTS OF INFANTS BORN WITH SPECIAL NEEDS?

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DEDICATION

This thesis is dedicated to:

My dear family, thank you for your acts of love… Mommy, I’m so grateful for your words, hugs, and cooking; with your actions you provide continuous care for my mind, heart, and body. Daddy, thank you for tell me to fill out an application to CSUN way back when I was going to graduate from high school. Because of which I continued to study towards a master’s degree from CSUN. To my two best brothers, thank you for helping me achieve my dreams. Ray, I’m so grateful we would run errands so that I could take a break and so that I could remember to just breathe. Rick thank you for giving me the room to write. I truly value that space and the times you would help me out with my computer. To my dog Jack, thank you for reminding me of the importance of play. I mentally needed those walks away from the computer.

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TABLE OF CONTENTS

Signature Page ii
Dedication iii
Acknowledgment v
List of Tables vii
Abstract viii

CHAPTER I – INTRODUCTION 1
  Statement of the Problem 1
  Purpose 3
  Definitions 4
  Assumptions 6
  Limitations 6

CHAPTER II – REVIEW OF LITERATURE 7
  Parental Efficacy 7
  Parent Reactions 7
  Parent Processing and Coping 9
  Coping Approach 10
  Mothers’ Response 11
  Importance of Caretaking 12
  Mothering Role Decisions 12
  Fathers’ Response 13
  Stress Impact 13
  Importance of Parenting Task 14
  Role Models 14
  Perceptions in Competency 14
  Grandparents a as a Support Means 15
  Grandparent Response 16
  Parent to Grandparent Response 16
  Grandparent Impact on Care 17
  Factors Influencing Relationship 18
  Sibling Role 19
  Family as a Team 20
  Sibling Isolation, Frustration, and Fears 21
  Coping Thoughts 23
  Protective Factors for Siblings 23
  Diagnosis and Disclosure 24
  Successful Adaptation 26
  Support System 27
  Importance of Play 27
  Play Dilemmas 27
  Facilitator Role 28
  Play and Theory 28
  Application of Play 30
Parents and Play ........................................... 31
Play Assessment ........................................... 31
Early Intervention .......................................... 32
Individualized Family Service Plans ............. 33
Early Intervention as a Support Tool .......... 33
Key Worker Role ........................................... 34
Overcoming Conflicts .................................... 35
Culturally Diverse Family Experiences ......... 36
Better Family Outcomes ............................... 37
Family Outlook ........................................... 37

CHAPTER III – METHODOLOGY .................. 40
  Procedures ............................................... 41
  Questionnaire .......................................... 41
  Sample ................................................. 45
  Pilot Group ............................................. 45
  Focus Group ............................................ 47
  Measurements .......................................... 48

CHAPTER IV – RESULTS ............................ 51
  Section 1 Statistical Demographics ............ 51
  Section 2 Data Analysis ............................ 57

CHAPTER V – DISCUSSION ......................... 77
  Summary of Findings .................................. 78
  Discussion of Findings .............................. 79
  Limitations ............................................ 84
  Implications ........................................... 85
  Recommendations ................................... 87
  Conclusion ............................................. 91

REFERENCES ........................................... 93

APPENDIX A ........................................... 101
APPENDIX B ........................................... 109
APPENDIX C ........................................... 110
APPENDIX D ........................................... 111
APPENDIX E ........................................... 112
APPENDIX F ........................................... 114
APPENDIX G ........................................... 115
APPENDIX H ........................................... 116
APPENDIX I ........................................... 117
LIST OF TABLES

Table 1 - Parents’ self-reported parent dyad statistical demographic 54
Table 2 - Parent reported basic demographic information of their child 56
Table 3 - Parent reported basic demographics of child sibling living in the household 58
Table 4 - Parents’ initial reaction and impact on parental abilities 61
Table 5 - Typically developing child’s role within the family 65
Table 6 - Impact of diagnosis on the interactions with extended family 67
Table 7 - The importance of play in assisting with family cohesion 70
Table 8 - Parents shared sources of support and their response to the support 73
ABSTRACT

TRANSITION FROM PARENTAL COPING TO PARENTAL EFFICACY: WHAT FACTORS SUPPORT PARENTAL EFFICACY DEVELOPMENT FOR PARENTS OF INFANTS BORN WITH SPECIAL NEEDS?

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Master of Science in Family and Consumer Sciences

The purpose of this study was to contribute to the understanding of parent as advocates in obtaining positive parental efficacy in their role as parents of infants challenged with special needs. The researcher chose CHIME Institute, located in Woodland Hills, California and in conjunction with California State University Northridge Child and Family Studies Center inclusive program, located in Northridge, California, to implement a self-report survey questionnaire. The organization services infants/toddlers/children under five diagnosed with special needs by incorporating the child’s physical, cognitive, and social needs and services in an inclusive classroom environment. A self-report data questionnaire was used to for a sample response of 5 dyads (n=10) regarding their grief process towards parent advocacy and obtainment of parental efficacy. Inductive analysis evaluated parent response to infant’s diagnosis, grief processing, family dynamics, impact on parenting, knowledge of child’s needs and rights, acquisition of knowledge, familial support from extended relatives, and the role of play as sources of support in developing more positive parental efficacy perceptions. Dyads acknowledged supportive factors such as parent knowledge, the role of siblings, and
grandparent involvement as influential components towards positive attitudes in their ability to parent.
CHAPTER I
INTRODUCTION

In recent years the recognition of the special consideration involved with the births of infants with special needs has increased. The Center for Disease Control estimates that between 120,000 to 160,000 infants each year, born in the United States, are born with limitations or challenges (Hebbeler, Spiker, Mallik, Scarborough, & Simeonsson 2003). This estimate suggests that between 1% and 15% of the U.S. born children born each year have a special need. As part of these infant’s larger family systems, the involvement of their parents must be acknowledged. The parents of these infants are also impacted by the special considerations relating to these children. An estimated 200,000 families receive services, specifically for children under age three. Parents are provided home, center and program based instruction on the care of their child’s specific needs. Parents are then encouraged to utilize the information in their homes with both their nuclear and extended family members in caring for their child. In obtaining this child-caring knowledge to effectively respond to the needs of their child, parents may gain positive views in their roles as parents. The parents developing views and attitudes in terms of demonstrating their ability or competency towards becoming successful parents is established as their parental efficacy (Hess, Feti, & Hussey-Garner, 2004).

Statement of the Problem

Parents provide their infant with a sense of security and identity into which they can grow into and become a confident and capable adult. According to Vacca (2006), strong attachments are long lasting between infants and parents, especially those infants
challenged with special needs. Parents of an infant with special needs exhibit more stress, which can create an added negative perception of parenting (Pelchat, Ricard, Bouchardy, Perreault, Saucier, 1998). Daily stressors can increase in intensity and lead to more negative reactions create perceptions for parents. These factors can cause parents to have negative perceptions towards their infant; in some cases it can lead to abuse or neglect. This stress is therefore associated with decreased levels of optimal parent-child interactions which can create insecure attachments (Osteberg & Hagekull, 2000). Parents of special needs tend to experience higher levels of life event demands that increase parental stress and decrease a parent’s perception of their responsiveness to their infant’s needs.

Parental responsiveness can be related to the types of disabilities the infant is diagnosed with (Vacca, 2006). It can relate to their level of stress and their ability to react to their infant's needs. This can be related to the gender of the parent: the mother, as the primary caregiver of the infant, typically exhibits more levels of stress. The level of adaptation can influence the amount of stress that is placed on a parent (Macias, 2001). Higher levels of stress may make it increasingly difficult for parents to read cues of infants and respond accordingly. Past research has indicated that physical or medical risk conditions were possible predictors of maladjustment. However recent research now indicates that special needs are not associated with the predisposition towards maladjustment (Vacca, 2006).

Complications of chronic health issues increase the degree to which parents experience stress. These parents are at higher risk for maladjustment. Positive protective factors that can potentially counter these effects are parents adapt to new demands by
gathering information on technical and medical issues to assist with the decision-making processes. If parents are able to reevaluate the situation and respond accordingly, they are less likely to experience high levels of stress, particularly when the type of disability has a more positive long-term outcome (Macias, 2001).

Purpose

The purpose of this study is to analyze the transition of parents from the grief and coping stages related to having an infant born with or identified as having special needs to the development of positive parent efficacy. Specifically, this thesis is meant to identify the supporting factors into the positive development of parental efficacy. The identification of positive factors into positive parental efficacy development assists in strengthening parental outlook in meeting the needs of their infant. The research will provide insight and understanding of how the needs of one family member affect the family dynamics as a whole.

It will enable family care professionals to understand the family as a unit, while identifying the role of each member within the family unit and each member’s role as they support the member in need of assistance. By gathering this information, this research will enhance professional understanding of how families cope and respond to a family member’s needs in times of stress. The research will evaluate the role of play as a facilitator in family bonding. To this end, the research will identify common trends related to the families’ transitions through the coping process to positive parental efficacy outlooks for parents of infants with special needs. Factors such as the time of infant's diagnosis, special needs discloser, familial support systems, parental attitudes, and family outlook will also be reviewed as contributing factors towards positive parental efficacy
development.

Definitions

For the purpose of this study, the researcher has chosen to link infant and toddler under the larger umbrella of infancy for any child under the age of 2 years and 6 months. The research will recognize any family meeting the criteria of having a child of 2 years and 6 months or younger in age with a special need, as having an infant eligible for participation in this thesis research.

Throughout the field of special education the terminology of special needs is vast in its usage to cover the umbrella of disabilities and their related issues. Research terms utilized within the field include but are not limited to: special needs, developmentally challenged, developmentally delayed, developmentally handicapped, or developmentally disabled (Fogel, 2001). In consideration of the research the term recognized with possessing the least amount of negative connotation is infants with special needs.

By definition, a special need refers to a birth defect affecting the body or brain. Such birth defects can be acquired during birth or shortly after birth. Typically birth defects affect the development of the individual, often leading to delays. Developmental delays can typically occur in one of the following five areas: the infant’s cognitive development, physical development, communicative development, social/emotional development, or adaptive development.

Early intervention is defined as a process of systematic provision of services. Types of services range from educational to therapeutic. The goal of such service therapies is to support families in assisting their infants with special needs in meeting their developmental needs (Papalia, Olds, & Feldman, 2002).
Educational and therapeutic services are typically designed through play styles. *Play* is recognized as the work of an infant that involves social interactions which mold their learning through the provision of meaningful experiences by significant adults in their natural setting (Walker, 2002).

Currently, the Early Head Start (EHS) program assists families in comprehending and implementing the Individualized Family Service Plan (IFSP) (Wall, Taylor, Liebow, Sabatino, Mayer, Farber, Timberlake, 2005). Early Head Start was created as part of a subsection during the reorganization of the Head Start program. The Individualized Family Service Plan is a formally written document involving the regional center servicing the infant with special needs and the family of the infant (Zhanga, Schwartzb, & Leec, 2005). This formal document includes the terminology of the diagnosis. It classifies the specific developmental delays or the potential at-risk delays that may be experienced by the infant as well as the specific resource services that are available for the infant and family. Providers of these services work with the family towards establishing a partnership to minimize the barriers of accessing services and parental comprehension of care (Denboba, McPherson, Kennney, Strickland, Newacheck, 2006).

*Parental responsiveness* is considered to be related to a parent’s ability to recognize, identify, respond to, and both appropriately and effectively meet the needs of their infant with special needs.

*Parental efficacy* is established through a parent’s ability to positively perceive their capability in effectively interpreting and responding to their infant and in their view of themselves in their role as a parent.
Assumptions

This research study was designed with certain assumptions.

- Families will voluntarily participate willingly and without pressure from researcher.
- Families will be able to read and comprehend research English questionnaire since they live in the United States.
- Families are given ample time and freedom to respond to and return survey to researcher.
- Families responding to questionnaire will answer questions fully and honestly.
- Data entry and analyses are conducted accurately.

Limitations

This thesis will aid the understanding of the how parents of children born with special needs develop parental efficacy; however, certain limitations affected this study. The data was collected using self-report questionnaires.

- The researcher formerly worked for the CHIME program.
- Families may have altered or edited information shared in survey due to time lapse between experiencing the situation and time of reporting information.
- The sample is limited to individuals from CHIME which can limit the generalization of the research.
- The representing special needs of the children in this study are the reflection of parent interpretation of their child’s special need as previously assessed by an expert.
CHAPTER II
REVIEW OF LITERATURE

Parental Efficacy

Parental efficacy relates to the set of beliefs a parent adapts towards their ability to competently and effectively fulfill the cognitive, social and physical parenting tasks related to their child’s needs (Thomas, Feeley, & Grier, 2009). Parental efficacy influences the transition to parenthood and positive behavioral outcomes for their child. For parents it protects against depressive symptoms by positively influencing cognitive, emotional, behavioral and motivational responsiveness levels for care giving.

Educational classes can serve to reduce depressive symptoms and increase the overall quality of families’ lives (Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2010). Parents with greater levels of patience felt better able to handle challenges that arose. Positive attitudes and “not giving up” mentalities augmented perceptions of parental efficacy.

The health of the infant directly correlated to a parent’s parental efficacy views (Churchill et. al., 2010). Improvements in growth and development enhanced parent perception. When the health of the infant diminished parents encountered situational loss of control that translated into an inability to change or improve their infants health. Illness of infant impacted a parent’s ability to care for child. Parents view care giving decisions and actions as means of providing care. Decision related to the acquisition of therapies and services. Actions were connected to physical touch, closeness and interactions.

Parent Reactions
A parents’ initial response to the birth of their infant with special needs is one of overwhelming shock at a challenging situation of which they possess very little knowledge of how to cope with (Pearson, Simms, & Ainsworth, 1999). Parents then enter a process of bereavement as they suspect that something is wrong even prior to being told. According to Vacca (2006), there are twelve common parental reactions to the birth of an infant with a disability:

- Devastation, being overwhelmed, traumatized
- Shock, denial, numbness, and disbelief
- Feelings of crisis and confusion when attempting to cope
- Sense of loss of the "hoped for child"
- Grief (similar to that experienced at the death of a loved one)
- Future hopes are challenged or destroyed
- Guilt, responsibility, and shame
- Strong anger towards the medical staff involved with the child
- Wondering the what-if's, if the child dies
- Lowered self-esteem and parental efficacy as providers and protectors
- Strained marital and family relations
- Disruption in family routines

Such stressors, such as denial or the loss of hope for a child can negatively impact the parent-child dyad (Vacca 2006). For example, in research lead by Gallagher, Fialka, Rhodes, & Arceneaux, (2004), denial was considered to be a protective device used by the parents when they were unprepared to cope with the problem and its implications. The research also indicated that the sense of loss of the ‘hoped-for child’ can be a
stressor. Prior to the birth the process of parental preparation for their infant includes the parents’ imagining of their child's likes, dislikes and possible future (Vacca, 2006). After the birth, when faced with an infant with special needs, the parents must reevaluate the feasibility of their infant experiencing these hopes. Parents recognize the challenges that having a special need place on a child (Esdaile & Greenwood, 2003). Parents’ credit their child with extra effort they must make towards positive outcomes.

**Parent Processing and Coping**

Through the grief process, parents exhibit prenatal, postnatal, and later parental responsiveness interactions as part of their coping skills towards their infant with special needs (Vacca, 2006). In the prenatal state, parents have perceived expectations of a safe delivery, followed by the subsequent healthy growth of their child. The expectation of the parent is of a long life filled with the images of their infant's likes and dislikes in terms of their ‘hoped-for child’. In the postnatal state, parents’ process blame and a sense of fear related to their unprepared emotional state to relate to their infant. Parents’ exhibit upset over the loss of the future experiences their infant may not have the opportunity to fulfill.

Parents may feel they are the ones challenged as opposed to their infant (Vacca, 2006). Parents face the knowledge that their infant may have limiting impediments and that as the parent they need to respond to their infant’s unique needs (Kerr & McIntosh, 2002). As parents, they may perceive that their mistakes may cause further harm or death to their infant, causing parental insecurity in their responsiveness and their ability to care (Vacca, 2006). For parents, their ability to care for their infant relates to their ability to know their infant (Thomas et al., 2009). By knowing their infant parents are then able to meet the needs of their infant.
Parents struggle with concerns over their infant’s ability to survive and the potential impact on their infant’s future development (Graungaard & Skov, 2006). Lack of information can increase concern and increase fear of uncertain outcomes (Kerr & McIntosh, 2002). For example, how a parent holds a child or how they feed them may have later effects on the developmental outcome of their infant.

