2019

Phenomenological Study on Social Workers with children with special needs

Natasha Yvette Mike
Walden University

Walden University

College of Social and Behavioral Sciences

This is to certify that the doctoral dissertation by

Natasha Y. Mike

has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

Review Committee
Dr. Jeanna Jacobsen, Committee Chairperson,
Social Work Faculty

Dr. Debora Rice, Committee Member,
Social Work Faculty

Dr. Andrew Carpenter, University Reviewer,
Human Services Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
2019

Abstract

Phenomenological Study on Social Workers with Children with Special Needs

by

Natasha Y. Mike

MSW, Valdosta State University, 2013

BSW, Albany State University, 2005

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Social Work

Walden University

May 2019

Abstract

Parents with children with special needs experience challenges when caring for their children. These challenges may be uniquely affected by the parent's employment. Because social workers are in professional roles, understanding their lived experiences provides awareness of the needed services and resources that help social workers maintain effectiveness in their home and work life. This phenomenological study explored the lived experiences of social workers who have children with special needs. Bronfenbrenner's ecological theory guided this study. Criterion and snowball sampling were used to recruit 8 participants. Data were gathered through 3 in-depth semistructured interviews. Moustakas phenomenology method was used to analyze data. Two themes emerged from the data (a) coming to terms with having a child with special needs and (b) balance of home and work life. Sub-themes included (a) self-care, (b) supervision, and (c) having an awareness of resources. Part of the experience included social work parents recognizing, understanding, and accepting that their child has a special need. Balancing home and work life was an important aspect for the participants. Part of balancing home and work life for these participants was ensuring the use of self-care methods, adequate supervision, and being aware of resources to mitigate their stressors related to their child's special need. The findings may be used to create positive social change by informing administrators, specialists, counselors, and the profession of social work about areas of focus for strategies and interventions to address the needs of social workers parenting children with special needs.

Phenomenological Study on Social Workers with Children with Special Needs

by

Natasha Y. Mike

MSW, Valdosta State University, 2013

BSW, Albany State University, 2005

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Social Work

Walden University

May 2019

Dedication

I dedicate this dissertation to my parents (Lester and Carolyn Jackson), who have inspired and supported me throughout the process. Because of you, I am a better person and it is because of you, I have the drive and fight to always finish what I start.

I love you immensely!

Acknowledgements

I would like to thank my Chair, Dr. Jeanna Jacobsen, and committee member, Dr. Debora Rice, for assisting me on this journey. I am forever grateful and thankful for the unimaginable insight the two provided me in the process. I would like to thank my University Reviewer, Dr. Andrew Carpenter, for his insight and judgement throughout the process.

I would like to thank my children, Jiya, Ke'Marion, and Jaylum for their unselfish ways during times when they felt they needed mommie the most. I would like to thank my husband, Derrick Mike, for his patience, love, and support throughout this process. I also would like to thank my close friends for the support, push, and love shown throughout the process. I finally thank the participants for helping make this project possible.

I love you all!

Table of Contents

List of Tables v

Chapter 1: Introduction to the Study...1

Background 5

Problem Statement 7

Purpose..10

Paradigm 10

Ontology 11

Epistemology 11

Axiology 12

Research Question 12

Theoretical Framework...13

Nature of Study 13

Definitions...14

Assumptions...14

Scope and Delimitations 15

Delimitations..15

Limitations 15

Significance..16

Summary 19

Chapter 2: Literature Review..20

Research Strategies 21

Ecological Theory 21
Children with Special Needs 23
Parenting 25
  MicroSystem Level 30
  MesoSystem Level 31
  Exosystem Level 35
  Macrosystem Level 36
  Social work 39
  Burnout in Social workers 40
  Challenges with Work and Family 42
  Social Workers as Parents 43
Literature Summary 44
Chapter 3: Research Method 45
Research Design and Rationale 45
  Research Questions 46
  Research Tradition: Phenomenology 47
Role of the Researcher 48
Methodology 50
  Participant Selection Logic 50
  Instrumentation 52
  Interview Guide 53
  Procedures for Recruitment, Participation, and Data Collection 53

        Data Analysis Plan 56
    Issues of Trustworthiness 57
        Ethical Considerations 59
    Summary 62
Chapter 4: Results 64
    Setting. 64
    Demographics 64
    Data Collection 66
    Data Analysis 68
        Discrepant Cases 71
    Evidence of Trustworthiness 73
        Credibility 73
        Transferability 74
        Dependability 75
        Confirmability 75
    Findings 75
    Individual Composites 76
    Themes 96
        Coming to terms with having a child with special needs 96
        Balance of Home and Work 99
    Summary 107
Chapter 5: Discussion, Conclusions, and Recommendations 108

Interpretation of the Findings..109

Theme 1: Coming to terms with having a child with special needs 109

Theme 2: Balance of Home and Work Life 114

Limitations of Study 121

Recommendations/Future Research..121

Implications...123

Conclusion 123

References..125

Appendix A: INTERVIEW PROTOCOL 156

List of Tables

Table 1. Participants Demographics……………………………………………………70

Chapter 1: Introduction to the Study

Social workers are instrumental when advocating for the needs and services of individuals and families. Social workers advocate for needs and services when working with children. Social workers may work with children who have some deficits and limitations that require additional needs and services from social workers. Some children have special needs that can create difficulties for families. For this study, children with special needs are those children who have cognitive, behavioral, learning, emotional, physical, or developmental issues. When children have been identified as having a special need, families can have a hard time finding support and resources that will assist with the care of their child. As a result of having a hard time with support and locating resources, families may face difficulties managing their lives. Social workers, however, are professionals who make attempts to assist families with resources for their children to address the concerns and issues that families have as a result of the child having special needs.

Social workers who have children with special needs may face unique difficulties in their lives because they experience stressors both at home and in their professional lives. Although there has been research to show both a parent's experience (Hwang & Kerney, 2014) and social workers' professional experiences with working with children who have a special need (Dupre', 2012), there appears to be no information on the lived experiences of social workers who have children with special needs.

Raising awareness of this phenomenon among social workers may help to promote an understanding of how this group perceives their lived experiences with being a social worker who has children with special needs. As stated in the above paragraph, social workers primarily work with children to promote social justice and welfare. Increasing knowledge and information on social workers who have children with special needs may create awareness for employers surrounding educational training to decrease stress and burnout.

Social workers have specialized training that equips them to work with children with special needs and other individuals that are victims of social injustice (Greene & Kropf, 2015). Because of this specialized training that equips and qualifies social workers to work with children with special needs, having the experience of being a parent with children with special needs provides the social worker with a different perspective. It is important to look at how social workers perceive and interpret their lived experiences with having children with special needs. Considering the lived experiences of this group it may provide awareness on the needed services and resources to help this group maintain effectiveness in balancing their home-to-work/work-to home life.

Social workers are change agents, so if they can engage in their profession effectively, it will positively affect their clients, client's families, and larger systems (Greene & Kropf, 2015). Creating awareness and supports, the social worker may be able to provide more efficient and effective services to the children they work with and to their children at home, thereby making the social worker more effective within their work and home environments.

In this chapter, I first provide the background of the current literature and gaps in knowledge about this phenomenon. Then, I explain the research problem and the gap in the literature that this study will attempt to fill. I provide the purpose of the study and the specific research question this study will attempt to answer. I further explain the theoretical framework that is the foundation for the study. Following the framework, I clarify definitions of terms, assumptions, and limitations of the study along with reasons the study is significant.

I conducted a phenomenological qualitative study to look at the lived experiences of social workers who have children with special needs. Phenomenology studies place emphasis on understanding an individual's experience and how they view the experience while experiencing it (Moustakas, 1994). The lived experiences of social workers who have children with special needs is important to understand because social workers have been trained to work with children that have special needs and implement services but being a parent and a social worker with a child with special needs is a unique experience. Social workers are trained in various aspects to advocate for individuals, provide opportunities for individuals to enhance their capacity to address their own needs, and ensure meaningful participation in decision making for all people (NASW, 2008). Being a social worker who has a child with special needs potentially places the social work parent on the opposite end of needing a social worker to do the things they have been trained to do, and this is what potentially makes it a unique experience for the social worker that has children with special needs. Exploring the lived experiences of these social workers who have children with special needs helped me understand their perceptions, thoughts, feelings, work, and home life. I conducted this study on social workers who have children with special needs because it not only impacts social workers, the social work profession, or other helping professions, but it could potentially impact children with special needs and their families who receive services, referrals, and resources from social workers.

Children with special needs particularly have needs that are greater than children that do not have special needs. Children with special needs require more attention and supervision, and their parents potentially require more time away from work to address the needs the children are having (Crettenden et al., 2014; Price & Oliverio, 2016). Social workers who have children with special needs face these same challenges and also have to take time off from work to meet the needs of their children. Depending on the severity of the child’s special need, the social worker, just like the non-social work parent, may work part-time or fewer hours and would potentially have to stop working (Crettenden et al., 2014). Should a social worker or non-social work parent have to stop working due to meeting the needs of their child, they could become poverty stricken and would most likely have to utilize governmental assistance as a means of support for healthcare and food (Sherman et al., 2013). Educating the community and society at large about social work and non-social work parents’ lived experiences with having children with special needs may allow the society to become supporters and advocators of change so that services and resources meet the needs of the children without always relying on government assistance. The use of governmental assistance means obtaining funds from taxpayers and having taxpayers fund the services and resources to families within the communities (Sherman et al., 2013).

Background

Children with special needs can have difficulty with meeting certain milestones throughout their childhood (Mauro, 2016). When children have difficulty reaching milestones because of a special need, this can create a problem for parents. On many occasions, supervision of these children is required for a 24-hour period (Price & Oliverio, 2016), leaving parents feeling stressed and overwhelmed. Parental stress, in general, is defined as stress that parents experience because of the social, environmental, and daily responsibilities they have due to caring for their children (Cronin & Becher, 2015). Many parents who have children with special needs experience stress and feel they are in constant crisis mode due to their child's special need whether it is behavioral or developmental (Mount & Dillon, 2014). Some parental stressors include social and financial issues, migraine headaches, back problems, and digestive complaints (Brehaut et al., 2004; Gallagher & Whiteley, 2012; Tong et al., 2003). Stressors that parents of children with specific developmental special needs experience include insufficient sleep, smoking, and increased blood pressure (Gouin, da Estrela, Desmarais, & Barber, 2016). Parents also experience stress with maintaining employment due to their children having special needs (Earle & Heymann, 2012). Parents with children with special needs experience tension at work, and tension is intensified because the care the child needs constantly increases (Crettenden et al., 2014). These parents tend to have more absences from work because of doctor appointments, specialist appointments, and counseling appointments (Cole et al., 2016).

Social workers work with children who have special needs, including behavioral, mental, physical, and learning issues. When working with this population, social workers also face challenges that may lead to stress and burnout (Kalliath et al., 2012). Studies have reported social workers being frustrated, overwhelmed, stressed, and burned out when trying to work with children who have special needs (Lightfoot & LaLiberte, 2006; Shannon & Tappan, 2011b). Social workers, when working with children who have special needs could potentially face increased levels of stressors due to parenting children with special needs.

In efforts to examine and understand the lived experiences of social workers who have children with special needs, I explored over 100 articles. I was unable to locate literature about the lived experiences of social workers that have children with special needs. The scope of literature that I found pertains mostly to a non-social work parent's experience with caring for a child with special needs and the challenges those parents face as a result of caring for a child with special needs. Literature examined a social worker's experience when working with children with special needs (Liberte, 2006; Shannon & Tappan, 2011b), but there were no research studies found about the lived experiences of social workers who have children with special needs. In attempts to locate literature with this focus, I read over 100 articles, searched through 10 different databases, and consulted with Walden University librarians over five different times, yet I found no research with this focus. There was one article found within one of the academic databases in the Social Sciences index that discussed a father's story depicting himself as a special educator and psychologist and having a child with special needs. He discussed his perceptions and thoughts regarding having a child with special needs, but not working with children with special needs (Hornby, 1992). Because I could not locate literature pertaining to social workers lived experiences, thoughts, and perceptions about having children with special needs, this study explored those lived experiences. Conducting this study further allowed me to explore and understand those experiences, the perceptions, and beliefs of social workers who have children with special needs.

Problem Statement

I did not find research pertaining to social workers who have children with special needs and further information is needed to explore and understand the lived experiences of this group. I located two articles that indicated that being a social work professional and a counselor having a child with special needs, but they do not discuss their perceptions and thoughts about having children with special needs. Parents and group home staff find that caring for children with special needs is demanding and stressful (Hwang & Kerney, 2014). Social workers who parent children with special needs experience stress both at home and work. Hwang and Kerney (2014) suggest the parent and professionals are both distressed from caring for children with special needs, and this can create an atmosphere or burnout for the parent and the professional. It is important to explore these lived experiences of social workers in efforts to understand how they perceive and interpret their experiences being a social worker who has children with special needs.

Parents who have children with special needs have a greater experience with stress than other parents that have children that do not have special needs (Crettenden et al., 2014). Many of these parents face financial burdens, exclusion from society, inequality, and a lack of resources to address the child’s special needs (Dowling & Dolan, 2001; Green, 2007). Parents of children with special needs can also become overwhelmed, have feelings of regret for having the child, and isolate themselves from friends and family depending on the severity of the child's special need (Home et al., 2015).

Social workers are change agents that help locate resources for families in need and implement resources as needed to families that are in need (Bachman & Comeau, 2010). Social workers work with families to help them identify and find coping techniques to better deal with the child's special needs (Bachman & Comeau, 2010). Social workers, however, face challenges in implementing the appropriate services to individuals in need. Social workers, therapists, and counselors often face the burden of having heavy caseloads, lack of funding for resources to assist families on their caseloads, and sometimes lack the knowledge around what the needs are for children with special needs (Mosely & Tiney, 2005). As a result of working to meet the need of these individuals, social workers can experience burnout and compassion fatigue (Diaconescu, 2015).

There is literature exploring the challenges that social workers face when working with special needs (Bachman & Comeau, 2010; Diaconescu, 2015), but there is no literature found on the lived experiences of social workers who have children with special needs. There is literature regarding the need for further research to address a social worker’s competence level on serving individuals with special needs (Dupre’, 2012). Literature also presents the need to have further research on the lived experiences of social workers that is central to their well-being (Kalliath & Kalliath, 2014). Exploring how social workers interpret and perceive children with special needs will provide a greater understanding of how they perceive having children with special needs. Understanding and exploring these individuals' thoughts, feelings, perceptions, and interpretations will add awareness to the social work and human services profession as to how social workers can be more effective in their practice as well as within their homes.

Previous researchers have looked at the experiences of non-social work parents with children with special needs (Ha et al., 2008) but did not examine parents that are also social workers with children with special needs. Parents, in general, experience different challenges with their children with or without a special need. Previous research addressed the experiences that these parents face but neglect to discuss social workers as parents with or without children with special needs. Social workers, in general, are at high risk for stress and burnout when working within this profession (Diaconescu, 2015). Social workers also experience issues such as lack of time for their self and increased time caring for a child with special needs within their work-to-home life (Kalliath & Kalliath, 2014; Lambert, 2006). Social workers, as a result, will potentially experience higher stress levels and burn out when adding having children with special needs. In order to understand how social workers who have children with special needs, it is important to understand their interpretation and perception of experiences of having children with special needs. By exploring this phenomenon among this group, there may be a better understanding among the social work profession and human services profession of how to implement strategies, interventions, and resources to reduce stress and burnout and create an effective balance within the work-to-home life.

Social workers who are parents can face the same experiences as non-social work parents that are not social workers, but the unique difference is that social workers are trained specifically to work with vulnerable populations. It is important to understand and explore the lived experiences of social workers who parent children with special needs to know if they have the same experiences or if their experience is different. Therefore, research on understanding and exploring the lived experiences of social workers who have children with special needs is beneficial.

Purpose

The purpose of this qualitative study was to explore the lived experiences of social workers who have children with special needs. As noted above, parents who have children with special needs face challenges and stressful times when caring for their child who has special needs. Social workers also face challenges when working with families and children with special needs. My goal for this study was to explore the lived experiences of social workers who parent children with special needs.

Paradigm

According to Ponterotto (2005), a paradigm is a set of beliefs that guides how an individual think about the world around them. Guba and Lincoln (1994) stated that paradigms represent a worldview of how an individual sees it. A research paradigm sets the context for the study (Ponterotto, 2005). To understand the lived experience of individuals, it is important to understand both what they objectively experience in their environment and their interpretation of that experience. These lived experiences are influenced by interactions at the microsystem (interaction between parent and child), at the mesosystem (influence of school, etc.), and macrosystem (how community values parenting and special needs resources) (Bronfenbrenner, 1994). In this phenomenological research, I took the position of an interpretivist/constructivist view where the phenomenon is based on the individual's perception of the phenomenon (Guba & Lincoln, 1994; Ponterotto, 2005). According to Ponterotto (2005), the constructionist/interpretivist paradigm is based on reality being intuitive and that an individual's interpretation of their experience is based on their thoughts about the experience (Ponterotto, 2005). It was important to understand this paradigm because it allowed me to look at how individuals perceived and interpreted their lived experiences about the phenomenon.

