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RESILIENCE AND POST-TRAUMATIC GROWTH IN PARENTS OF CHILDREN WITH SPECIAL NEEDS

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RESILIENCE AND POST-TRAUMATIC GROWTH IN
PARENTS OF CHILDREN WITH SPECIAL NEEDS

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

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

by
Elizabeth Anne Sidener

June 2018

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ABSTRACT

From the day their child is diagnosed, parents of children with special needs are traveling on a journey of extremes. The stress parents experience can lead down many paths filled with stress, worries, and concerns as their constant companion. These conditions exert extreme pressure on parents and can lead to life-altering changes. Parents who are resilient and able to cope with continuous change will ultimately weave through the unknown to a place of positive growth known as post-traumatic growth. The research project was based on qualitative data obtained from interviews with eleven parents of children with special needs.

One of the many service professionals these parents interact with on a regular basis is service coordinators. Service coordinators know many personal details related to each family and are in a position to support parents positively to encourage post-traumatic growth. Separate interviews were conducted with nine service coordinators to collect qualitative data for this project.

The researcher also conducted an analysis of peer-reviewed research articles and discovered the key factor related to parent's resilience is encouraging social support provided by peer parents. This increases their resilience and is a critical factor towards achieving positive post-traumatic growth.

During research analysis, the researcher found Family-Centered Care to be the most promising method for service coordinators to interact with families and increase the factors of resilience in parents. The current focus at Regional

Centers is person-centered thinking. While this practice is beneficial for the clients served, it lacks the holistic consideration of the client and their family together. Future practice recommendations for service coordinators would include policy changes within the Regional Centers to focus on parent's strengths to discern the supports required to provide the highest quality of care for their children. Training for service coordinators to promote resilience and increase post-traumatic growth in parents would provide additional support in a parent's life. Support is the key factor in supporting post-traumatic growth. When parents feel supported, they can achieve more and join in stronger collaboration with service coordinators.

Keywords: parents, children with special needs, parenting, resilience, post-traumatic growth, family-centered care.

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CHAPTER ONE

ASSESSMENT

Introduction

This research project focuses on how increasing levels of resilience lead to post-traumatic growth in parents of children with special needs. This chapter contains an explanation and rationale for utilizing post-positivist research to conduct this study. Furthermore, a literature review which defines resilience and post-traumatic growth in parents of children with special needs is discussed. Finally, the theoretical orientation utilized for this study is examined and the value of this subject matter for social workers in the field.

Research Focus and/or Questions

The research focus of this study concentrates on parents of children with special needs and their increased levels of resilience while undertaking such a life-altering experience. The Americans with Disabilities Act / ADA definition of an individual with disabilities is “one who has a physical or mental impairment that substantially limits one or more of the major life activities such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working; has a record of such impairment; or is regarded as having such impairment” (Americans with Disabilities Act, 1991, Pub. L. No. 101-336, § 2, 104 Stat. 328) is utilized for this project.

This project emphasizes the positive and negative influences which contribute to parental resilience and lead to post-traumatic growth. Resilience is defined as “the ability to withstand and rebound from crisis and distress” (Heiman, 2002, p. 159). Post-traumatic growth is defined by Calhoun and Tedeschi as “gains that result from the struggle with tragedy, trauma, or loss” (Calhoun, & Tedeschi, 2006, p. 21). Parents of children with special needs continually overcome setbacks and start over again as they face challenging situations while simultaneously advocating on behalf of their children. Parents undergo confounding conditions in the realms of medical systems, educational systems, and within society at large (Landsman, 1998). Some parents grieve the loss of having a “typical child”, the dreams and aspirations they had for their child, and at each developmental stage which is not met (Ellis, 1989). While parents endure many stressful experiences resulting in grief and loss, they also adapt and move forward after each loss with the knowledge they have gained to take on the next obstacle (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003). In peer to peer interactions, parents can communicate what they have learned with other parents to assist them with similar challenges. Parents share resource information, services related to their child’s needs, experience comradery and support other parents (Calhoun & Tedeschi, 2001). Post-traumatic Growth phenomenon contains these and numerous other positive experiences.

Paradigm and Rationale for Chosen Paradigm

The post positivist approach has been utilized for this project with an applied research design. The researcher utilized an applied research design to bring light to the “societal concern” (Patton, 2015, p. 32) pertaining to challenges, adversity, struggles, joys, and positive growth experienced by parents of children with special needs. On the other continuum, the applied research design has been employed to uncover methods to overcome hurdles in communication (Patton, 2015, p. 32) between parents of children with special needs and their service coordinators at Regional Centers who coordinate services on behalf of their children.

The researcher utilized post positivism, an interpretive research paradigm, which acknowledges what may be true for a group or culture in general, may be unique to another individual in the same situation (O'Leary, 2007, p. 6). Each parent who participated in this project has a child with special needs. However, each participant's life experiences are unique and they have different interpretations of what it means to parent a child with special needs. Post positivism considers that individuals live and connect with many interrelated systems. As Thomas Merton has written “no man is an island” (Merton, 2005, p. 65). Parents interact with numerous systems, such as their families, friends, community members, organizations, and society. Humans live within communities and do not exist in a void. In Ventura county, parents of children with special needs interact with the Regional Center. Service coordinators at the

Regional Center serve as parent's point of contact to receive many of their child's special services and supports ("Information about Regional Centers," n.d.).

Positive relationships between parents and service coordinators are important in the creation of more fulfilling and independent lives for their child as they grow into adulthood ("Service Coordination," n.d.).

The post positivist paradigm provides a flexible platform which allows for updates, changes, and alterations of the research question through the interview process. This occurs as the researcher gains more clarity on this population of parents and service coordinators (Rubin, & Rubin, 2016, p. 51). This process is comparable to "puzzling out the research question through layers of discovery" per Rubin & Rubin (2016). The post positivist approach acknowledges fluidity and change as part of the research process with human participants which allows the input of each participant to contribute and the study changes organically and naturally (Parry, Gnich & Platt 2001, p. 216).

Applied research has been employed with the "units of analysis" being organized under the categories of "group" and a "sub-category" of individual (Morris, 2006, p. 90). The group category consists of parents of children with special needs. Whereas the individual sub-category is comprised of the service coordinators participants. Service coordinators play an indispensable role as a critical relay agent who assist parents with accessing information, services, and supports for their child ("Guide to Lanterman Regional Center," 2009, p. 10). The post positivist design provides information on the contributing factors for

increasing levels of resilience and post-traumatic growth through the use of face to face, semi-structured interviews with individuals from each group of participants (Ponterotto, 2005). The design was utilized through the use of interviews with disclosure of personal family history by the parents (Ponterotto, 2005). Through the interview process, the researcher sought to highlight and emphasize parent's strengths. This information was also employed to determine how service coordinators positively contribute to increased levels of resiliency and post-traumatic growth in parent participants.

Service coordinators assist parents by coordinating services for their children and are intimately familiar with their client's family history ("Rights under the Lanterman act: The Regional Center is your starting point," 2013). Service coordinators who demonstrate empathy for parents and understand their strengths, and knowledge, increase opportunities to form constructive relationships (O'Leary, 2004). This type of positive relationship promotes collaboration between both groups (O'Leary, 2004). The service coordinator can contribute by coordinating services and resources with parents in a manner in which parents feel supported in their endeavor to organize necessary therapy and resources for their child (Kupper, 2003). When relationships between service coordinators and parents are positive and mutually agreeable, parents feel supported in the coordination of their child's special care needs (Dinnebeil, Hale, & Rule, 1996).

Literature Review

Introduction

The literature review focuses on concepts which are important to understanding the unique challenges parents of children with special needs face unique challenges from the day their child is diagnosed. The stages of grieving related to diagnosis and raising a child with special needs are discussed. Additionally, some of the extreme stresses and challenges confronted by these parents are outlined. Finally, the movement of parents from feeling overwhelmed by stress to acceptance and new normal are reviewed.

Diagnosis and Denial

Diagnosis does not always occur immediately at birth. Some disabilities do not emerge until a child is days, months, or even years old. A disability is something which is not foreseen unless prenatal tests show unusual results or there is a family history to cause concern. It is the rare parent who will take the diagnosis of any disability in their child in stride (McKeever & Miller, 2004). More frequently, the departure from a "typical" parenting experience occurs for the parent at the point of diagnosis (Boström, Broberg, & Hwang, 2010). At diagnosis, parents experience many common emotions to this distinct life challenge including feelings of grief, anger, shock and denial (Heiman, 2002). This new and alarming information requires time and thought to penetrate the parent's reality. (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003). For some parents the denial process may go on for many years; in some households one

parent may accept the diagnosis while the other parent remains in denial (McKeever & Miller, 2004). The reality of disability and its implications for a child's future may feel too difficult to accept (McGill-Smith, 2014).