Through interactions, parents and infants can experience success in connecting with the use of flexibility and adaptation. Parents may face emotional stress related to their perception of whether they are doing things correctly (Kerr & McIntosh, 2000; Vacca, 2006). Challenges to parental perceptions and parent-infant connectedness are the parents' ability to adapt to a child's diagnosis (Vacca, 2006). Included in a parent's ability to adapt are their levels of distress, uncertainty, avoidance and isolation towards their infant's diagnosis. Parents' unease and distress may be related to their experience in seeing delays in their child's development or medical care. The fear that not everything is being done for the sake of their infant can translate into the feelings that they have failed their child (Graungaard & Skov, 2006).

Parents coping with their infant's diagnosis may face knowledge that their child will experience limitations in development and subsequently witness their infant experience these limitations (Kerr & McIntosh, 2000; Vacca, 2006). Infants may exhibit limitations in their inability to perform certain movements or tasks. Parents coping through the interaction follow a normative phase, a self-study phase, an acceptance phase and the determining quality of life phase which includes planning for the future.

*Coping Approach*

Two main types of coping styles have been attributed to parents; a problem
focused coping style and an emotional coping style (Graungaard & Skov, 2006). Both coping styles are strongly influenced by the diagnosis process and the certainty of the diagnosis. An unknown diagnosis causes greater fluctuation in the degrees of coping than an identified diagnosis.

The problem based coping involves managing or altering the perceived problem. This necessitates gathering information related to the special need, learning new skills that will benefit their infant’s development, and placing a certain amount of control on the decisions and actions of the professionals attending to the infant. Parents may seek to second opinions or alternative medical approaches to actively control their infant’s care decisions.

The emotional based approach involves regulating their emotional response to the situation. Some parents may retain hope that there was a misunderstanding, they may create positive future images or ignore the significance of the condition. Emotional based coping is helped along by gathering social support, focusing on the infant’s abilities and possibilities, and by reevaluating their beliefs to identify positive outcomes.

**Mothers’ Response**

Mothers report significantly more physical health complaints, higher rates of depression, increased stress and anxiety, and emotional distress (Pelchat, Ricard, Bouchardy, Perreault, & Saucier, 1998). Mothers have a higher incidence of feeling role restrictiveness in terms of feeling trapped in their role as a parent. A mother may experience increase demands on her which can increase the rate at which mothers experience social isolation (Macias, 2001). Mothers may face difficulties in locating adequate care for her infant to engage in social interaction; older mothers tend have
higher levels of stress (Kerr & McIntosh, 2000; Macias, 2001).

 Mothers coping with stress endure a higher physical and psychological risk
(Esdaile & Greenwood, 2003). Inappropriate self blame was a potential risk for maternal
stress and depression. Mothers tend to report higher levels of tension, distress, and stress
related to caring for their infant than fathers (Olshtain-Mann & Auslander, 2008). If a
mother was unable to care the pregnancy to full term, mothers describe feels of guilt.
Mothers that initially experienced high levels of stress were less sensitive and more
controlling during play interactions.

 Higher levels of maternal social support decreased the risk of depression while
increasing parent satisfaction perceptions (Esdaile & Greenwood, 2003). Paternal
efficacy was considered to be a predictor of maternal perception towards their child’s
adjustment. Quality interaction between a mother and her child increased maternal sense
of paternal efficacy and served to decrease maternal stress.

Importance of Caretaking

 Concentrating on care needs, such as breastfeeding and other perceived normative
parenting care duties, are means by which mothers cope (Graungaard & Skov, 2006).
During the disclosure process mothers may find themselves attempting to mentally
strengthen their child with their own energy. As they move past the point of shock they
are better able to focus and minimize the amount of energy spent on despair and fear.

Mothering Role Decisions

 Mothers tend to make decisions related to their infant’s special need and generally
are more aware of service needs than fathers (Dote-Kwan, Chen, & Hughes, 2009).
Mothers seek out information about their infant’s current and future service needs.
Reading materials related to the coping mechanisms of other parents facing a similar situation were also sought out. Mother will often reduce their work hour to part-time status or chose to take on mothering care giving as a full time role (Maul & Singer, 2009).

Fathers’ Response

Fathers reported similar findings related to their emotional wellbeing in terms of parenting infants with special needs (Pelchat et al., 1998). According to research conducted by Lee, Miles, & Holditch-Davis (2006), fathers serve as important coping tools for mothers. Fathers make decisions for infants with chronic or physical special needs directly after birth while mothers are still recovering. They tend to be responsible for finding information and resources. In later months they assist with household chores (Pelchat et. al., 1998). This typically drops off after the infant is about 3 months old.

Stress Impact

As fathers levels of stress increase fathers demonstrate decreased levels of parental efficacy (Thomas et al., 2009). This risk is greater for first time fathers. Perceptions of anxiety over meeting the needs of their infant may lead to depression symptoms which reduce the father’s sense of mastery and competency. Fathers may also experience feelings of isolation but may choose to keep these emotions to themselves in an effort to not further upset their partners (Hall, 1996). Holding on to these emotions may increase the stress fathers’ experience. These combined emotions serve as a predictor in terms of their perceived parental efficacy capabilities.

Fathers experiencing high stressors face decreased satisfaction in parenting (Esdaile & Greenwood, 2003). Fathers sought more information related to their child’s
condition and how to teach their child (Dote-Kwan et al., 2009). This can lead to decreased levels of adjustment for their child. Long term future perceptions tend to be needed by fathers so that they can grasp a more concrete concept of the future (Graungaard & Skov, 2006).

**Importance of Parenting Task**

Everyday parenting tasks support positive views if parental efficacy for fathers (Thomas et al., 2009). By talking, playing, feeding, bathing and attending to diaper needs of an infant a father learns how to care for his infants needs. Fathers with infants in a Neonatal Intensive Care Unit (NICU) experienced a sense of lost at being unable to perform parenting tasks that inhibited their ability to begin to learn about their infant. Most fathers take on the care giving role while the infant’s mother recovers from the birth and delivery.

**Role Models**

For infants experiencing long term stays in the hospital, primary care nurses supply pivotal role models for fathers in gaining care knowledge regarding their infant’s needs (Thomas et al., 2009). Fathers observe nurses to gain care handling techniques. Past personal experience in care giving enhanced care ability opinions. Being raised in a large family was mentioned as one source of previous experience. Other sources of knowledge gaining sprouted from the infant’s grandmothers.

**Perceptions in Competency**

Fathers perceive themselves as possessing higher levels of competency in caring for sons than daughters (Olshtain-Mann & Auslander, 2008). Fathers that relate to sons do so based on perceived competency that they are more emotionally equipped and
possess more experience related to males needs. Fathers also view work as a source of comfort (Olshtain-Mann & Auslander, 2008). Work is an establishment in which they can view themselves as experts. The value of work is based on their ability to financially provide and support their family’s needs. Fathers may choose to leave one employment for another for the additional time it may offer them to be available for their family (Maul & Singer, 2009). At times it may offer lower pay but the benefit of time compensates for the decrease in finance in some fathers’ opinion.

**Grandparents as a Means of Support**

Vadasz (1987) recognized that families are no longer self contained nuclear systems. Grandparents are active and important members of the family network. Grandchildren connect differently to grandparents than they do with parents (Schuntermann, 2007). Grandparents are considered to be more actively involved in the lives of their grandchildren. Grandparents living healthier, more active, longer lives are attributed to increased grandparent involvement (Scherman, Gardner, Brown, & Schutter, 1995). Activities that grandparents participate in with their grandchild included playing games, going for walks, providing love and encouragement (Gardner & Scherman, 1994).

Grandparents achieve a sense of status and satisfaction from the role of grandparenthood (Schuntermann, 2007). A grandchild with a special need may be seen as a potential complication to the relationship of its parents and extended family members. Grandparents are the first individuals’ parents contact regarding their infant’s special needs (Findler, 2007). Grandchildren represent the extension of the family’s future. Grandchildren are viewed as a chance to secure the family’s long lasting future (Mirfin-Veitch, Bray, & Watson, 1997). Special need circumstances place the predictability of the
future at risk. Conditions related to special need issues causes grandparents to re-evaluate and readjust the future of the child (Vadasy, 1987).

**Grandparent Response**

Grandparents undergo similar states of shock and grief as they learn of existence of special needs related to their infant grandchild (Scherman *et. al.*, 1995). Unlike parents, grandparents do not typically receive support and subsequently lack a complete understanding of their grandchild’s situation. Grandparents are forced to adapt on their own by actively seeking out information regarding their grandchild’s situation (Vadasy, 1987). They endure feelings of helplessness and experiencing little control (Scherman *et. al.*, 1995).

For grandparents they undergo an additional stressor of witnessing their own child progression through a stressful situation. As such, grandparents offer support, comfort and assistance in attending to everyday immediate needs. As grandparents, they must embrace the dual role of responsibility learning what is necessary for their grandchild and their own child. Concerns for long-term impact on grandchild needs and the impact these needs will place of their child’s marriage arise.

**Parent to Grandparent Response**

Parents view lack of understanding on part of the grandparents as an obstacle and as such may experience unsuccessful adjustment (Gardner & Scherman, 1994). Grandparents’ acceptance decreases feelings of isolation for parents and enhances the positive impact of successful adjustment. Grandparents who are unable to accept their grandchild’s situation experience strong sense of anger, denial and grief. These emotions may inhibit the grandparent from offering support to the parents at a critical time of
stress.

The grandparent positive response to the grandchild can serve as a model for family members (Gardner & Scherman, 1994; Mirfin-Veitch et al., 1997). Most grandparents accept the grandchild even before having a complete understanding of their grandchild’s condition. In certain instances the grandparent is able to fully accept the grandchild before the parents are able to. Grandmothers become an important source of support for parents (Trute, Worthington, & Hiebert-Murphy, 2008). Grandmother involvement is a supportive factor towards increased mother self-esteem that leads to higher levels of parental efficacy.

Parents prefer the informal support offered by families to the formal support that professionals may extend (Findler, 2007). Informal support from family members allows for a mutual exchange and reciprocity minimizing a sense of dependency and helplessness. Decreased dependency and helplessness reinforce parent opinions of their parental efficacy.

Grandparent Impact on Care

Grandparent take on roles connected to possessing child care expertise, being a playmate or babysitter (Vadas, 1987). This may be connected to the ideal that a grandparent is committed to and ready to help their family (Findler, 2007). Grandparents may offer a safe place for the infant to stay for babysitting purposes anywhere from daily care to as few as two times a month (Gardner & Scherman, 1994).

Grandmothers tend to offer emotional support. When this type of emotional support is available to a parent, adjustment is strengthened and leads to a lesser degree of stress (Trute et al., 2008). Mothers that were offered support from the paternal
grandmother felt more positively towards their infant and less parental stress. Maternal grandmothers were reported as offering the most support. Maternal grandmothers may experience fear or guilt related to potentially passing on the cause of their grandchild’s condition (Schuntermann, 2007). Paternal grandmothers’ pain is related to the uncertain future demands that are placed on their sons.

Parents reported that grandmothers that stayed for an extended time with parents after the birth of their infant felt it supported their transition into parenthood (Thomas et al., 2009). The care giving actions of grandmothers assisted a father’s ability to fulfill care giving task by learning to interpret infant behaviors and ways in which to support growth and development. Grandmother’s care actions provided direct teaching thru observation and demonstration. These tools increase parental efficacy perceptions. Fathers without available role models experienced decreased levels of parental efficacy.

**Factors Influencing Relationship**

The quality of the relationship between parent and grandparents impact the interactions that are exchanged between grandparent and grandchild (Mirfin-Veitch et al., 1997). Interactions may be also be impacted by the restrictions of the infant’s needs (Gardner & Scherman, 1994). Parents often become the mediating factor for interactions (Mirfin-Veitch et al., 1997).

Families with a history of long term closeness maintained positive relations and were viewed as being involved families and continued closeness (Mirfin-Veitch et al., 1997). Open and effective communication was linked to a continued closeness among family members. Families that exhibited problematic relationships demonstrated a decreased ability to communicate effectively.
Communication between members affected the ease with which members could request assistance. Parents with involved member experienced greater ease (Mirfin-Veitch et al., 1997). Grandparents tended to offer support without being asked. Grandparents were more apt at recognizing needs and relieving parents of needing to ask. Families with less involvement commented that grandparents needed to be informed and parents resented the need to ask. These actions sustained poor communication patterns. Strong communications between parents and grandparents also served to diminish concerns related to interference and boundary crossing actions.

_Sibling Role_

Senner and Fish (2012) recognize sibling relationships as being the longest lasting and second only to that of a parent-child relationship. Siblings serve as a sense of security for their siblings with a special need in parents’ mind (Graunegaard & Skov, 2006). Siblings are regard as being able to identify with one another (Maul & Singer, 2009). Over time siblings will either draw closer to one another or grow more distant over their life span dependent on the various phases of their lives. Siblings provide for one another an opportunity for pro-social interactions and adaptation skill building. Sibling become a source of positive influence and support for their sibling with a special need by offering age appropriate participation in care taking. Research indicates that is higher for same sex siblings.

Siblings serve to influence each other’s development. Siblings gain pro-social resources, positive change, greater compassion, helpfulness, maturity, empathy, and a greater understanding of differences (Kilmer, Cook, Munsell, & Salvador, 2010). Many siblings acknowledge that they benefit from building an increase sense of compassion,
ability to understand others and gain an appreciation of their own good health and intelligence (Orfus & Howe, 2008). Spending time and playing with their sibling are considered positive experiences related to having a sibling with a special need. Helping their sibling to learn new things and the moments where their sibling either shares with them or demonstrates affection are also valued. Female siblings view hugs and kisses as the most uplifting. Male siblings shared that spending time and playing with their sibling as the most uplifting.

Sibling play an important role in assisting sibling’s with a special needs to gain knowledge and experience related to social play. Siblings offer a more natural teaching method for playful social interactions by acting as effective trainers (Bass & Mulick 2007). Social play teaches children to initiate, prompt and reinforce social interaction cues. Thru play initiation, response of social behaviors increases. Social play leads to growth in cognitive, social, cultural competencies for both siblings.

**Family as a Team**

A healthy family is dependent on all its members (Orfus & Howe, 2008). By working together in a team mentality families build cohesion and created a buffer against stress. Siblings learn to develop their coping mechanisms from their parents, relatives and teachers. The nurturing environment of their home enhances positive sibling adjustment and aid in connecting to their community. The expansion of family resources and caregiver social support can offer positive qualities towards adjustment.

Most siblings gain knowledge through observation, asking question and listening to adult discussions (Hames, 2005). Awareness can come at as early as age seven, when abstract thoughts begin to form. Social responses towards their sibling with a special need
teach them to understand about abilities. It aids in learning to make predictions for their sibling’s future abilities and gain knowledge about the condition their sibling in living with.

**Sibling Isolation, Frustration and Fears**

Feels of isolation may occur from parents effort to protect their child(ren) by concealing information related to the condition (Dodd, 2004). Parental distress may influence discussion related to condition with siblings. Communication and trust were linked to open relationships between parents and their children. Siblings benefited from information that was age appropriate. Interactions with their sibling contributed to feelings of involvement. While positive parental adjustment supported their child(ren)’s awareness of their sibling’s needs. It also promoted positive attitudes and perceptions towards their siblings.

While many parents are able to acquire parent to parent support siblings may face a lack of support (Conway & Meyer, 2008). Siblings face similar experiences, stresses, and pressures as their parents. Siblings that seek information do so to possess knowledge to answer the questions of their peers and friends regarding their sibling’s condition. These siblings require a forum to express and vocalize their concerns. They need assistance in understanding the feelings and emotions related to having a sibling with a special need. Siblings play an important role in the lives of their siblings and may require aid to recognize the importance of their role.

Siblings were found to experience some negative effects related to their sibling having special needs (Maul & Singer, 2009). According to Kilmer, Cook, Munsell, & Salvador (2010), siblings’ feelings and experience conflict related to:
- Depression
- Anxiety
- Embarrassment
- Fear
- Withdrawal
- Guilt
- Resentment
- Irritability
- Aggression
- Peer conflict

Often these sibling perceived levels of loneliness were high. Some younger siblings would take on the role and responsibilities of an older sibling to assist their parents (Maul & Singer, 2009). Siblings often mimic their parents’ care giving actions with the infant with special needs. They assist with household chores. Female siblings were more likely to take on parent like roles than sibling roles. Many male siblings endure peer and psychosocial problems (Schuntermann, 2007).