Ontology

Ontology defines the nature of reality and being (Ponterotto, 2005). Ontology defines the form and nature of reality and identifies what can be known about reality. The belief within interpretivism is that there are many individuals that can have the same experience but report different experiences based on their interpretation of what their experience with the phenomenon. According to Ponterotto (2005), the perspective of an interpretivist is that information is subjective and can be influenced by the individual's experience (Ponterotto, 2005).

Epistemology

Epistemology defines what is known about reality (Ponterotto, 2005). Interpretivists believe that people's interpretation of reality is all that can be measured and that reality is socially constructed. That reality can be captured by describing the lived experiences of the participants (Patton, 2002; Ponterotto, 2005).

Participants in this study discussed their lived experiences in detail. Epistemology also defines the relationship between the researcher and the participant. The researcher will interact and engage with the participant and will have an opportunity to share in knowledge and understanding of the participant's experience with the phenomenon (Lincoln & Guba, 2005; Ponterotto, 2005).

Axiology

Axiology defines the values, hopes, and expectations of the research (Ponterotto, 2005). I used the ecological perspective to look at individuals in a person-in-environment, therefore I looked at the individual holistically. I honored participant's voices and their reality in this study. I realize that I held values and hopes about the phenomenon, but I bracketed my ideas so that my values did not influence the participant. I knew that it was impossible for me to eliminate my biases, but I utilized bracketing to help me beware of my biases. I allowed participants to participate in the interviews as they chose and I allowed their voices to be the dominant voice of the discussion. I allowed participants to discuss their interpretations of their experiences. I captured the perception of the participant's experience and stayed true to their lived experiences of the phenomenon and not my own.

Research Question

The research question that I used to guide this study was: What are the lived experiences of social workers who parent children with special needs?

Theoretical Framework

I used Brofrennbrenner’s (1970) ecological theory as the theoretical base for this study. I used Bronfenbrenner's ecological theory to understand social workers who parent children with special needs from a person-in-environment perspective. Ecological theory encompasses five different systems that help individuals understand how their environment influences them (Bronfenbrenner, 1994). The makeup of these systems is the microsystem, mesosystem, exosystem, macrosystem and chronosystem. I included these systems in Chapter 2. I used ecological theory to guide my literature review; I used the theory to know what to ask and how to analyze the data. I used the ecological theory framework to help me frame the phenomenon and provide information on the lived experiences of social workers who have children with special needs. I used the ecological theory to understand what factors at different levels might influence participants experience with the phenomenon. I also used the theory to help me identify environmental factors that create the context in which the phenomenon is experienced.

Nature of Study

The nature of this study included a qualitative methodology with a phenomenological design. I used phenomenology methods as outlined by Moustakas (1994) because it allowed me to explore the lived experiences, perceptions, thoughts, and beliefs of individuals that share the same or similar phenomenon. In this phenomenological study, I studied the phenomenon of the experiences of social workers who parent children with special needs. I recruited social workers who have experience with the phenomenon to participate in the study. I gathered the experiences of each participant through in-depth semistructured interviews. Interviews are a tool used in qualitative research to allow researchers an opportunity to ask open-ended questions and further explore in detail the experience of the phenomena (Janesick, 2011). I coded and transcribed the semistructured interviews. I used the phenomenological process outlined by Moustakas (1994) as the basis for analysis in this study. This process provided insight and knowledge into lived experiences of social workers that have special needs children.

Definitions

The primary terms used in this study are as follows.

Children with Special Needs: children having some mental, behavioral, cognitive, or learning diagnoses listed under its umbrella (Mauro, 2016).

Parent: primary caretaker for a child or children, which may include biological parent, foster parent, adoptive parent, or an extended family member who has taken on the primary care taking responsibilities for the child, such as a grandparent.

Social Work Parent who has children with special needs: a parent that is a social worker and has a child/ren with special needs (mental, behavioral, cognitive, or learning diagnosis)

Assumptions

Assumptions in qualitative research are beliefs that researchers believe to be true in the study. I assumed in this study that social workers who have children with special needs will have the same or similar experiences of any parent with children with special needs. I further assumed that this study was worthy of being studied because social workers parenting children with special needs are a unique experience. I viewed individuals that were chosen to participate in this study as co-researchers who had a vested interest in contributing their knowledge to the study.

Scope and Delimitations

The purpose of this phenomenology study was to explore the lived experiences of social workers who parent children with special needs. I sought to explore these social workers to gain better insight into their experiences of parenting children with special needs. I looked at social workers who parent children with special needs regardless of their marital status, the age of the child with special needs, and the diagnosis of the child as this will be self-reported by the social work parent. This study was limited to social workers who have children with special needs so that I could capture the full lived experiences of the group. As a result, I was not able to generalize to all social workers. Social workers who have children with special needs is a unique experience that would provide insight to others that have the same or similar experience.

Delimitations

There were delimitations to this study. I did not ask any social worker who had children without special needs to participate in this study. Next, I did not look only at a social worker’s experience with working in the social work profession but at those who work in the profession and have children with special needs. For this qualitative phenomenological study, I examined only social workers who have children with special needs.

Limitations

The purpose of the study was to explore the lived experiences of social workers who parent children with special needs. Phenomenology works with a small sample size so that I could go in-depth into the experiences while working with manageable data. I recruited social workers that have children with special needs. Results might be different if I included social workers who worked only with children and did not parent children with special needs. I looked at the individuals who volunteered for this study as another limitation of my study. There were more women volunteers than men given the target population, limiting transferability to fathers. Flyers were put out on social media asking participants to participate, and only women chose to participate in this study. One participant made attempts to encourage a male social worker that was a father to participate in the study, but he chose not to participate; therefore, I addressed limitation by clearly explaining it and avoided overgeneralizing to fathers.

Biases could play a significant role and influence the results of this study. I am a social worker who has children with special needs. To address these biases, I utilized bracketing as a tool to set my thoughts, perceptions, and beliefs aside to understand the data that I collected.

Significance

There are several reasons why this study was significant. This research provided a greater understanding of the lived experiences of social workers who parent children with special needs. This study filled the gap and added to the body of knowledge in the professional practice of social workers and the larger society. Results may benefit the social work profession, individuals in other helping professions who experience parenting children with special needs, and the larger society.

Social workers parenting children with special needs is a unique experience. Social workers receive training that provides different approaches, resources, and services to vulnerable populations. Social workers are not only equipped to offer many services, but they are employed to meet the needs of many vulnerable populations. Social workers, however, must meet those same needs of their family in which could potentially pose a challenge. Should social workers have to meet the demands of their children with special needs, it could force them to stop working or lose work hours. Price and Oliverio (2016) suggest that non-social work parents are facing lower employment status and are not able to advance their careers due to caring for a child with special needs. A loss in work hours or having to stop working to care for children with special needs may affect the larger society as these parents could fall to, or below the poverty level (Price & Oliverio, 2016). When families are at the poverty level, they frequently seek the assistance of federal government programs to help offset indirect costs and access to affordable healthcare (Sherman et al., 2013). If a social worker stops working, it could potentially force the social worker to seek government public aide assistance like the non-social work parent, and this would decrease their ability to contribute economically to the larger society.

The positive social implications of this research study may inform the larger society on the lived experiences of social workers who parent children with special needs. This study examined the challenges and difficulties of social work parents faced with having children with special needs. I will share information gathered on the challenges and difficulties faced from social work parents with children with special needs with human service professional at seminars, conferences, and support groups to continue supporting effective practice for parents and support groups to advocate for their family needs. I will share information pertaining to barriers of limited job prospects for social work and non-social work parents due to caring for their children with special needs at seminars and conferences. I examined information surrounding employment opportunities, work, and home stress for social workers with children with special needs and will share the information during conference presentations, seminars, job fairs, and parent support groups. These professionals can use this information to provide better supports and services, allowing parents to continue working in their social work career.

Other positive social implications may inform society on the need to assist social work and non-social work parents with supports, resources, and services to address the challenges and difficulties of caring for a child with special needs. I will share information gathered in this study surrounding the challenges and difficulties of caring for a child with special needs with community agencies, extended family, and support groups during monthly and yearly meetings on ways to assist with caretaking of children with special needs. Community agencies such as health care providers, counselors, therapists, psychologists, parent to parent groups, and mental/behavioral health providers may be able to utilize this information so that they can build on to the services provided to the families they serve. I will share additional positive social implications of the needs and barriers for supports to parents and children with special needs within the school systems at school leadership meetings, conferences, and seminars. Once I share the information with teachers, administrators, and principals during conferences and seminars, the information may encourage staff to have additional and extensive training that builds on the current knowledge and understanding surrounding parents and their children with special needs.

Summary

There were challenges of parenting children with special needs regardless of the role or title of a parent (Price & Oliverio, 2016). This study provided a greater understanding of the challenges and lived experiences of social workers who have children with special needs. Social workers are known to work with children with special needs to empower and assist them through difficult times in their lives. Chapter 1 entails the background to challenges and difficulties that parents in general face with their children with special needs. There is research that has looked at the experiences of parents with children with special needs, (Ha et al., 2008; Hauser-Cram et al., 2001; O’Connell et al., 2013; Park & Chung, 2015) but does not examine parents who are also social workers. In the next chapter, I will provide a comprehensive overview of the literature about this issue, the conceptual framework, the problem, and the purpose of this study.

Chapter 2: Literature Review

In this review of the literature, I show that there is a need for continued research on the lived experiences of social workers who have children with special needs. Parenting children with special needs have been researched, and emphasis has been placed on the overwhelming barriers to meet the needs of a child with special needs (Home et al., 2015), but there is no research about the lived experiences of social workers who have children with special needs. Because there is no research on the lived experiences of social workers who have children with special needs, I had to broaden my literature search to show the lived experiences of non-social work parents with children with special needs. The literature used within this literature review depicts current literature as a result to capture the lived experiences of those parents who have children with special needs.

In this chapter, I use Bronfenbrenner's (1974) ecological theory to frame the research and understand how parents are influenced by different systems within their environment. The ecological theory provides a perspective that captures human growth and development in the actual environments in which persons live by looking at five different systems including the microsystem, mesosystem, exosystem, macrosystem and chronosystem (Bronfenbrenner, 1974).

In this literature review, I first discuss the research strategy that I used to obtain the literature that informed this study. Next, I present ecological theory as the guiding theoretical framework for this research. I reviewed the literature on the theory’s five systems, as they related to parenting children with special needs. Finally, I discuss the challenges social workers face as parents.

Research Strategies

When conducting the literature review, I used the following databases: SocINDEX, PsychINFO, PsychARTICLES, MEDLINE, Thoreau Multi-Database Search, Google Scholar, ProQuest Dissertation & Theses, and ERIC. Key terms used in my searches were: *special needs, children with disabilities, children with special needs, social work, social workers, parents, parent-child interaction, stress, burnout, parental engagement, parent-teacher,* and *ecological theory*. In attempts to locate literature with this focus, I read over 100 articles, searched through 10 different databases, and consulted with Walden University librarians over five different times, yet no research with this focus was found. I then broadened the literature search to these terms in efforts to gain an understanding of special needs, the experiences of parents with special needs children, and the lived experiences of social workers who parent children with special needs.

Ecological Theory

To fully understand the lived experiences of social workers who have children with special needs, I used Bronfenbrenner's ecological systems theory in this study. Specifically, I used the ecological theoretical perspective to understand the environmental influences that potentially could have helped shape the perception of social workers who have children with special needs. Ecological theory encompasses five subsystems that help support and guides human growth; these subsystems include the variety of relationships between individuals and their environment (Bronfenbrenner, 1994). The ecological perspective enables researchers to capture what influences or affects individuals in their environment from a microsystem, mesosystem, exosystem, and macrosystem, and chronosystem level. Ecological theory in this study revealed how environmental influences were the external forces from which shape the lived experience based on how parents in the study's population perceived and interpreted those experiences (Algood et al., 2013).

A microsystem is a pattern of activities, social roles, and interpersonal relations experienced by the developing person in a given face-to-face setting within their environment (Bronfenbrenner, 1994). For example, in this study, I used the microsystem to look at what influences the level of interaction between the parent and child with special needs. A mesosystem interconnects two or more settings of an individual's life (Bronfenbrenner, 1994). I used the mesosystem level in this study to look at the interaction between a social worker parent's work and parenting experiences. Exosystems is a linkage of two or more settings in a person's life, meaning that one microsystem can impact another microsystem in the individual's life (Bronfenbrenner, 1994). For example, by using the exosystem level, I looked at a child's interaction with school staff and a child's peer group; these microsystems can impact the parent whether the relationships between the two are positive or negative. A macrosystem is a culture, belief systems, and lifestyles of a community (Bronfenbrenner, 1994). In my study, the macrosystem level included the laws and policies about services that assist special needs children. Chronosystem characterizes the change in the person or person's environment over time (Bronfenbrenner, 1994). Using the chronosystems in my study, I looked at how the social worker who parents a child with special needs interprets and perceives the influences of their lived experience in life over time. I used ecological theory to understand child development and what influences the child in his or her environment. I used the ecological theory to focus on social workers who have children with special needs. I used the ecological theory framework to understand how individuals and their environment are connected as they transition through life. Parents with children with special needs experience multiple challenges from influences within their environment. Investigating the factors that influence a social worker who parents children with special needs allowed me to explore and understand the stressors, burnout, financial burden, work and family conflict that some of these social worker's face.

Children with Special Needs

To fully understand the lived experiences of social work parents with children with special needs, it is important first to understand the term "special needs." It is important to understand how parents perceive special needs and how they might interpret their experience of being a parent of children with special needs. The term "special needs" is defined as the experiences of children having some mental, behavioral, cognitive, or learning diagnoses listed under its umbrella (Mauro, 2016). According to Mauro (2016), children with special needs have difficulty in meeting milestones or display an inability to participate in activities oppose to other children without special needs. Children with special needs may have issues that affect their learning, cognitive, behavioral, developmental, and mental abilities (Mauro, 2016).

There are some children with special behavioral needs that present problems with their ability to pay attention or sit still for extended periods of time in certain settings such as the school. These may cause the child difficulty with learning any material (Centers for Disease Control and Prevention [CDC], 2015). According to the CDC (2015), children who have a special need associated with behavioral health have greater behavior issues and act out on impulse; these children have difficulty with establishing interpersonal skills and are often viewed as unruly, defiant, and disobedient. These behaviors can create challenges for parents.

When looking at children with special needs, it is important to look at the work of Milton Seligman. Seligman is a seminal author who studied children with special needs before his retirement and wrote the book titled "Ordinary Families, Special Children: A Systems Approach to Childhood Disability" with the assistance of Rosalyn Darling in efforts to gain an understanding about families and their children with special needs. Seligman and Darling (2009) studied and wrote on experiences of families who had children with special needs. Seligman and Darling (2009) studied the reactions, perceptions, and thoughts of parents when they found out their child had a special need. Some parents shared their thoughts of having premonitions that something would be wrong with their child prior to their child being born, some other parents shared their feelings of believing they had done something wrong in life as a result of their child having a special need. Many other parents shared in Seligman's study their feelings of resentment, loneliness, and the need to supervise their child with a special need at all times.

In this book, parents shared their perception of having a child with special needs and the type of support from family, friends, and professionals needed to assist them through their tough times. Many parents initially felt that once their child received a diagnosis or was determined to be different, many of their family members were unable to understand the child’s special need and dismissed it by saying, of “the child will get better in time, or the child will catch up” (Seligman & Darling, 2009). Many other parents felt that their family were supportive of them as parents and their child with special needs; however, they did not understand the full concept of the child having a special need. There were others who felt the church was a support to them as they were there to help assist with the physical caring of the child, meeting the emotional needs of the family, and even providing financial assistance. Seligman and Darling (2009) found that parents could share their thoughts and feelings of being both upset and accepting of their child’s special need to others with the help of professionals and support groups. Seligman and Darling (2009) also found that professionals served as a great support to parents in helping them develop and formulate supports to deal with having children with special needs. Seligman and Darling (2009) also discovered how siblings were at times both upset and understanding with their sibling having a special need. Seligman’s work with understanding family perceptions when dealing with children with special needs is important as he depicted some of the challenges parents faced when having children with special needs. His work also provides background and foundation to understand the challenges families’ face when having children with special needs.