Acceptance of the diagnosis of disabilities in a child can be analogous to the process of grief. Wherein, the grieving represents the loss of a "typical" child (Knestrict & Kuchey, 2009). After the shock and denial fades, parents often experience other stages of grief including anger, bargaining, and depression (Prigerson & Maciejewski, 2008). Finally, parents can experience some form of acceptance. As in grieving the death of a loved one, grief experienced by parents of children with special needs is not linear but more akin to a process of moving backwards and forwards through the stages (Ryan & Runswick-Cole, 2008). Diagnosis is only the first stage of their unique parenting journey (McGill-Smith, 2014).

Parenting Challenges and Post-Traumatic Stress Disorder

There are many factors that influence the degree of difficulty parent's experience. First, is the parent's mental and emotional status (Bluth, Roberson, Billen, & Sams, 2013). The next factor is their perceived level of parenting ability (Bluth, et al., 2013). Following this is their level of familial support (Bluth, et al., 2013). Then, their financial and economic status (Blth, et al., 2013). Finally, their community and professional support (Bluth, et al., 2013). Some parents cannot endure the difficulties and challenges of parenting a child with special needs without experiencing post-traumatic stress disorder (Landolt, Ystrom,

Sennhauser, Gnehm, & Vollrath, 2012). The situation and their child's continuous special needs can overwhelm the individual's ability to adapt and cope and their mental health is detrimentally affected. When this occurs, parents experience diverse reactions including behavioral issues such as irritability, hostility, and social isolation ("Relieving parental stress and depression: How helping parents helps children", 2010). They can also experience psychological effects such as flashbacks, severe anxiety, and fear (Zoellner & Maercker, 2006). Parents can also experience sleep disturbances such as insomnia and nightmares (Ellis, 1989). Finally, parents can feel emotionally detached from others and have intrusive thoughts (Franck, Wray, Gay, Dearmun, Lee & Cooper, 2015). When parents experience post-traumatic stress disorder there is an immediate need for therapeutic counseling to address the symptoms and the root causes (Ellis, 1989). Once the initial concerns have been addressed, parents must work on building a supportive network and practice regular self-care (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003) to avoid falling again into this psychological abyss.

Resilience

On the other hand, parents who are emotionally healthy, have supportive family, friends (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003) and community resources (Hastings, Allen, McDermott, & Still, 2002) are more likely to deal with the endless special needs parental challenges in a resilient manner ("Parental resilience: Protective & promotive factors", 2013). Resilience is defined by Cicchetti as an "individual's ability to withstand stresses and not manifest

psychological dysfunction” (Cicchetti, 2010). Resilient parents are said to “bounce back” from challenges and approach them from a multitude of different angles to achieve the desired result (Peer & Hillman, 2014). Parents of children with special needs face many challenges including issues involving their “development, emotional matters, academic concerns, medical problems, and social anxieties” (“Parenting children with learning disabilities, ADHD, and related disorders”, n.d.). With love and partnership from family and friends, community and financial support, parents can handle challenges as they occur (National council on disability U.S., 2012). This support assists parents in rebounding again and again so they are able to engage and achieve their goals (National council on disability U.S., 2012).

Liminal Space

Somewhere in between resilience and positive development is a state of liminal space (McKeever, & Miller, 2004). Liminal space was described by author Richard Rohr as the place between the familiar (Rohr, 2003), or life before the child with special needs, and the complete unknown (Rohr, 2003), or the time following diagnosis and life challenges that follow (Franks, & Meteyard, 2007). A key feature of following the path from resilience to post-traumatic growth is parent’s acceptance during this time into the unknown until they achieve their new normal (Tedeschi, Park, Crystal, & Calhoun, 2014, p. 225).

Post-traumatic Growth

Post-traumatic growth is defined as a construct of positive psychological change that occurs as the result of one's struggle with a highly challenging, stressful, and traumatic event (Calhoun, & Tedeschi, 2004). Post-traumatic growth is an individual's personal expansion and ability to move beyond post-traumatic stress into acceptance, and to come to a place where they see the positive effects of their life challenges (Triplett, Tedeschi, Cann, Calhoun, & Reeve, 2012). Post-traumatic growth involves positive life changes that would not have occurred had the individual never endured the event. Some of the contributing factors to post-traumatic growth include high levels of family cohesion (Calhoun, & Tedeschi, 2014, p. 241) and adaptability (Calhoun, & Tedeschi, 2014, p. 243), a secure and rewarding career (Tedeschi, Park, & Calhoun, 2008, p. 106), healthy psychological coping mechanisms and strategies (Tedeschi, Park, & Calhoun, 2008, p. 110), an optimistic life view and having a positive disposition (Zoellner, & Maercker, 2006), experiencing an internal locus of control (Zoellner, & Maercker, 2006), and finding value and deep meaning in the experience (Breitkreuz, Wunderli, Savage, & McConnell, 2014). Parents can increase the potential for experiencing post-traumatic growth by their willingness to share their personal family story to others and allow themselves to be vulnerable (Goddard, Lehr, & Lapadat, 2001) to be willing to reach out and accept help from others (Heiman, 2002) make an effort to network and find others who understand from their own personal experience what it is like to have

a child with special needs (Neves, Cabral, & da Silveira, 2013), make an effort to find meaning in their life story (Tedeschi, & Calhoun, 1996), and be willing to overcome the obstacles that come their way (Bannink, 2014, exercise 21, p. 103).

Another area of great importance concerning post-traumatic growth involves combating the fatigue parents inevitably experience, known as the burden of care (Seliner, Latal, & Spirig, 2016), from the constant extra effort required to care for their child with special needs. Parents can address this issue when they engage in frequent self-care (Murphy, Christian, Caplin, & Young, 2007), stay connected to supportive friends, family and community members (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003), acknowledge the level of burden and be willing to ask for help as needed (Murphy, Christian, Caplin, & Young, 2007), and focus on their strengths and positive attributes (Irvin, Summers, Behr, & Turnbull, 1989), so parents can be re-energized by their ability to express profound and unconditional love for their child with special needs (Harland, 2007, p. 105).

Conclusion

In conclusion, parents of children with special needs move through stages of grief and crisis (Ellis, 1989). They adapt and continually change by bouncing back resiliently (Irvin, Summers, Behr, & Turnbull, 1989). Parents experience Post-traumatic Growth when they find meaning in their struggles (Tedeschi, &

Calhoun, 1996). Most importantly parents use what they have learned by sharing their journey with other parents experiencing similar situations (Calhoun & Tedeschi, 2001).

When Service coordinators acknowledge parent's strength and resilience as an asset, they can work together collaboratively with parents (Dinnebeil, Hale, & Rule, 1996). Service coordinators working within a family-centered framework with parents can evaluate and coordinate the most appropriate services for the child while supporting the entire family unit (Johnson, Abraham, & Shelton, 2009). Family-centered care assists Service coordinators and parents in reaching common ground (Raver, & Childress, 2015, p. 42). Family-centered care supports parents to feel more involved, educated, and assisted in the coordination of resources and services during their special needs parenting journey (Raver, & Childress, 2015, p. 32).

Theoretical Orientation

Bronfenbrenner's ecological systems theory (Onwuegbuzie, Collins, & Frels, 2013) is utilized as the principal theoretical approach for this study. Ecological systems theory can be visualized as a series of concentric rings of enlarging circles (Onwuegbuzie, Collins, & Frels, 2013, Figure 1). At the center of the diagram is the parent or "individual" (Darling, 2007). Immediately following is a larger ring which includes the parent's immediate family, friends, school, workplace, religious community, and neighborhood representing the

“microsystem” (Bronfenbrenner, 1979, p. 22). In the next circle is the “mesosystem” (Bronfenbrenner, 1979, p. 25) which represents the connections between the “microsystem” (Kazak, 1986) and the next layer called the “exosystem”. The “exosystem” which includes environments indirectly linked to the individual including economic systems, political systems, educational systems, laws, department of human services, and the government (Bronfenbrenner, 1979, p. 25). Finally, the last circle represents the “macrosystem” (Bronfenbrenner, 1979, p. 26) which includes the norms, values, culture and customs in which the individual resides.

Service coordinators work in conjunction with families within the "exosystem" (Worcester, Nesman, Raffaele, & Keller, 2008). When service coordinators provide family-centered services they engage in a supportive role while facilitating both resilience and post-traumatic growth potential in families (Walsh, 2002). Family-centered care is a service centered approach that recognizes the importance of the family and puts the health and well-being of the entire family at the forefront of decision making (Duenas, Landry, & Torok, 2012, p. 4). Family-centered care includes services for families with a child who has special needs including child care (p. 6), family resource centers (p. 5), family counseling (p. 1), support groups (p. 7), information on financial assistance (p. 6), as well as resources and advocacy information for both parent and child (p. 13).