Due to the demands placed on their parents, siblings often claim that they were deprived of their parents’ time and attention (Schuntermann, 2007). Parents strive for equality among their children but time constraints amplify the level of difficulty (Dodd, 2004). Parents recognize that the level of involvement for their children with special needs is often more intense and difficult (Hughes, Valle-Riestra, & Arguelles, 2008). They also express the sentiment that they believe their child may miss out on activities because of their home responsibilities.
Sibling risk can arise when expectation to undertake parental like care taking responsibilities become burdensome (Schuntermann, 2007). Other risk such as attention difficulties and conduct problem may also occur. Siblings can face increase conflict, increased behavioral problems, decreased positive interactions, and decreased opportunities for out of the home activities. As a result siblings development of their personal autonomy may suffer and they may receive reduce availability of parental support.

Coping Thoughts

Stress coping mechanism that children learn are either internalization, accepting responsibilities or feelings of remorse, or externalized, that attribute control to others (Orfus & Howe, 2008). They may also learn to implement humor, suppression, self-sacrifice, and practice anticipation of next stress. The most common coping thoughts that siblings use are centered on wishing their sibling’s special need never happened, making things different, and fixing their problems. Female siblings concentrate on trying to think of answers while male siblings concentrate on the special need never happening.

Protective Factors for Siblings

Positive peer relationships and strong friendships are considered protective factors for siblings with a sibling relation that have a special need (Schuntermann, 2007). These siblings demonstrate enhanced self worth and ability to cope. The potential for negative risk outcomes and vulnerability are lowered. Additionally, siblings can benefit from support groups (Senner & Fish, 2012). Siblings participating in support groups have higher positive outcomes, a stronger knowledge base and awareness of their sibling’s condition, higher self esteem, and increased social-emotional adjustment.
Parents value sibling support groups as they reference a need to assist their child(ren) to cope with their sibling’s special need (Dodd, 2004). Siblings must learn to cope with limited time with their parents, worries about the future, guilt over feelings of anger and embarrassment over sibling’s condition. In many cases, siblings face bullying and teasing. As well as stressful home situations due to tiredness, sleepless nights while at the same time attempting to manage school requirements. Support groups are viewed as a means for their child(ren) to connect to others in a similar situation.

Diagnosis and Disclosure

Parenting difficulties related to an infant with special needs may increase the level of stress that parents experience (Olshtain-Mann & Auslander, 2008). Major causes for apprehension for parents are concerns for the survival of their infant and the long-term potential effects on the infant’s development. Prolonged hospital stays can tax a parent emotionally (Thomas et al., 2009). With an increase in stressor factors, the greater potential of lower levels of parent efficacy enhances. Stress taxes the psychological resources of parents.

These stressful experiences are enhanced by inhibiting factors towards carrying out the parenting role (Olshtain-Mann & Auslander, 2008). Parents may be separated from their infant due to equipment and testing which can limit the opportunities to foster attachment (Thomas et al., 2009). Parents may exhibit feelings of doubt causing them to experience uncertainty in themselves as parents and view parenting as difficult. These stressful experiences may delay the attainment of perceived parenting roles and parental efficacy impacting long-term parent-child interactions.

Parents that suffered from high levels of stress experienced lower levels of
perceived parental competency (Olshtain-Mann & Auslander, 2008). The long term needs of their infant increase the level of stress experienced. Parents feel “hopeless” when they begin to question their own ability to care for the needs of their infant. When parents experience depressive symptoms they are less likely to be interactive, less supportive and demonstrate higher levels of negativity (Churchill et al., 2010). Parents presenting with depressive outlooks can have less effective parenting skills that adversely affect the family function. Parent attitudes and parent-child interactions tend to be more negative. Depression reduces a parent’s perceived sense of control and parental empowerment. Parents experiencing depressive symptoms face increased challenges related to adapting to the needs and responsibilities in caring for their infant’s special needs. Chronic health conditions impact a parent emotionally, socially and financially.

The manner in which a parent is disclosed that their infant has special needs can affect later parental perceptions towards efficacy and responsiveness (Pearson, Simms, Ainsworth, & Hill, 1999). In a study on disclosure between eighty-one percent and ninety percent of parents suggested that they preferred to experience a direct disclosure process as opposed to an indirect disclosure. Parents given indirect disclosure later felt they were negatively affected by seeing their infant grow with special needs. Parents that felt they were provide sufficient information possessed more positive views. Around forty-three percent to fifty-six percent of parents were disclosed together of their infant’s special needs. Nine out of nineteen were told separately. Forty-seven percent felt that only if the situation was justifiable should they have been told separately. At the time of disclosure parents appear to want information related to the condition, its cause and effects on the child’s development (Kerr & Intosh, 2000).
Diagnosis plays an important part in parents’ ability to cope (Graungaard & Skov, 2006). A diagnosis at the initial stage can increase parent ability to cope. Later diagnosis decreases coping due to uncertainty. Dissatisfaction can arise because of uncertainty by altering the parental perception of what they can do for their infant. A positive result of uncertainty in the diagnosis process is that it can promote problem solving coping skills that have a positive effect on parent efficacy. Parents’ seek to facilitate the process of acquiring a diagnosis by searching for information thru their own research and urging of testing. A diagnosis supports a parents’ in their expectation and perception of being able to control the future. A known future enables active coping skills that can reduce stress.

**Successful Adaptation**

When parents are able to adapt they display a higher sense of parental control influenced by a sense of parental empowerment (Churchill *et al.*, 2010). Coping is a significant predictor in successful parenting. Parent ability to cope can predict a child’s future wellness and adaption to their condition. Care giving needs require parents to plan ahead for successful outcomes. Some time adaptations made by parents include slowing down, going to bed later or rising earlier, making a concentrate effort to arrive to places early to accommodate the time and care needs of their infant (Maul & Singer, 2009).

Accommodation allows parents to create proactive efforts to problem solve perceived stressful situations. Another component in accommodation is the redesigning of family roles, relationships and responsibilities. Research attributed this process of adaptation to family coping styles in terms of family resiliency and their ability to manage the current situation. Some parents create a view of a family team (Maul & Singer, 2009). Family members work together in close collaboration to give each other
breaks in primary care responsibilities. Families with additional children take turns spending time and doing activities with the other siblings. One parent assumes the primary care giving role for the infant with special needs while the other parent spends the time with the other sibling(s).

Support Systems

Support serves the role of enhancing mutual self esteem and self efficacy in both infant and parental development. Considerations include child and parent well-being, the primacy of the parent-child relationship, and assistance in interpreting subtle communication signs (Bruder, 2000). Support validates the infant's attachment to their parent. Understanding parental needs in relation to responsiveness of their infant is linked in terms of helping with positioning and handling strategies to encourage optimal interactions. This can include helping with interpreting motor movements and assisting in the distinguishing of reflexive patterns or reactionary patterns (Casby, 2003). Parents can learn to respond to their infant through the process of play.

Importance of Play

Play serves the purpose of teaching infants social skills (Frascarolo, Favez, Fivas-Deseursinge, 2003). Casby (2003), suggest that parent takes on the role of examiner for the infant. Play is constructed in their natural setting with the provision of items for use. Parents then model a behavior or action and the child then imitates the same behavior or action. The quality of social stimulations and interactions are important (St James-Roberts & Alston, 2006). Infants that receive significantly less interactive structural play with mothers have higher levels of risks in long term outcomes.

Play Dilemmas


Special needs can inhibit easy access to play materials and facilities (Hewitt-Taylor, 2008). This can lead to reliance for others to facilitate play opportunities. Communication becomes managed by others that lead to differences in play experiences. Physical needs can lead to exclusion due to equipment, toys and facilities being hard to acquire. The opportunities for spontaneous play are decreased as well. Families must travel to facilities that can accommodate the needs of their child. This can lead to fewer opportunities to socialize locally and within their community.

**Facilitator Role**

The parent acting as the facilitator is responsible for shaping the environment and making it interactive, which can improve the long term outcome of an infant with special needs (Casby, 2003). In consideration that play is a process parents should focus on the process rather than the product of outcomes (Walker, 2002). Play that creates interesting and stimulating situations tend to exhibit positive, responsive, naturalistic, and focused qualities (Casby, 2003). One such example is demonstrated between mother-child turn-taking interactions. Papalia, Olds, & Feldman (2002) mentioned that up until two months infants can imitate the response of sticking out their tongue when adults have modeled the behavior of a part of their body the infant cannot see, known as invisible imitation. In later months infants can imitate demonstrate imitation of body movements that they can see which is known as visible imitation and occurs around nine months of age.

**Play and Theory**

The theory of Piaget focuses on the concept of stage development for cognitive processes (Papalia et al., 2002). His theory is based on the premise that children adapt to their environment based on their experiences. Children learn organization of thought by
using patterns of learned behaviors called schemes. Every new piece of information is assimilated until equilibrium and balance is established in the comprehension of new information. For infants this process of learning new information can be determined through their physical motor development action and their cognitive awareness of the materials they manipulate.

The sensorimotor stage occurs between birth and age two, with six substages:

1) The first substage occurs from birth to one month and involves the infant gaining control over inborn reflexes.

2) The second substage occurs from one month to four months. This is the primary circular stage where the infant repeats pleasurable bodily sensations such as sucking their thumb.

3) The third substage is from four months to eight months and is known as the secondary circular stage where the infant begins manipulating objects beyond their own body such as shaking a rattle.

4) The fourth substage between eight to twelve months involves coordination of schemes such as crawling to a desired toy.

5) The fifth substage is from twelve to eighteen months and involves tertiary circular reactions. Infants vary actions to get similar results such as squeezing a rubber duck to see if it will squeak the same way it did when they stepped on it.

6) The sixth substage of a mental combination of eighteen months to two years is when the child exhibits representational ability. This included the use of symbols to mentally recall objects representation and then take action. This then becomes
deferred imitation since infants are imitating things that are not necessarily in
front of them.

Application of Play

The developmental range of play begins with the stage of exploration at the age of
two months (Papalia et al., 2002). An infant in this stage exhibits behaviors such as
shaking, banging, and turning over objects. Infants will additionally utilize sensory
experience and movements that involve hearing, seeing, touching, and moving while
engaged in play. The second is the functional stage, at twelve months the child beginning
to use an object as it was intended, such as pushing cars and opening and closing items.
The later functional stage occurs around twenty months where the child exhibits
behaviors of using objects appropriately, such as puzzles, stacking blocks, and applying
crayons to mark on paper. The creative-symbolic stage at twenty-four months uses
symbols. Acquisition of this stage can be demonstrated in the act of play by using a box
to represent a choo-choo train (Casby, 2003).

Research suggests that play behavior of infants and toddlers is reflective of early
cognitive development (Papalia et al., 2002). The early levels of sensorimotor–
exploratory play are reflective of the early stages of sensorimotor development (Casby,
2003). Later forms of play, such as functional–conventional and symbolic play may be
suggestive of the later stages of sensorimotor development. It can also be representative
of early aspects of preoperational development. Children with developmental limitations
and restrictions are more likely to demonstrate difficulties in play, especially symbolic
play. Depending on the type of developmental restriction development play experiences
can also be affected.
Parents and Play

Parents engage in different types of play (Frascarolo et al., 2003). Both parents are sensitive to the infant and pick up on cues. As indicated by research mothers tend to vocalize more, hold the infant more often, and focus on interest, delight, or catching and holding the infant’s attention. Through this the infant learns to regulate themselves emotionally. Research has indicated that fathers spend less time caring for their infant and more time involved in play with their infant. Fathers tend to be more physical in play that can involve more teasing and uncertainty at the cognitive level.

Play Assessment

Play can be the basis of valuable developmental assessment and intervention strategies (Casby, 2003). Play activities, behaviors, and interactions are some of the only available forms of observation of infants, toddlers, and children suspected of having a developmental delay. Play provides infants with parallel, interactive and supportive relationships that include early social, cognitive, representational, communicative, and linguistic developmental opportunities (Walker, 2002). Infants are more likely to demonstrate the development of symbolic play with significant individuals that can lead to shared meanings between infant and parent. Parents of infants with special needs learn to be responsive to their infants’ needs through play.

When engaged in parent-infant play, modifications can be made to enhance the play process (St. James-Roberts & Alston, 2006). Parents can provide support through the provision of various materials. Parents can create experiences that are as close to normal for infant with special needs through modification and adaptation. Adaptive equipment or materials can modify the environment for the infant. Such modifications
may include providing sufficient space for the infant to move around, talking with the infant, responding to requests, guiding the infant in problem solving, and providing feedback support as the infant engages in play (Walker, 2002).

_Early Intervention_

Epley, Summers, & Turnbull (2011) identify five main family outcome goals of early intervention:

- Ensure that parents know their rights and are able to effectively advocate for their child’s rights
- Assist families to understand their child’s special needs and their abilities
- Help families in the development and learning processes of their child.
- Act as a support system
- Enable families in gaining access to desired services and activities in their community.

The parent role is fundamental in identifying needs that enhance the outcome and quality of life thru individualized services. Concerns, priorities and resources may not be sufficient to promote positive family outcomes. A joint determination between families and early intervention practitioners is essential. Families that have infants with special need early intervention support services to enhance and support the development of their infants and the family’s well being.

Russell (2008) suggests that as high as one in thirteen families receives social support services. Early Intervention assists families with obtaining, maintaining and implementing service for the infant. Generally services are conducted in play styles. Early Intervention programs assist families with parent education (Walker, 2002). They
highlight parental responsiveness to reading, identifying, and responding to infant cues. Communication strategies that are appropriate and meaningful are also discussed. Early Intervention seeks to improve an infant’s ability to interact through adaptation of movement patterns.

Early intervention (EI) programs were formed under Part C of the Individuals with Disabilities Education Act (Wall et al., 2005). The goal and effort of early intervention is to target infants from birth to age three and assist their families. They are community based programs funded through competitive grants initiated by the Department of Health and Human Services. The Family Partnership Agreement (FPA) delineating family outcomes, responsibilities, timetables, strategies and progress in achieving the projected outcomes for an infant with special needs in consultation with the family.

*Individualized Family Service Plans*

The Early Intervention process involves Individualized Family Service Plans (IFSP) (Wall et al., 2005). IFSP’s evaluates the infant’s progression and the family’s needs in different areas. IFSP’s identify the current level of development of the infant in the five domains. It identifies the family’s priorities, concerns, and defines current and needed resources. It serves to identify the major outcomes that can be expected to be achieved by the infant in terms of time and duration. It specifies the early intervention services that will be provided in the natural environment. It provides projected dates for initiation and duration of services. It identifies the service coordinator coordinating the services; the steps for transition to special education services.

*Early Intervention as a Support Tool*
Early intervention serves to enhance parents understanding of child development in terms of their infants special needs (Welhman, 1998). Early intervention takes a proactive approach at decreasing delays, mediating current problems, striving to prevent future deterioration by attempting to limit handicap acquisition. The main focus of early intervention for families is to promote family functioning by recognizing parents as consumers (Dunst, 2002). Early intervention seeks to support families by respecting parents as decision-makers concerning their infants’ needs. Early intervention empowers parents in creating goals and identifying services through partnerships (Judge, 1997; Popich, Louw, & Eloff, 2006). These types of support practices can lead to increase perceptions of parental responsiveness and parental efficacy. According to Baldry, Bratel, Dunsire, & Durrant (2005), family centered intervention methods, such as early intervention, can increase family levels of well being and function while decreasing risks of child abuse due to positive perceptions towards parenting abilities.

**Key Worker Role**

Sloper, Greco, Beecham, and Webb (2006) identifies components that assist parents in their role as provider for their infant. Parents need emotional support from quality programs. Programs and services need to be relevant to each family to be effective (Kontos & Diamond, 2002). Each family and child has unique needs that require specific tools support families. Families seek to have information about the services available to their infant and family (Sloper et al., 2006). Parents are interested in being listen to, supported, assisted in gaining control back, positive perceptions, build strength focused plans, focus on the family, and increase child safety (Zhanga et al., 2006). They need guidance and advice to identify and address their needs. Key workers
can assist families in representing themselves to obtain coordinating care and improve access and availability in implementing them (Kontos & Diamond, 2002; Sloper et al 2006).

**Overcoming Conflicts**

Professionals and families may come into conflict due to the scheduling of meetings that all parties are required to attend (Zhanga et al., 2006). At meetings goals are defined, some families’ may lack understanding and knowledge of child development. Some families are unable to understand goals established prior to meeting with the programs that are implementing them. To assist with clarity family support can be offered by preparing staff to meet with parents. Share practical knowledge of strategies that families can use with infants that families can participate in the process. Inform parents of ongoing child development monitoring that increases parental knowledge and provides parental empowerment. The forging of links between families and communities had highest rates of positive outcomes.