Parenting

Literature pertaining to a social workers’ lived experiences were not found but literature pertaining to the lived experiences of parents in general who have children with special needs was found and discussed within this review. In order to fully understand lived experiences that social workers who have children with special needs, I broadened the literature review to address those lived experiences of parents in general who have children with special needs. Parenting is a general term that is defined by an individual's perception or experience. According to the American Psychological Association (2017), parenting practices around the world share three goals: ensure a child's health and safety, prepare a child for a life as a productive adult, and transmit cultural values to the child. It is important to note that an individual's interpretation and perception gives meaning to the term parenting, despite the APA's (2017) definition of parenting practices.

Parenting is a unique experience that many individuals can experience but have different interpretations and perceptions. When children are born, parents have expectations that their child will be healthy, smart, and full of life. Even before a child is born, parents have hopes, dreams, and expectations for their child. Zechella and Raval (2016) reported that parents have expectations that their children will be high achievers academically and professionally, have the ability to live independently of their parents, and eventually, one day have their own family. Expectations shaped by the parents' beliefs, morals, rules, values, and ways of thinking are transmitted to children through their parents' behavior toward them (Peterson et al., 2014). A child's development specifically shapes their parent's views and behaviors towards them. When children identify as having special needs, parents tend to re-think their expectations, aspirations, and beliefs they initially had for their children. Zechella and Ravala (2016) also reported that mothers have shared in their study having to re-prioritize their expectations and values for their children with special needs once the child has identified with having a special need. Once parents have identified their children with having a special need, they are often faced with challenges.

According to Issurdatt and Whitaker (2013), parenting has specific challenges, and how parents interpret these challenges will determine the outcome for the entire family. Having some knowledge surrounding how a parent perceives and interpret their parenting experience when dealing with their child/ren with special needs provides understanding about the barriers and possible burdens they face when caring for their child. According to Ma et al. (2013), some parents perceived that having a child with special needs was an issue that they simply had no control over, so they found ways to educate themselves and address the issues that came daily. Ma et al. (2013) also discovered that parents expressed feelings of being ashamed and stigmatized when issues arose surrounding caring for their children with special needs.

Ma et al. (2013) conducted a study of client perceptions to determine whether a multifamily group intervention program was helpful or unhelpful to families dealing with children with special needs. Ma et al. (2013) reported that some parents felt they had no control over things that were happening in their lives and they began isolating themselves from their support systems. Parents perceived that family members and teachers were putting negative labels on their children with special needs and labeling the parents as being inadequate (Ma et al., 2013). The study conducted by Ma et al. (2013) continued detailing how parents expressed how this type of behavior from others helped further their perception and thought of being stigmatized and the need for isolating themselves from others. Parents would isolate themselves and preoccupy their times with the care of their child, their household chores, and other things that were demands as a result of caring for their child (Ma et al., 2013). Some parents also felt that the care of their child with special needs were becoming a full-time job and found it easier to discuss their issues with parents that had children with special needs (Ma et al., 2013).

Being a parent of a child with special needs can be very challenging. Parents often experience different levels of stress due to the care associated with having children with special needs. There are parents that live with psychological stressors that place parents in positions where they tend to engage in harmful behaviors that will affect their health. According to Gouin et al. (2016), some of the psychological stressors that parents face, affect the body and increase the production of inflammatory markers such as cortisol and C-reactive protein. Gouin et al. (2016) also stated that many of these parents also find it hard to get sufficient sleep, and they pick up habits such as smoking. The study conducted by Lindo et al. (2016) includes information on how parents can become overwhelmed and stressed. Children, depending on the severity of their disability, require daily supervision and assistance with the essential needs in life. Some parents have to learn different communication skills and learn new behavior/discipline techniques to help lessen the stress with their child (Price & Oliverio, 2016). This type of care creates stress and financial burdens for the parent with a child with special needs (Price & Oliverio, 2016). As children with special needs grow, their needs may change, and this potentially adds additional challenges to the parents. Some of these additional challenges are described as labor-intensive to the parents and include having minimal time for, a social life, vacation, and spending intimate time with significant others (Woodgate et al., 2015). Woodgate et al. (2015) found in their study that parents, in general, felt that they lost their ability to participate in “normal” life events and activities. In this study, I focused on intense parenting to children with complex care needs. Parents reported that they felt judged by professionals and others as a result of caring for their children with special needs (Woodgate et al., 2015). Literature, however, did not detail information about social workers who have children with special needs although they can potentially face the same challenges, stress, overwhelming feelings, and burdens when caring for their children as do other parents with children with special needs.

Stress is a difficulty that parents experience with having a child or children with special needs. Stress is defined as a negative emotional experience that is accompanied by physiological, behavioral, and cognitive changes that can affect a person’s overall well-being of life (Antonopoulou et al., 2017). Cronin and Becher (2015) defined parental stress as being stress that parents experience as a result of their social and environmental responsibilities from everyday life events. Stressors arising from health care costs, childcare costs, educational needs, and the balance of home and work all are factors of stress experienced by parents of children with special needs (Cronin & Becher, 2015; Kalliath et al., 2012). Having children with severe disabilities increases the stress level of parents (Hartley et al., 2016; Woodgate et al., 2015). Price and Oliverio (2016) concur and add that these parents deal with the stress of caring for a child with special needs, and they experience different emotions such as despair, remorse, and grief. Feizi et al. (2014) also reported that parents experience higher stress and bear loads of stress when they have children with severe special needs. Parents reported symptoms of stress such as being irritable, unable to concentrate, lack of appetite, dizziness, and breathlessness (Lindo et al., 2016). In conducting this literature, it was important to understand what influences social workers who have children with special needs while in their environment.

MicroSystem Level

The use of the ecological theory in this study reveals an understanding of what external forces within the environment helped to shape parents lived experiences of how they interpreted and perceived those experiences. First, I took a look at the microsystem level of the ecological perspective. The microsystem level in the ecological theory is a pattern of activities, social roles and interpersonal relations that individual experience in a direct setting (Algood & Harris, 2013). The microsystems level allowed me to look at the immediate interactions between the parent and the child. The parent-child interaction can affect how the parent provides care, love, and attention to their child with special needs (Algood & Harris, 2013). Parents are known to love and care for their children, but there are times when the needs of their children become so demanding that the love and care can influence the parent-child interaction (Garner et al., 2013). For example, when the interaction and relationship between a child and their parent are positive, it usually is contributed to the parents having positive thoughts and behaviors (Thompson & McFerran, 2015). Thompson and McFerran (2015) found in their study that parents described changes within the quality of the relationship they have with their children. Thompson & McFerran (2015), stated that parents felt they were able to better interact with their child and be with their child due to their ability to engage with their children. Schuiringa et al. (2015) stated that parents engage with their children better if they are accepting of the child. When the parent-child interaction is negative; however, the cause can potentially relate to the parent feeling overwhelmed and stressed. Parenting practices, however, become differentiated when a child has an identified special need. A parent's ability to accept that their child has an identified special need is important to understand. Parents may have to change the way they interact, engage, and discipline their children with special needs in contrast to the way they do so with their children who do not have a special need. When children have special needs, it can present challenges and stressors for the parents and have effects on the parent-child interactions (Fenning et al., 2014). Because of these stressors and challenges parents have and depending on the child's special need, many perceive they have to use a harsh tone, provide more structure, and commit to being stern with the child (Ma et al., 2013). Some children have special needs that are best benefited by interventions that professionals have shared that are appropriate for the child. Depending on the severity of the child's special need, the parent can use evidenced-based interventions and engage the community and school support to promote healthy interactions.

MesoSystem Level

Bronfenbrenner (1977) describes the mesosystem level of the ecological theory of the interactions among two or more of the individual's microsystems (activities, social roles, or interactions). Teachers and family members play an important role in both a child's life and their parent's life. Many parents interact with their child's teachers and family members daily depending on the level of support needed or wanted. When I look at these two environmental influences, I can understand that they are the external forces that helped shape the lived experiences of parents based on the interpretations and perceptions of the parent's experience.

Parents expect that children with special needs and children without special needs will attend school and given equal time and attention. Children with special needs seemingly need more time and attention from their teachers (Celyan & Aral, 2016). Because children with special needs require more time with their teachers, the parent exclusively must spend more time talking with their child's teachers about that child's special need. Teachers play an important role in both a child and their parent's life. Teachers have been equipped with specialized skills to work with children that identify as having a special need in which create less worrying and frustration within the child and the parent. Teachers, however, find it hard to work with children with special needs while also trying to work with children who do not have special needs (Avramides, 2013; Broomhead, 2013; Krull et al., 2014). Ceylan and Aral (2016) conducted a phenomenological study and stated that the opinions of classroom teachers and inclusive practice found that both teachers and parents could become more informed on the needs, services, and resources for children with special needs. This study also noted that more effective and efficient in-service training seminars are beneficial for teachers and administration. Another study notes how more children with special needs are being rejected socially more often than their peers who do not have special needs (Krull et al., 2014). Rose et al. (2017) concur that peer relationships are pivotal in the development of children with special needs but found that they are less likely to demonstrate success in relationships.

MacFarlane and Woolfson (2013) found that teachers who participated in an in-service training period demonstrated feelings that were more positive towards working with children with special needs compared to teachers who did not attend the in-service training. This study also found that teachers perceived attempting to teach children in an inclusion setting was problematic and was accompanied by negative teaching attitudes, which made it difficult for the child with special needs. It is important to look at teacher's perceptions and interpretations of children with special needs because their perceptions and thoughts provide a better understanding of how this external force has helped to shape parent's perceptions and interpretations of their lived experiences with having children with special needs.

Teachers in one study conducted in the Arab community and culture perceived that there are barriers to working with children with special needs due to negative attitudes from students and staff, related environmental barriers, scarcity of learning resources, unsuitable curriculum, and evaluation modules, and family and society barriers (Amr et al., 2016). Many of the teachers in this study perceived that the peers of children with special needs made it difficult to produce a learning environment for children with special needs (Amr et al., 2016). Teachers perceive that there is a lack of time available to spend with children that have special needs in the classroom (Amr et al., 2016; Sadioglu et al., 2013). Teachers were unclear about their roles and expectations on how to teach and provide inclusion services for children with special needs.

Amr’s et al. (2016) study discovered, the classroom sizes, resources, and buildings were not equipped and set up in a way to address additional needs of children with special needs and this created a problem for teachers when including children with special needs on a day to day basis. Teachers also perceived that the learning outcomes were not applicable for children with special needs and they were not aware how to appropriately set goals and outcomes around these children to ensure they were able to learn on a day to day basis (Amr et al., 2016). Lastly, teachers in this study perceived that family members were not supportive of the inclusion of their children and often had negative attitudes as it related to understanding their child’s special need (Amr et al., 2016).

Al Natour et al., (2015) concurred with Amr et al. (2016), about teachers not having clear roles and expectations of inclusion in the classroom with children with special needs. Similarly, Dapudong (2013) found that teachers perceived that they were not prepared to work in inclusive classrooms with children with special needs because they were unclear about their roles and expectations. Varcoe and Boyle (2014) also found that teachers who have pre-service training before to entering the classroom found they could view children with special needs being in an inclusive setting more positively than teachers with the previous experience entering the training. Experienced teachers viewed having more of a negative attitude towards the inclusion of children with special needs. The ability to work with teachers is important because it can contribute to the success of the child and alleviate stress to parents surrounding their children’s education. Parents are dealing with stress and being overwhelmed with the care they provide for their children but working with their child’s teacher could help alleviate the stressors they could have around the child’s education.

Family members are instrumental because of the level of support they can provide to parents and the children that have special needs. Parents of children with special needs experience higher levels of stress than parents of children without special needs and need a high level of support from extended family members. Social support influences family functioning (Gallagher & Hannigan, 2014). Social support is needed from family members to assist parents in caring for their child with special needs. Lim and Chia (2017) found that support from family members will assist the primary parent in their caregiving role and reduce burnout and depression. That study found that the support of financial assistance from family members for these parents with children with special needs would be beneficial as it would help to take care of some medical, therapy, and other fees that parents have to pay (Lim & Chia, 2017). Lim and Chia (2017) discovered that family members could assist with respite so that parents could enjoy hobbies and a personal timeout.

Exosystem Level

The exosystem of Bronfenbrenner’s ecological theory is where the parent is not actively involved in a setting, but the setting can significantly influence the parent. I looked at the peer group of the child with special needs so that I can understand how a parent perceives and interprets their lived experiences of having a child with special needs. Parents have hopes that when they send their child to school, they will be able to engage in social activities and establish relationships with children without special needs.

Some children depending on the severity of their special need will not have activities as other children with special needs. Research, however, revealed that children with special needs experience isolation, rejection, and difficulty forming relationships among their peers (Lim & Chia, 2016, Ma et al., 2013; Caylen & Aral, 2016). According to Amr et al. (2016), children with special needs are perceived by their peers as having behavioral issues and communication issues. The interaction between children with special needs and children without special needs is discussed as being limited if any at all (Garrett et al., 2017). Avirimades (2013) concur that children with special needs most likely have less social interactions and relationships with their peers, while Garrote (2016) and Grutter et al. (2015) argue that they have not found this to be so. Children with special needs are perceived to understand that their social relationships are unlike others and therefore can present problems at times. When having the ability to perceive that this is the culture from peers, children with special needs can experience the same feelings of stress, rejection, and isolation as it does the parents. Most parents attempt to shelter their children from these types of behaviors and prefer to deal with other parents and children that have special needs that are dealing with the same issues of their child (Ma et al., 2013).

Macrosystem Level

The macrosystem level of Bronfenbrenner's (1977) ecological theory depicts how embedded an individual is within their culture. It is important to understand how the culture of the community can influence a parent who has a child with special needs. In most communities, there are schools, community centers, and other agencies that attempt to educate the community on individuals with special needs. To understand the culture of the community and how the community views children with special needs, I looked into how that culture potentially influences and shape a parent’s perception surrounding their lived experiences.

When looking at the culture of the community, I looked first at school systems. Many school systems have had to implement different types of policies and procedures relating to helping children with special needs. The school system typically offers services to children with special needs, but there are times when the school system fails to meet the needs of children that have special needs. Services, however, that many schools offer children with special needs include: inclusion, supports and strategies for behavior management if behavior interferes with learning or with the learning of others, communication, assistive technology devices or services, language needs as related to the Individualized Education Plan (IEP) and 504 Plans (Mason & Goldman, 2017). The IEP and 504 Plans are plans that seek to provide accommodations to children when there has been an identified need with their academics (Mason & Goldman, 2017). The culture of most schools is welcoming and accommodating to meet the needs of the children with special needs and their families. While parents are advocating for the rights of their children's needs, they are also partnering with the community and others to ensure services for their children continue.

When I looked at community centers and other agencies, I looked at the culture of these entities. Parents have connected with other parents through support groups, internet group chats, focus groups, and other different types of meetings as a means of understanding that their children can have a life that is the best fitting for them depending on the child's special needs (Algood et al., 2013). There still lies in some instances a struggle with obtaining the full support of agencies and the community with getting the services for children with special needs (Home, 2015). In most instances, research shows that parents who have children with special needs who can pay for services can access and afford community resources within their communities (Walker et al., 2016). There are other times when parents with children with special needs do not have the same access to community resources within their community due to living in poverty, lacking finances for the treatment needed, and the lack of affordable resources to the family (Rosen-Reynoso et al., 2016; Walker et al., 2016). Many rural town communities lack services and resources for parents and their children with special needs. When this lack of resource becomes an issue for the parent and child with special needs, parents have to take their children out of town to receive affordable and available resources for their children (Walker et al., 2016). As parents have to find quality community support and resources for their children, they can become overwhelmed. Parents experience being overwhelmed and isolated due to the cultural attitudes of the community and the lack of social acceptance and support (Zavirsek, 2014). Parents face challenges and stigma concerning their child having special needs and requiring support within their community. My community, for example, incorporated a parent-to-parent coalition to serve as resources and as emotional supports to other parents that have children with special needs, but not all communities provide this support. According to Home (2015), there are some areas where families continue to face increased burdens from lack of support, financial assistance, service to address the needs of children with special needs.

Social work

While families and parents individually are experiencing these challenges, there are professionals available to assist these families. Social workers have been instrumental in working with the special needs population in many facets such as school settings, mental health facilities, medical offices, etc. Social workers when working with children with special needs also collaborate closely with their parents. Social workers play a significant role in the lives of families and are required to provide interventions, resources, and services to persons that are in need. While social workers are instrumental in the lives of families as they provide services and resources to help with their issues, social work parents with children with special needs need those same services. Social workers are trained and equipped with skills from classroom teachings and practice settings, but there is no literature about the social work parent's perception or availability to such services they often provide other families. Therefore, it is important to explore further social workers who parent children with special needs. I first look at social workers and the work they provide to individuals and their families.