A focus on ecological systems theory is significant to this research study because it demonstrates the substantial importance of systems surrounding

parents of children with special needs (Algood, Harris, & Hong, 2013). These surrounding systems have a direct impact on parent's level of resiliency (Benzies, & Mychasiuk, 2009) and affect how parents respond to challenges they frequently encounter. The systems theory also demonstrates how important positive interactions between all levels of the system are to individuals and family units as they struggle to maintain optimal functioning and resilience (Benzies, & Mychasiuk).

Potential Contribution of Study to Micro and/or Macro Social Work Practice

Service coordinators play a vital role in many families' village of support by highlighting positive aspects of parenting a child with special needs (Goodman, 2011, p. 5). Family-centered service coordinators focus on providing parents of children with special needs with information, encouragement, and optimism (Dunst, & Dempsey, 2007) and encourage resilience; both optimism and resilience are factors in post-traumatic growth. Family-centered services embolden families by acknowledging they know their children best and want what is best for them (Raver, & Childress, 2015, p. 33), that every family is unique (Raver, & Childress, 2015, p. 36), and that families function optimally when the family feels supported in their community (King, Teplicky, King, & Rosenbaum, 2004).

During initial stages of this project, the researcher utilized a micro practice approach involving individuals, families, and service coordinators. However, as

the project progressed, the researcher found it beneficial to include a macro practice approach to include information on organizations which play a decisive role in enhancing resiliency in families who have children with special needs.

Summary

This chapter was comprised of information related to the research topics of resilience and post traumatic growth. It also provided information on the post positivist research approach with an applied design focus which includes both the family, as the unit, and parent, as the individual, relating to the subjects for this study. Next, a literature review was performed with information provided concerning the topics of diagnosis and denial, grief and acceptance, parenting challenges and post-traumatic stress disorder, resilience, liminal space, and post-traumatic growth. Following that, a detailed account of Bronfenbrenner's ecological systems theory was defined. Finally, the potential contribution to micro and macro social work practice was outlined.

CHAPTER TWO: ENGAGEMENT

Introduction

Chapter two provides an explanation of the project engagement process at the research study sites. It also describes engagement with participants. Information is also provided on the methods of self-preparation. Additionally, variations in participants concerning diversity, ethics, and political issues are addressed. In conclusion, the utilization of technology in the research process is reviewed.

Research Study Site

This project has two research study sites. First, parents of children with special needs were interviewed. The parents are individuals who were recruited through a local non-profit organization which caters to parents of children with special needs in the Ventura County area. These individuals were sent a flyer via email and posted on the gatekeeper's Facebook page. The flyer contained the researcher's email address and phone number which interested parents utilized to make contact with her to participate in the study. Once parents made contact with the researcher, she informed the participants of the purpose of the study. Then she asked them if they wished to participate in the study. When parents

were agreeable the researcher made an appointment with them and arranged to meet with them to complete the interview process at their home or office.

The research study sites for the parent interviews were their home or office settings. The researcher met with parents and engaged with them throughout the interview process.

The gatekeeper for parent participants was the founder of a local non-profit organization which serves parents of children with special needs. The founder agreed to send the research recruitment flyer to her email list of parent participants. The email recruitment program was used to inform potential participants about the purpose of the study. The email also requested their participation. The parents who agreed to participate were provided with the researcher's contact information and the researcher spoke with them or corresponded via email to set up interview time and place.

The second research site was a southern California regional center. Regional centers serve and support individuals with developmental disabilities and their families ("Information about Regional Centers", n.d.). The California Department of Developmental Services includes "intellectual disability, cerebral palsy, epilepsy, autism, and related conditions" in their definition of developmental disabilities ("Welcome to DDS", n.d.). The California regional centers were first established by means of the Lanterman Developmental Disabilities Act. The Lanterman Developmental Disabilities Act, otherwise known as the Lanterman Act, was initially passed in 1969 by the State of California

legislature (Frank D. Lanterman Regional Center, 2009, p. 4). This act was intended to provide individuals with developmental disabilities and their families with services and support so they could receive the same human rights as individuals without disabilities (“A consumer's guide to the Lanterman Act”, 2001). Parent activists played a key part in the creation of this legislation and lobbied for the passage of this Act (“50th Anniversary: History of the Regional Centers of California”, 2016, p. 10). The Act was an essential component in the process of moving children with developmental disabilities out of institutions and returning to home settings. This action was facilitated by the regional centers providing services and resources so individuals with developmental disabilities could be cared for by families in their homes (“50th Anniversary: History of the Regional Centers of California”, 2016, p. 10). This act provided services and supports to make remaining in their family home a reality for developmentally disabled individuals (“Lanterman developmental disabilities services act and related laws”, 2016).

The research study site for service coordinator participants was the Southern California regional center offices in Oxnard, Santa Barbara, and Simi Valley. The manager of services and supports, who supervises service coordinators at the regional centers, was the gatekeeper for the service coordinator study participants (“Job opportunities: manager of services and supports”, n.d.). The manager of services and supports was contacted and given explanations concerning the project objective. Afterwards, the manager

requested approval from upper management so service coordinators could be asked to participate in this project. Ultimately, the request was approved by upper management. The manager of services and supports emailed the research recruitment flyer to service coordinators on the employee email list. Upon receipt of the flyers, service coordinators decided independently if they wanted to participate in the research project. Interested service coordinators then contacted the researcher directly via email and coordinated meeting date and time. Interviews with the service coordinators took place in private conference rooms at the regional centers located in Oxnard, Santa Barbara, and Simi Valley.

Self-Preparation

The researcher's life experience has been the ultimate self-preparation. As a parent of a child with special needs, the researcher had real-life experience in both the challenges, the extreme highs and lows of experiencing parenting and early death of her own child with special needs. The researcher self-disclosed these facts with participants prior to participation in the study. The researcher suspects participants may feel more comfortable sharing with a parent who has gone through similar experiences. However, self-disclosure was provided on a limited basis as this research is based on the participant's life story and not influenced or overshadowed by the researcher's similar parenting journey.

In preparation for entering the research sites, the researcher attended local area conferences and educational events geared toward parents of children

with special needs. These educational experiences educated the researcher on current issues and concerns related to parenting a child with special needs in her area. The researcher is also subscribed to a variety of email newsletters which provide pertinent information and concerns related to parents of children with many types of disabilities, including developmental disabilities. The researcher also read peer-reviewed journal articles on developmental disabilities and parenting to gain a deeper understanding of current challenges and concerns on the topic of parents of children with special needs and their interactions with service coordinators at regional centers. Finally, the researcher reviewed current and historical information concerning California regional centers to understand further the role service coordinators play in their interaction with parents of their “consumers”.

The researcher is aware that challenges exist between service coordinators and parents of children with developmental disabilities. This awareness was gained through personal experience, by conversations with other parents of children with special needs, and with service coordinators. Although the relationship between these two groups of individuals is often cordial, there is also underlying unspoken tension. This may occur as both groups have differing ideas about the other person’s role that are based not on facts, but rather on opinions or previous negative interactions. On the part of the parents it can be related to a desire to have their child’s needs met which has yet been unfulfilled. While in the case of the service coordinators, it can be due to their frustration due

to limitations on the resources they can provide to families and sensing parents are being unreasonable in their requests for services and resources. One goal of this research is for the service coordinators to gain more intimate understanding of the struggles and challenges encountered by parents of children with special needs. Additionally, the researcher sought to provide parents with understanding of the role of the service coordinators, what services they can provide, and the process by which they make their decisions. The hope of the researcher is for both parties to gain more understanding and acceptance of their interactions and to promote relationship based on mutual respect and open communication.

Diversity Issues

This project is inclusive in its scope and every effort has been made by the researcher to embrace and include parents from a wide variety of cultures, genders, religious traditions, and socio-economic backgrounds.

The researcher predicted there may be a possibility that inclusion of fathers or male parental figures would be difficult in the study. The researcher was concerned male participants might be more challenging to engage in participation. However, the researcher made every effort to extend invitations to both men and women during the project to obtain a balanced perspective and participation. The purposeful inclusive nature of this study serves to create a research project not solely based on the mother's role in parenting a child with special needs but encompasses the father's role as well.

Ethical Issues

Ethical issues are critical to ensuring each participant's privacy. The participants interview recordings and data files were numerically coded to safeguard their privacy and to ensure their information is kept confidential. The data is held on a secure external drive to be accessed only by the researcher for use on this project. Participants were notified prior to participating in the study of their right to confidentiality and were provided with informed consent forms prior to recording their interviews. These consent forms notified participants that their participation was voluntary, that no monetary (or otherwise) compensation was provided, that they could leave the study at any time or request that information they had previously provided be removed from the research records. Participants were also informed that all private and sensitive information they shared with the researcher is kept completely confidential ("Stanford human subjects definitions", n.d.)