Partnerships between parents and professionals can either enhance or impede the infant’s outcome depending on interactions and transactions that occur between the two parties (Dunst & Dempsey 2007). Effective relationships serve to empower parents through knowledge giving and positive attitudes and behaviors of control, compliance and competencies for their infant’s care. It can positively influence parent functioning by increasing perceptions of control over life events. Additionally, parent’s perceived capabilities increase as they experience a sense of control in accessing desired support resources. Help giving styles that allow parents to act as participators increase parent competencies by actively involving them in joint decision making processes. Empathy
and active listening with parents improve relational interaction between parents and professionals.

**Culturally Diverse Family Experiences**

Culturally and linguistically diverse parents face challenges related to advocating for their child (Lo, 2008). They needed more support and parent education. Parents demonstrated a preference to being consistent in utilizing the same methods of intervention as professionals. Though barriers exist that may inhibit full collaboration between parents and professionals. Professional and parents must establish a sense of parity in which each participant is considered to possess equal value towards the role of decision-making (Olivos, Gallagher, & Aguilar, 2010). It increases a family’s ability to develop decision-making skills for their child’s goals and outcomes.

At times cultural disconnection may occur. Issues of mistrust, suspicion, and resistance may develop (Olivos et al., 2010). At time parents may feel that they should follow and not lead the direction of decision-making. Parents may require translator that are not readily available (Lo, 2008). Some families found terminology used to be confusing. Families fear that values and ideas contrary to the dominant culture may be viewed as concerning (Olivos et al., 2010).

The main building block of collaboration is the understanding of family support systems and the ways in which the families value them (Olivos et al., 2010). Culture and community are two factors influencing a family’s values, perceptions and interactions with their child (Dote-Kwan et al., 2009). It incorporates the leveraging of family resources to improve the quality of services that are identified for the child (Olivos et al., 2010). Concerns related to household finances, a sense of lacking information, and the
level of adequacy of the resources must also be considered (Dote-Kwan et al., 2009).

**Better Family Outcomes**

In a study conducted by Wall, Taylor, Liebow, Sabatino, Mayer, Farber, and Timberlake (2005), ninety-four percent of parents informed of service eligibility participated in a survey about early intervention involvement. Parents were surveyed to analysis involvement in early intervention programs and identify key factors for parent continuation. A greater percentage of parents were more likely to continue with the application process when approached and assisted through the paperwork process. Support from professionals was identified as a key component in parent persistence with program usage.

**Family Outlook**

Families coping with infants with special needs transition through a grief process involving denial and the loss of the hoped for child (Vacca, 2006). Parents experience stress in relation to their infants’ diagnosis, gender of the parent, their ability to adapt. Mother experience higher levels of stress as the primary caregiver (Macias, 2001). Fathers serve the role of protective factors of mothers stress. Fathers acquire information, allocate services, and in the role of decision after the infant’s birth.

A parents’ initial experience with their infant’s health care professionals can have lasting influences on their ability to cope (Graungaard & Skov, 2006). One influencing factor is the degree of sympathy and understanding the professionals offer parents. As is the time lapse between the suspicion of a special need and the diagnosis is provided. Although in some parents must face an unknown diagnosis over having an identified diagnosis. For parents that experience a long diagnosis process a higher rate of
dissatisfaction and parental depression is noted (Tran, Medhurst, & O’Connell, 2009). Often the emotional distress is underestimated; the need for information being a large contributing factor.

Parents faced with infants experiencing special needs desire information related to aiding in their infant’s development (Mahoney, Kaiser, Girolametto, MacDonald, Robinson, Safford, & Spiker, 1999). Early intervention assist in attain in useful and necessary developmental skills, it assist in establishing and managing daily routines, and it serves to enhance play and social interactions (Epley, Summers, & Turnbull, 2011). For early intervention to be effective it is critical that parents be involved.

Play is a valuable component in parental infant relations. Play provides an infant with social interactions with their parent. Both parents’ exhibit equal levels of responsiveness and consideration towards their infants cues. Mothers tend to be more engaged in turn taking type of play (Frascarolo et al., 2003). Fathers engage in higher level cognition interaction of teasing with unpredictable outcomes. Play serves the role of assessment of cognitive levels infants with special needs through Piaget’s theory of sensorimotor development (Papalia et al., 2002). Infants involved in symbolic play exhibit higher levels of functional play and cognition.

Play that is engaging and stimulating serves to assist in an infants’ development (Casby, 2003). Facilitation of significant play can be provided to parents through the use of services provided by early intervention programs (Walker, 2002). These programs assist families in responding to their infants needs by understanding terminology, recognizing and responding to cues, utilizing play as a teaching tool.

Parents’ responsiveness is a primary factor in the outcome of their infant’s long
term life outcome (Baldry et al., 2005). Their view of themselves as a parent affects their ability to both perceive and respond to their infants needs. Positive perceptions enhance a parents’ efficacy and their perception of their ability to demonstrate parental responsiveness. Support enhances positive views of parental efficacy and their skills in parental responsiveness. Play is considered the primary forum through which parents can interact to benefit their infant’s development provide more positive long term outcomes (Walker, 2002). Early intervention can educate parents on best practices and solution based techniques on how to interact effectively with their infants through Individualize Family Service Plans.

Families that have addition children must learn to respond openly and honestly to their children regarding the special needs subject matter (Hames, 2005). Concerns for future children weigh on the mind of the parents (Graungaard & Skov, 2006). The possibility of their other and/or future children may be at risk or face complications must be considered. Parents may also question the impact on siblings and require assistance in receiving counseling (Dote-Kwan et al., 2009). Parents list the lack of information as cause for greatest amount of stress. As such parents need aid in recognizing and creating support system while comprehending complex service systems.
CHAPTER III

METHODOLOGY

The data collected for this thesis was part of a convenience sample by way of a self administered questionnaire conducted with parents of infants with a special need. Each respondent had an established partnership with the CHIME Institute and the CSUN Child and Family Studies Center inclusive program.

The CHIME program serves families with children with special needs. The CHIME organization has an infants and toddler program that serves child ages zero to three with special needs known as the CHIME Early Intervention program. Children ages two years six months may receive assistance from CHIME Charter elementary or at their collaborative partnership program at the California State University Northridge (CSUN) Child and Family Studies Center. Parents receive support in meeting their children’s needs thru individualized innovative services that are developmentally appropriate and cohesive with the therapies and activities intervention their child needs. Physical, socioemotional, occupational, and speech therapy services are fostered in a pro-social interactive play environment.

CHIME Early Education program was founded in 1991 and is located in Chatsworth, CA. The CHIME Institute and CSUN Child and Family Studies Center collaboration began in 1994 and is located in Northridge, CA. Dr. Jerry Ann Harrel-Smith is the center director of the CSUN Child and Family Studies Center, as well as, a full time professor for the Family Consumer Science Department, Family Studies students. Annie Cox M.A. is the program director of CHIME Early Intervention and the collaborative CHIME inclusive preschool and kindergarten component at the CSUN
Child and Family Studies Center.

**Procedures**

To measure the means by which parents develop parental efficacy an exploratory qualitative research design with a focused sample survey of five parent dyads (a total sample of 10) was conducted. Questions explored the family dynamics and their past history with their infant’s special needs experience. Parents were asked to describe their experience from their infant's birth and their infant's diagnosis to the coping process they underwent through written statements. The roles of the family support systems were analyzed, such as the role of siblings and/or extended family members in care taking of the infant, as well as, how care knowledge and care needs information to meet the needs of the infant were distributed among family members. Responses were utilized to identify parent perception on role of efficacy in regards to their child with special needs.

**Questionnaire**

The survey measurement utilized in this thesis was created by the researcher based on past research found in the review of literature in conjunction with the researcher’s knowledge base of the subject. The researcher has unique qualifications which enabled her to develop a relevant measurement to analyze the perception of parents regarding their progress to parental efficacy.

The researcher has a B.A. in Child Development form CSUN that provided her with the knowledge base to relate theoretical framework to the research findings of the review of literature by formulating a relevant open-ended questionnaire. At the time of the instrument development, the researcher had partaken in the Family Consumer Studies graduate level Research Methods and Seminar in Research courses at California State
University Northridge. Additionally the researcher had practical knowledge of both the CHIME Institute and the CSUN Child and Family Studies Center as a researcher who was previous employed as a CHIME assistant and mentor teacher at the CSUN Child and Family Studies Center. This practical knowledge enabled the researcher to determine relevant thematic areas of inquiry. The survey protocol was developed in collaboration with committee chair Dr. Jerry Ann Harrel-Smith and approved by the CSUN Human Subjects department.

The following questions were asked of parents with children with special needs:

Section 1 involved general identifying background information. The questionnaire provided a combination of nominal and ordinal questions requesting identifying information regarding:

- Age
- Sex
- Occupation
- Highest level of education
- Parent living in the same household with child
- Additional individuals living in the household and related identifiers
- Knowledge sources
- Services plan utilized and age at which it started

The information was utilized to discern commonalities and dissimilarity based on the continuous and categorical variables differentiate from the responses.

According to Patton (1990), qualitative inquire should have good questions that at minimum are open-ended, neutral, clear and singular. It is recommended that
noncontroversial questions encourage straightforward descriptions that are fairly to easy to answer. To this end, Section 1 focused on age, gender, occupation, education, and current relationships status of the parents and corresponding child’s gender, age and needs questions. These responses require minimal recall and interpretation of the questions asked. Background questions, as Patton describes, can be boring although the information may be necessary to make sense of subsequent information. These questions should be linked to descriptive information and experiences. To allow for this, each family was asked about additional siblings living in the same household. Families were asked to provide relevant age, gender, and role in sibling’s life information if relevant.

Section 2 focused on open ended responses by respondents to questions requesting their description of an experience, their response to an experience, description of addition individuals’ involvement, or play practices related to the caregiving needs of their child’s special need.

- Please describe your initial reaction as a parent:
- Please describe your experience through this process:
- Please describe how this affected your parenting:
- Please describe how you shared your child’s needs with sibling(s):
- Please describe sibling(s) reactions (If applicable):
- Please describe if these need(s) has affected interactions with siblings (If applicable):
- Please describe how you shared your child’s needs with extended family:
- Please describe the family’s response and reaction:
- Please list and describe ALL family assistance and type of assistance provided:
• Please describe how this may have affected interactions with extended family:

• What does your family like to do together?

• What role does play have on your family interactions?

• Please describe your child’s need(s):

• What services are received (If applicable)?

• Overall, how has all the knowledge you have gained impacted your parenting?

As such, Section 2 expands on Patton’s concepts by focusing on the qualitative responses parents provided to the “process” of diagnosis and subsequent mourning period at the loss of their perceived child. The sequence of these questions follows Patton’s suggestion that once either experiences or activities have been detailed it is acceptable to inquire about interpretations, feelings and opinions. To minimize the threatening nature of these questions, they were asked in conjunction with a series of questions related to current activities and experiences. To enhance the quality of responses and to allow for “open-ended” responses, questions were designed for qualitative inquiry that allows for the researcher to determine dimensions, themes, words/images respondents utilized to describe feelings, thoughts, and experiences. The goal of the researcher was to allow for respondents to freely use language to represent what they desired to share on the subjects areas presented.

All surveys were transcribed into English and Spanish by the researcher, who is fluent in both the English and Spanish verbal and written languages. Participants were offered the choice of either language to which they could choose to respond. The researcher of this study has unique qualifications which enable her to translate and comprehend sample survey communications without cultural and linguistic barriers. The
researcher is fluent in the Spanish language. Additionally, she has both educational and practical knowledge in the fields of early childhood development and special education needs.

Spanish responses were to be transcribed verbatim into English by the researcher. To ensure translations were accurately transcribed “Google translator”, located on the Google online website, was to be referenced and used to review translations. All participating families responded in English to the survey questionnaire.

Sample

The data for this research was collected from parents with infants challenged with special needs utilizing services received through the CHIME program. Participants responded to a self-report questionnaire regarding parent response to infant’s diagnosis, grief processing, family dynamics, impact on parenting, knowledge of child’s needs and rights, acquisition of knowledge, familial support from extended relatives, and the role of play. Parent/guardians reported on age, gender, education, and their child’s age and gender by responding to the self-administered survey questionnaire.

Enrolled parental dyads of the CSUN Child and Family Studies Center that chose to participate in the sample made up the accessible population. A total of 5 dyads (n=10) participated in this study. The gender of participants was distributed as five females and four male spouses living in the same household with their child. The age of the parents completing the survey ranged from 33 years to 44 years for the mothers of the child. The fathers’ ages ranged from 34 to 44 years for the four out of five fathers. For the one father that lived out of state no age was provided.

Pilot Study
Family subjects were part of the CHIME Early Education program and were asked to voluntarily participate. All parents of an infant with a special need enrolled at the CHIME Early Education program during the data collection period were invited to participate in the study. A survey questionnaire was disturbed to family meeting the research criteria. Families received a letter introducing the researcher as a California State University Northridge Family Consumer Sciences graduate student working on towards her master’s degree. Survey questionnaires were distributed at the end of the programs meeting time during a discussion group. Each participant was given a written consent form to review and sign acknowledging their agreement to participate. The consent form also provided the participants with notification that they could choose to withdraw from the research study at any time.

The questionnaires were presented to participants by the CHIME Early Education program teaching team. The collaborative teaching team consists of Annie Cox M.A., Director of Early Education Programs for the CHIME Institute, Jodie Agnew-Navarro, M.A., lead center based Early Intervention Specialist, Olga A. Quirarte, M.A., home-based Early Intervention Specialist, and Frances (Fran) Smith, M.A., C.C.C., Speech Pathologist. Both Annie Cox and Olga A. Quirarte are fluent bilingual speakers and writers in English and Spanish.

Individual participants were asked if they would like to complete a copy of the survey questionnaire in either English or Spanish. The panel then encouraged participants to take the opportunity to reflect on the statements and topic presented in the survey. Each participant was provided the opportunity to reply to each question and statement regarding their role as parents of an infant with a special need. As participants concluded
filling in their own responses, the forms were then sealed in a white envelope and
gathered in a manila folder for the primary researcher’s analysis. The teaching team was
to gather the responses and return the completed instruments to the primary researcher to
review the data. Several weeks passed without participants returning.

After several weeks without any responses from the respondents invited to
participate in the research, the researcher met with committee member Annie Cox. Annie
Cox shared the following feedback that families felt overwhelmed by the survey
question, they felt they were too difficult to respond to, and that they did not have the
time to dedicate to respond to the survey.

**Focus Group**

Through continued discussion with Annie Cox, the researcher was invited to
survey the families enrolled at the CSUN Child and Family Studies Center that has an
inclusion component. The school offers preschool and kindergarten aged families
enrollment through the CHIME program. This allows for the children to participate in a
typically developing inclusive classroom while still receiving assistance from CHIME
support teachers. The children are eligible to receive their therapeutic services within the
classroom while playing and interacting with typically developing children.

As way of explanation, Annie Cox offered the insight that many of the families
enrolled in the Infant/Toddler program were still too close to the event or still undergoing
the process of diagnosis and were not mentally or emotionally prepared to answer the
questions. This was most probably the reason the researcher was unable to gather
responses from the pilot group the researcher had originally sought to survey. So by
instead extending the survey to the parents of the preschool aged children, parents would
be able to better reflect on their process into parental efficacy as a reflective questionnaire.

With this information, the researcher contacted her committee chair Dr. JerryAnn Harrel-Smith and discussed the new proposed research plan. After obtaining Dr. Harrel-Smith’s consent, the research proceeded to complete and submit a revised Human Subjects Protocol. On June 21, 2012 permission to extend the survey to the preschool families of the CSUN Child and Family Studies Center CHIME families was granted as an exempt permission. With the new approval, the researcher asked Annie Cox to share the surveys with the preschool families and invite them to participate. Joining her in the recruitment of participants was Erika Barnathan, an inclusion specialist and special education teacher for CHIME preschool and kindergarten program. After speaking with either Annie or Erika, each family chose to take home a copy of the survey question and respond on their own in legible print for the researcher to privately review.

Within the first three days of the survey being offered to 10 families for participation there were three responses. By the end of the week two additional families responded and returned completed surveys. Once there was a fifty percent return rate of the surveys, the researcher conferred with her committee chair. The two mutually agreed that the quality of the responses provided by the five respondents would suffice for the purpose of this research study.

**Measurement**

This thesis is based on five parent dyad responses to a self-reflective hand written instrument regarding parent perception of efficacy in their role as parents of infants with special needs. Measurement responses were utilized to determine the supporting factors
through the process parents of infants with special needs obtain parental efficacy in caring for their child’s unique needs. The instrument responses generated qualitative research data. As such, qualitative research methods for data collection and analysis were explored to understand the perception of parent views of their transition towards positive parental efficacy.