Social workers have been called into action to play key roles in the lives of children that live with various special needs from day to day. Social workers are change agents that seek to assist and help families overcome issues or concerns that have become burdensome. Social workers also seek to promote social and economic justices for children and their families. Social work according to Papp and Racz (2016) is a practice-based profession and academic discipline that promotes social change, development, social cohesion, and the empowerment and liberation of people. Social workers also tend to engage individuals and families in efforts to help families address life challenges and enhance their well-being (IFSW, 2014). Social workers historically worked with individuals that had special needs through the lens of a medical model. This lens placed barriers on social workers as the focus was not on helping the individual to address their social, mental, and physical well-being but on providing treatment or finding a cure to the child’s special need. It is important to understand how this lens may have shaped the perceptions of social workers when they address children with special needs and their families. To understand the professional activities of a social worker, I looked at the previous articles; these articles add literature on what social workers are attempting to do.

Many of these social workers attempt to work with family members by helping them process their feelings about the child's special need. Social workers also work in other healthcare settings to assist families when they have difficulties due to their child's special need. Some social workers work with mental and behavioral health professionals by connecting the child with special needs with an appropriate agency. These workers attempt to utilize skills they have been trained with to promote social and economic justice. As social workers try to use their skills to assist parents with children with special needs, they can experience burnout and stress that may affect their work and home environments (Osvat, 2013).

Burnout in Social workers

To fully understand how important a social workers’ role is and their experience when parenting children with special needs, it is important to understand how burnout in social workers influence their lived experiences. Social workers commit themselves to protect and empower individuals that experience vulnerabilities. While empowering others and ensuring that services are implemented to meet that individual's needs, many social workers neglect their health and forget time for self-care (Osvat, 2013). Osvat (2013) conducted a study surrounding burnout in social workers. The study depicted social workers experience of burnout including physical and emotional exhaustion, feelings of being overwhelmed, feelings of being impatient, feelings of loss of motivation, low self-esteem, feelings of disappointment due to work demands, repetitive work, lack of support, hearing emotional burdens from families, and taking on problems of the families.

Burnout is known to affect groups of emotionally exhausted people that have feelings of depersonalization and a reduction in personal accomplishment (Sa´nchez-Moreno et al., 2015). Naveed and Naveed (2013) consider burnout to be "a unique, effective response to the prolonged and chronic interpersonal stressors which depletes a person's energetic and coping resources" (p.113). Social workers are among many professionals that pose a risk of experiencing burnout because of their care and diligence to enhance the well-being of others.

Social workers when working with children and other vulnerable populations are expected to be emotionally healthy in efforts to provide adequate resources to their families. Social workers are also expected always to maintain a level of self-awareness and self-care to ensure they are emotionally healthy (NASW, 2008). Human behavior, however, is unpredictable and the work with children is even more unpredictable.

Social workers when working with children can become mentally and physically worn. Might place individuals will be at risk of not receiving the best and appropriate care to meet their needs (Diaconescu, 2015).

Challenges with Work and Family

The home and work life of a social worker is important to understand because both can have negative consequences on the social worker's ability to perform their job and home duties. While it is unknown how social workers perceive their lived experiences of being a social worker who has children with special needs, it is important to understand the general experiences of a social worker’s challenges with work and family. To fully understand the influences of the social workers' home and work life, I looked at the social worker's interaction with children at the exosystem level and pulled from the most updated literature. Literature about the social worker’s challenges with work and family was minimal. Social workers, however, work with vulnerable populations to assist them with social justice, self-determination, advocacy and promotion of life satisfaction (NASW, 2008), but the job can be demanding and stressful (Antonopoulou et al., 2017). Some of the experiences that make the job stressful for social workers are high workloads, shortage of staff, lack of supervisory support, role conflict, and role ambiguity (Osvat, 2013). According to Kalliath et al. (2015) when social workers face these challenges, their family and their work suffer.

Kalliath and Kalliath (2015) stated that workers experience family-work role conflict that impedes on family time by working long hours while having no support or autonomy from their organization. Additional stressors and challenges social workers experience as a result of working with children with special needs are burnout, stress, compassion fatigue, depressive symptoms, and role overload due to the high-level demands of the job (Kalliath & Kalliath, 2015). Research about social workers' experiences, challenges, and stressors are not relating to parenting children with special needs, but there is research about the work and family role of social workers in general.

The research on work and family role of social workers helps me understand the influence on the social worker's work and home environment. Social worker's that work with populations that are stressed and strained are highly vulnerable when juggling both work and family roles (Dottan & Kormosh, 2016; Kalliath & Kalliath, 2015). High workloads, withdrawal, impatience, and tension are all stressors and issues that influence a social workers' family when they experience stress from work (Diaconseau, 2015). A social worker's finances can also be affected negatively as much as a non-social work parent with children with special needs in which can add to the stress the social work parent. Social workers who have children with special needs may have to miss days from work to care for their child with special needs. These stressors are possibly due to social workers parenting children with special needs.

Social Workers as Parents

Social workers that parent children with special needs can experience problems; it is important to understand how a social worker perceives and interprets the challenges they face by being a social work parent with children with special needs. Parenting children is challenging, but it can be more difficult for social workers that work with special needs children and that are parents of children with special needs. I found no research about lived experiences of social workers that are parents of children with special needs, but these parents can have some of the same experiences. Stoesen (2005) discusses briefly in an article, a social worker (Janice Fialka) changing roles from a social worker working with adolescents to a social worker parent with a special needs child. Stoesen (2005) discussed the pain and hurt Fialka felt related to her son's needs and to the care he received from the other professional, but the article did not address the lived experiences of this parent as a social worker.

Literature Summary

This literature review provided information about the parental experiences of parents when parenting children with special needs. There was no research found about the lived experiences of social workers who parent children with special needs. Children with special needs create unique challenges and stressors for parents (Home et al., 2015). There continue to be unexplored unique experiences of social work parents in the literature. Bronfenbrenner’s ecological perspective provided insight into influences that could affect experiences of social work parents in the literature. Additional research is needed to explore the lived experiences of social workers who have children with special needs. In chapter 3, I will provide the research methodology of the study.

Chapter 3: Research Method

The purpose of this phenomenological qualitative study was to explore the lived experiences of social workers who have children with special needs. Chapter 3 includes details for the methodology of this study. Chapter 3 includes information regarding the research design and rationale, role of the researcher, participant selection, procedures for recruitment, and issues of trustworthiness and ethical considerations of the study. The research design and rationale of the study includes information regarding the use of a phenomenological approach. In this study, I explored the lived experiences of social workers that have children with special needs. This section also includes information on the tradition and background of the phenomenological approach in this study. I explain my role as an observer with insider knowledge about the phenomenon in which allowed me to participate in discussions with the participants. This section further includes information on how I managed my biases although there were no risks or ethical issues that came up.

I discuss in the participant selection section, the criterion and sampling strategy used for the study. I further explain the data collection procedure in the instrumentation section. I describe the procedures for recruitment. I explain the issues of trustworthiness and the validity and credibility of the study. The ethical considerations section in this study includes information regarding how I managed the data obtained from participants, the consents, confidentiality, and respect for participants.

Research Design and Rationale

Qualitative research is made up of conceptual frameworks that inform how researchers address social problems, individuals, or groups (Creswell, 2013). I chose a qualitative design because it is the best type of methodology to answer my research question. According to Denzin and Lincoln (2015), qualitative research stresses the socially constructed nature of reality, the intimate relationship between the researcher and the phenomenon being studied, and the situational limitations that shape. Qualitative research allows the researcher to seek answers to how social experience is created and given meaning (Denzin & Lincoln, 2015). I chose to use a qualitative design over quantitative and mixed-methods because quantitative studies emphasize measurement and analyze relationships between variables and not processes (Denzin & Lincoln, 2015) and this would not give me insight into the lived experiences addressed in my research question. Phenomenological qualitative studies, specifically, are an opportunity for researchers to explore the perceptions, thoughts, and beliefs of individuals in detail, which is why I selected it as my design. The use of a phenomenological study according to Moustakas (1994) emphasizes trying to understand the experience and what the meaning of the experience means to the individuals experiencing it. The use of a phenomenological approach within this study provided a comprehensive description (Moustakas, 1994) which enabled me to explore the lived experiences of social workers who have children with special needs. This study’s phenomenon was the lived experiences of social workers who have children with special needs.

Research Questions

The research question I use to guide this research study was: What are the lived experiences of social workers who parent children with special needs?

Research Tradition: Phenomenology

German philosopher Edmund Husserl was one of the founders of phenomenology. Husserl's basic premise was that the reality of an individual consisted of phenomena as they perceived or believed it in human consciousness (Moustakas, 1994). Phenomenology studies are used primarily to explore the common phenomenon that several persons have experienced at some time in their lives (Creswell, 2013). According to Moustakas (1994), phenomenological studies describes the phenomenon in detail to include what the individual experienced and how they experienced it. Holloway (2005) stated that phenomenology describes individuals lived experiences and attempts to draw out the meaning of that experience. Phenomenological studies also examine human experiences through the description of those lived experiences of individuals (Donalek, 2004). The phenomenon I studied in this research project was looking into the lived experiences of social workers who have children with special needs.

A transcendental phenomenology was an approach to phenomenological studies that helped me understand and put this study in perspective. Moustakas (1994) presented transcendental phenomenology as being less focused on the researcher's interpretations but more on the description of the experiences of the individuals. I utilized bracketing. Researchers use bracketing to set their personal experiences to the side in efforts to have a fresh perspective of the phenomenon (Moustakas, 1994), which in this study are social workers that have children with special needs experience. Bracketing coined by Husserl was an effort to identify what the researcher expects to discover and purposely put those ideas aside (Donalek, 2004). The bracketing process I used allowed me to self-reflect in a journal, so that I kept my biases and ideas separate from the work that I was doing.

Role of the Researcher

According to Denzin and Lincoln (2005), researchers who conduct qualitative studies are the human instrument and must take into account their perceptions, beliefs, and feelings. Donalek (2004) stated Husserl developed the process of bracketing to identify what the researcher expects to discover and purposely put those ideas aside. I am a social worker who parents children with special needs, and I understood that my experiences were not always like the experiences of other social work parents of children with special needs. As a result of being a social worker who has children with special needs, I understand my experiences mediate my interpretation with participants. Although it may be perceived that I share similar experiences in this phenomenon, I recruited participants from the general population and not from personal or professional systems. As an observer, I shared some of my experiences of being a social work parent with children with special needs at the end of the interviews with the participants. I shared my experiences at the end of the interview so that I did not influence the participants' thoughts throughout the interview. I, as an observer in this study, used bracketing and reflexivity to make an accurate interpretation of this study. Because I have my own personal lived experience of being a social worker with two children who have special needs, it was essential that I put my ideas, thoughts, and feelings aside about the phenomenon I am studying. My experiences with having two children with special needs consists of day to day challenges, but the use of bracketing my personal thoughts, perceptions, and interpretations about the experience allowed me to distinguish those biases, preconceptions, and pre-beliefs about other social workers lived experiences with having children with special needs. I ensured that I used bracketing to set aside my preconceived experiences to understand the experiences of other social work parents who have children with special needs. In addition to bracketing, I used self-reflexive journaling. Researchers use self-reflective journaling to help them refine and sharpen their skills and be self-aware as the researcher (Janesick, 2015). I recorded my thoughts, beliefs, biases, and reflect on them so that I was more conscious and self-aware. Self-reflexive journaling is a tool to address and assess problems (biases and perceptions a researcher has from the interviews and concerns from the participants) (Janesick, 2015).

My experiences as a social worker over the past 10 years have allowed me to work with families that experience many dynamics, such as physical abuse, family violence, domestic violence, and children who are being abused and neglected. I have worked with many children with special needs, and I have seen their parents struggle with providing care for their children. I also parent children with special needs, and I have struggled with managing home and work life. My children are a joy to have in my home, but there are times I can resonate with other parents who have children with special needs. I currently have a bachelors and master’s degree in social work, and I have received training while obtaining these degrees that helped to formulate my thoughts when working with and parenting children with special needs but there are times in my experience, I struggle and need to be empowered.

Information learned, and knowledge obtained could raise awareness in society on potential limited job prospects for social work and non-social work parents due to caring for a child with special needs. Knowledge surrounding the different challenges social workers with children with special needs experience could raise awareness with colleagues and other helping professionals. Awareness of the phenomenon in this study could enhance the skills a social worker currently possesses while understanding more of what their perceptions and interpretations are surrounding their lived experiences. This study includes information regarding insight to social workers who have children with special needs by helping them become aware of triggers and stressors that may create stressful situations in the work place and home environment.

Methodology

Participant Selection Logic

I used a criterion purposive and snowball sample for this study. The population included any social worker who has children with special needs. I looked at social workers who have parented children with special needs regardless of their marital status, the age of the child with special needs, or the diagnosis of the child that was self-reported by the social work parent. Criterion purposive sampling involves selecting participants who have some predetermined criteria of importance to each other (Patton, 2002). I chose criterion purposive sampling because it aligned with phenomenological qualitative studies. Phenomenological studies are primarily used when a researcher explores the lived experiences of a group of people that either share or have shared the same phenomenon of study. The use of criterion study allowed me to further my study by reaching out and exploring the perceptions and interpretations of social workers who have children with special needs. I used criterion purposive sampling because the participants shared in the experience of being a social worker who has children with special needs. According to Rudestam and Newton (2015) snowball sampling is a process that allowed me to ask participants if there are any other persons they may know that can speak with me about the phenomenon I am studying. Snowball sampling means participants could invite others that have experienced or were currently experiencing the phenomenon to contact me so that they may participate in the study (Rudestam & Newton, 2015). The logic for using both the criterion purposive and snowball sampling was to obtain enough participants who informed my research question so that the experiences of social workers that have children with special needs are understood. The use of criterion purposive and snowball sampling allowed me to engage with a small number of participants who share the phenomenon. I contacted participants who were social workers who had children with special needs through the use of social media, the parent-to-parent organization within my local community, national social work organizations, and a flyer that I constructed to recruit participants.

No specific rule mandates selecting a sample size for phenomenological studies (Lincoln & Guba, 1985; Marshall, 1996). Sample sizes in qualitative studies are set on the information the researcher wants to know, the purpose of the study if the information will be useful, and if the information is credible (Marshall, 1996; Patton, 2002). Patton (2002) proposed that sample size should be few, but the information obtained should be extensive in detail. I proposed to recruit 10 social workers, but I stopped recruiting after eight participants as I had reached saturation. After six interviews, major themes emerged within and between the individuals’ experiences and had begun to repeat. When

I believed I had reached saturation, I interviewed two more women to ensure that new themes would not present themselves. Because of the use of this small sample size, I obtained in-depth information about their experiences. When the information retrieved became redundant, there were no new information brought forth by additional interviews and the saturation of the sample was achieved (Lincoln & Guba, 1985; Patton, 2002). I achieved saturation when there was no new information brought forth by the participants.

Instrumentation

The use of qualitative research allows the researcher to be the primary instrument when gathering and analyzing information from participants (Patton, 2002). As such, I was the primary instrument for this study. Qualitative researchers use interviews as a means to elicit views and opinions from the participants (Lincoln & Guba, 1985; Patton, 2002). I used in-depth interviews in this study to engage participants and obtain an understanding of their experience. I audio-recorded semistructured interviews so that I could accurately capture the participant's stories. I conducted in-depth semistructured interviews to ask open-ended questions and let discussions with participants flow. Participants were invited to participate in two follow-up interviews so that I further engaged and have them elaborate on their experiences based off of the questions asked during the initial interviews. I used prolonged engagement as a strategy during this process to enhance the trustworthiness of the research. Prolonged engagement according to Lincoln and Guba (1985) is when the researcher spends sufficient time in the setting of participants to understand the culture, setting, or phenomenon of interest. The use of prolonged engagement allowed me to spend time with the participants and build trust with them while analyzing and making decisions about the information that is relevant, important, and of interest for the study. I explained to the participants that the initial interview would last for an hour and a half and the two follow-up interviews would last approximately 30 minutes. All interviews varied in length of time, and one interview went over the hour and half time allotted, and that was at the participants' discretion. I explained to the participants that the follow-up interviews would be audio-recorded and could be face-to-face, skype, or telephone call. I conducted interviews via telephone call due to the preference of participant's and the geographical location of the participants.

Interview Guide

Since I was the primary interviewer, my interviews generated discussion from my research questions (Rudestam & Newton, 2015). Interview questions consisted of open-ended questions that were delivered in a semistructured manner so that I could allow participants the opportunity to talk freely while sharing their experiences. I asked the participants to describe and explain their experience of the phenomenon. The interview questions were developed based on theory and extensive literature research. To further establish validity, feedback from my committee members were taken and polished so that questions were appropriate. I also had a trusted colleague that did not have any interest in this study conduct the same interview with me as I used with the participants to understand their experience in this study. I wrote the interview questions in a way that allowed me to provide information about the phenomenon as it was designed to do.