All interviews were held in either the parent's home or office, or in the Service coordinator's private conference rooms at their respective regional center office. The interviews were open only to the participant and the researcher unless the participant requested an observer be present.

Study participants have been coded as P, for parent, and then a letter starting with A,B,C... related to the order of their participation in the study. Service coordinators are alternatively being coded as SC, and then letters starting with A,B,C,... was assigned based on the order of their participation in

the study. No names, or other identifying information were utilized for coding study participants information.

Interviews with both groups of participants were individually recorded with an audio recording device which included a USB port and the data was transferred to the researcher's personal computer after each session. The researcher transcribed each interview after the recordings were downloaded to the computer. After transcription, the researcher deleted the audio files from the hard drive. The researcher also deleted the associated Word documents after coding had been completed for the research project.

The researcher was a parent to a child with special needs who had passed away in 2009. During the research process, she remained an impartial observer during participant interviews. She kept her observations and opinions private. She approached receiving information in an unbiased manner and remained realistic while maintaining awareness of her preconceptions (O'Leary, 2007, p. 47).

Political Issues

The researcher averts political issues to the best ability of her ability. The information provided by both parents and service coordinators is kept completely separate and confidential.

Parents may have opinions and beliefs that their needs are not being met by service coordinators. Parents may learn from another parent that they are

receiving certain services for their child, while the other parent has been denied the same services for their own child. This type of occurrence can lead to the belief that there is a personal bias behind approving services for certain clients. Parents may not be aware or informed of the intricate rules and regulations imposed on service coordinators in their workplace and the rationale behind their decision making (“Funding the work of California’s Regional Centers”, 2013, p. 52-58). This situation presents an opportunity for the service coordinators to be open and honest about the decision-making process so parents know exactly why they are making decisions.

On the other hand, in many cases service coordinators have not experienced parenting a child with special needs themselves and therefore do not have a personal understanding of the burden parents experience. In this case, they may not be sympathetic or understanding to concerns parents are reporting in this study. This provided the researcher with an opportunity to provide educational information for clarity where understanding may be lacking on the part of the service coordinators.

The Role of Technology in Engagement

A digital recording device was utilized to record interviews with parents and service coordinators. Initial and follow up contact was made with individuals via telephone and email. Parents and service coordinators were given written consent prior to the usage of recording devices. Recording interviews with a

digital recording device allowed the researcher to be present and fully engaged with the participant during the interview process. Additionally, utilization of a digital recording device chronicled accurate recording of the interviews which the researcher later transcribed and analyzed via laptop computer.

Summary

This chapter discusses the process of engagement the researcher engaged in to become informed about the challenges and struggles parents of children with special needs and service coordinators who assist them. Parents coping mechanisms and resilience factors were considered. Self-preparation was outlined with information provided about the researcher's personal experiences and interest in this research topic. Next, the interest in creating a diverse population of participants was conveyed. Following, was a discussion on ethical issues and the importance and methods of confidentiality utilized to maintain participant privacy. Subsequently, potential political issues between the difference in opinion and the views of parents and service coordinators was addressed with possibilities for clarification in both groups. Finally, the role of technology was outlined including information on the usage of digital recording devices and laptop computer used for transcription.

CHAPTER THREE

IMPLEMENTATION

Introduction

This chapter explains in detail the implementation methods employed for the research project. Contained within this chapter are information on the study participants, details on participant selection, data gathering and the analytic process. Information is also included which details the research results. Finally, the termination process and follow up with research participants is explained.

Study Participants

Participants for the study included 14 parents of children with special needs from Ventura County. Ventura County is the 12th largest county in California, with a total estimated population of 850,536 individuals (“United States Census Bureau. Quick facts, Ventura County, California”, 2015). Ventura County contains 10 incorporated cities which include Camarillo, Fillmore, Moorpark, Ojai, Oxnard, Port Hueneme, Santa Paula, San Buenaventura Ventura, Simi Valley, and Thousand Oaks (“County of Ventura, California. About us”, 2011). Although Ventura County is predominantly Caucasian (“ZIP Atlas. Percentage of whites in Ventura”, n.d.) the county also includes a wide diversity of multicultural ethnicity and racial groups (“County of Ventura, California. About us”, n.d.). Per the United States Census Bureau, as of July 1, 2015, of the total number of individuals

counted in the Ventura County census, 85% were designated as “white only”, 2.3% were “black or African American”, 1.9% were “native American”, 7.6% were “Asian alone”, .2% were “native Hawaiian” and/or “Pacific Islanders”, 3.3% individuals were comprised of “two or more ethnic/racial categories”, and 42.3% were “Hispanic or Latino American” (“United States Census Bureau. Quick facts. Ventura County”, July, 2015).

Additionally, as of 2015, there are a total of 199,398 children living in Ventura County who range in age from zero to 18 (“Summary. Ventura County. Child demographics: Ventura County”, 2015). These children live in a variety of household arrangements including within married couple households (63.9%), male householder, no wife households (42.2%), and female householder, no husband households (33.0%) (Ventura County Public Health, “Ventura County (VCPACT) trend report”, 2015, p. 11).

The California Department of Education, division of special education has most recently reported that during the 2015/2016 school term there were 17,315 children with special needs living in Ventura County (“Special Education enrollment by age: Ventura County”, 2016). The categories of disabilities included in this data are intellectual disabilities, hard of hearing, deaf, speech and language impairment, visual impairment, emotional disturbance, orthopedic impairment, specific learning disability, deaf-blindness, multiple disability, autism, and disabilities due to traumatic brain injury (“Special Enrollment by age: Ventura County”, n.d.). Finally, the children living in Ventura County reside with a variety

of different guardians, with 86.7% of children living with their biological parent(s), step parent or adoptive parent(s), 11.5% of children living with their grandparent or another relative, and lastly 1.9% of children living with their foster parent(s) (“Ventura County (VCPACT) trend report”, 2015, p. 25).

The other group of participants in this study were nine service coordinators who work at various Regional Centers in Ventura County. Regional Centers of California, per State of California Department of developmental services, are “non-profit corporations located across California that help individuals with developmental disabilities and their families, with access to services and resources in their community” (“Regional Centers”, n.d., p. 1). Service coordinators work on behalf of the Regional Center as case managers in a social work role (“Regional Centers employment opportunities”, n.d.). Service coordinators work with “consumers”. “Consumers” are defined by the State of California Regional Centers as individuals who have been diagnosed with a developmental disability prior to the age of 18, which is indefinite in nature, and their families (“Eligibility Criteria for Services for and Adults”, n.d.) The conditions covered under this umbrella term of developmental disabilities includes cerebral palsy, epilepsy, autism, and other similar conditions which include developmental and intellectual disabilities (“Guide to Lanterman Regional Center”, n.d., p. 4). Regional Center service coordinators utilize person-centered planning to assist in the removal of barriers to obtaining services so consumers can reach their greatest personal potential (“Department of developmental services & Regional

Centers, wellness initiative projects”, 2001, p. 9). The fundamental goal of person-centered planning is to contribute towards each consumer’s greatest ability to become independent and to utilize methods of self-determination (“Self-determination program”, n.d.). Self-determination is defined by the Regional Centers as the consumer and family’s ability to have more “freedom, control and responsibility” obtaining eligible services (“50th Anniversary: History of the California Regional Centers”, 2016, p. 36). Regional Center consumers range in age from newborn babies, children and adolescents, to adults and finally elderly individuals (“Who is eligible”, n.d.). The Service coordinators work within different age groupings and geographical areas to provide services for all age ranges of their consumers (Frank D. Lanterman Regional Center, 2009, p. 10).

Service coordinators are one of the many individuals employed at the twenty-one California Regional Centers (“FAQ’s about Regional Centers”, n.d.). These Regional Center employees are social workers who have experience within the field of developmental disabilities. They are also individuals who are skilled at connecting families with essential community resources and therapy providers (“FAQ’s about Regional Centers”, n.d.). According to Disability Rights of California, the Lanterman Act and Regional Center’s purpose is to afford individuals with developmental disabilities and their families the opportunity to adequate levels of health, safety, and to promote their freedom of choice, dignity, inclusion in society, and finally to encourage their independence and productivity as they grow older (“Principles for addressing the restructuring of services and

supports for state developmental centers”, adopted 1999, amended 2014). Service coordinators are tasked with assisting consumers and their families individually with these items from a person-centered planning process (“Person-Centered planning: Building partnerships and supporting choices”, 2001, p. 4). Person-centered planning utilizes a strength-based perspective concerning individuals with developmental disabilities and their families. These individuals are referred to as “consumers” by Regional Centers and their staff (“Person-centered planning: Building partnerships and supporting choices”, 2001, p. 3).

The study is all-encompassing and comprehensive in the recruitment for both groups of participants; parents of children with special needs and service coordinators from the Tri-Counties Regional Center. The hope of the researcher is inclusive of all genders; both male and female, and any other variations. Lastly, the study was open to individuals of every sexual orientation, racial ethnicity, and religious preference.