Each participant was asked to respond from recollection on the process of their infant’s identification of special needs. Survey material was reviewed to identify similar themes, patterns, and time frames. Each response was individually read to identify themes (Strauss & Corbin, 1998). A process that Patton (1990) refers to as inductive analysis. Themes emerged out of the data. This occurs after collection of materials has been review instead of being imposed on the data prior to collection. The material collected was compared and contrasted similar parental experiences, stressors, or opinions as developed from the research indigenous concepts. These themes were then compared to the information gathered in the review of literature.

The themes that emerged by each respondent were compared based on topic area. Patton (1990) recognizes that the findings produced from qualitative research culminate in making sense of data through analysis, interpretation and the presentation of findings. The essence of the data is revealed through the identification of significant patterns and the building of a framework that communicates the meaning of the data. In qualitative research there is no formula to determine significance but relies on the analytical intellect of the research analyst.

According to Patton (1990), the process of qualitative data analysis is a creative process and each analyst must form one’s own creative process. For this reason, the
researcher developed a coding system that incorporated the first five letters of the alphabet as the first initial to each of the respondents’ family last name. The coding system was utilized to maintain the privacy of each participant. The researcher sought to maintain the quality of the qualitative research without jeopardizing the integrity and anonymity of the participants. To protect the identity of the families, each individual was coded with a pseudo identity and pseudo family last name.

Once the information was coded, the researcher followed Patton’s (1990) suggestion to organize the raw data into a basic descriptive data format that is consistent with case studies. The qualitative data was organized into categories that reflect the myriad of dimensions, factors, and variables drawn from the responses. These responses were woven together to formulate an idiographic framework for further interpretation and reflection by the researcher.
CHAPTER IV

RESULTS

Following with Patton’s (1990) assessment of purposeful qualitative research the first task is the description of analysis. In qualitative analysis the analyst must apply rigor and discipline by presenting a solid description of data first. Analyst may be tempted to put together coherent answers to the questions by attempting to interpret the research. But Patton resolutely states that the “thick description” must first be presented.

Section 1: Statistical Demographics

Patton (1990) suggests that findings be presented by grouping together people, processes, issues and key events. Grouping individuals are considered primary units of analysis then a case study of the people within the group may be focused on. To relate the responses back to Patton’s determination of qualitative analysis the responses from the survey were transcribed into a formulated Table depicting the statistical demographical make-up of the parents participating in the research study. Each child’s statistical demographic was transcribed into a Table representing each child’s gender, age, the parental description of their child’s needs and related needs unique to their child. An additional Table described siblings in the family.

Three mothers were listed as parent 1 in the returned surveys indicating themselves as primary respondent of the questionnaires. Two fathers were listed as parent 1 as primary respondent of the questionnaire. As such n=10. (See Table 1)

Respondent 1: “Abbott-Jones” family.

The primary respondent of family one, coded “Abbott-Jones”, “Sarah” was a single mother living with her daughter coded “April” (3.5 years old). “Sarah” reported
herself a “mama” for occupation with a baccalaureate degree at the age of 44 years old.

“April’s” father, coded “Sam” “is trying to create a situation where he can see her on the
weekends.” No further details were offered in relation to his demographics.

Respondent 2: “Baldwin” Family

The primary respondent of family two, coded “Baldwin”, is listed as mother “Kelly”.
Her male spouse is coded as “Kevin”. They living in the same house hold with
their son “Brad” (5 years). “Brad’s” mother is 33 years old and father is 35 years old.
“Kelly” has a doctorate degree and works as a pharmacists. “Kevin” is a manger with a
baccalaureate degree. As noted in Table 3 “Brad” has a younger brother, coded “Steve”
(3.6 years old) also living in the same house hold.

Respondent 3: “Carter” Family

The primary respondent of family three, coded “Carter”, is listed as homemaker
mother “Janet”. She listed her age as 32 years old and listed surgical tech as an additional
occupation for herself. Her education level is listed as high school with trade school as an
additional education choice. Father, “Jack” is a male of 44 years old and is works as a
produce department manager. His highest level of education is cited as being high school.
They live together with their son, “Cain” (4.2 years).

Respondent 4: “Darby” Family

The primary respondent was listed as “Mike” father to “Dillon” (5.11 years old)
and spouse to “Mary”. “Mike’s” age is 40 years old and highest level of education is
some college education. He has a career as a director of development. “Mary’s” age is 41
years old. Her highest level of education is a baccalaureate with a professional occupation
as a tax preparer. Additionally as noted in Table 3 living in the same household is
younger daughter “Rose” (3.1 years old); younger sibling to “Dillon”.

Respondent 5: “Elliot” Family

The primary respondent was listed as “Todd” father to “Elton” (5.4 years old) and spouse to “Tracey”. “Todd” is 39 years old and is an attorney with a Juris degree. “Tracey” is a Law office manager with a Juris degree at the age of 39 years old.

Commonalities and Comparisons

Each of the families represented in the tables demonstrate similar commonalities of a child that once was an infant diagnosed with a special need. All parents processed a minimal of high school education and currently are have a career. For the purpose of this study the researcher has recognized the occupation titles of “Homemaker” and “Mama” as careers.

Four of the families consisted of married spouses living in the same house hold with their child(ren). One family consisted of a single parent house hold with her child. The age range of parents for mothers was from 32 to 44 years of age. For fathers it was 35 to 44 years of age.
Table 1:

*Parents’ self-reported parent dyad statistical demographic.*

*(n=10)*

<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Age</td>
<td>44</td>
<td>N/A</td>
<td>33</td>
<td>35</td>
<td>32</td>
</tr>
<tr>
<td>Occupation</td>
<td>“Mama”</td>
<td>N/A</td>
<td>Pharmacist</td>
<td>Manager</td>
<td>Homemaker</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Surgical Tech</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Producing Dept</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Manager</td>
</tr>
<tr>
<td>Highest level of Education</td>
<td>Bachelors</td>
<td>N/A</td>
<td>Doctorate</td>
<td>Bachelors</td>
<td>High School</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>High School</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Some College</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Bachelors</td>
</tr>
<tr>
<td>Relationship status</td>
<td>Single. Separated from father of child</td>
<td>Separated from mother of child</td>
<td>Married. Living in same household</td>
<td>Married. Living in same household</td>
<td>Married. Living in same household</td>
</tr>
<tr>
<td></td>
<td></td>
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<td>Married. Living in same household</td>
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<td>Married. Living in same household</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Married. Living in same household</td>
</tr>
</tbody>
</table>

*Note:* Gender is not specified for some individuals.
Each of the dyads represented in this study have experienced parenting an infant with a special need. Central themes relating to the important process each dyad underwent were deemed as a worthy organizing subject for analyzed as suggested by Patton (1990). The “Carter” family experienced the youngest aged occurrence of infant special needs diagnosis with their son “Cain” at age 3 months. The “Elliott family received a diagnosis for their son “Elton” at the age of 2 year and 6 months as the eldest recognized aged infant in this study. All of the family listed speech as a common source of needed support for their infant. Two families recognized the need for assistance in sensory behaviors and interactions. (See Table 2)

Three out of five families shared their child’s diagnosis as being Autism. Two families shared a description of their child’s needs in lieu of a labeled diagnosis. The “Baldwin” family chose to offer speech as their son “Brad’s” special need. The “Carter” family chose to respond that their son “Cain” special need involved self help assistance.
Table 2:

*Parent reported basic demographic information of their child.*

(n=10)

<table>
<thead>
<tr>
<th>Child Demographics</th>
<th>“April Abbott-Jones”</th>
<th>“Brad Baldwin”</th>
<th>“Cain Carter”</th>
<th>“Dillon Darby”</th>
<th>“Elton Elliott”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current Age</td>
<td>3.5 years</td>
<td>5 years</td>
<td>4.2 years</td>
<td>5.11 years</td>
<td>5.4 years</td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
<td>Male</td>
<td>Male</td>
<td>Male</td>
<td>Male</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td>2 years</td>
<td>1.11 year</td>
<td>3 months</td>
<td>1.6 year</td>
<td>2.6 years</td>
</tr>
<tr>
<td>Child’s needs</td>
<td>Autism</td>
<td>Speech</td>
<td>Self help assistance</td>
<td>Autism</td>
<td>Autism Spectrum Disorder</td>
</tr>
<tr>
<td>Unique care</td>
<td>Language deficits, disruptive &amp; sensory behaviors</td>
<td>Sensory &amp; play with others</td>
<td>Communication and fine motor</td>
<td>Speech and social delays</td>
<td>Occupational &amp; speech therapies</td>
</tr>
</tbody>
</table>
Families were asked to list additional members of the nuclear and extended family currently living in the household. No additional extended family members were listed for any of the five families as living in the same household at the time of the study. Two families did mention their nuclear family did include a second child. In each case the second child was a younger sibling to their oldest child that was diagnosed with a special need. (See Table 3)

The “Baldwin” family included a second son at 3.6 years old named “Steve” in this study. The “Darby” family has a younger daughter that the researcher named “Rose” whom is 3.1 years old. The age between siblings is 1.6 years for the “Baldwin” family and “1.11” years for the “Darby” family. The remaining three other families that participated in this study reported that they had no other children living in the same household at the time of the study.
Table 3:

*Parent reported basic demographics of child sibling living in the household.*

\[(n=10)\]

<table>
<thead>
<tr>
<th>Coded Name</th>
<th>“April Abbott-Jones”</th>
<th>“Brad Baldwin”</th>
<th>“Cain Carter”</th>
<th>“Dillon Darby”</th>
<th>“Elton Elliott”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship</td>
<td>N/A</td>
<td>Steve</td>
<td>N/A</td>
<td>Rose</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td>Younger brother</td>
<td>N/A</td>
<td>Younger sister</td>
<td>N/A</td>
</tr>
<tr>
<td>Gender</td>
<td>N/A</td>
<td>Male</td>
<td>N/A</td>
<td>Female</td>
<td>N/A</td>
</tr>
<tr>
<td>Age</td>
<td>N/A</td>
<td>3.6 years</td>
<td>N/A</td>
<td>3.1 years</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Section 2: Data Analysis

In this section the questions were designed to gather factual, knowledge based, opinion and feelings responses from the families. They were analyzed to assess their parental perception of their parental efficacy throughout the diagnosis process and subsequent parental grief and coping. As Patton (1990) states, the process of interpretation and data necessitates making sense of the words respondents used. To do so a researcher must look for patterns and piece together what is said from one section to another. Additionally only the quotations and important data should be utilized for analysis.

As such, the themes that emerged from the reflective qualitative responses of parents’ of infants with special needs were summarized into tables for comparison. Each table in this section is a representation of issues and additional processes each family underwent throughout this process. The researcher presented the information consistent with Patton’s (1990) description of a case study in which cases must stand allow and later involve compare and contrast of the phenomenon of interest.

Central themes, commonalities and varying parental perceptions were analyzed. Parental reactions and actions were grouped together (see Table 4). Pertinent information regarding parental perceptions of the impact of the process, grief, coping and interactions were divided into two Tables. The parent perceptions on the topic related to interaction with younger siblings were represented separately (see Table 5). Comments, thoughts, and opinions in regards to extended family members were grouped into a separate table (see Table 6). The role of play in relation to family activities and family togetherness were grouped for analyze (see Table 7). Another Table represents a concise tabulation of
parents’ process into the parental expert role (see Table 8).
Table 4:

Parents’ initial reaction and impact on parental abilities.

\((n=10)\)

<table>
<thead>
<tr>
<th>Description of initial parental reactions</th>
<th>“Abbott-Jones” Family</th>
<th>“Baldwin” Family</th>
<th>“Carter” Family</th>
<th>“Darby” Family</th>
<th>“Elliott” Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not know what was coming. Cried for days.</td>
<td>Concern. Wanted immediate intervention to see positive benefits.</td>
<td>Mother was speechless for hours. Father cried and needed to leave for a few hours.</td>
<td>Wasn’t very worried. Thought child would start talking.</td>
<td>Immediately consumed by indentifying and understanding son’s needs. Determined to secure all proper and necessary services/interventions.</td>
<td></td>
</tr>
<tr>
<td>Diagnosis from</td>
<td>Pediatric Psych Department</td>
<td>Doctor. Regional Center.</td>
<td>Doctor and hospital personnel</td>
<td>Therapist referred to Regional Center for testing.</td>
<td>N/A</td>
</tr>
<tr>
<td>Process towards indentifying child’s needs</td>
<td>Hellish. Arduous. Grief over the loss of a perceived child with whom to hold conversations. Vision changed.</td>
<td>“Luckily” had CHIME. Regional center provided everything asked for.</td>
<td>Mourning process. Lost and helpless. Got over it and got it together. Prayer for strength and guidance. Met “most incredible” individuals. New road of life.</td>
<td>1.6 years old initial speech delay diagnosis. Therapist referral for Regional Center testing. 2 months later speech and floor time therapy. Attended CHIME.</td>
<td>Confusing and challenging. Experienced conflicting reports from two evaluators. Challenging to quickly educate and navigate regional center and Los Angeles school district. Fortunate to be able to share with CHIME staff their experiences.</td>
</tr>
<tr>
<td>Additional Stressors or challenges</td>
<td>Recent separation from father of child</td>
<td>N/A</td>
<td>89 day stay in NICU</td>
<td>Parenting a child with special needs and a typically developing child.</td>
<td>Conflicting regional center psychological evaluations.</td>
</tr>
<tr>
<td>Affect on parenting</td>
<td>Made stronger. Everything is about little accomplishments. Expectation is thrown out the window.</td>
<td>Learned strategies to use at home.</td>
<td>Became parents that they never thought they could be. United as parents for “differently abled” child. Advocates. Patience.</td>
<td>Speech delay, couldn’t sit child down to explain. Still would try but wouldn’t always work.</td>
<td>Strong advocates for their son.</td>
</tr>
<tr>
<td>Continued impact</td>
<td>More at peace with life. Sometimes continued fears of disasters. Still asks for advice. Previously dependent on others now possesses feelings of expertise where daughter is concerned.</td>
<td>Better parents to both sons. Strategies apply to all children.</td>
<td>Continued strength. United as parents for “differently abled” child. Stronger family relationships. Help son and others in similar situation.</td>
<td>Everything learned impacts how they parent.</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Each dyad responded to questions regarding each respondent’s initial reaction to the assessment that their child was identified as having a special need (see Table 4). In the case of the “Abbott-Jones” family mother “Sarah” commented that she cried for days after receiving the doctor's assessment. “Sarah” described the doctor asking her, “You know what coming, right?” She went on to comment that she was unsure if she was in denial or the comments from family and friends that “she’s fine” had convinced her to believe that.

For the “Baldwin” family, both parents expressed that their immediate reaction was concern. Both parents, “Kelly” and “Kevin” wanted to obtain immediate interventions services for their son, “Brad”. “Carter” family shared that “Janet” was left speechless for hours and “Jack” cried and needed to leave for a few hours. The “Darby’s” family response was of lack of concern. Parents “Mike” and “Mary” continued to believe that their son “Dillon” would speak soon. Both “Elliott” parents commented that they became consumed with acquiring appropriate services for their son and understanding “Elton’s” needs.

Three out of five families choose to comment on the emotional process of acquiring a diagnosis for their child. Families shared comments such as, “Hellish” from “Sarah”. While “Dillon’s” parents found the process to be “confusing and challenging”. The “Carter” family expressed that they felt “lost and helpless”. “Janet” and “Jack” found that they experienced a “mourning period”. They went on to share that they “got over it” together. “Sarah” also shared that she underwent a grief period over the loss of her perceived child that she could “hold conversations with” and “share feelings with”.

Two families choose to comment literally about the direct process. The “Baldwin”
felt that the Regional Center gave them all that they asked for and that “luckily” they had the CHIME organization to assist them. The “Darby” family shared that they got a diagnosis when “Dillon” was 1.6 years old. Then with the therapist referral to Regional Center they obtain services 2 months afterwards. In contrast the “Elliott” family received conflicting reports from two evaluators. As parents they need to learn the ways to navigate the Regional Center and Los Angeles school district to meet their son’s needs. They two felt “fortunate” to have the CHIME organization to share their experience with.

Four out of five families underwent additional stressors during their child’s diagnosis process. “Sarah” and “Sam” had recently separated when the doctor diagnosed “April”. They “Carter” family experienced the stressor of having their infant son “Cain” spend the first 89 days of after his birth in the hospital NICU. The “Darby” shared that an additional source of stress comes from parenting two children. In this family’s particular case one child with special need and a child that is typically developing. The “Baldwin” family also had a second child that was typically developing but did not share the impact this played on the family role of stress.

Four out of the five families expressed that they had received a diagnosis for their child’s needs from either a doctor or a referral to the Regional Center evaluator or therapist. The researcher was able to infer that the “Elliot” family was able to obtain a diagnosis but was unclear on where the diagnosis was obtained from. The family’s responses were unclear as to what between the conflicting reports of the two evaluators and the parents “learning to navigate” the Regional Center and Los Angeles school district.