Procedures for Recruitment, Participation, and Data Collection

Once I received approval from IRB, I recruited social workers that have children with special needs. I used both the criterion purposive sampling and snowball (chain) sampling for recruitment. Criterion purposive sampling allowed me to select participants that were social workers who have children with special needs. When I used snowball sampling, I asked participants if they knew of anyone else who would like to participate in the study and ask the participant to have that person to contact me.

As a means to recruit social workers that had children with special needs, I reached out to national social work organizations and social media sites such as Facebook and LinkedIn to both social workers and non-social workers because I was in search of social workers with children with special needs. The flyer advised participants on the purpose of the study, the procedures that will be used in the data collection, the participant's right to withdraw from the study at any time, the known risks associated with participating in the study, the protection of confidentiality of the participants, and benefits to the participants in the study.

Being the primary instrument for this study, I conducted, transcribed, and analyzed the semistructured interviews held with participants. Since I was looking to have in-depth interviews with the participants, I set initial interviews to last an hour and a half. When conducting my interviews, I listened carefully and reflected on what the participant said so that I could engage and build more of a rapport with the participants as they shared their experiences. I shared my experiences with participants, but it was not until the end of the interviews.

The initial interviews consisted of semistructured questions that I audio-recorded. I used two electronic devices to audio-record the interviews in case one device failed.

Interviews consisted of asking participants to engage in face-to-face interviews either in person or through the use of videoconferencing software, such as Skype. At the beginning of the initial interviews, I explained to participants that after the first interview, I would take at least one month to transcribe the notes from the interviews. During the first interviews, I explained to participants that I would like for them to participate in follow-up sessions to ensure that I have accurately captured their thoughts, beliefs, and perceptions. I advised the participants that the follow-up sessions would be one month after the initial interview and take approximately thirty minutes. I further let the participants know this interview would be audio-taped as well. I explained to them that the follow-up session would ask further clarifying questions that came about as I was transcribing the notes. When I completed the second follow-up interviews, I used a composite structural-textural process for each participant and provided the participants with a description of their story. According to Moustakas (1994), the structural-textural process is where composite descriptions are integrated to develop a synthesis of the meanings and essence of the experiences of the participants. The composite description is comprised of both textural and structural descriptions to develop a synthesis of the meanings and essences of the participants lived experience (Moustakas, 1994). I used this process in efforts to obtain feedback and ensure that I have captured the meaning of the participant's experiences. I allowed participants the opportunity to provide me with any corrections or updates at that time. In addition to conducting interviews, I continued to utilize my self-reflexive journal to sort out my biases, thoughts, and personal perceptions. I recorded in my journal my observations during the interview process with the participants.

Data Analysis Plan

The analysis process involved organizing data, coding and organizing themes, showing the representation of data, and interpreting data gathered from the participants. I used open coding. Open coding (Miles et al., 2014) allowed me to create categories for data that summarized what I saw happening. I coded for significant statements and meaning units. Significant statements are statements that reveal how participants were experiencing the phenomenon and meaning units were those statements that were grouped into larger units (Moustakas, 1994). Meaning units are statements that are listed and clustered into common themes (Giorgi, 1985; Kvale, 1983). In this study, I coded transcripts for significant statements and meaning units that indicated important aspects of the phenomenon.

As I moved forward through the analysis process, I immersed myself in the data by reading and transcribing transcripts. I coded transcripts for statements, word phrases, and verbatim quotes that indicated important details of the phenomenon. Next, I used Moustakas (1994) horizontalization process where I gave each code an equal value of importance. I engaged in phenomenological reduction where I reduced codes to non-repetitive codes, and I combined those codes into categories. Next, I used an imaginative variation, a process where I attempted to imagine every possible variation that I could include as a part of the phenomenon. I then wrote a textural description detailing what the participant's experience was with the phenomenon (Moustakas, 1994). Next, I used a structural description process where I described how participants experience the phenomenon in this study. According to Moustakas (1994), the structural description describes the setting and context in which the phenomenon was experienced. The context of the child's special needs, the type of special need, and the type of care that is required to provide for the child that has special needs influences how the social worker that has a child with special needs experience this phenomenon. I wrote a composite textural-structural description for each depicting both how and what the participant's experience is. The composite description depicted the participant feeling about the child having special needs, their interpretation of special needs, and the impact of life on them and the child that has special needs. I used the textural-structural description to detail and provided the essence of the experiences from the themes that emerge throughout the analysis process.

Negative case analysis is a valuable qualitative strategy to further ensure credibility or validity (Eisner, 1991; Lincoln & Guba, 1985; Patton, 2002). I used negative case analysis in this study to search through the data looking for evidence that disconfirmed themes. I used negative case analysis to identify data that was conflicting from stories that were similar in efforts to understand how their experience fit into themes.

Issues of Trustworthiness

Trustworthiness in qualitative research is parallel to the term rigor in quantitative research (Patton, 2002). According to Lincoln and Guba (1985), credibility, authenticity, transferability, dependability, and confirmability establishes trustworthiness. To ensure trustworthiness of this study, I used prolonged engagement, member checks, peer review/debriefing, and negative case analysis. The use of prolonged engagement allowed me to spend time with the participants and build trust with them while analyzing and making decisions about the information that was relevant, important, and of interest for the study. As I was actively listening, I listened for information that was important to use within the study. I continued this process through all the interviews with participants. I used member checks by providing each participant with a composite description of the interview to help me reflect on the accuracy of the accounts they have provided to me. Participants had an opportunity to provide their thoughts about the analysis and I corrected the information missing from the stories that they have provided. I took the feedback received from the participants and corrected the information gathered so that it provided the accuracy of the accounts of participants. I used peer reviewing/debriefing as a strategy to share my thoughts and beliefs with a colleague based on the information I have obtained from interviews. This strategy is explained more in detail in Chapter 4. The use of this strategy allowed my peers and colleagues an opportunity to review with me the biases, thoughts, perceptions, and misunderstandings I had with the information I was receiving from the participants. I used this strategy to have a peer play the role of the "devil's advocate" to ask me hard and difficult questions so that I could document and be aware of my thoughts and beliefs. The use of this process allowed me the opportunity to sort out what I felt but report the information that is accurate from the participants. I documented these peer sessions in my journal to understand my biases.

Transferability is the ability for results in the study to be in similar contexts (Lincoln & Guba, 1985). Rich, thick description was used to establish transferability. I provided specific details and an abundant amount of descriptions of the participants surrounding their behaviors to allow transferability. I used my journal to reflect on my thoughts, perceptions, biases, and observations of the study. I used journaling as an audit trail. An audit trail according to Patton (2002) are steps the researcher took to evolve in their thoughts while in the analysis process. I used reflexivity. The use of reflexivity according to Moustakas (1994) is when a researcher is aware of their biases, values, and experiences with the phenomenon. I used reflexivity to discuss my experiences as a social worker that has children with special needs. I explained how my experience had shaped my interpretation of social workers that have children with special needs.

Ethical Considerations

As a researcher, it is my responsibility to act and ethically respond to others. I am a social worker, and I live by the Code of Ethics. All social workers are expected to uphold the National Association of Social Workers (NASW) Code of Ethics as an everyday guide for the professional conduct of social workers. A component in the Code of Ethics (NASW, 2017) for social workers is maintaining confidentiality. As I conducted this study, I did not fulfill the role of a direct practice or clinical social worker, but I was responsible for abiding by the standards of the Code of Ethics. Because I am a social worker, I abide by the standards of the Code of Ethics. I understood that this study could have potential risks with participants becoming emotional and talking about unresolved issues. Participants shared their thoughts, feelings, and emotions around having children with special needs. There were times when participants expressed having unresolved feelings around their child’s special need, but no participant needed a referral or list of resources to address their feelings. There were no risks identified by the participants; therefore, I did not have to consult with my committee to take further action.

In addition to abiding by the NASW Code of Ethics, I work at the Division of Family and Children Services where I am a mandated reporter. A mandated reporter in the state of Georgia (doctors, volunteers, clergy, social workers or social services person) is an individual who is required to report or cause reports to be made if they have reasonable cause to believe that suspected child abuse has occurred. I am held to this standard while on official business or not; I advised participants as a part of the informed consent process my obligation to report suspected abuse as a part of the informed consent process.

I obtained approval from IRB # 01-05-18-0466771 to conduct this study. I submitted the necessary documents that met Walden University guidelines to IRB for approval. I submitted to participants a full disclosure that informed them: the right to withdraw from the study at any time, the known risks associated with participating in the study, the protection of confidentiality of the participants, and benefits to those that participate in the study. I treated each participant fairly, and I treated them with respect to ensure that risks are minimal. I provided each participant with a $5 Walmart gift card for their participation at the end of the second interview. Because participants took time out of their schedules to participate and share their stories, I wanted to provide them with a small token of thanks. The gift card amount was a small amount and did not have any influence on any participant to participate in the study. According to Head (2009), researchers who decide to pay participants with gift cards or with monetary payments understand ethical guidelines that the payment is not used for coercive participation and researchers should avoid exploiting participants, but the gift was given as an expression of thanks for taking the time out to participate. Participants had the opportunity to withdraw from the study at any time but no participant withdrew from the study, and all received their Walmart gift card. If a participant had wishes to withdraw from the study, I would have consulted with my chair and committee member.

I used pseudonyms to protect the identity of the participants. I stored this information in the database on my computer where I was the only one to access any information because it was password protected. I used an audio recorder to conduct the interviews; and once completed with the initial set of interviews, I transcribed them. I stored transcribed notes into a file cabinet in my home where it is under lock and key. I provided a composite description of the transcribed notes that I wrote up based on of the participant’s accounts of their story as a part of member checking to ensure the accounts of their story were accurate after the first set of interviews.

The use of member checking was a critical part because I wanted to ensure the participant's information was accurate. This process allowed participants to alter or retract information they felt comfortable with sharing at the time but would later feel uncomfortable with sharing. Once I complete the analysis, transcription of the notes, and successfully defend the information in the study, I will delete all information from my recorder. In addition to deleting all information from my recorder, I will keep raw data for five years, and then it will be destroyed.

Summary

This study was important as it was designed to explore the lived experiences of social workers with children with special needs. Using Bronfenbrenner's ecological theory, my goal was to gain information on the experiences of these social workers. Such information is important to the social work profession and may provide insight into environmental influences that create a challenge and difficulty for both social work and non-social work parents.

Chapter three began with understanding the research design and rationale of the study, the phenomenological research tradition, the role of the researcher, participant's selection, procedures for recruitment, instrumentation, and the data analysis of the study. This study used the transcendental phenomenological approach to detail the descriptions of the participants' experiences. This method allowed me to have a fresh perspective and deeper understanding of the participants' experience. This method also allowed me to focus less on my interpretations but more on the description of the experiences of the individuals.

I discussed in chapter three issues of trustworthiness and ethical considerations. I used methods of prolonged engagement, member checks, peer review/debriefing, and negative case analysis to establish issues of trustworthiness and maintain ethical standards. I established credibility and maintained ethical standards when dealing with participants directly and indirectly by the continued use of member checks and self-reflexive writing. I used member checks as a method to provide participants with composites of their stories to ensure I captured an accurate account of their experience. I used self-reflexive journaling to document my thoughts and biases throughout the process of this study. I provide in Chapter 4, the data results from interviews that were held with participants to address the research questions.

Chapter 4: Results

The purpose of this qualitative study was to explore the lived experiences of social workers who have children with special needs. I used the phenomenology approach to provide an in-depth description of participants experiences. The results of this study include information regarding the research question, what are the lived experiences of social workers who parent children with special needs. This chapter includes the research setting, participant demographics, data collection, and the data analysis and then presents the results.

Setting

It is important to establish a setting that allows the researcher and the participant the opportunity to talk freely in a safe environment. I offered participants the option to meet in a neutral place, but I conducted all interviews via a telephone call. There were eight interviews conducted for this study, and I held all eight interviews via telephone call due to participants' living in different states and participants' work schedule. I did not have to collect site agreements because I completed each interview by telephone. Each interview was engaging and allowed for open-ended dialogue pertaining to the research question. There were no distractions during any of the interview sessions because participants chose times that were conducive to their schedules.

Demographics

The demographics and characteristics of the eight participants interviewed in this study included their ages, marital status, education, and geographical location. I used pseudonyms for all participants to maintain confidentiality. I referenced participants as

Mae, Kate, Helen, Shan, Kelsey, Eva, Kay, and Sue. Table 1 provides a summary of the participants including information about their child's special need. All eight of the participants were married and received support from their spouses in the care of their child with special needs. All participants in this study were married, but not all were married to their child's father. The participant's ages ranged from 37–68 with an average of 42. Mae and Kate live on the East coast in an urban area where there is an abundance of resources that they can access. Helen lives on the West Coast in an urban area where there is an abundance of resources she can access. Shan, Kelsey, Eva, Kay, and Sue all live on the East coast in a rural area where they travel at least 45 minutes to a community that had more resources than where they lived.

All eight participants had received higher level education and all had both a BSW and MSW. All the women have varied work experiences within the social work profession. Mae, Kate, and Helen are clinical licensed social workers. Kate in addition to holding a clinical license has obtained her PhD. in Education. Mae has experience working in a mental health clinic and private practice. Shan, Kelsey, and Eva all have experience as both a child welfare social worker and a medical social worker; meanwhile, Sue only had experience in child welfare.

Table 1

Participant Demographics

Participant	Participant Age	Social Work Experience	Child's Age	Child's Special Need
Mae	45	Mental Health, Private Practice	14	ADHD, Cerebral Palsy
Kate	41	Education	13	Autism
			9	Muscular Dystrophy, ADHD
Shan	38	Medical, Child Welfare	10	Sickle Cell Anemia
Helen	38	Private Practice	2	Bronchomalacia
Kelsey	41	Medical, Child Welfare	17	Learning Disability
Eva	44	Medical, Child Welfare	20	Chaka Marie Toothe
Kay	38	Medical, Child Welfare	11	ADHD
Sue	68	Child Welfare	38	Epilepsy

Data Collection

Seven participants responded to the recruitment flyer that I placed on social media sites such as Facebook and LinkedIn. The eighth participant responded to me after hearing about the study from her former colleague. The timeframe of recruitment was three months. Once participants scheduled their interview times and preference of interview via telephone call, they received an electronic informed consent form to sign before the interview. Before starting the initial interview, I advised each participant of the requirement of three interviews total, the initial and follow-up interviews. I had proposed to conduct face-to-face interviews either in person or using video conferencing software, such as Skype, with each participant. However, due to the location of the participant and their preferred method of communication, all interviews were held via a telephone call.

Before the interviews began, I asked each participant whether they had any questions about the consent form and there were none. Once the participant stated that it was okay and gave consent to proceed with the interview, I began recording. I audio recorded each of the interviews. Each initial interview session lasted between 45 and 120 minutes depending on the details each participant provided during each response. At the end of each interview, I stopped the recording and provided details on next steps with the study.

I transcribed the audio recordings and notes after each initial interview. The length of time to transcribe the interviews was between 1.5 to 4.5 hours. I conducted follow-up interviews where I obtained permission again to record. Once participants permitted the recording, the follow-up interview was held asking for clarification from notes and recordings that I had transcribed. The length of time for the second follow-up interviews was from 10 to 30 minutes.

I discussed and explained to each participant that after I completed the composite structural/textural description of their story as a part of member checking, I would send it to them by email as this was the preferred method by the participants to review. I sent each participant a summary of their interview but not a composite structural/textural description that is present in this study, as I developed the composite through further analysis. The composite structural/textural description in this study provides what the participant’s experienced and how they interpreted their experience, whereas the summary described everything the participant said in the interview.

During the process, I emailed participants a summary. I asked participants to advise if there were any corrections needed and if there were corrections needed, I would make the changes. I gave participants the opportunity to review the summary to make sure I captured their experience and to ensure that my interpretations were not biased.

A third follow-up interview lasted about 5 to 10 minutes to discuss if there were any further changes to their experience and three participants recommended minor corrections to their stories, which I made. I transcribed a total of 37 single typed pages from all three interviews with participants. The transcription of the three interviews includes information obtained from participants that allowed them to share their stories of their experience with having a child with a special need.

I found I had reached saturation in this study when the same themes were recurring. Initially, I had proposed to interview 10 participants, but I found I reached redundancy with six participants. All participants expressed unique stories, but all participants shared a commonality in how they experienced the phenomena. After interviewing six participants, themes started to emerge, and no new information resulted from the additional interviews.

Data Analysis

I used Moustakas’s (1994) phenomenology method to analyze data. I present in the findings section, a complete description of the phenomenon using phenomenology analysis. Before and during the analysis process, I used a journal to record my personal experiences of being a social work parent with children with special needs. I used the process to self-reflect and listed my biases, perceptions, thoughts, attitudes, and beliefs. This process of self-reflection and journaling is known as bracketing. When writing a phenomenological qualitative study, bracketing is an important step that must be used (Moustakas, 1994).