Selection of Participants

A purposive method of sampling was utilized with two homogenous study samples. The first group of study participants consisted of parents of children with special needs recruited from a local non-profit special needs parent email list. The second group of study participants consists of service coordinators from Regional Centers in Ventura county.

The researcher worked with a local non-profit organization to connect with parents of children with special needs in the Ventura county area. The non-profit organization was established to assist parents of children with special needs with support they need to access available community resources and services for their children (“About non-profit organization”, n.d.) The non-profit organization coordinates a monthly coffee break meetup for moms, a monthly mom’s night out, and a monthly dad’s night out. These gatherings are open to anyone in the community and are wonderful opportunities to network and speak with other parents (“Family support services. Monthly gatherings”, n.d.). These meetings assist parents in easing loneliness and isolation parents of children with special needs often experience (Solomon, Pistrang, & Barker, 2001). Since their inception, this non-profit organization has maintained an email list of parent participants. The “gatekeeper” of the organization emailed a participant recruitment flyer, created by the researcher, to all their parent participants via email and also posted to their group Facebook page. The gatekeeper also distributed the participant recruitment flyers to parents at their monthly community events.

There are approximately 200 individuals within the organization’s email list as well as those who attend their monthly community events (M. Berenstein, personal communication, February 11, 2017). The parents who participated in this research project included both men and women. The parents ranged in age from their late 20’s to mid-50’s. Their incomes varied from those in a lower

middle class to upper middle class economic status. A multitude of religious affiliations are represented, including parents who are Jewish, Christian and Atheists (M. Berenstein, personal communication, February 11, 2017). The initial sampling was purposive with direct outreach via an email “blast”. An electronic flyer outlining the project information was sent to prospective parents with a request for response to the researcher. Print research recruitment flyers were also distributed by the organization facilitators at their group meetings and events. In addition to the direct purposive sampling techniques, snowball/chain sampling was utilized during the interview process with parents. The researcher requested referrals from parent participants for their friends interested in participating. The snowball effect only applies when additional research participants are included whom are referrals from the parents originally participating in the study (Morris, 2006, p. 93).

Service coordinators were selected through the “gatekeeper” at the Regional Center. This “gatekeeper” is their direct supervisor. When the approval was granted by upper management for their participation in the research project, the supervisor forwarded a participant recruitment flyer to the service coordinators at the various Ventura Regional Centers. Recruitment flyers were also posted in their break rooms to recruit additional service coordinators. The researcher’s contact information was provided on all flyers.

Data Gathering

Qualitative data gathering practices included face to face interviews (Edwards, & Holland, 2013, p. 43) with parents of children with special needs and service coordinators at Ventura County Regional Centers.

Prior to answering researcher's questions, participants were asked to review and sign both informed consent and debriefing forms. First, participants confirmed they understood their participation in the study. Next, they confirmed they understood their participation was voluntary and they could withdraw their involvement at any time. After that process was complete, the study participants provided a brief narrative history of their life with their child to the researcher. Parents were asked essential questions, extra questions, and throw away questions (see Attachment A). The same process was utilized during the interviews with the service coordinators. They were asked about their career choice as a service coordinator, their communication and interaction styles utilized with parents, their view of parent's strengths, weakness, and their opinions about parent's resiliency and growth due to this parenting challenge (see Attachment B).

Initial engagement involved interviewing parents, hearing their stories, gathering information and data, and being inquisitive about their struggles, experiences, joys, and challenges while being a parent to a child with special needs.

Engagement strategies consisted of researching challenges parents of children with special needs commonly struggle with. Of special interest is their adaptive levels of resilience as they undertake this life-changing parenting experience. The researcher also studies relevant positive and negative factors which influence each parent's level of resilience as they face extreme challenges and sometimes traumatizing experiences. Finally, the researcher investigated internal and external factors involved in creating both positive and negative experiences for parents.

Phases of Data Collection

Face to face interviews with parents were utilized. A purposely selected sample of parents of children with special needs was used as well as service coordinators who directly serve and interact with these families.

During the first phase of data collection, parents were contacted by the researcher via phone and/or email. The researcher and parent discussed their meeting place for the interview, such as their own home or one occasion an office conference room. Next, the researcher and parent met for the interview portion of the meeting. The parent was provided with the informed consent information. Again, parent participants could opt out of participation at any time if they felt uncomfortable or no longer wished to participate. The participants were informed that all personal data is confidential and the researcher utilized a random number generator to code all data. No names or identifying information

were used for study purposes. The interview was recording on a digital device and was transcribed later by the researcher. The interview then proceeded with the narrative-historical portion followed by the prepared questions. Once the interview portion was completed the researcher asked the parent for any final questions or concerns they had. Finally, when the interview was complete, the researcher thanked the participant again and left the meeting site.

During the second phase of data collection, the researcher listened to and transcribed the digital recording of the parent participant interviews. After the transcription process was completed, the researcher made additional notes for their use during the coding process.

During the final phase of data collection, the researcher reviewed the transcribed digital recordings and their personal notes. The researcher determined if questions for future parent participants required any changes or if questions should be added to make the interview process more thorough. Finally, the researcher reviewed all elements of the interview process to determine if they were relevant to the project (Morris, 2006, p. 96). This process resulted in tailoring the interview process for future participants to have the most insightful and discerning interactions possible.

Data was gathered in a similar fashion with service coordinators. With this group, the meeting places were private conference rooms at various Ventura County Regional Center offices. The data included the service coordinator's interactions with parents. The goal of the researcher was to determine how these

family-centered focus interactions assist in increasing parent's strengths, resilience and positive growth. The researcher also looked at areas where parents and service coordinators can come together to work as mutual advocates for the children with special needs.

Interviews with service coordinators were also be recorded via digital recording device and were later transcribed by the research into a Word document.

Data Recording

As respects the parents, the interviews were open with a narrative storytelling style which the researcher had reviewed in peer-reviewed journal articles. The researcher is interested in uncovering the power of storytelling in healing and transformation. Voicing your story is part of the process of self-awareness. Next, questions were asked of the parent participants to uncover their strength and resilience, in spite of their straining circumstances while raising a child with special needs. The researcher reviewed an array of literature studies related to parenting children with special needs and compared this study's research findings with the information discussed in peer-reviewed journal articles. The point of the comparison is to determine if any new information or findings in this study could add to the body of literature that already exists.

Interviews were held face to face in natural home settings for parents and in private office and conference room settings with service coordinators. The

interviews were documented with a digital recording device which were later transcribed. As deemed appropriate, valuable insights were noted for future reference by the researcher with pen and paper during the interviews.

Data Analysis

Qualitative data analysis was employed together with open coding, axial coding, and selective coding. Open coding was utilized as interviews were transcribed, reviewed and broken down into themes and categories to assist in future interviews (Morris, 2006, p. 113). Examples of open coding are themes involving feeling overwhelmed during initial diagnosis, adjusting to diagnosis, feeling loss for what may have been, coping mechanisms utilized, adjusting to the peaks and valleys of having a child with special needs, wanting to learn more about child's condition to educate themselves, accepting reality of situation, discovering a new normal, etc.

Next, axial coding was employed to explore further themes uncovered during the open coding process. Once themes were determined, axial coding data analysis was utilized to determine corresponding and contributing factors to resilience and post-traumatic growth in parents of children with special needs (Morris, 2006, p. 113). Additional categories were also established including items such as parent's backgrounds, perspectives on disability, disorders and syndromes, and their concerns related to parenting a child with special needs.

Finally, during selective coding, data was analyzed to develop relationships between the categories developed during open coding and axial coding (Morris, 2006, p. 117). Selective coding pulls together information from both open and axial coding to create a “story” or “study” for the research proposal in full, not based only on the individuals interviewed (Flick, 2008, p. 302). The process of selective coding allowed the researcher to create an overarching “storyline,” and resulted in a “central theme” and “category” (Flick, 2008, p. 302). As suggested by Morris (2006) the researcher also read peer review journal articles to find corresponding patterns of “reaction and decision making” from similar research participant studies and utilized Word and Excel computer programs to assist in the qualitative data coding process (Morris, 2006, p. 117).

A conditional matrix was created to put all three categories into a framework or visual model (Morris, 2006, p. 119). The matrix shows how different themes are related in the process of diagnosis, denial, life experiences, challenges, stress, joy, pain, confusion, acceptance, gaining knowledge, reaching out, accepting assistance, self-help, support systems, and a “new normal”. These themes are related to the multi-faceted and ever-changing life of a parent of a child with special needs. These factors are also factors related to the parent’s levels of resilience and their success at achieving post-traumatic growth. The conditional matrix ultimately assists the researcher in determining if this study has either a micro or macro “level of interaction” (Morris, 2006, p. 120).