Each of the five families did share that parenting a child with special needs
affected their parenting in a positive way. “Sarah” commented that it has made her stronger. She has learned that expectations get thrown out the window and that “everything is about the little accomplishments”. Although, “Sarah” did share that she continues to fear “disasters” she is at more peace with life. She went on to say that she use to depend on others for answers she now feels like she is the expert on her daughter “April”.

The “Baldwin” family shared that they have learned strategies to use at home and it has taught them to be better parents to both their sons. It is their view that the strategies they have learned can be applied to both sons. The “Carter” family shared that they have become “the parents that they never thought they could be”. As a family they have become stronger and more united. They feel they have gained patience and become advocates for their son “Cain”. They seek to continue to help their son and others in a similar situation.

The “Darby” found it initially difficult that they could not sit their son “Dillon” down and explain things to him. They shared they still tried but it “wouldn’t always work.” But now they feel that everything they learn impacts how they parent. The “Elliott” family shared they have become strong advocates for their child.
Table 5:

_Typically developing sibling's role within the family._

_(n=10)_

<table>
<thead>
<tr>
<th>Sibling relationships</th>
<th>“Abbott-Jones” Family</th>
<th>“Baldwin” Family</th>
<th>“Carter” Family</th>
<th>“Darby” Family</th>
<th>“Elliott” Family</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N/A</td>
<td>Younger sibling. Same gender. Male older, male younger.</td>
<td>N/A</td>
<td>Younger sibling. Opposite Get along really well.</td>
<td>N/A</td>
</tr>
<tr>
<td>Sibling reaction</td>
<td>N/A</td>
<td>Parent perception that since he is a younger sibling not much to share.</td>
<td>N/A</td>
<td>Never directly told her. Sibling is three. Younger sibling knows that older</td>
<td>N/A</td>
</tr>
<tr>
<td>Impact on sibling interactions</td>
<td>N/A</td>
<td>Wants to play with older brother. Lack of reciprocation can lead to sadness at times in younger brother.</td>
<td>N/A</td>
<td>Seeks to play with older sibling more than he wants to.</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Two of the five dyads had one additional child and responded to questions to regarding the younger sibling’s role and interactions with their older sibling (see Table 5). The “Baldwin” family has a younger son, “Steve”. And the “Darby” family has a younger daughter “Rose”. Both families were asked to share thoughts, views, and opinions on their children’s sibling relationship. They were also asked about their perception of their youngest child’s reaction to their sibling’s special needs. Additionally to share the impact of their eldest child’s special needs on their children’s sibling interactions.

The “Baldwin” family shared that they have two sons. “Kelly” and “Kevin” collectively decided that since “Steve” is a younger sibling “there wasn’t much explaining to do” regarding “Brad’s” special needs. In terms of impact on relationship “Steve” wants to play with “Brad”. At times a “lack of reciprocation” can cause “Steve” to become sad.

For the “Darby” family, younger sister “Rose” and “Dillon” are opposite genders. Likewise, “Mike” and “Mary” have decided that since “Rose” is three there isn’t much need for explaining “Dillon’s” needs to “Rose”. “Mike” and “Mary” mentioned that “Rose” is aware that her brother does not speak much and will often speak for him. “Mary” and “Mike” state that “Dillon” and “Rose” get along well. “Rose” will often seek “Dillon” out for play more than “Dillon” would like to. The “Darby” parents state that “Rose” forces “Dillon” to play.
Table 6:

*Impact of diagnosis on the interactions with extended family.*

(n=10)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents described how son was behind compared to other child and that he needed extra help to catch up.</td>
<td>Guidelines for behavior services when dealing with her daughter.</td>
<td>Due to child’s mother being speechless maternal grandmother shared information with other members of the family.</td>
<td>Family has been with them thru the process so there has never been a big moment of sharing.</td>
<td>Shared information openly with extended family.</td>
<td></td>
</tr>
</tbody>
</table>


| Family assistance provided to family | Child’s father is out of state. Maternal grandmother is unable to help. Maternal aunt is a widow with twins unable to help. Parental relatives out of state. | Both set of grandparents help watch him. | Out pour of support. Maternal grandmother spend every day of the 89 days that child was in the NICU alongside child’s parents. Other members did their best to be there as well. | Father’s parents live with family six months out of the year. They provide support and child care. | Emotional support |

| Impact on family interaction with extended family | Financial strain prevents interaction. Daily lives limit assistances. Out of state family viewed as part of social circle if lived closer. | Grandparents implement same strategies as parents. Families on same page. Overall, no different. | Family relations have become stronger. | Hoping and praying with family that child will start to talk. | N/A |
Each dyad responded to questions regarding the role of extended family in the lives of the nuclear family (see Table 6). It also describes the reactions and relationships that the extended families have had towards the parents and child with a special need. Four out of five families shared positive experiences and support from extended family members.

The “Baldwin” family chose to disclose a description of how their son “Brad” was behind compared to other children and that he needed extra help. They describe the response from their extended family to be “very supportive”. They shared that both sets of grandparents are actively involved in caring for both grandchildren. The parents have also found that the grandparents will implement the same strategies as parents when proving child care. The family has found no differences in interactions between the nuclear family and the extended family.

The “Carter” family has found that their relationship with the extended family has become stronger. “Janet’s” mother shared the news of “Cain’s” needs with the larger family unit. “Janet” shared that it was due to her sense of speechlessness and “Jack’s” need to get away for a few hours. The extended family shared in the parents’ tears of joy and pain. They felt an out pouring of support. “Janet’s” mother spent each of the 89 days that “Cain” was in the NICU at the hospital. “Janet” also shared that other members did their best to be there but that she understood that they “couldn’t be there as much as they wanted to”. But overall “Janet” felt “they did their best”.

The “Darby” family shared their family has been there with them throughout this process. For this reason there was no need to have a big moment of sharing. “Mike” and “Mary” shared that their extended family has been very positive and have offered loving
support. “Mike’s” parents spend six months out of the year living with them and when they do they offer support by proving childcare.

According to the “Elliott” family they have shared information openly with their extended family. As such the family has appreciated the open communication and has provided emotional support.

Of the five families the “Abbott-Jones” family, single mother “Sarah” shared that the response from her extended family has not been positive. “Sarah” stated that her family “doesn’t seem to buy into” her daughter’s diagnosis. Instead she states she receives “a lot of rolled eyes”. Additionally, “Sarah” shared that her family ignores the guidelines that she asks to have followed when “dealing” with her daughter. Guidelines that she has received “via her behavior services and input from the CHIME staff”. Her direct response to the question of her extended family offering support was, “Suffice to say I don’t have support.”

“Sarah” expanded that “my daughter’s dad does not help with ‘April’ at this point”. Her mother is unable to help and her sister is a widow with twin sons “one MR” so her family does not help. “April’s” paternal grandparents live out of state “and not seen her in about a year”. “Sarah” explained that due to finances they are disconnected but believes that if they lived closer “April’s” paternal grandparents would be “part of our social circle”.
Table 7:

*Parent commented on the importance of play in assisting with family cohesion.*

(*n=10*)

<table>
<thead>
<tr>
<th>Family togetherness activities</th>
<th>“April Abbott-Jones”</th>
<th>“Brad Baldwin”</th>
<th>“Cain Carter”</th>
<th>“Dillon Darby”</th>
<th>“Elton Elliott”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Play dates, swimming, beach, park, hiking, movies.</td>
<td>Amusement parks, regular parks, grocery shopping, and walks outside.</td>
<td>Relaxing together. Good quality quiet time without therapies. Everyday activities such as tooth brushing, washing hands, and changing clothes.</td>
<td>Play outside, read books, play with cars, draw, watch TV, tickle fights.</td>
<td>Eating, playing, listening to music and watching TV. Trips to the zoo and Disneyland.</td>
<td></td>
</tr>
</tbody>
</table>

| Parent perspective of play on family interactions | Daughter loves to play. It can get exhausting to fulfill daughter’s demands but does her best to balance playtime with having daughter occupy herself. | Find activities that son enjoys because if he is happy everyone is happy. | A major role. Family interactions are used to teach their son daily activities. | Try to have lots of fun, it brings the family closer. | Play is used to engage, interact, and communicate with their son. |
As part of the research the participating families were asked to share family activities that promoted togetherness are described (see Table 7). The respondents were also asked to comment on their perspective of the role that “play” had on their family interactions. The “Abbott-Jones” family shared that they participated in play dates, swimming, hiking, and watching movies together. They also visited the beach and park. “Sarah” commented that “April loves to play.” “Sarah” expressed that she could find fulfilling her daughter’s demands exhausting. But went on to say that she does her best to balance playtime with having her daughter occupy herself. Playing independently she noted is an emerging skill. She also added that “April” loves to play with her father, “who is a wonderful playmate for her”.

The “Baldwin” family participates in walks outside, trips to the grocery store, attending parks and amusement parks as their family togetherness activities. Parents “Kelly” and “Kevin” added that “finding activities that ‘Brad’ enjoyed” were important. That if “Brad” is happy then everyone is happy.

The “Carter” family explained that relaxing together and that “good quality quiet time without therapies” were family togetherness activities. They went on to share everyday activities such as tooth brushing, washing hands and changing clothes were family also considered family togetherness moments. Play was a major role in family interactions used to teach “Cain” daily activities.

The “Darby” family plays outside, reads books, plays with cars, watches t.v., and engages in tickle fights. “Mike” and “Mary” explain that they try to have “lots of fun together, because it brings the family closer.” The “Elliott” family also watches t.v. together. They also play, listen to music, and eat together. The family also takes trips to
Disneyland and the zoo. Much like the “Darby” family the “Elliott” family uses play to engage, interact and communicate with their son.
Table 8:

Parents shared sources of support and their response to the support.

(n=10)

<table>
<thead>
<tr>
<th>Sources of information</th>
<th>“April Abbott-Jones”</th>
<th>“Brad Baldwin”</th>
<th>“Cain Carter”</th>
<th>“Dillon Darby”</th>
<th>“Elton Elliott”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric psych</td>
<td>Doctor. CHIME.</td>
<td>Doctor. People</td>
<td>Doctor. Regional</td>
<td>Doctor. Individual</td>
<td>Doctor. Regional</td>
</tr>
<tr>
<td>department for</td>
<td>Regional center.</td>
<td>they met at the</td>
<td>Center. Other</td>
<td>Research. CHIME.</td>
<td>Center. CHIME.</td>
</tr>
<tr>
<td>Regional Center SC.</td>
<td></td>
<td>Research</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advocate. CHIME</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infant/toddler CFSC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>preschool staff.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSUN Family Resource</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Center. Other parents.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(met thru CHIME).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual research.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Response to sources of support</th>
<th>“April Abbott-Jones”</th>
<th>“Brad Baldwin”</th>
<th>“Cain Carter”</th>
<th>“Dillon Darby”</th>
<th>“Elton Elliott”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular doctor no help.</td>
<td></td>
<td>Everything that</td>
<td>“Its funny how</td>
<td>N/A</td>
<td>Regional center</td>
</tr>
<tr>
<td>Pediatric psych depart doc...</td>
<td></td>
<td>was asked for</td>
<td>life works...you</td>
<td></td>
<td>was confusing</td>
</tr>
<tr>
<td>told parents: “you know</td>
<td></td>
<td>has been</td>
<td>end up meeting</td>
<td></td>
<td>and challenging.</td>
</tr>
<tr>
<td>what's coming right?” they</td>
<td></td>
<td>received.</td>
<td>the most</td>
<td></td>
<td>Very fortunate</td>
</tr>
<tr>
<td>did not.</td>
<td></td>
<td></td>
<td>incredible</td>
<td></td>
<td>and blessed to</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>individuals</td>
<td></td>
<td>be part of</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>who open up</td>
<td></td>
<td>CHIME. Able</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>the roads to</td>
<td></td>
<td>to openly share</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>a ‘new’ life.”</td>
<td></td>
<td>experiences.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Grateful for</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>support.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Plan type</th>
<th>IFSP/IPP</th>
<th>IFSP/IPP</th>
<th>IFSP/IPP</th>
<th>IPP</th>
<th>IFSP/IPP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child's age when plan</td>
<td>At 2 years</td>
<td>Suggested at</td>
<td>Suggested at</td>
<td>2.6 years</td>
<td></td>
</tr>
<tr>
<td>started</td>
<td>suggested</td>
<td>1.11 years he</td>
<td>1.6 years old</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>from services;</td>
<td>would benefit</td>
<td>would benefit</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>IFSP 2.1 yrs IPP</td>
<td>from services.</td>
<td>from services.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3.1 yrs</td>
<td>At 3 years put</td>
<td>At 1.8 started</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>into place.</td>
<td>services.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Types of services</th>
<th>20 hrs a week ABA. 16hrs a month supervision @ ABA. Inclusion @ CFSC Lab school thru Chime. 1 hr speech. 30 min. occupational.</th>
<th>Speech. OT, Adaptive skills. Before 3 years.</th>
<th>Speech 2x/week Floortime 2x/wk</th>
<th>CHIME I/T 1/wk</th>
<th>Speech and occupational therapies.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CHIME</td>
<td>Speech 2x/week Floortime 2x/wk</td>
<td>CHIME I/T 1/wk</td>
<td>Speech and occupational therapies.</td>
<td></td>
</tr>
</tbody>
</table>
A representation of other sources of support and information the parents utilized on their path to gain positive parental efficacy and a boarder sense of parental expertise related to their child’s needs was also analyzed (see Table 8). It also explores the family responses to the sources of outside of the family support systems.

Five out of five families found themselves in the role of individual researcher in allocating information regarding their child’s particular needs. Three out of five families expressed that CHIME was a source of information for their families. Four out of five families mentioned the Regional Center as an existing establishment as part of the process they underwent to obtain services for their child. “Sarah” was the sole participant to mention the CSUN Family Resource Center as a local community resource. The “Carter” family identified friends as a source of information in addition to the people they met at the hospital. The “Darby” family and “Sarah” mentioned that other parents assisted them. The “Darby” family did not share through what means they became acquainted with these individuals. All five families mentioned their doctor as an individual that led to their child’s diagnosis.

The “Carter” family spent the first 89 days of their child’s life in the NICU commented that, “its funny how life works… you end up meeting the most incredible individuals who open up the road to a ‘new’ life.’” Their quoted indicated a positive experience with doctors, other professionals, and other individuals they have interacted with. The “Baldwin” family shared that throughout this process they have been able to receive the necessary services and therapies that they requested from the Regional Center. The researcher was able to infer that the family was able to work collaboratively with the organization to meet the needs of their son “Brad”.
The “Elliott” family remarked that their experience with the Regional Center psychological evaluators was both confusing and challenging. Their son “Elton” received conflicting reports and as parents they took on the challenge of learning the means of “navigating the road to services”. They quickly need to educate themselves. They commented that they were “grateful” at receiving the support from the CHIME Infant/Toddler staff.

For “Sarah”, “April’s” regular doctor was “no help at all.” “Sarah” shared that at the time of the disclosure the doctor made the comment “you know what’s coming right?” At that time she did not. She did comment that, “I don’t know what we would do without the people who have become our support system.” The researcher was able to infer from this statement that positive support systems outside the family unit have been established. The “Darby” family reframed from presenting any specific remarks regarding their reaction or response to outside of the family support systems and/or organizations.

According to the responses of the families, each child received services and/or therapies within one month to thirteen months of the diagnosis process. The “Baldwin” family commented that the suggestion that “Brad” could benefit from services and therapies was made to them when he was 1.11 years old. “Kelly” and “Kevin indicated his services and therapies did not begin until he was 3 years old. No further details were offered as to why there was a thirteen month gap between the initial suggestion and onset of services. The “Carter” family indicated that “Cain’s” services began at three months after his initial release for the NICU.

After plans were put into effect each child received a series of therapies. The
range of therapies and services included occupational, speech, physical therapies and adaptive skills. Four of the families listed CHIME program as part of the services their child acquired. The “Baldwin” listed CHIME as the sole therapy or service that “Brad” benefits from.

Three out of five children received speech therapy sessions. Four of the children obtain at least 4 months of occupational therapies. Only one family, the “Carter” family, listed physical therapy among the services that they had obtained for their child. Both the “Abbot-Jones” family and the “Darby” family listed ABA as an additional service their child utilizes. Solely the “Darby” family mentioned floor-time as a therapeutic session their son “Dillon” receives. Overall each family was able to obtain specialized therapies or services that directly relate to their child’s unique care needs.