As I continued with analysis, the process began with me immersing myself into the data by reading and re-reading the transcripts. First, I coded transcripts for word phrases, statements, and meaning units that were important details of the phenomenon. Then, I used the horizontalization process where each code was valued to be equally important. I took statements and meaning units and reduced them until there were no repetitiveness or overlapping categories. I identified codes, reduced the codes, and combined the codes into categories. I identified over 100 codes initially and then grouped the codes into five categories. Themes emerged from these five categories such as challenges of home life, challenges of work life, acceptance of the child special need, balancing day to day life, and feelings around having a child with a special need. I then reduced those categories to two themes. The two main themes were: (a) coming to terms with having a child with special needs and (b) balancing home and work life. These themes guided the structural/textural composite descriptions.

Structural and textural descriptions are aspects within Moustakas's (1994) phenomenological method that gives a complete description of an individual's experience. Structural descriptions are used to describe how participants experience the phenomenon; meanwhile, textural descriptions are used to describe what the participant experiences with a phenomenon (Moustakas, 1994). The structural description includes descriptions surrounding how participants experienced the phenomenon such as, how they interpreted their experience and how they perceived the experience. Textural description includes descriptions surrounding what the participant’s experience was with being a social worker with a child with special needs such as what were the experience around their thoughts, feelings, and behaviors. How participants experience being a social worker with a child with special needs depends on the context and factors such as the type of special need the child has and the type of care that is required to provide for the child that has special needs. I used the textural-structural description to detail and provide the essence of the experiences from the themes that emerged throughout the analysis process. Context is important in understanding how being a social worker with children with special needs is experienced. The context of the child's special need, the type of special need, and the type of care that is required to provide for the child that has special needs influences how the social worker that has a child with special needs experiences this phenomenon.

Using imaginative variation, I imagined every possible variation I could in efforts to determine the essence of the lived experiences of these social workers with children with special needs. I looked for variations in themes based on similarities and differences within the participant’s stories. For example, all participants’ children had an identified special need, but each participant’s child had a different type of special need. Although participant’s children had different types of special needs which caused them to face challenges unique to their child’s special need, all participant’s experienced stressors and emotions that created challenges for their lives.

Discrepant Cases

I used a qualitative strategy termed discrepant/negative case analysis. This strategy is used to search for elements of data that do not support or contradicts patterns that emerge from the data (Lincoln & Guba, 1985). I used this method to ensure rigor by comparing categories to subcategories, to themes and disconfirming evidence. When the main theme emerged, I looked at composites from participant’s stories that were not similar to other stories, and when these stories did not fit with others, I compared them with stories that confirmed stories which accurately reflected the experience of the participants.

I used my journal to record my notes, ideas, patterns, and interesting bits of information brought up by the participants**.** Writing notes and recording them in my journal allowed me to think of additional data that I needed to collect from participants in telling their story. In addition to using my journal, I used prolonged engagement where I interacted with the participants to understand and interpret their stories. I used member checking to ensure the participant’s information was accurate. Once the first set of interviews were complete, I transcribed the interview notes, and I provided the participants with a composite description of the interview. The participants had the opportunity to review and provide feedback or clarification of their composites. In addition to member checking, I used a strategy known as peer reviewing/debriefing.

I used peer reviewing/debriefing to review with peers and colleagues my biases, thoughts, and perceptions of the information I received from participants. I used my peers and colleagues to discuss different thoughts I had around some of the information reported by participants. I used my peers in this method to help me separate my experiences from those experiences that participants reported. I conversed with my peers for at least 30 minutes week to week during the analysis process. For example, Kate reported struggling initially with having a child with special needs but now looks at having children with special needs from a strength-based perspective. I share in the experience with Kate of having a child with ADHD, but there are still times when the strength based perspective seems not to work. I could have easily believed that Kate was not sharing the true feelings and thoughts of her experience with having a child with that special need. I used my peers and colleagues to help me process this thought and bias.

Rich, thick description was used to show how the analysis was grounded in the data (Lincoln & Guba 1985). As mentioned, I used a journal to write notes and to understand the context of the perceptions, thoughts, culture, interpretations, and meanings around the phenomenon. The use of rich, thick description allowed me to provide the reader the opportunity to understand and interpret the concept and meaning of how and what social workers experience was like when parenting a child with special needs. I also used quotes to capture the objective of the participant.

Evidence of Trustworthiness

Credibility

Credibility according to Lincoln and Guba (1985) ensures research findings are an accurate reflection of the participant's experiences. Before I began data collection, I used a bracketing process to set aside any biases or preconceived notions that existed. Once interviews were complete, I provided participants with a summary description of their stories as a part of member checking. The member checking process allowed participants to provide feedback to their stories for accuracy. Of the eight total participants, only three of the participants provided clarification on their responses, although I gave all the participants the opportunity to provide clarification. Feedback from the participants was minimal. For example, Helen clarified the name of a book she referenced during interviews that helped her come to terms with her son having a special need. Another participant had revealed reading a similar book, and I wrote the wrong name, but Helen wanted to give credit to the author because the book helped her through difficult times. Mae for example, had to clarify her response of being in shock and not saying anything to her mother in law when the mother in law rudely and bluntly said something in reference about a photo of Mae's daughter. Mae clarified that she didn't say anything at the time when her mother-in-law made the statement that upset her, but she thought about what she would like to have said to her mother-in-law. Mae felt that her mother-in-law was not understanding and did not have realistic expectations when her daughter was younger.

Transferability

Transferability is the ability for results in the study to be in similar contexts (Lincoln & Guba, 1985). Transferability refers to the ability that findings to be applied to a similar situation or phenomenon, like social workers with children with special needs (Lincoln & Guba, 1985). The themes of coming to terms with having a child with special needs and balancing home and work life while having a child with special needs may be representative of other social work parents with special needs children who did not participate in this study. Findings in this study revealed that social work parents face difficulties and challenges as they parent their child with a special need. Participants in this study varied in age, race, and geographic location and shared similar experiences. These participants also shared similar experiences in-spite of having children with different types of special needs from other children. Findings in this study may be applied to other helping professional parents that have children with special needs. Findings in this study may or may not apply to social work parents that are fathers as there were no fathers of children with special needs who participated in the study.

I used convenience sampling and participants may in some way be different than those who did not volunteer. The two major themes, coming to terms with having a child with special needs and having to balance home and work life may be able to be applied to similar populations, such as other parents with special needs children who are highly educated, skilled, and trained professionals.

Dependability

I addressed dependability by obtaining detailed information from a group of people that shared similar experiences in this study. Additionally, I obtained dependability by interviewing participants until responses became redundant. Member checking also provided the researcher with an opportunity for participants' responses to remain consistent. In addition to member checking, I allowed a colleague to ask me questions from the interview to ensure questions were appropriate.

Confirmability

I created an audit trail, a self-reflexive journal, to support confirmability in this study. The audit trail was my research journal that served as a process that ensured the details of data analysis, interpretations of the researcher, and the decisions that led to findings of this study were transparent and consistent. I used my research journal as my audit trail, and the journal included an account of my idea, thoughts around my biases, notes from brainstorming, and the process I took to ensure my data was grounded in the analysis. All data is kept including, audio records of interviews, transcripts, and researcher notes and saved for five years and available for review if it is needed.

Findings

I present in this section, composites that provide textural/structural descriptions of each participant. I then present the specific themes that represent the essence of social workers' experiences with children with special needs. I note that I tell the participant's stories from my perspective.

Individual Composites

Mae

Mae is a 45-year-old social work parent that parents only one child. Mae is married and has incredible support from her husband. Mae has been a social worker for over 19 years and has worked in various settings to include a mental health facility, medical setting, and private sectors. Mae is currently unemployed due to her job cutting back employees. Mae, however, is looking for employment but has not placed much emphasis on it now due to spending as much time as needed with her daughter as well as taking time for herself before re-entering the workforce. Mae's daughter is 14-years-old and has diagnoses of Cerebral Palsy and ADHD. Mae's daughter was diagnosed with Cerebral Palsy at or around six months of age and ADHD in her toddler years. Mae, at the time of her daughter's diagnosis, was a social worker and she did not allow herself to think much about her child having a special need as she focused on trying to get the appropriate services in place to meet the needs of her daughter. Mae's daughter, however, does not stand or walk independently and she uses forearm crutches a lot of the time, a walker some of the time, and if they are going longer distances, she will use a manual wheelchair. Mae's daughter diagnosed in her early years is now age 14 and Mae realizes she still has some unresolved feelings as it relates to her child having special needs, "I'm just not adjusting as easy as others." For Mae, "having a child with special needs in a sense is a type of ongoing loss regardless of when the diagnosis was given or when the issue is first noticed." She resents the thought that her child will never get to do the things that others will do. "There is the thought one has about your friend's children doing or being able to do the things that your child has not done or your child's friends being able to do the things that your child has not."

She feels like she is on a journey with her child and this journey places them in a new area where she has not been before. She has not worked through her anger and at times feels that what she and her daughter have had to go through related to her daughter's special need is unfair. Mae feels that there are others that embrace the journey differently, but she has not gotten to the point of acceptance and sometimes feel emotionally stunted although she is a social worker. There are times when she feels she should be in a different place but feels it could be due to her not giving herself time to work through her issues of her child having special needs.

Mae remembers times when she was employed she would have to get dressed an hour earlier before waking her daughter up and getting her dressed. Mae would have rough starts to her morning, and when she would get to work, she would be worn, "I have been in a battle, and I'm pretty worn out." Mae also remembered times when she felt tired before starting to work because of having to address her daughter's behaviors before getting to work. She would also experience being overly tired by the end of the day on those days. Because of starting work tired and worn, Mae found it hard to be patient with clients' irritability or their frustration because of everything she had to deal with at home. She also felt it is challenging to listen to clients' problems and stressors and felt like her emotional energy was being taken up. Mae's job was stressful and demanding. When she got home she found managing her emotional energy was even more challenging because she had to address the issues at home with her daughter. She was unable to tell her child to go and do this or that and found that it was more work when she got home.

Mae felt that when she was at work, there would be times when she would have to wrap up her feelings because she would have clients to see and she would have to deal with their issues and problems. She remembers many times when she spent a lot of emotional energy working with clients and had only minimal energy left to deal with personal issues. When she attempted to allow herself to address personal issues around her thoughts and feelings about her child's diagnosis, she pushed them down, more specifically when she was at work. If she was at work, she did not want to address her inner thoughts and feelings because she did not want to look "teary-eyed" therefore she "reluctantly" allowed herself to be in the "client chair" or give space when there was time allowed to do so. So, she put herself in the category of "I'm a social worker, and I'm strong." Mae felt that part of her experience is knowing the way parenting affects you. She realizes that she may have had to deal with her personal life in different ways than others because of the nature of her child's special need and the fact that other parents may have time to process the thought of their child having issues more so than she has.

Kate

Kate is a social worker that is 41 years old. She is a wife and a mother of two boys that have identified special needs. Kate has been a social worker for over 19 years. Kate began her early years as a social worker in a child and adolescent program in an acute care behavioral hospital in the state she currently resides. Kate however currently works in education as a social worker, as well as owns a business. Kate has two boys that have special needs. Kate's oldest son has diagnoses of Autism, ADHD, and Muscular Dystrophy. Kate's youngest child has a diagnosis of ODD and ADHD. Kate faced some stressful times when her children were younger and diagnosed. Kate said:

> Times were pretty stressful for the family when the youngest entered kindergarten, and we didn't know what was going on because we did not see those behaviors there at home, but at school he was having those behaviors and so at that landmark coupled with the landmark of the oldest being diagnosed with muscular dystrophy those probably were the two times when it was really, really difficult.

When Kate learned of her oldest son's diagnoses, despite the stressful times, she did not allow the news to defeat her, bring her down, or make her feel less than a mother. Instead, she was empowered to learn and understand what she could do to ensure he has a good life. As a social worker however experiencing stressful times, Kate views having children with special needs and experiencing stress through the lens of the strength-based perspective. Kate has had some stressful times but relies on her husband and the skills she has obtained as a social worker to help work through any thoughts she has. Kate and her supportive husband have not and do not focus on the special needs of their children, "what they cannot do" but place emphasizes on "what they can do." There are times when it takes her oldest a bit longer to complete tasks because of the type of illness he has, but she expresses being patient and understanding with him. She focuses on the positives that he can do and if they need to come back to something they will pick it up on another day. "I try to use the strengths perspective and push my oldest son to do things he can, but with his cognitive ability there is only so much he can get through before he results back to doing what it is he wants to do.” Her youngest son responds to and comprehends positive re-enforcements, praises, and strengths a lot better than her oldest son, and he can see the short-term awards that she and her husband both teach him on.

When the children were born and first diagnosed, Kate and her husband immediately communicated positive thoughts to themselves as it related to their children. Kate seemingly has viewed the special needs of her children in such a way to help build them and educate others on moving forward and not allowing anything to stop them from doing what they are capable and able to do. Kate feels she has an understanding clinically on how autism, attention deficit disorder, and ODD works and so although she does not always overlook some of the things done by her children, she feels it gives her more insight than a parent who is not clinically trained. In her experience, she finds it helpful to communicate with her children and others about things that are going on, and has often found herself doing things she has advised other parents to do with their children; even in self-management so that she can care for her children and they care for theirs.

Kate’s job is demanding as she works in education as a social worker, along with running her own business. She also feels that her home is the third job. Her main employment is not a typical 8-4 job where she gets off directly at 4 PM, so some days she struggles to maintain a balance between the job and the home. There are days when she is exhausted so when she gets home the only thing she wants to do is cook or fix a sandwich, help the children take baths and get them in the bed so she can get in the bed too. For the 2-3 days of the week she finds herself overly exhausted at work, she walks in the home and turns everything over to her husband, and he knows he must take over everything with the boys for that night as she is too exhausted to do so. Kate has the support of her husband to assist her with their children along with setting routines and expectations that help her with the children. “The children are able to get their homework done at school so when they get home if they still have homework it is only one or two questions.”

Helen

Helen is a 38-year-old married social worker with one child age two that has a special need. Helen’s child has a diagnosis of bronchomalacia, which causes him to have a trach, ventilator, and a G-Tube. He also has pulmonary hypertension. Helen’s son diagnosed at birth with a special need that posed challenges with managing her thoughts and feelings surrounding her child’s special need. Helen’s son was born at 25 weeks which made him a preemie with these issues. Helen was terrified, overwhelmed, and felt helpless when her son was born due to him being so tiny and fragile also because there was so much to learn surrounding caring for her son because of his special need. Helen’s son was so tiny, and she had reservations around wanting to hold him. “You have these reservations about holding him, and you’re thinking the nurses will tell you that it’s possible that he cannot handle you holding him, but also tell you can try holding him unknowingly if he can handle it or if you can handle holding him.” Helen’s son was fragile and tiny, and she had so many reservations and she would not allow him to be left alone.

Helen was fearful and scared that something would happen to her child if she did not always have eyes on him. When she first brought him home, his care required 24-hour supervision. Because there was a requirement of having to supervise her son for 24-hours and balance the home, Helen found it challenging. Helen said,

> In the beginning, when we first brought him home my mother would come and stay for a couple of hours, and that would allow us to go to the grocery store, and that was very helpful, she did that for months, and she would come once a week and be the second person there. If I needed to go to work, I would leave my husband, and a nurse at home or my mom would come over and replace me. In addition to my going to work, if I needed to go to the store or my husband wanted to go on an outing, the nurse and the other person would be at home. We tried to make sure that were always two persons in the home with our son in the beginning.

The nurses are in the home 24 hours a day, five days a week. She and her husband are responsible for his care on the weekends. When her son was first born, there were two persons with her son 24 hours a day because they were scared to leave him by himself with just one other person in case he began choking on something. They would not leave their son for 30 minutes to go to a store or to get themselves together for the day. She felt, "someone needed to be there to administer CPR while the other person is calling 911". During this time, she and her husband both would be home with the nurse and this continued for months. There was a constant fear that something would happen to her child if only one person were left to supervise her child because of the seriousness of his special need. If the nurse called in due to having sickness in her family, she and her husband would take everything that her child needs into their room and he would sleep in their room.

Helen found it hard to manage and balance her life; she indicated that "managing and balancing life is an incredibly hard thing to do," although she is a social worker. When Helen's son was first born and for a year or two afterward, she was unable to work for about 8-9 months, and life for Helen and her husband felt abnormal, "there were so many things that were not right when you first have a baby." She felt a loss of time, specifically in the beginning as she fought for things to be normal or make them slightly more normal than what they were. She, however, tried what she thought would bring some normalcy to them and one of those things were by getting a picture with Santa Claus since it was his first Christmas. Other things she would do as he aged would be to share in times with her parents at their home, take a trip to the beach, take a trip to the zoo, buy him toys, and take him to other children's birthday parties. Helen engaged in these different things but would continue to have feelings of abnormality. It was not until she read a book named, "On the Night You Were Born" by Nicole Tillman, that changed her perspective and view on having a child with special needs. Once she read the book and connected with other support groups, she realized that "this is doable."