This process was dynamic and did not occur in a linear fashion. It changed over time with additional parent and service coordinator interviews. The researcher was informed of important themes as the interviews progressed. The process was malleable and flexible to emerging themes. Adjustment to categories and themes were applied during the study as additional findings were uncovered during interviews with research participants.

Once parents were interviewed and their responses were recorded, all documentation was reviewed to determine themes which emerged during these interviews. Of particular interest were themes related to post-traumatic growth and resiliency in parents of children with special needs, as well factors which contribute to the positive growth and responses. The role of each parent's family, friends, and social work professional's involvement in the process of personal growth was also explored in depth.

After each interview, the researcher took time to reflect and review the information gathered to determine how it related to and builds upon the premise that parents of children with special needs grow and change due to their experiences. This demanding life transformation ultimately changes parent's lives forever. Outsiders may only perceive the negative connotation of this parenting experience. However, the intent of this study is to show the positive effects experienced both by parents, their families, their interactions with service coordinators and ultimately with society at large.

The research focus describes and explains how parent's experiences having a child with special needs propels them into experiencing grief and trauma. But more importantly, the purpose is to show how parents move beyond these negative states into powerful positive experiences through their resilience and ultimately achieve positive post-traumatic growth.

Family history information was gathered through interviews with the parents of children with special needs. These interviews were utilized to achieve clarity on the concepts of resilience as respects parent's real-life experiences raising a child with special needs. Interviews gave parents the opportunity to tell their personal story of having a child with special needs. The information and data gathered has assisted the researcher in gaining a comprehensive understanding of parent's struggles and joys to assist in joining parents and service coordinators on a common ground where they can come together in a positive manner based on equality and understanding.

Communicating Findings

Research project findings will be communicated to the California State University San Bernardino Social Work Graduate Research Department. At the completion of the project, a final report will be presented, and the researcher will also display their project findings on the CSUSB Scholarworks website ("CSUSB ScholarWorks," n.d.). The researcher will be provided with a link to their study

online which they in turn can share with project participants to review study results.

Termination and Follow Up

After each interview, the parent and service coordinator participants were thanked for their participation in the study and asked for additional comments, questions, and concerns they may have. Participants were given details involving project results which can be viewed at the end of the 2018 school year via a web link on the CSUSB ScholarWorks website.

Participants were provided with a website link to view the project results on CSUSB ScholarWorks website. Participants were given the option to include their comments and thoughts concerning the project on the website directly to the researcher.

Summary

This chapter provided detailed information on the research sites for this project including natural home settings for parents and office settings for service coordinators. Participants were drawn from a non-profit organization's parent email group comprised of a diverse set of parents of children with special needs. The participants were recruited from a wide-ranging area in hopes of containing a diverse population sample comprised of different cultures, nationalities, genders, religious affiliations and socio-economic backgrounds.

While, service coordinator participants were comprised of participating individuals from Ventura County Regional Centers. Next, information was provided on the qualitative research method utilized for this project along with the sample questions answered by participants, recording and transcription methods. Next, the open, axial, and selection coding methods utilized were described.

Finally, study disbursement details were described which entailed sending an email to each study participant with a website link for CSUSB ScholarWorks where they can view the final study results. The final project will be posted on the CSUSB ScholarWorks website which represents the termination phase of this project. Participants can view the project results via the website link. Participants will be encouraged to share their viewpoints of the final research project findings.

CHAPTER FOUR

EVALUATION

Introduction

This chapter outlines the findings of the research project. Included are demographic information on research participants including parents and their children with special needs, and service coordinators at a southern California Regional Center. Emphasis is placed on the salient themes found during the research process. These themes include resilience in parents of children with special needs, parent's movement through the stages of change model related to loss and growth, and the disengagement between parents of children with special needs and their service coordinators who direct and manage services for their children. Finally, there is a discussion of the limitations and implications of this study.

Qualitative Data Analysis

Parents of children with special needs

There are twelve parent participants who participated in this study. Of the total, 58% were women and 42% were male. All but one parent interviewed is married, the remaining individual is divorced. Eight of the twelve participants reported their ethnicity as Caucasian. In addition, one parent identified as Hispanic, one as Asian American, and the final individual as Jewish. Every

parent who participated is currently working with the exception of two stay-at-home mothers. As respects education levels, three participants are high school graduates, two have associate of arts degrees, five have bachelor’s degrees, one holds a professional certification, and one has a law degree.

Each parent participant disclosed demographic information regarding their child. Excluding one participant, all parents were from a Ventura County mom and dad’s “night out” group. Each mother agreed to be interviewed face to face. Alternatively, the fathers preferred to complete their research documents and return the paperwork to the researcher via mail or email. Amongst the twelve parents there is a total of nine children; two of the children are fraternal twins. The children range in age from as young as seven years old to the oldest child who is nineteen. Additionally, the parent participants reported their child’s diagnosis. The children’s demographic information is detailed in Table 1 below.

Table 1. Demographic Information for Children with Special Needs

Gender	Age	Diagnosis	Current Level of Education
F	14	Chromosome Abnormality/Syndrome Intellectual Disability Speech/Language impaired	High School
F	15	Chromosome Abnormality/Syndrome	High School

Intellectual Disabilities

F	9	Autism	Elementary
F	9	Global Developmental Delays	Elementary
F	19	Cerebral Palsy	Transition after high school
		Brain Malformation	
		Optic Nerve Hypoplasia	
F	13	Cerebral Palsy	Middle School
		Epilepsy	
		Speech / Language Impaired	
F	7	Autism	Elementary School
		ADD/ADHD	
M	12	Autism	Middle School
		Blind	
M	15	Autism	High School

Service Coordinators

The second group of participants included eight service coordinators who work at a Southern California Regional Center. These individuals coordinate care and services for their clients with developmental disabilities. Seven of the eight service coordinators who participated were female. Only one participant was male. Of the eight individuals, four are Caucasian, four are Hispanic, and the remaining coordinator is Asian/Pacific Islander. Six of the coordinators have

reached a masters level of education while two have a bachelor's degree. Their degree specializations include social work, human development, marriage and family counseling, clinical psychology, sociology, and public administration. In addition, this group of service coordinators included two individuals who work in the Early Start program, one who works with elementary school age children, and four who work with adults and seniors. Finally, the individuals I interviewed ranged in years as a service coordinator from working as short as one year, to as long as 15 years in this career.

Data was collected from parents and service coordinators based on separate questionnaires (See APPENDIX A) developed by the researcher. The questionnaires (See APPENDIX A) include open-ended questions, which participants could choose to answer. They also had the option to pass on a question if it did not apply to their family or work experiences. The researcher met with each parent separately in their homes for the interviews with the exception of the fathers who chose to type or write their answers on the questionnaires directly and return to the researcher via mail or email.

Alternatively, the researcher met with the service coordinators individually at a private conference room located at the Regional Center where they worked. One service coordinator chose instead to type her answers and email them back to the researcher. The researcher took brief notes during the interviews with both parents and service coordinators. All interviews were documented on the researcher's digital recording device. Later, the researcher would listen to the

interviews and transcribe each one onto a separate Word document. The documents were titled with their initials and either PR for parent or SC for service coordinator to differentiate them. Once all of the interviews were completed and transcribed, the researcher made separate documents by question. The new documents were named according to their related question. Next, the researcher converted the text into tables with three columns onto the Word document. First, was a column listing the initials of either the parent or service and PR or SC. Second, was a column which was left blank for coding use. Finally, was a column was creating with the answers to the related question per parent or service coordinator.

Next, the researcher began the grounded theory coding procedure. Open coding was utilized initially to uncover codes based on quotes by participants as well as codes the researcher began recognizing during overview of all interviews. The researcher read and reviewed the answers line by line in the Word table. The researcher kept coding notes while reading through each interview document.

After open coding, the researcher moved to axial coding and searched for themes which joined the open codes together into more coherent themes.

Finally, the researcher proceeded to utilize selective coding to uncover the overarching story line and bring codes and themes together into a comprehensive narrative.