According the results of this study, major findings centered on the following emergent themes: a) the means by which additional stress impact parent coping and ultimate obtainment of parental efficacy, b) the role of grandparent involvement and support offered, c) the role of typically developing siblings in assisting and interacting with their sibling with a special need, d) the impact of parent actions in obtains care knowledge and services for their child with a special need. These themes emerged out of inductive analysis; based on the indigenous concepts identified from the data. These themes were deemed relatable to the research findings discussed in the review of literature by the researcher.
CHAPTER V
DISCUSSION

The purpose of this Master’s thesis was to examine what factors serve to support parents of infants’ with special needs in developing self efficacy through positive transition from grief coping of the loss of their perceived child. Respondents responded to a self-reporting questionnaire. The measurement was created by the researcher in response to thematic topics from the review of literature.

A pilot study of infant and toddler parents was initially conducted at the CHIME Infant/Toddler program in Woodland Hills, Ca. The researcher found that participants were too close to the diagnostic process of their child to comfortably respond. As such a focus group five dyads was gathered from the CHIME Institute’s collaborative inclusive program with the CSUN Child and Family Studies Center in Northridge, Ca. This inclusive program assists parents in providing their child with their necessary therapies and services while interacting and playing alongside typically developing children. At no time are the children “pulled out” of the classroom instead therapeutic sessions and services are incorporated in to the everyday play of all the children.

Each respondent reported on their initial reaction to their child’s diagnosis of needs and services. They also so reported on family involvement in care for their child and family response to their child’s needs. Respondents were asked to share sources of knowledge for their child’s care needs, as well as, the means by which they obtained their child’s care information and services.

The research from this study can be utilized by professionals to assist families undergoing the process of diagnosis, grief processing the loss of their perceived child,
and learning to cope towards positive parental efficacy views. The information in this study can assist professionals in indentifying stressors and assisting in allocating and utilizing available support systems. Each family may face individualized stressor unique to their family yet families must still learn to cope beyond its impact of the family dynamic. The allocation of support systems can assist parents in their transition from grief to coping and ultimately positive perceptions of parental efficacy. Some support systems may include parental efforts of advocacy for their child, extended family members, and siblings of their child.

**Summary of Finding**

The major findings of this study centered on emergent themes that primarily demonstrated themselves to be supportive factors in a parent of a child with a special need developing parental efficacy. Families experiencing grandparent involvement and support appeared to demonstrate comfort and appreciation from their involvement. The family without grandparent support discussed how it impacted their ability to parent. Families with a typically developing siblings in addition to their child with a special need shared the ways in which interacts positively assisted. They also commented on the emotional impact the typically developing sibling experienced. For some families the importance of taking action in acquiring their child’s care needs assisted in obtaining care knowledge and developing parental expertise. The data also shared the means by which additional stress impacted parent coping and ultimately their obtainment of parental efficacy. Through inductive analysis of the basic raw data these indigenous concepts emerged (Patton, 1990). These research findings are share commonalities and disparities with research findings discussed in the review of literature.


Discussion of the Findings

The inductive analysis of the data identified that families with grandparent involvement were appreciative of their assistance and support. The “Baldwin” family shared that both sets of grandparents were actively involved in providing care for family’s two children. The family shared that when the grandparents care for the children they implement the same care strategies as the parents. They went on to describe that both sets of grandparents have been very supportive. For the “Darby” family support has come from both sets of “Dillion’s” grandparents by means of positive loving support. Support has particularly come from his paternal grandparents since they stay with the family six months out of the year. When they stay they offer childcare assistance for the parents.

For the “Carter” family grandparent involvement was valuable to the parents. After their son “Cain” was born the news left them speechless. “Cain’s” maternal grandmother shared “Cain’s” health information with the rest of the family. She also spent each of the 89 days that “Cain” was in the hospital at his parents’ side. Other members of the family shared in “Cain’s” parents’ tears of both pain and joy.

These findings are consistent with the research finding from the review of literature. When grandparents demonstrate positive responses to their grandchild it can help to serve as a model for other family members as was the case for “Cain’s” family (Gardner & Scherman, 1994; Mirfin-Veitch et al., 1997). Additionally “Cain’s” maternal grandmother offered the family emotional support which is consistent with research (Trute, et al., 2008). Emotional support from grandparents is viewed as a form of informal support that allows for mutual exchange that minimizes dependency and
decreases dependency by reinforcing parent opinions of the parental efficacy (Findler, 2007). The role of grandparents in providing child care was consistent with findings from Vadasy (1987). Parent comments in regards to shared tears of joy and pain and offerings of loving support indicate grandparent and extended family members’ acceptance of their child which according to the research can serve to enhance positive parental adjustment and decreased feelings of isolation (Gardner & Scherman, 1994).

Another member of the family that served to support parents in their efforts to care for their child challenged with a special need is their typically developing siblings. The “Baldwin” and “Darby” family shared that their younger child would seek out their older child to play with. For “Steve Baldwin” there were instances of lack of reciprocation that would cause “Steve” to become sad. In the case of the “Darby” family “Rose” would force “Dillon” to play. They also shared that “Rose” is aware that her brother does not speak much and that she will often speak for him. Both parents commented that the siblings got along. And both set of parents decided that the younger sibling was still too young to share information about sibling’s needs.

Similar to the findings of Maul and Singer (2009) the researcher found the siblings represented in this case study were able to identify with one another and provided for one another pro-social interactions. As Bass & Mulick (2007) state that siblings offer a more natural play teaching model by acting as effective trainers. Another commonality identified was that siblings gain knowledge through observation and interactions (Hames, 2005). “Rose” is aware that her brother does not speak much but both of her parents has deemed “Rose” too young to share information regarding her brother’s care needs.
Sibling “Steve’s” occasional times of sadness is consistent with research findings that siblings can experience some negative effects associated with their sibling’s special need (Maul & Singer, 2009). “Steve’s” feelings of sadness and lack of play reciprocation was representative of other siblings’ feelings found in other studies. Although the review of literature did find that typically developing siblings may assume care taking roles similar to their parents no information was identified in relation to “Rose’s” actions of speaking on behalf of her brother.

The actions of typically developing siblings supporting the sibling challenged with a special need assist parents to incorporate pro-social interaction therapies. Families with additional children also face the potential stressors of addressing care need explanations to the typically developing child as they become older and are able grasp their sibling’s need more fully. Parents of additional children must also assist their children to understand and cope when lack of reciprocation from their sibling with a special need causes hurt or upset.

Another factor that supports parents in obtaining parental efficacy is contingent on the efforts parents make to become advocates for their child. Each of the families represented in this case study acknowledge that they each needed to conduct their own research. In the case of the “Elliott” family, parents “Todd” and “Tracey” quickly learned to navigate themselves through the policies of the Los Angeles school district and those of the Regional Center to obtain services for their son “Elton”. The families engaged in a problem based coping approach that involved gathering information (Graungaard & Skov, 2006). The “Elliott” family additionally demonstrated use of the problem based approach by learning and acquiring the skills that would benefit their child.
In contrast the “Carter” family emulated the emotional base coping approach in the initial days of “Cain’s” NICU hospitalization. “Janet” prayed for strength and guidance. Each of the parents initially felt confused, overwhelmed, lost, or experienced denial. Each of these emotions are considered common reactions to receiving news that their child has a special need (Vacca, 2006).

Each of the case study participants reflected on their initial reaction to their current perception of themselves as parents. Each of the parents was able to share positive reflections in regards to their parenting ability. Both “Janet” and “Sarah” shared that they either got over it or had a vision change but in both instances they chose to move past their grieving and mourning period into a more proactive state.

Reflections included “Sarah’s” comments that she is more at peace with life. And although she may still ask for advice she previously depended on others she now feels she is the expert where her daughter is concerned. Parenting a child with a special need has made her stronger and taught her to throw expectation out the window. That everything is about the little accomplishments.

The “Baldwin” parents shared that they are better parents to both their sons. That the strategies they learned can be used at home. And that they are able to apply the same strategies to both their children.

The “Carter” family believes they have become the family they never thought they could be. They have become united as parents for their “differently abled” child. This has established stronger family relationships. They see themselves as advocated and have gained patience. They demonstrate continued strength. They are able to help their son and others in similar situations.
The “Darby” family shared although they can’t sit their son down and explain things to him because of his speech delays they find it doesn’t always work. But they added that everything they learn impacts how they parent.

The “Elliott” family found themselves consumed by the need to secure all proper and necessary services and interventions. Throughout the process of evaluations for their son they found themselves to be confused and the situation challenging. As a result they have become strong advocates for their son.

Each of the families faced their own set of stressors and challenges put were able to ultimately obtain positive parental efficacy. “Sarah Abbott-Jones” faced lack of family support but was able to find assistance from CHIME Institute that aided her in meeting her daughter’s needs. This assistance led to her perception of being an expert where her daughter is concerned. The “Baldwin” family had valuable support avenues from both sets of grandparents and a typically developing sibling to interact with their child with a special need. As parents they both desired to seek out and obtain immediate interventions for their son. They combined factors enabled the parents to demonstrate positive parental efficacy.

They “Carter” family learned a new road of life and ultimately became advocates for their son. The support of their family, particularly “Janet’s” mother assisted them to cope and process their son’s NICU experience and later care needs. As for the “Darby” family, they experienced an initial sense of denial towards their son’s situation. They had grandparent support and a second child to aide them in assisting “Dillon” with his speech delay. Their reflection that everything they learn impacts as demonstrative efforts as scaffolds towards parental efficacy. The “Elliott” family endured confusing and
conflicting evaluations in their process to navigate the path to services for their son. They also had the support of extended family members. These factors enabled the “Elliotts” to obtain parental efficacy. As such, each of the families were able to obtain parental efficacy with the aid of supportive factors. Factors included grandparent involvement in caring for their child or offering support, a typically developing sibling for their child with a special need, proactive actions to obtain services and care needs for their child.

Limitations

This study was conducted in collaboration with both CSUN Child and Family Studies Center and the CHIME Institute. The researcher recognizes that the participants of this study are not a generalized representation of the population of parents with special needs. The respondents of this study had a child with a special need enrolled in the inclusive classroom setting. Additionally, parents were responsible for reporting the diagnosis of their child’s special needs. As such, some parents choose to share the name of their child’s diagnosis. Other parents in the study choose to share more generalized care needs that their child may have. Parent’s response to the researcher’s inquiry into their child’s special need may have meet with confusion in terms of what the researcher was asking. It is also possible that some of the parents are still waiting for a specific diagnosis from an expert evaluator. Since this study was conducted as an anonymous self reporting questionnaire the researcher was unable to clarify with the participants’ their intended respond.

Throughout the process of this study the researcher discovered the need to be sensitive to the grief/coping process of families. By attempting to conduct the survey with families closer to the diagnosis process the researcher found that families were not
prepared to discuss the ongoing process through a questionnaire. It is possible that several of the families were not emotionally or mentally prepared to answer questions regarding care needs of their infant with a special need.

Some of the families undergoing the process may have not yet received specific diagnosis of their child’s long term care needs. Parents that are early on in the process of diagnosis and disclosure may still be in the initial stages of grief or acceptance. For this reason parents may lack a complete comprehension of their child and be unable to discuss their transition into positive parental efficacy. As committee member Annie Cox mentioned during a discussion, families at the beginning of the process are attempting to learn to bond with their little one.

The topic of special needs is considered to be new research (Hebbeler, et al., 2003). Studies began in the last 15 to 25 years and have focused on including children in large scale studies about children needs. Children with special needs were not traditionally included in these large scale studies. Studies tended to be small scale and relatively new. Larger scales are focused on the specific diagnosis of the child and relate to the labeling and identifying of the disability. Most research reflects the larger population of boys identified with special needs. Consequently findings were not representational of entire child population due to exclusion of infants with special needs. The field was unable to benefit from research findings since population was not inclusive of infants and families with special needs (Hebbler & Spiker, 2003).

*Implications*

To include infants with special needs in future research, special consideration and intended tools utilized in an assessments would require redesigning. The data collection
of infants with special needs would be considered challenging. Assessment of their skills or needs would be inhibited by their inability to complete required tasks and would result in an incomplete analysis. Information gained from these infants would be considered invalid and would be excluded from the overall measurements. Cost are considered drawbacks in this type of research area, such as modification of research questions, locating sample population, and extra instrumentations would create time delays for researchers.

Research designs have been explanatory or exploratory type research. The questions have been designed in to qualitative type interviews. These tend to be semi structured and self-administered questionnaires. Researchers have utilized Likert scale to rate parental opinions related to program assessment in meeting their family needs. Newer studies are focusing on parent involvement in the process of building partnerships with programs to work together to help infant have better outcomes.

Research suggests that the inclusion of special needs into research has allowed for base comparison of typically developing infants and infants with special needs (Hebbeler, et al., 2003). This information can provide essential information about family dynamic comparisons on how parents with infants with special needs and parents of non-delayed infants are affected by stress. This can lead to a more in-depth investigation of parental responsiveness and parental efficacy among these two parents groups. It could also potentially examine the role of internet support in parent responsiveness and efficacy. Sarkadi & Bremberg (2005) has begun to examine how parents use the internet as an accessible tool with respondents reporting higher levels of self-esteem of frequent users that organize to meet each other.
Research can also be extended to the familial responses and roles of extended family members. This can encompass the introduction of the new infant to the family and the level of participation in care provided by extended family members. It could also investigate the role of support from extended family members for developing parents achieving parental efficacy and parental responsiveness skills.

**Recommendations**

This particular study was conducted as an anonymous self reported questionnaire. To this end, the researcher was unable to contact the participants for follow up clarification on responses. This also inhibited the researcher from expanding on topics with respondents. For this reason the researcher recognizes the value future research that would enable the expansion of the scope of the research to include follow up interviews. Or another research option would be to conduct the instrument of measurement into an interview rather than a questionnaire.

Should the researcher choose to maintain the questionnaire process, due to time or convenience of research method, the incorporation of a more fully realized pilot study should be implemented. Through a more fully realized pilot study the researcher can introduce concepts, themes, or terms and better gage the reception and understanding of parent participants. This will enable the research to create a more formalized and concise questionnaire from which the researcher can gather relatable data for the research study.

The researcher should demonstrate sensitivity to families currently at the beginning of the diagnosis/disclosure process and understand that parents may see research studies directed at their coping process as an additional stressor or potential threat questioning their ability to parent. Instead parents of infants, toddlers, or younger
aged children new to this process maybe more receptive to speaking to researcher in person or participate in a focus group by meeting up with other parents in a similar situation. The added incentive of having other individuals enduring a similar experience may allow for a more free-flowing and open discussion of topics.

Other possibilities of area of interest for future research may include interviews or the use of a measurement instrument with either the grandparents or other actively involved extended family members. Areas of discussion could include their support role and actions in response to the nuclear family’s needs. In what capacity do they assist their children and grandchildren in terms of emotional, physical, or financial care needs. What sources of information did grandparents utilize to empower themselves in regards to their grandchild’s special needs. A discussion on grandparent coping mechanisms and grief processing they underwent would offer a more substantial understanding of possible unique stressors grandparents of infant or children with special needs face.

Additionally, research into the experiences and mental, social and emotional processes of typically developing siblings of children with special needs encounter. The research from such studies would enable professionals to identify patterns of behavior that support their sibling. As well as, identify the specific stressor or needs of typically developing siblings to ensure that their voices and concerns are addressed. A research study regarding their knowledge base of their sibling’s needs may assist parents in understanding exactly how well they comprehend their sibling’s needs and what information they would like to have access to.

The process of grief and coping for parents of children with special needs has been acknowledge through research, the development of support groups, and community
resources designed to assist parents in obtaining services for their child. This research study has highlighted other potential issues in relation to this process. Parents early on in this process endure a grief and coping experience and may find themselves overwhelmed by the information and expectations of parenting a child challenged with a special need. They must learn to transform their thought process from having a disabled child to the understanding that they are parents to a differently abled child.

As such parents of infants with a special need or parents at the onset of the diagnosis process would benefit from having an advocate or mentor to aide them through this process. The individual taking on this task would need to demonstrate sensitivity to culturally and linguistically diverse families and their unique needs and vulnerabilities. As well as, understand that their role is not that of an expert with all the knowledge base on a specific condition or need but that of a guide for parents. They would ideally acknowledge the parents need to emotionally connect to their child and would assist with bonding. Assisting families to bond with their child will enable parents to connect to their abilities to effectively parent their child.

Once bonding has begun, the mentor or advocate would guide the families through the process of diagnosis, obtaining services and seeing to their implementation. The advocate or mentor would also connect parents with other parents experiencing a similar situation or having successfully transitioned in positive parental efficacy roles. The goal of a mentor or advocate would be to guide parents in their journey to effectively parent their child and meet their child’s unique needs. Understanding that the best way to assist parents is by empowering them to care for their child by assisting them in discovering the ways they can connect to their child and the ways they can care for their
child. The advocate or mentor would also remind and support parents to care for their own mental, emotional, physical needs.