Her son is three now and although she feels that life has become very normal, there are still days she would say the opposite as her child still has some delays. She strives to make what she calls a normal life work for the family. She now "deals" with him having a trach and 24-hour nurses that are in the home five days a week and considers this to be a part of her norm. She now feels that she has gained more perspective that this is who her son is with extra accessories, so she and her husband try to make the best of it and enjoy. Before she could gain more of a perspective with her husband, she and her husband went to couple's therapy. She and her husband went to couple's therapy because having a child with a special need was hard for them to process despite her training as a social worker. Her son was born before their 1st anniversary, and they were newly married, but they learned how to support each other through those times.

Shan

Shan is a 37-year-old medical social worker that has worked in the social work profession for approximately 12 years. Shan's married with two children age ten and seven but only one child has an identified special need. Shan's husband is not the father of either of her children but supports her and the children in every aspect of their lives. Shan's child has sickle anemia SS. Sickle anemia SS is a specific type of Sickle Cell. Shan's daughter also has asthma. Shan's daughter in addition to being diagnosed with sickle anemia SS and asthma she had a CVA (stroke) in 2011. This type of stroke is a physical stroke discovered on a scan that doctors conducted during a hospital stay. At 18 months Shan's daughter was lethargic, gazing off, and staring off into space. "My child wasn't eating, she was throwing up, and her blood count was very, very, like off the charts, they were abnormal," and this is when she found out her daughter had sickle cell.

Shan immediately went into "adjustment mode," and it didn't take her long to adjust to the news of her daughter having sickle cell. She attributes being able to adjust to the news of her daughter's illness to be a social worker before she became a mom. She understood that there is an adjustment period that comes with persons having chronic illnesses as well as dealing with individuals in her field. She has had to adjust, but she tries very hard not to allow her daughter's illness to stress her out. There are times when she has become frustrated because of the process her daughter goes through by having this illness as well as the responsibility of taking her daughter to medical appointments. However, she strives not to allow herself to become stressed.

Shan has a great support system, but she had moments of despair especially when her daughter was small despite support from her family and her daughter's paternal family. She had support from her family and her daughter's father, but she did not have the option to take a step back from caring for her daughter. Shan said,

> Me and my daughter's father are not together, and I am the primary caretaker; Although he was a support, he had the option to say, "I'll be there shortly," or "I have to go to work," or "I can't come right now". He had those options, and it used to make me upset that I could not say to my daughter,". We are not going right now," "I can't come right now,." "I did not have those opportunities to do that. And when my daughter would get sick, and I had plans already or had something to do, I would have to put my plans on hold.

She continues to care for her daughter and implement supports and resources for herself and her daughter but still feels like things are unfair at times. "I almost felt that things were unfair that I had to center my life around her so that I would get upset with my daughter's dad, I wanted him to be able to endure the same things I had since I was her mother." Shan works as a medical social worker and knows that there are things she and her daughter will endure, but she struggles at times with the thought of having to do things by herself as well as having to see her daughter go through the things she goes through when her illness flares up. Shan said,

> When my daughter is sick late nights, I have to get up and get her out of bed while she is still sleeping but because she has fevers I have to take her and drive to the ER without knowing how long we will have to be there and so her dad is not there, so sometimes I get mad. I get upset because I'm not able to take away some of the things from her, like the pain and I wish I could take away some of the things she has to endure. Sometimes I feel depressed, not clinically depressed but it makes me feel down or helpless, and so I would get upset with the thought.

Before becoming a medical social worker, Shan worked in Child Welfare as a social worker. Shan had to quit this job to care for her daughter. Shan felt that she could not work in child welfare and take care of her daughter healthcare needs. Shan, however, is aware of the feelings she has for her family overall but has had hard times processing things when her daughter is sick. She has become more insightful, attentive, and aware of when child is entering a crisis.

Kelsey

Kelsey is a 41-year-old social worker that is married with one child age 17. Kelsey's child has an identified learning disability. Kelsey has worked as a social worker for 10 years. For three and a half years of her social work career, Kelsey worked in child welfare with the remaining six and a half years as a medical social worker. When Kelsey learned that her son had a learning disability she was not a social worker. Kelsey, however, received her degree in social work when her child was age 10. Kelsey found parenting her son as challenging and difficult before obtaining her degree in social work and actively working as a social worker.

Kelsey specifically was challenged mentally and emotionally surrounding having to deal with her son's learning disability. When Kelsey's son was in the 1st grade, he did not comprehend his academics as quickly as others his age could. Kelsey was in denial about her child not being able to comprehend his academics despite the resources she or teachers employed to assist him. In addition to being in denial, Kelsey would also get mad at her son because he could not retain the information she had just discussed with him. "I mean I would have just gone over the information with him, and he would just sit there and look at me like I do not know what you are talking about,". Because her son was unable to grasp the information, Kelsey's frustration increased because she did not understand how her son did not know the information. Kelsey was in such denial that she would not adhere to teacher's advice to get the child assessed for the learning disability. Kelsey would continue this denial for years and would place her son into different schools to prove the teachers wrong. "I am going to show them that he can do this work." When Kelsey enrolled her son into another school in which was a private school, there was a positive turn-a-round with his academics. Kelsey withdrew her son from the public-school system and enrolled him into a private school system where there were smaller classes and more time provided for one on one intervention with the teacher to complete work.

When Kelsey's son was about nine years of age in the 4th grade, he was enrolled back into the public-school system partly because the private school sector stopped their academics at the 4th-grade level. During the transition of her son from private-school back to public-school, Kelsey had obtained her degree in social work and became a social worker within child welfare for a couple of years where she worked with families who had children with multiple special needs. Kelsey felt that she had been equipped with skills to help others get through tough times and help them to mitigate or reduce their anxieties around their child's special needs. Kelsey however, still found it hard to manage her feelings and thoughts around her child's special need.

Kelsey's son retained 5th-grade after returning to public-school. Kelsey felt helpless because he had done so well in private-school. When Kelsey's son was in 5th grade at the public-school, she found herself spending late night hours helping to complete homework although they would start the homework as soon as they got home. Kelsey said,

> I could see the frustration over his face, and so my frustration would increase. I can remember just having to take him to his dad after school so that he could help him with his work because I would get so mad at my child. I also remember saying, "What is going on with me" and "How could my child not know things," when I have worked so hard for him to know things and put every resource before him? I just could not understand it.

Kelsey felt like a failure and felt completely helpless. Kelsey had placed her son's ability to not comprehend things quickly as other children on herself as if it was something she had control over. She had been able to help others in her profession get through these tough times with their children having these issues more effectively than what she was doing. After being a social worker, Kelsey felt that she was failing her son because nothing she did seem to help him. She was unable to fathom that her child of all people would have a learning disability. Kelsey would stay up at night and cry at the thought of her child not comprehending the academics as she thought he should, she would wake up in the middle of the night thinking about what could she do. She obtained a tutor for him but he was unable to retain what was learned initially until he got older. Kelsey felt shame, guilt, and embarrassed because her son was retained two grades, once in the first grade and once in the fourth grade. She believed that teachers, other professionals, and her friends thought she was not providing her son with the tools needed to succeed in his academics.

Despite Kelsey having these thoughts and feelings of being a failure, Kelsey had support from her husband, extended family, and child’s teacher. Kelsey’s family would support her in making her own decisions for her son as they felt she knew what was best for him. After a conversation with her son’s teachers along with putting herself aside, Kelsey would allow her son to complete testing to receive the resources that would help him daily. Once Kelsey allowed her son to complete an assessment through testing, he received services that assisted him. Kelsey’s son had been retained but was granted authority to participate in a program that allowed him the opportunity to skip two grades if he did well. Kelsey now felt a sense of relief but still felt a sense of shame because she was now a social worker and her son had to receive assistance to this magnitude. Kelsey said,

> I am okay with the process, but I just hate that I was so bull-headed and would not see that my child needed help. I felt that people would look and talk about me and say, look at her, she must not be teaching him at home, she is a bad parent, her child does not know anything, and in reality, he was suffering but I could not get out of my way and on top of that I was a social worker.

Eva

Eva is a 44-year old social worker with two adult children, one boy, and one girl. Eva's daughter is 20 years of age and has a diagnosis of Chaka Marie Toothe. Chaka Marie Toothe is an illness that affects her daughter her legs, feet, and arms. This illness limits her physical abilities such as walking, running, jumping, skipping, and hopping, and she cannot carry objects. Eva, when her daughter was two years old, began noticing that her daughter was taking longer to walk than expected. She noticed her daughter favored crawling over walking. She remembered thinking, "Why is this girl scooting over this floor versus walking"? She also noticed that her daughter struggled to stand for long periods and it took great effort for her to take steps, "I said something just isn't right with this." When her daughter turned three years of age, she figured there was something more going on and that further evaluation was needed. "See, with my son I did not have these issues, but I knew something was not right with her turning 3 and not wanting to walk as much". Eva got the evaluation of her daughter and realized that her daughter had an illness known as Chaka Marie Toothe. Eva went through a period of being angry, blaming, denial, and depression. Eva immediately shut others out and clung to her husband, her daughter, and her son. She blamed her husband's side of the family because they have family members with the same illness. Eva stopped going out with friends as she thought she had to always be there for her daughter. Eva began sheltering her daughter in her toddler and teenage years and continues to worry now about her life choices.

Eva was not a social worker when her child received a diagnosis, but she experienced many of the same mixed emotions as a non-social work parent. When her child turned seven, Eva obtained a Masters of Social Work and became a child welfare social worker. Eva worked as a child welfare social worker for eight years but then switched jobs to become a medical social worker in a hospital. After Eva became a social worker, her capability to manage her emotions was a lot easier at times, but there was still a level of difficulty she faced with managing her emotions and feelings surrounding understanding why her daughter had to be the one with this illness. Feelings surrounding life not being fair continued to plague Eva's mind, but she knew that "pity parties" and feeling sorry for herself was not an option. She reminded herself and her daughter that they could visit the place of "why me" and "life isn't fair," but they could not live there.

During her daughter's teenage years, her daughter went through a period of feeling left out among her friends and her family. Eva, as a mom and social worker, tried to be there for her daughter but there were times when Eva felt helpless in trying to help her daughter understand her illness and why she was born with the illness. Eva spent countless nights in tears and praying to God requesting that he help her daughter understand that she had done nothing wrong and to know sometimes life deals individuals a hand that they are not always happy. “I did not know what to tell her at times, I felt stuck in helping my child, I could not understand how I was able to help so many others but could not help my child.”

Eva struggled with thoughts of her daughter not being able to do the things that other children her age would do because they did not have a special need. Despite Eva’s difficulties, thoughts, and emotions with her daughter’s illness, she always felt the need to make herself available, a sounding board, and a safe place for her daughter to share her thoughts, fears, and needs without worrying about ridicule. Eva would also begin to include small activities for herself that allowed her time for self.

Eva had shut a lot of family out but managed to reconnect with her extended family throughout the years, when Eva's daughter received the diagnosis. She continued, however, to center her life and everything around her daughter so much until she now strongly believes that both she and her and husband focused so much on their daughter illness that they did not take time out for each other and now they are separated.

Kay

Kay is a 38-year-old married social worker with one son age 12 that has a diagnosis of ADHD. In Kay’s mind, her son was unofficially diagnosed when he began school as a Kindergarten. She met with the pediatrician and discussed the behaviors she had seen, and the pediatrician prescribed medication for ADHD, but there had not been an evaluation completed from a psychologist/psychiatrist. Kay believed her son was being a typical child that displayed having higher energy than what she had seen from other children. When Kay's son received a diagnosis with having ADHD, she had been practicing as a child welfare social worker for at least two years. Kay has almost 13 years of experience as a social worker and currently works at a hospital as a medical social worker. Kay remembers her experience with her son initially as being "crazy." Kay said,

> Teachers were calling 24/7 and saying, hey you need to get him evaluated and you need to come out to the school because he won't stop talking and he won't stop moving around; I can't control him, I put him in the seat and he pops right back up and he can't stop talking, he is talking out of turn.

These daily calls were emotionally draining for the first nine years for Kay and her husband. "How do you explain your child bouncing off the walls and beds, he had so much energy until it was ridiculous." Kay had gotten a prescription for medication from her son's doctor, but her husband did not want to put their child on medication. Kay wanted him on the medication, and the teachers wanted him on the medication because his behaviors were too much to handle. She and her husband would have heated verbal arguments to the point where if someone that did not know them, they would be scared and think they certainly would get into a physical argument. She and her husband did not get into physical fights, but there were many nights they disagreed about their child taking the medication. Kay, aggravated, eventually allowed him to take the medication because the calls from the school continued daily.

Kay felt she was stigmatized, she was frustrated, and she was overwhelmed with her son's behaviors, the school calling her daily, and her husband's denial of their son having a special need. She found it hard not to be frustrated with everything she was going through. She was employed as a child welfare social worker during the times her son's behaviors were "off the charts," and her job was very stressful.

She, however, had family that could help her through the process, but the family did not assist much because of his behaviors. She thought that family was supposed to help when needed, but that was not the case for her as they would tell her "you know how your child act." There were many times when her family would say hurtful things, but she would overtime not worry about the things that were said.

Sue

Sue is a 65-year-old married retired social worker with two adult children, one boy, and one girl. Sue has retired for over six years now, she began her career in child welfare and retired in administration as a child welfare social worker. Sue was a social worker before her son was born and much of her experience with her son having special need has been as a social work parent. Sue's son is age 38, and he has epilepsy. He was developmentally on target for a few years of his life until one day he started having seizures and has a diagnosis of seizure disorders, namely epilepsy. Shortly after turning three or four years of age his life changed in which ultimately changed Sue's life. She had to take him to Emory for testing and evaluation. He was given medication there to help with epilepsy, but something went wrong with the treatment, and suddenly he forgot how to feed himself, and he forgot that he had been potty-trained. "I didn't know what to think at this point, like what happened to my baby; he forgot what I taught him." He had to get a feeding tube, and she had to teach him how to do other things all over again. Sue said,

> Unknown to me at the time, there were somethings he would never re-learn to do on his own, and I can't tell you the type of thoughts that started going through my head. I had one child that was doing exceptionally well and one child that probably did not realize he was in the world. He, however, is not one that I would have given away. He is a loving child, and everyone loves to be around him and this most times allowed me not to think much of his illness until he had seizures. I try very hard to stay positive because I figure if I am positive I can look at him in a positive light.

Throughout his life as a child, he would have 15-20 seizures within a week despite being on medication. When he would have those seizures, there was nothing she could do but allow them to take its course. She found it difficult when trying to get his seizures under control and sometimes frustrated with trying different medications to control them. Those times were extremely painful and difficult, but those times also helped her to empathize with the clients. Sue said,

> I did not know what to do but I was willing to try anything to lessen him having those seizures, I would have let him try marijuana if they prescribed it. I felt so helpless looking at him when he would have a seizure.

When he became an adult, he began knowing life in a wheel chair. He broke his ankle a year after she retired and found himself in a wheelchair and she has been pushing him around ever since. He continues to be non-verbal and incontinent, and he wears diapers. She cares for him 24 hours every day, and although she cares for him daily, she does not allow him to keep her from doing what she is doing as she takes him everywhere she goes. She is a treasurer at the church and loves going to the church and getting with some of the women of the church. She has a routine schedule with feeding him, dressing him and putting him in the bed. Some days are better than others, but she is grateful to have family to assist her through the difficult times.

Themes

The themes in this study depicted patterns of data that provides an important description of how and what the participant's experienced. There were two themes in this study, and they were 1) coming to terms with child having a special need and 2) balancing home and work life. These two themes are the broader view of the participant's experience. After that, I discuss sub-themes such as self-care, supervision, and participants having an awareness of resources regarding their interaction with this phenomenon as a break down to state the effects of what the participant experienced and how the participants interpreted that experience. These factors are important within the study as they were influences on the experiences of the participants.

Coming to terms with having a child with special needs

Coming to terms with having a child with special needs in this study is defined as social work parents recognizing, understanding, and accepting that their child has a special need. When children were born with or were discovered to have a special need, participants in this study initially experienced different emotions. Many of the participants in this study struggled initially to admit to themselves their thoughts, feelings, and emotions they were having around having a child with a special need.

Participant's initial experiences with having a child with special needs can occur in a variety of manners. They may, for example, experience grief, loss, denial, anger, confusion, and guilt. They may also experience love, joy, and happiness. Some of the participants in this study experienced feelings of loss, anger, and confusion at the birth of their child while others experienced these feelings over time. Participants' in this study experienced challenges in managing their emotions around their child having a special need. Participants' experiences varied, but some participants' felt the need to pray and adjust their expectations. A couple of the participants expressed anger, guilt, shame, and denial although they were social workers. Mae said,

> There are times when I would have anger at my body and say things to myself like, I'm just not adjusting as easy as others. I have not worked through my anger and feel like this is unfair. I know there are others that have embraced this journey but I'm not at the point of acceptance, and I feel emotionally stunted.