Data Interpretation

Stages of Grief

The overarching themes found during coding related back to the researcher's initial hypothesis that raising a child with special needs has many facets related to the stages of grief. In this study the first stage of grief, denial, was not represented in the parent participants. The parents expressed knowledge of their child's disability either during pregnancy, at the time of birth, or within the first year of life. None of the parents expressed being in denial of their child's disability. They were the first to acknowledge there was an issue and had assist their children's physician with the reality that something out of the norm was happening with their child, their health, and their development. In one case, the mother knew from the day her child was born that something was wrong. Her concerns fell on deaf ears in the hospital and she was sent home with her child. She said in her interview "something was just not right. It didn't feel right. The nurses wouldn't come and visit like they did when my first son was born" (L-PR, July, 2017). Months later she noticed her son was flinching in an unusual manner and she suspected seizures. She brought this to her doctor's attention but initially he said it was "just minor clonic jerking that would go away as her son grew and matured" (L-PR, July 2017). Again, this mother did not feel heard and her internal wisdom told her that her baby's movement was seizures. Finally, the seizure activity began to intensify and her child lost control of some of his bodily functions. The mother took him to the emergency room and finally she

received a diagnosis. However, it was delivered in a cold and dismissive manner. The doctor stated “and by the way, the baby has brain damage” (L.PR, July 2017). The baby was now five months old. The news was devastating. A service coordinator made an excellent point about the differences between mothers and fathers in this grieving process:

Women are able to express emotions and grief, men have a harder time with that. It's fine to have support groups, but men sometimes have a harder time with that. So maybe a little family therapy doesn't hurt. Particularly for men, because they want to take care of things and fix things and when they can't they don't know what to do. (L-SC, August, 2017)

Anger, the second stage of grief, was a prevalent theme in this study. Parents did not relate feelings of anger towards their child. The anger was expressed towards the frustrations parents experienced dealing with professionals and trying to break through barriers towards obtaining services for their child. Finally, parents expressed anger directed by their frustration of unfair treatment of their child and others in her special needs class. This mother relayed a recent situation where she needed to advocate along with other parents to fight the move of her daughter's whole program to a high school. She stated they received no preparation from the school for this dramatic change until

getting a letter in the mail that stated “the whole program is moving” (M-SC, June, 2017). She expressed that she believed the school was trying to do it “under the radar” (M-SC, June 2017). She and the other parents went to school board and now the program is not being moved. She noted “the kids need stability”. Her anger towards this unfair change and her activism helped to alleviate this situation and helped her daughter and the other children maintain the school location.

The third stage, bargaining, was not represented in this study. At the point of the interviews the parents I interviewed had reconciled earlier feelings of ambivalence and struggling with their child’s disability and had come to a place of acceptance within themselves of what is. When asked if they would tell their former selves anything about this experience one father summarized this theme best “I wouldn’t tell my former self anything. I have enjoyed the experiences and love my kids the way they are” (J-PR, June, 2017).

Depression, the fourth stage of grief was found across the participants. It was typically represented by the lack of self-care and total dedication to their child, in spite of how they were personally deteriorating. One mother in particular expressed this by speaking about two experiences first. She was barely sleeping since her son was crying around the clock and she lacked any respite, her husband worked full time, she had another baby, and had no local family support. She went to the doctor in sheer exhaustion when her son was about two years

old and asked him if she could “die from a lack of sleep”. He assured her that she would survive and said “that’s ridiculous”. A year later when she returned to his office for a checkup and she was in a better place, he said “God, you could have totally died but I thought if I told you that at the time you would have died right there in my office!” (W-SC, June, 2017). On another occasion she was bitten by a recluse spider. She felt the bite but didn’t look to see what had happened or investigate any further. Days later her husband noticed the whole back of her leg was black so she went to the doctor. The doctor asked about the typical physiological responses to this type of bite “are you extremely exhausted? Lethargic? Stressed?” she said “That’s my norm, I’m always on the brink of death”. The doctor said, well you are already starting to heal and just sent her home with cream to put on the bite. She stated she was so focused on the baby that she was not a priority. “I was just so, I don’t have time. I’ll deal with that later. It’s almost like a nature thing. You are just so focused on the baby” (W-SC, June, 2017). This mother has endured the early years of turbulence. Her son is a teenager and she now has the time and energy to focus on her own self-care once more.

One service coordinator noted the importance of self-care for parents.

In her interview, she stated, well first, main thing is, you need to take a break, you need to take care of yourself. I mean if you are on overdrive and you aren’t stopping, you are spinning out of control. So, I really try to hear them and what their needs are. She speaks with families about the

possibility of utilizing In Home Supportive Services (IHSS) for respite or relief care. Families can sometimes qualify for this service and the IHSS worker can provide them with a break so they can have a time to do something for themselves. (U-SC, August, 2017)

Finally, acceptance, the fifth stage of grief was present in every parent I interviewed. Each participant had their own unique form of acceptance but they had all found that the importance of the child overcame the disability. These parents had found acceptance of their child's disability. After many years of trying every therapy possible this mother had some sage advice not to "waste money, time and emotion trying to make" your child "normal". She suggested taking this time to bond with your child instead, like you would with a typically developing child. At the time she stated there was "this urgency of finding therapies, doctors, searching for what they could do". It took a while to realize "I needed to just love her and go with that first!" (MA-SC, August, 2017).

Resilience

The parents I interviewed were incredibly resilient. They had all faced "adversity, trauma, tragedy and significant sources of stress" (Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014) while raising their child with special needs. Instead of "falling into a pit of despair" (L-PR., July, 2017) they "bounced back" and tried even harder to achieve goals and advocate on their children's behalf. These parents would stop at nothing to provide the best

possible care for their children and to ensure that others entrusted to their care did so as well. One mother explained this when she stated

“Maybe there are going to be a lot of challenging moments that you will be able to get past and get through and your child is going to be happy because they have you and your determination to do the things for him or her. It’s going to pay off. You are their support. My son can’t tell me that (with words). The way that he cuddles with me and seeks me out amongst a crowd. That makes me feel good.” (S-PR, July, 2017)

A service coordinator also made note of the way she recognizes the resilient spirit in parents she has worked with

I see resilience as never giving up. Never stopping and always asking questions or wanting the best advocacy for that person, for that family member. (U-SC, August, 2017)

Another service coordinator described resilience in parents this way:

The resilience of a parent with special needs is the ability to bounce back and it comes in waves. Go ahead and have a good cry but still be able to look at the positives. As a parent of a child with special needs I’ve had to have those good cries but I think it’s also important but not to lay down and spiral down. I think with parents of children with special needs it’s the ability to feel that kick in the stomach and be able to rise from it. Take a deep breath. And then forge on. I see that in practically all the parents, it’s a process. (L-SC, August, 2017)

Post-traumatic Growth

The other predominant theme found in the parent participants was the concept of post-traumatic growth. This concept is defined as “positive change experienced as a result of the struggle with a major life crisis or traumatic event” (Tedeschi, & Calhoun, 2004, p. 2). Each parent participant has overcome hurdles to receive treatment which honors and respects the dignity of their child. They realize that while having a child with special needs requires a great deal of planning. They must also remain flexible as things can change rapidly. One father stated

“Both my wife and I recognize the best laid plans of mice and men go by the wayside when you have children, especially when you have a child with special needs. You can adapt to some degree but there has to be an amount of slack provided” (MI-PR, July, 2017).

Parents care for their children with love, compassion, and inner strength. They are supported by their “tribe” of peer parents who relate from personal experience what they are going through, who offer suggestions and support, and friendship in this lifelong journey. Every parent I interviewed realized that their child was with them for life. Their children will not be leaving home to go to college, get married, or start a career. This is a lifelong commitment that they are devotedly committed to. One father stated in this regard “our daughter will always be with us, there is not going to be an empty nest, so to speak” (D-PR, August, 2017). Parents come to realize that they need support on their journey. They find

this support from their family, their friends, and with other parents of children with special needs. One mother described her mom's night out group as a place where she feels "supported and the comradery is inspiring" (M-PR, June, 2017). Another mother said in her interview

"I look up to people who have been handed a bad situation and still manage to smile, be kind, and look for the good in others. I would say in general I'm more appreciative of people who have had things go wrong but don't choose to let it define them" (MA-PR, August, 2017).

Parenting their child with special needs is a labor of love that each parent has come to accept wholeheartedly.

Implications of Findings for Social Work Practice

Based on the finding presented in this project, the suggested course of action to bring service coordinators (micro social workers) and parents of children with special needs closer together would be to implement new policies at the California Regional Centers. Parents reported that frequently, their only contact with coordinators was at their Individualized Educational Program (IEP) meetings or something similar, which are held on an annual basis. This situation tended to be different only with parents of children who take part in the Early Start program. During the Early Start program, when children are age zero to three, their service coordinators speak with parents on a monthly basis. The Early Start service

coordinators I spoke with also advised they are updated weekly by the early intervention therapists. These therapists work directly with the parent and child in their home to create a schedule of activities which encourage the child's positive growth and development. Additionally, parents reported having contact with service coordinators when they were attempting to secure new services for their children or when there is a problem with the service providers. Therefore, communication between service coordinators and parents is generally limited to occasions when there is a request for services on the part of parents or during annual planning meetings. Service coordinators and parents could benefit from regular contact communication. This contact could be viewed by the parents as demonstrating care and concern for the parents and children they serve. Additionally, service coordinators would benefit from becoming more personally acquainted with their clients and families more broadly. This connection would allow service coordinators to gain understanding on the stages of change and loss families are currently experiencing; i.e. grief, loss, and positive growth. Getting to know parents more intimately would increase positive communication between the two parties accordingly. This type of regular communication could also reduce the friction experienced by both parents and service coordinators when they both understand better where the other person is coming from and do not perceive them as an adversarial figure.