This study also highlighted the need for support groups for both grandparents and siblings of children with special needs. They individuals serve to support parents through this process. As sources of support, they too deserve to have support offered to them. Support groups that can assist would aid both siblings and grandparents understand and discuss their experiences in caregiving are needed. These two groups are underrepresented in research and as such few programs have been designed to meet their unique support needs.

Each of these groups would benefit from expert support for the family. So much of the current research and programs available to families tend to focus on their role of being the expert on a specific need. This particular design fails to acknowledge that first and foremost that each of these families have a child they are striving to connect to and care for. It also fails to recognize that it is entire a family system in need of assistance. Each member is interconnected and part of a larger family system. The worries, hurts, or stresses of one member of the family impact all members in different ways. Each member’s needs must be recognized and attended to, to ensure that each member of the family unit is receiving adequate care and assistance towards successful coping and care efficacy.

Each of the families involved in this study were able to connect to a program, such as CHIME, that assist families through their process and discovery of caring for their child. The CHIME organization offers an inclusive play and learning environment for families with children challenged with special needs. Parents can interact and connect
with other families with children challenged with special needs and parents of typically developing children. The pro-social environment invites parents to remember to recognize that the child or person comes first and the need second. This allows parents to connect emotionally and physically to their child. And with the assistance of CHIME staff members jointly discover the means to attend and care to each child’s unique needs. The approach of this organization serves as a valuable model in assisting parent and family members in connecting with and caring for a differently abled child. The development of similar programs would offer direct assistance to families experiencing similar grief and coping experiences.

Conclusion

The purpose of this study was to contribute to understanding of what factors support parents in their effort to transition from parental coping to parental efficacy for parents of infant/children with special needs. The findings in this study demonstrate that positive involvement of extended family members, such as grandparents, assist parents by offering emotional and physical support to parents. Typically developing siblings also provide positive support by aiding the capacity of motivators to their siblings with a special need. Parents also develop positive parental efficacy development through their efforts in obtains and acquiring therapeutic service and care knowledge related to their child’s special need. The results of the study suggest that professionals should identify additional stressors impacting a parent’s ability to develop parental efficacy and should assist families in the indentifying of positive support resources. These support systems should recognize that each member of the family faces unique needs and challenges that impact all members of within the family unit. As such professionals and programs should
acknowledge each member of the family as a unit within a whole family system.
REFERENCES


Gardner, E., & Scherman, A. (1994). Grandparents' beliefs regarding their role and relationship with special needs grandchildren. *Education & Treatment of*
Children, 185-197.
Judge, S L (1997). Parental perceptions of help-giving practices and control appraisals in early intervention programs. Topics in Early Childhood Special Education, 17


disabilities. Special Education,


APPENDIX A

Survey Questionnaire

Section 1: Family Information

Please respond by providing the following basic information related to your family.

Parent 1

Age: _____ years

Sex: (Please Check Mark Appropriate Answer “X”)

______ Male    ______ Female

Occupation: ______________________

Education: (Please Check Mark Appropriate Answer “X”)

____High School    _____Some College    ____Baccalaureate

____Post Baccalaureate/Masters    ____Doctorate    ____Other: ________________

Relationship Status: (Please Check Mark Appropriate Answer “X”)

____Single    _____Married    _____Long Term

____Separated    _____Divorced

101
Parent 2 (Please fill out if applicable)

Age: ______ years

Sex: (Please Check Mark Appropriate Answer “X”)

______ Male        ______ Female

Occupation: __________________________

Education: (Please Check Mark Appropriate Answer “X”)

_____ High School       _____ Some College       _____ Baccalaureate

_____ Post Baccalaureate/Masters  _____ Doctorate  _____ Other: ________________

Currently living in the same household? (Please Check Mark Appropriate Answer “X”)

______ Yes ______ No

Child

Current Age: _______ years _______ months

Sex: (Please Check Mark Appropriate Answer “X”)
_______ Male  _______ Female

How old was your child when the suggestion was made that your child could benefit from additional services or therapies? ________years _________months

Please describe your child’s need(s):

Sibling(s)

Age(s): ________years _________months

Sex: (Please Check Mark Appropriate Answer “X”)
_______ Male  _______ Female

Please identify all relatives living in the same household: (Please list the number of people for each category)

_______ Parent
_______ Brother
_______ Sister
_______ Cousin
_______ Aunt
Section 2: Parental Response & Coping Information

Please share and describe your experience related your child’s need in each situation.

Immediate Family

Please describe your initial reaction as a parent:

Please describe your experience through this process:

Please describe how this affected your parenting:

Sibling Relationships (If applicable)
Please describe how you shared your child’s needs with sibling(s):

Please describe sibling(s) reactions (If applicable):

Please describe if these need(s) has affected interactions with siblings (If applicable):

Extended Family

Please describe how you shared your child’s needs with extended family:

Please describe the family’s response and reaction:
Please list and describe ALL family assistance and type of assistance provided:

Please describe how this may have affected interactions with extended family:

Section 3: Knowledge of Child’s Rights

What did you use to gain knowledge about services your child could benefit from?

(Please Check Mark Appropriate Answer(s) “X”)

_______ Doctor

_______ Other person: ________________________________

Additional Comments:

Does your child have Individualized Family Service Plan?

(Please Check Mark Appropriate Answer “X”)

_______ Yes _______ No

How did you receive information of your child’s legal rights?
(Please Check Mark Appropriate Answer(s) “X”) 

_______ Individual Research  
_______ Doctor  
_______ Family Member  
_______ Other: _____________________________

At what age was the plan put into effect (If applicable)?

_______ Years ________ Months

What services are received (If applicable)?

Section 4: Parental Expertise

What does your family like to do together?

What role does play have on your family interactions?
Overall, how has all the knowledge you have gained impacted your parenting?
February 25, 2009

Concepcion Jarz
7029 Katherine Ave
Van Nuys, CA 91405


Dear Ms. Jarz:

Enclosed for your records is a copy of the cover sheet of your approved Human Subjects Protocol Form. Please note that your project has been approved as exempt. If there are any changes to your protocol, you must contact the Office of Research and Sponsored Projects to ensure your project is still within the exempt guidelines.

If you have any questions, call this office at (818) 677-2901.

Sincerely,

Suzanne Blanding, Compliance Officer
On Behalf of
Committee for the Protection of Human Subjects

enclosure
APPENDIX C

HUMAN SUBJECTS PROTOCOL APPROVAL FORM
CALIFORNIA STATE UNIVERSITY, NORTHBRIDGE

This Protocol Approval Form must be completed for all California State University, Northridge faculty and student research which involves human subjects. Additional material(s), as described below, must be attached to this form at the time it is submitted to the Standing Advisory Committee for the Protection of Human Subjects (SACPHS) in the Office of Research and Sponsored Projects (GRS 265, ext. 2901). In ALL cases, RESEARCH MAY NOT PROCEED until authorized by the Committee. You will be notified of the action of the Committee following the receipt of an original and nine copies of this form and all required supplementary information (see below) in the Office of Research and Sponsored Projects. ALL SIGNATURES MUST BE OBTAINED PRIOR TO SUBMISSION.

Brief, excerpted definitions and guidelines regarding research involving human subjects appear on the attached instructions. For a copy of complete regulations, contact the Office of Research and Sponsored Projects. Read all instructions before completing the form. ONLY TYPEWRITTEN FORMS WILL BE ACCEPTED.

1. Title of research Transition from parental coping to parental efficacy: What factors support the development of parental efficacy for parents of infants born with special needs?

2. Name of researcher(s) Concepcion Jara Campus ext
Family Consumer Sciences

3. Address 7025 Katherine Ave Home phone 318 - 590 - 4611 Email Address cjara23@yahoo.com
Van Nuys Ca 91401

4. Name of Faculty Advisor Jerry Ann Hazeldine, Ph. D. Faculty Advisor ext. 3131

5. Period of Project (see pg. 1-Itemized Instructions) From December 1, 2008 To April 20, 2008

6. Check one: ☐ Faculty Research ☒ Student thesis ☐ Other (specify)

Course prefix and number FCS 698C Course title Thesis/Graduate Project

7. Check one: ☐ Unfunded ☒ Funded Date (to be submitted)

8. History of Protocol: ☐ New ☐ Renewal Approval Date

9. Does this protocol contain modification(s) from a previously approved protocol? ☐ Yes (explain) ☐ No ☐ N/A

10. Special procedures: (give detailed description on separate sheet) ☐ Radioactive materials ☐ Drug(s), Specify:

11. Is a Subject Bill of Rights attached? ☒ Yes ☐ No

12. Are copies of any questionnaire(s), survey instrument(s) and/or interview schedule(s) referred to in this protocol statement attached? ☒ Yes ☐ No

13. Is draft Informed Consent Form(s) attached? ☒ Yes ☐ No 14. Is a letter of permission attached? ☒ Yes ☐ No

15. SIGNATURES: Refer to pages 1-3 General Instructions letter D, before signing.

FOR SACPHS AND RESEARCH OFFICE USE ONLY

Chair, SACPHS, or Director, RSCH Date

Revised 2/08
March 9, 2012

Concepcion Jara
7029 Katherine Ave
Van Nuys, CA 91405

Re: “Transition from parental coping to parental efficacy: What factors support the development of parental efficacy for parents born with special needs” Research Protocol

Dear Ms. Jara,

Enclosed for your records is a copy of the cover sheet of your approved Human Subjects Protocol Form. Please note that your project has been approved as exempt. If there are any changes to your protocol, you must contact the Office of Research and Sponsored Projects to ensure your project is still within the exempt guidelines.

If you have any questions, call this office at (818) 677-2901.

Sincerely,

Suzanne Selken, Compliance Officer
On Behalf of
Committee for the Protection of Human Subjects

enclosure
APPENDIX E

Student Researcher
HUMAN SUBJECTS PROTOCOL APPROVAL FORM
CALIFORNIA STATE UNIVERSITY, NORTH RIDGE

1. Title of research: Transition from parental coping to parental efficacy: What factors support the development of parental efficacy for parents born with special needs?

2. Principal Investigator: Concepcion P. Jan
Major or Department: Family Consumer Sciences, Family Studies
Address: 7029 Katherine Ave Home phone: 818-590-4611
Van Ners, Ca 91405 Email Address: cepars@kalymo.com

3. Co-Investigators: 1. Student: 2. Student: 3. Faculty: 4. Faculty:

4. Name of Faculty Advisor: Jerry Ann Harrell-Smith, PhD Faculty Advisor ext. 3131

5. Projected Dates of Data Collection:
Begin Subject Recruitment/Data Collection: December 1, 2008 End Data Collection: December 31, 2012

6. Course prefix and number for thesis/grad. project: FCS 699C Course title: Thesis/Graduate Project

7. Check one: X Unfunded No Funding Source: Date (to be) submitted

8. History of Protocol: New X Continuing (Previous Approval Date: February 25, 2009)

9. Existing Data: Will this study involve the use of existing data or specimens (data/specimens currently existing at the time you submitted this project)? X No □ Yes
If Yes, attach documentation indicating the authorization to access the data if not publicly available and if accessing from an agency outside of CSUN.

10. Subjects to be recruited (Check all that apply)
a. Adults (18+ years)
b. Minors specify age:
c. Cognitively or Emotionally Impaired Persons
d. CSUN Students
e. Others (describe)
g. Using existing data, no subjects will be recruited

11. Data will include (check all variables that apply): You must specify all of this information in the Project Information form.
a. □ names of people h. X marital status o. X other, specify: Education
b. □ email address i. □ income p. □ social security number
c. □ street address j. □ job title
(d. □ phone numbers k. □ type of employers
k. □ job title)
e. □ age l. □ names of employers
f. □ gender m. □ types of employers
f. □ gender m. □ types of employers
g. □ ethnicity n. □ physical health report

12. Will subjects be identified by a coding system (i.e., other than by name)? YES X NO

13. Is compensation offered? YES □ NO X

14. If yes, describe (e.g., gift cert., cash, research credit).

15. Number of Subjects: 20

CSUN Office of Research and Sponsored Projects
Committee for the Protection of Human Subjects, Revised 10/06
17. Method of recruiting (elaborate in Section 2 of Project Information Form): CHIME Institute parent survey

18. Will there be any deception (that is, not telling subjects exactly what is being tested)? YES □ NO X (Provide justification for deception and explain how subjects are debriefed in Section 2 of the Project Information Form)

19. Potential Risk Exposure (Check all that apply): □ Physical □ Psychological □ Economic □ Legal □ Social □ Other, describe:

20. Data Collection Instruments (Check all that apply)
   a. □ standardized tests
   b. □ questionnaire
   c. □ interview
   d. □ other (specify)

21. Recorded by (Check all that apply)
   a. □ written notes
   b. □ audio tape
   c. □ video tape/film
   d. □ photography
   e. □ classroom observation

22. Administered by (Check all that apply)
   a. □ in person (group setting)
   b. □ in person (individual)
   c. □ telephone
   d. □ electronic mail/website
   e. □ mail

23. Findings used for (Check all that apply)
   a. □ publication
   b. □ evaluation
   c. □ needs assessment
   d. □ thesis/dissertation
   e. □ other (specify)

24. Are drugs or radioactive materials used in this study? YES □ NO X
   If yes, list the drugs or radioactive materials used in Section 1 of the Project Information Form and provide a detailed description of each, with justification for its use.

25. Are any medical devices or other equipment to be used in this study? YES □ NO □
   If yes, describe in detail the medical devices or equipment to be used in Section 2 of the Project Information Form.

26. Did you attach a copy of any questionnaire(s), survey instrument(s) and/or interview schedule(s) referred to in this protocol? YES □ NO □

27. Is a letter of permission for subject recruitment attached (if recruiting from an agency outside of CSUN)?
   YES □ NO □

28. SIGNATURES: Refer to page 1, General Instructions—letter D, before signing.

FOR SACHS AND RESEARCH OFFICE USE ONLY

Noted, exempt □ Approved, Minimal Risk
Approved, Greater than Minimal Risk □ Approved, Expedited Review

Chair, SACHS
Date: 2/7/12

CSUN Office of Research and Sponsored Projects
Committee for the Protection of Human Subjects, Revised 10/06
June 21, 2012

Concepcion Jara
7029 Katherine Ave
Van Nuys, CA 91405

Re: “Transition from parental coping to parental efficacy: What factors support the development of parental efficacy for parents of infants born with special needs?” protocol

Dear Ms. Jara:

The revision you submitted in connection with the subject protocol has been approved as exempt. If there are any further changes to your protocol, you must contact the Office of Research and Sponsored Projects to ensure your project is still within the exempt guidelines.

If you have any questions, call this office at 818/677-2901.

Sincerely,

Suzanne Selken, Compliance Officer
On Behalf of
The Committee for the Protection of Human Subjects

closure
Subject: Thesis Research Compliance
Date: Wednesday, June 6, 2012 9:17:26 AM PT
From: conncion Jara
To: Selken, Suzanne G

Good morning Suzanne Selken,
My name is Concepcion Jara and I am sending you the attached revised forms for my research, "TRANSITION FROM PARENTAL COPING TO PARENTAL EFFICACY: WHAT FACTORS SUPPORT PARENTAL EFFICACY DEVELOPMENT FOR PARENTS OF INFANTS BORN WITH SPECIAL NEEDS?" The new pieces cover the possible addition of interviews and expanding the range of parent participation to include parents of the other CHIME programs. Thank you for reviewing my forms and look forward to moving forward with my research once I receive your approval.
Sincerely,
Concepcion Jara

Modified protocol approved as exempt.

Jennifer L. Roach, Chair, Human Subjects Committee
Date 6/8/12
February 2, 2012

Standing Advisory Committee for the Protection of Human Subjects
California State University, Northridge
18111 Nordhoff Street
Northridge, CA 91330-8232

Dear Committee Members:

Concepcion Patricia Jara has permission to conduct the project entitled, Transition from Parental Coping to Parental Efficacy Project, at the CHIME Institute Early Education Programs. I am aware that the project includes survey questionnaires.

I can be reached at 818-677-2922 if you need to contact me.

Annie R. Cox, M.A.
Director
CHIME Early Education Programs
The thesis of Concepcion Patricia Jara is approved:

Angie Ciordano, Ph.D.  
8-1-2012  
Date

Annie Cox, M.A.  
7/13/2012  
Date

Jerry Ann Harrel-Smith, Ph.D., Chair  
7/31/12  
Date

California State University, Northridge