Summary

This chapter reviewed the process of qualitative data review the researcher utilized to uncover codes and themes within the interviews of both parents and service coordinators. Demographic details were outlined as respects the parents, their children with special needs, and the service coordinators. A data interpretation was also presented which covered the overarching themes found in the research related to the stages of grief, as well as the concepts of resilience and post-traumatic growth. Finally, some ideas were presented as respects possible implications for micro/macro social work interventions which could assist in building positive communication and benefit working relationships between parents of children with special needs and the service coordinators they work with at California Regional Centers.

CHAPTER FIVE: TERMINATION AND FOLLOW UP

Introduction

This chapter presents the termination steps of this study. There is a discussion of communicating findings to the research participants. Additionally, there is a section on ongoing relationships with parent and service coordinator participants. Finally, the dissemination plan is reviewed.

Termination of Study

The termination of the study was done at the end of each participant interview. The researcher provided the parent or service coordinator with a debriefing statement when the interview was complete. The researcher thanked participants for taking part in the research project and asked them make contact if they had any questions or concerns in the future. All paper and computer documents compiled in relationship to this study have been destroyed.

Communication of Findings and Dissemination Plan

The research project will be available on the California State University San Bernardino website Scholarworks upon completion. Scholarworks is an “open access institutional repository” where the general public can review “research, scholarship, and publications” of California State University, San Bernardino “faculty, staff, and students” (“CSUSB Scholarworks”, n.d.). The

researcher will advise project participants via email to confirm the project has been completed and advise they can view results on the Scholarworks website.

Moreover, project participants will be provided with the date, time, and location for the “poster day” presentation California State University San Bernardino. Research participants are welcome to attend during the portion of the event open for public viewing. The researcher’s project poster will be displayed in addition to all social work student project posters. Finally, the agency will be provided with a copy of the final research report for their records.

Ongoing Relationship with Study Participants

The researcher has no plans for future contact with the Regional Center beyond termination of this study. The researcher may interact with the parent of children with special needs in casual contact in their shared community.

Summary

Chapter five summarizes the termination process for this research study. The study was terminated after the collection of all interviews with both parents and service coordinators were complete. There is no planned future contact between the parent participants other than casual contact in the community, with the Regional Center, or with the service coordinators who participated in the study. The participants can review research results posted on the Scholarworks

website or they can choose to attend the public viewing at the “poster day” presentation located at California State University San Bernardino in June, 2018.

APPENDIX A
DATA COLLECTION INSTRUMENTS

College of Social and Behavioral Sciences
School of Social Work

INFORMED CONSENT

The study in which you are asked to participate is designed to examine the resilience and Post Traumatic Growth of parents of children with special needs of adults living in Ventura County. The study is being conducted by student researcher, Elizabeth Sidener who will be supervised by Professor Dr. Carolyn McAllister, School of Social Work, California State University, San Bernardino. The study has been approved by the Institutional Review Board Social Work Sub-committee, California State University, San Bernardino.

PURPOSE: The purpose of the study is to examine resilience and Post Traumatic Growth in parents of children with special needs.

DESCRIPTION: Participants will be asked questions concerning their family history as respects raising a child with special needs, their strengths and expertise as a parent of a child with special needs, challenges parents have faced and their problem-solving styles, sources of inspiration for parents, and some demographics.

PARTICIPATION: Your participation in the study is totally voluntary. You can refuse to participate in the study or discontinue your participation at any time without any consequences.

CONFIDENTIALITY OR ANONYMITY: Your responses will remain anonymous and data will be reported in group format only.

DURATION: It will approximately 45 minutes to complete the survey.

RISKS: There are no foreseeable risks to the participants.

BENEFITS: There will not be any direct benefits to the participants.

CONTACT: If you have any questions about this study, please feel free to contact Dr. Carolyn McAllister at 909-537-5559.

RESULTS: Please contact the ScholarWorks (<http://scholarworks.csusb.edu/>) at the Pfau Library, California State University, San Bernardino for the results of the study after June, 2018.

This is to certify that I read the above and I am 18 years or older.

I consent to an audio recording of the interview. Yes No

Place an X mark here

Date

909.537.5501 · 909.537.7029

5500 UNIVERSITY PARKWAY, SAN BERNARDINO, CA 92407-2393

QUESTIONNAIRE

Parent of Child with Special Needs Questions

Attachment A

Essential Questions:

- 1) Before the birth of your child, what would you consider to be your strengths and expertise?
- 2) What words come to mind when you think of your child's birth?
- 3) What words come to mind when you think of the past year?

Extra Questions:

- 1) Challenges
 - a) Do you know the stages of grief? Would you relate having a child with special needs to the grieving process?
 - b) Below are the clinical stages of grief. Can you relate to any these stages? What has been your experience through the process of moving through the stages of denial, anger, sadness, surrender and acceptance?
 - c) Do you consider yourself to be a problem solver?
If so, can you tell me at least one situation in which you used your ability as a problem solver in a positive way when it concerns your child's well-being?
 - d) Do you consider yourself to be spiritual or religious? If so, do you think your beliefs or religion have helped you while raising your child?

Additionally, please share one situation where your beliefs have had an impact in some way.

- 2) What are your sources of inspiration? I.e. books, other people who have overcome challenges, nature, family, friends, medical professionals, etc.
- 3) Do you think raising a child with special needs has inspired you to do anything differently in your life?

Throw Away Questions:

- 1) Looking back, can you think of a time when you were deeply encouraged during an interaction with medical professionals, educational staff (teachers and aides) or someone in the helping profession?
- 2) Before having your child did you consider yourself a planner? If so, how has having a child with special needs changed that?
- 3) Because of raising a child with special needs have you been able to give back to other parents or share your experiences with them? If so, please discuss one of example of this.
- 3) If you could go back in time before you had your child, knowing what you know now, what would you tell yourself about this experience?

Developed by Elizabeth Sidener

QUESTIONNAIRE

Service Coordinators Questions

Attachment B

Essential Questions:

- 1) How do you communicate with parents you serve who are dealing with a new diagnosis versus a parent that has been in the system for a longer period of time?
- 2) How do you determine parents of children with special needs strengths, weaknesses, and resources and bring these to the parent's attention?
- 3) How do you encourage parents to seek resources outside of their extended family and friends?
- 4) In your interactions with parents, such as telephone communication, IFSP and IPP meetings, do you find that attendees are mostly mothers? What do you see as the involvement of fathers and other extended family members in all forms of communication? Have you seen this as a direct correlation with extended family member's involvement and the level of success parents achieve on their parenting journey?

Extra Questions:

- 1) Getting to know the parents and family better
 - a) How do you explore the family's skills and interests?

- b) How do you recognize the family's concerns?
- c) How do you include cultural competency in your interactions with the parents and families you work with?

2) Resiliency Factors:

- a) What is your definition of resilience in parents of children with special needs?
- b) What are some common stress factors that you perceive in the families you work with?
- c) What do you observe as the most effective adjustment factors families choose to utilize in the face of stressful situations?
- d) Finally, what do you view as the most successful adaptations to stressful situations in the families you serve?

3) Collaboration with families:

- a) What are the skills you bring to parent interactions?
Can you name your strongest skill in this area? I.e. Effective listening, do you ask open ended questions.
- b) How do you express compassion and empathy for parents during your discussions?
- c) How do you balance addressing parent's concerns and requests with sensitivity?

- d) How do you engage in straight forward communication regarding what services are offered by your organization?

Throw Away Questions:

- 1) A) What inspired you to become a Service Coordinator?
B) What did you consider the profession would be like?
C) Compared to the time when you first started, how has your opinion of the job changed?
- 2) What do you feel is your role in assisting parents of children with special needs to become more resilient?
- 3) What are ways that you have observed different parents recovering and thriving in the face of their daily challenges and concerns?
- 4) If you could go back in time before you were a Service Coordinator, knowing what you know now, what would you tell yourself about this career experience?
- 5) In this challenging career as a Service Coordinator how do you tend to your own self-care?

Developed by Elizabeth Sidener

DEBRIEFING

DEBRIEFING STATEMENT

This study you have just completed was designed to gather data on the presence of resilience and post-traumatic growth found in parents of children with special needs.

This data will be used to educate professionals that work directly with parents of children with special needs on how to better serve this population.

This document serves to inform you that no deception is involved in this study.

Thank you for your participation. If you have any questions about the study, please feel free to contact Elizabeth Sidener (email: 005221407@coyote.csusb.edu).

If you would like to obtain a copy of the results of this study, please contact Elizabeth Sidener (email: 005221407@coyote.csusb.edu) after December 2018.

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