Shan said,

> There were moments of despair when my child was small as I felt things were unfair as I was always the one that had to take my child to the doctor, or get up with her in the middle of the night, although her father was a support.

Kelsey said,

> I was in denial about my son's learning disability, and so I took him out of the local public school and enrolled him into a private school to prove teachers

> wrong. I was so embarrassed when my child retained one of his grades, and so I felt that others would question what I was doing with him or why I wasn't helping him with his work.

Kay said,

> Am I a bad parent? I can't get him to behave, and I can't get him to act right, and I can't get him to get to school and to focus. I can't leave him with a caregiver without him showing out, and I get back without getting a bad report about his behavior.

Social workers are trained to recognize their thoughts and feelings, but there were times when it was difficult for most of the participants to do this because the experiences were personal. All participants trained in social work on how to help others manage their emotions, thoughts, and feelings. Two of the participants, however, were not social workers when their children were identified as having a special need but became a social worker years later. Once these two participants became social workers, they received training that taught them how to help others manage and recognize their emotions, thoughts, and feelings. Participants in this study, however, would continue to struggle with managing their emotions, thoughts, and feelings despite being social workers.

Parents with children with physical needs such as Cerebral Palsy or Chaka Marie Toothe may have different stressors to those parents who have children with other special needs such as learning disability or ADHD. There are different types of special needs that children can have. Parents have stressors, but some stressors are more severe than other stressors depending on the perception of the parent. Participants in this study, however, experienced stressors at different points in their life and did not report a lack of stress because of the type of special need their child had.

Balance of Home and Work

The second theme that emerged in this study was balancing home and work life. Balancing home and work life was an important aspect for the participants. These participants understood the need to manage both their home and work life as one could impact the other. These participants have children with special needs, and they had to ensure things at home were taken care of so that it did not impact their work. Part of balancing home and work life for these participants was ensuring they were using self-care methods, ensuring adequate supervision, and being aware of resources and services to mitigate their stressors when having to address their issues surrounding their child's special need.

All participants in this study found balancing home and work life as a challenge but made every attempt to keep work at work and home at home. All participants felt they could keep their home life and work life separate but found it difficult at times when things came up with their children. When Mae worked at a mental health facility, she felt that her job was demanding and stressful as she had to see as many clients as she could within a day. The demands presented problems for her when she wanted to get off and take her child to the doctor. Mae said,

> When I was working, there were times when I had to get off to take child to medical appointments, physical therapy, and occupational therapy appointments that were scheduled on a weekly basis and this was stressful as I worked in a

> facility where I almost had a quota to meet, and this job was where I had to see as many clients as one could.

Kate is an educator and would have to leave work to go and handle the behaviors of her child whenever they came up. Kate said,

> I would have to leave work from time to time to take children to doctor's appointments. I also would have to take time off to go to my youngest child's school to address his behaviors when he had behaviors.

There are some jobs in social work that seem to require a lot of time and can be demanding, overwhelming, and prohibit them from being able to care for their child properly. Shan said,

> I worked initially, but I quit my job to care for my child because the job I had as a child welfare social worker, I found that it was very demanding. When my child would get sick, my employer expressed that work still needed to be completed. I would have to take my child to get transfusions every week and so having a child that was sickly as my child was, my employment was not conducive for the onset of my child getting sick.

Participants that found employment with agencies with environments that were not so demanding felt that their job was very supportive of them taking time off to care for their child or children. Helen said,

> My job was very supportive of me taking time off to care for my son, and when he has appointments to come up now, my employer supports me with being off and making sure he is taken care of.

Eva said,

> I have been blessed to have great supervisors that would not mind allowing me to go take my child to any appointments or taking time out to be with her when she had a crisis.

Sue said,

I could bring my child to the job when I needed to or I could take off when I needed to. My supervisors were so great and never gave me a problem when it came time to get off and take my child to the doctor.When trying to balance home and work life, assistance from family members could be instrumental. Not all participants in this study had the support and assistance from their family members, but all participants had support from their spouses. Mae, Kate, and Helen had support from one or both of their parents. Kelsey, Shan, Eva, and Sue had support from other family members to help assist in caring for their child or children with special needs. Kay only had support from her spouse. When family members were not available or did not express an interest to assist participants in this study, the participants retreated and took on the responsibility for caring for their children with most of the assistance coming from their spouse or finding others that could assist them with caring for their child or children.

Self-care. Balancing home and work for most individuals can be demanding and challenging. Social workers are trained to ensure they use self-care to ensure a healthy balance when working with individuals and populations that are vulnerable. Not all participants were trained and educated in the profession at the birth of their child, but all had some knowledge around needing to take time for self. Two of the participants were parents before obtaining their social work degree, but as they were in the process of obtaining their degree, they were learning and training to utilize tips surrounding self-care.

Self-care is a sub-theme under balancing work and home life. For these participants to manage their home and work life, all participants recognized self-care as being a necessity in caring for their child with special needs. The engagement of self-care for these participants is important as it provided them with an outlet and a break from their everyday demanding duties of caring for their children with special needs. Mae engaged in activities and scheduled practices that gave her physical activity. She participated in sports and utilized coloring to help ease her mind and reduce stress. Shan get a massage at least 2x monthly, treat herself to a pedicure, manicure, and she would go out dancing. Eva likes to hang out with her friends even if it is for one hour once a week. Kay likes to hang out with friends or get a pedicure. Sue likes to go to the church and hang out with some of the women from the church, and Kate likes to watch “ratchet television.” Many of the participants found themselves trying to engage in self-care even if it would seem small to others; it was big for them. Each participant expressed the importance of taking time out for self to reduce the stress they had.

Supervision. Supervision is the second sub-theme under balancing work and home life. When trying to balance work and home life with children with special needs, the participants found they were unable to leave children without 24-hour supervision regardless of their age. Most of the participants reported getting their children supervised due to their special need. Mae started out ensuring that her daughter was supervised 24-hours because of her special need. Her daughter has cerebral palsy and is age 14, but she wanted Mae to allow her to stay at home and not attend a daycare program due to her age. Mae battled with the thought of allowing her daughter to stay at home over an hour by herself; she eventually allowed her daughter to stay at home for thirty minutes alone once or twice with the neighbor going over to check in on her.

Supervision of their children required the participants to take precautions to ensure their child/ren are receiving the proper care. It also required them to always be watchful in efforts to identify when something is going wrong with their child. Most parents emphasized and made attempts to supervise their children themselves or by appropriate formal caregivers because of their special need. These participants expressed understanding the necessity for their children to have adequate supervision and appropriate care as they are taught this as part of their values as a social worker and not only as a parent.

Kate shared that although her child was age appropriate to stay home, his special need prevented him from being by himself. Because the child needed someone to supervise him 24 hours daily, Kate had to find her son a program that would allow him to attend an afterschool program until she or her husband got off from work. Shan described having to be watchful of her child always because being watchful meant she could prevent the child from having a crisis. She describes having to be watchful of her child when playing with others to make sure they are not sick because this could trigger a crisis for her daughter. If others are sick, they can potentially trigger her daughter's illness, and she would have to be the one in the emergency room with her.

Supervision, however, is typical and is expected for children at certain ages but for these participant's supervision is a 24 hour, seven days a week job. These participants felt their children required this level of supervision daily because of the child/ren special need. Helen described having two people with her child always because of the type of special need he has and their fear of something going wrong with just one person being there. Because her baby has a trach, there was a fear initially that if one person was left home alone how would they be able to handle him if he is in a crisis. Helen expressed not being able to breathe for him, do CPR, and call 911 all at once.

Sue describes supervising her son at every feeding. She describes him as not being able to chew food and only being able to eat things such as ice cream. Her son does not swallow well, and Sue supervises his feedings to make sure that his foods are not getting hung up and that he is not choking on things. Kay described having to keep a close watch on her child to make sure he did not hurt himself when he was younger due to his hyperactivity. Kay: "He would bounce off walls, the bed, and chairs, and I was fearful for him, so I had to make sure I kept eyes on him at all times." All participants in this study understood the need for supervision for their children. Participants began to understand that ensuring supervision of their children would be a routine they would have to manage daily.

Awareness of Resources. Awareness of resources is the fourth sub-theme under balancing work and home life. Awareness of resources means knowing that resources are needed and having the ability to reach out to others for help to obtain the services needed. Understanding what resources, the children needed, provided the difference in mitigating their struggles and stressors to deal with their children having a special need. Most of these participants felt that they knew their child would need services and resources and were very open to the idea of the child receiving services. Kelsey was in denial about her son needing services, and it was not until after she became a social worker she understood how the services would benefit her son. Most of the participants were aware of the services needed for their child and acted upon them. Sue knew her son had a diagnosis of epilepsy, but after he turned 3-4 years old, the doctors could not tell her what was going on with her son for years, so she did not know what services to implement for him. As he got older his seizures increased and different interventions and medications were given in efforts to see what would work best. Kay battled with getting services for her son because of her thinking that she was a social worker and she knew how to handle her son on her own.

Many of the participants were proactive and did not feel stigmatized when engaging in the services and were proactive in obtaining the service for their child. Mae strives to be aware of resources and thinks that most times because she is a parent with a child with special needs, is more aware in some areas as it relates to knowing where the resources are more so than the average social worker. She sought psychotherapy services for her daughter even though it was not warranted now. By being proactive, her daughter would be comfortable with the therapist by the time hard issues came up, and it would be easier for her to discuss with the therapist about those issues that have come up. Kate reached out to the school to assist her oldest son with transportation to and from his school to home. She obtained transportation for her son when initially she was told he did not meet the requirement to ride the bus to the extended day facility. She is versed in the law when it comes to children with special needs that she filed for a due process with the Department of Education and had the denial for transportation overturned. Kate also sought out counseling for her son to help him with his ODD and ADHD behaviors. She wanted her child to talk freely and express himself with a counselor about the issues that were going on in his mind.

Most of the participants also felt compelled to educate individuals around them about their child's needs on a day to day basis as this helped their children get the services they needed. Shan educated school staff, family, friends, and individuals in the community around her child's illness. She educated teachers on what to look for in her child and was instrumental in constructing an individualized education plan for her daughter around her illness. She established communication with others to help ensure the child was going to obtain the same education as others. Kay helped to educate teachers on her how to manage her child's behaviors. There was constantly calling to her with complaints about her son's behavior in the classroom. After being fed up, she used that energy to learn all that she could about ADHD. She put together pamphlets on what to do and what not to do as it related to her child in the classroom. For the most part, these participants felt that having knowledge around how to access resources and using the resources was where their role as a social worker was very beneficial because they knew how to utilize the services and resources provided to them. These participants expressed obtaining a list of resources from their resource list and collaborating with other helping professionals to obtain additional resources to assist in getting the needs met for their children.

Most of these participants expressed finding other supports to assist them in getting the needed resource for their children. Kelsey initially did not utilize the resources and services that were provided by the school because she thought her child did not need the services due to her denial and stigma of being labeled as a bad parent. She was not a social worker at the time of needing to implement the service, but she was attending school to become a social worker. Although Kelsey was in school aspiring to be a social worker she felt difficulty to move out of the way so her son could obtain services. Two years later after becoming a social worker, Kelsey understood the benefit of her son getting the service and resource needed to move forward. Kelsey had begun working as a social worker in child welfare and was instrumental in helping moms obtain services for many children that were like her child. The services and resources to help Kelsey's son were explained to her explicitly and the service would assist her son daily. Kelsey is accepting of services but still struggles with knowing her child has a special need. Participants in this study continued to struggle with their child having a special need but understood the need to access services and resources to meet the needs of their children.

Summary

The purpose of this study was to gain insight into the lived experiences of social workers who parent children with special needs. The results in this chapter represent descriptive responses from interview questions, which represent the essence of this phenomenon. Results from the study yielded that participants struggled with coming to terms and accepting their child has a special need. These participants experienced loss, anger, frustration, and even became overwhelmed as they went about their day caring for their children with special needs. Most of these participants also found it difficult to maintain a balance between work and home. Many of the participants attempted to keep things separated but had to work hard at it and implement self-care into their lives to ensure they were taking care of themselves. Social workers who parent children with special needs shared their experiences, perspectives, and beliefs around the phenomenon they experienced daily. In Chapter 5, I will interpret my research findings, and I will discuss the limitations, recommendations for future research, and implications for social change.

Chapter 5: Discussion, Conclusions, and Recommendations

In Chapter 5, I interpret the findings, limitations, recommendations for future research, and implications for social change within the context of the literature and theoretical framework. The purpose of this qualitative study was to explore the lived experiences of social workers who parent children with special needs. My goal for this study was to understand and gain insight into the lived experiences of social workers with children with special needs by conducting a qualitative research study using a phenomenological approach. I used Moustakas's (1994) phenomenological approach to seek the essence of the phenomenon.

Two major themes and three sub-themes emerged through data analysis. The two major themes were, (a) coming to terms with having a child with special needs and (b) balance of home and work life. The three subthemes related to theme two were (a) self-care, (b) supervision, and (c) having an awareness of resources.

I discuss the five systems of ecological theory, the microsystem, mesosystem, exosystem, macrosystem, and chronosystem in the interpretation of findings. I discuss microsystem and macrosystem in theme one, and I discuss microsystem, mesosystem, exosystem, and chronosystem in theme two.

Interpretation of the Findings

My intent in this study was to explore the lived experiences of social workers who have children with special needs. The findings in this study were from the experiences of the eight social workers whom I interviewed. Developed from the research question, my field notes, literature review, and the theoretical framework are key findings that grounded the study. I identified two major themes and three subthemes through phenomenological data analysis.

Theme 1: Coming to terms with having a child with special needs

Learning that a child has a special need can have a significant impact on parents (Vanegas & Abdelrahim, 2016). Much of that impact might be influenced by the microsystem and the macrosystem. According to Bronfenbrenner (1974), the microsystem in ecological theory is an experience that is influenced by the direct interaction between a parent and a child. The macrosystem of ecological theory includes information around the culture of a community in which parent lives (Bronfenbrenner, 1979b). The messaging around individuals with special needs in a community can influence how parents perceive their experience with parenting their child with special needs. These two systems of ecological theory can be used to understand a parent's experience and have an impact on the way they interact, respond, and care for their child with special needs. Parents in this study faced difficulties and challenges while interacting with their child, responding to their child, and caring for their child with special needs.

Parents generally do not expect that their children will have special needs until they are faced with a child identified as having a special need (Lee & Park, 2016; Vanegas & Abdelrahim, 2016). When parents identify that their child has a special need, challenges arise, and their expectations shift about what they envision for their children (Vanegas & Abdelrahim, 2016). Participants in this study have children with a special need, and some participants described having to shift expectations from what they initially imagined life would be for their children. One participant in this study noted how her child would not be able to play like children who did not have special needs. Mae said,

> having a child with special needs in a sense is a type of ongoing loss regardless of when the diagnosis was given or when the issue is first noticed. There is the thought one has about your friend's children doing or being able to do the things that your child has not done or your child's friends being able to do the things that your child has not.

Another participant felt that she had to fight for her child to experience normalcy, unlike children that do not have special needs. Helen said,

> When my son was first born for a year or 2 afterward, life felt abnormal; there were so many things that were not right when you first have a baby. It felt like a loss of time, specifically in the beginning as I fought for things to be normal or make them slightly more normal than what they were. I now deal with him having a trach and 24-hour nurses, 5 days a week. I have gained more perspective that this is who my son is with extra accessories, so my husband and I try to make the best of it and enjoy the time we have with our son.

Parents have expectations of their children being high achievers in both their academic and professional lives, also living independently, and having families of their own (Zechella & Ravala, 2016). Because of having these expectations, parents re-prioritized their expectations and values for their children once the child had been identified as having a special need (Zechella & Ravala, 2016). Findings in this study revealed that participants had expectations for their children. While participants did not explicitly state what their expectations and values for their children were, they expressed the struggles they faced unlike parents with children who did not have a special need. These participants reported having to shift from thinking that their child would one day become independent in making sure their child would have 24-hour supervision by an appropriate caregiver. One participant in this study discussed how her thinking shifted from when her son was an infant into his adulthood. Her son was not born with a special need, but as he grew from an infant to a toddler, he was diagnosed with a special need. As her son aged, his identified special need required more of her becoming a caregiver than teaching him to become independent. The participant maintained being a caregiver for her child into his adulthood as he was unable to become independent.

Participants shared in their stories throughout this study about their children not having the ability to participate in activities in the same manner as children without special needs. Many of the participants expressed how they felt it was unfair that their children were unlike their peers. This information aligns with research that found parents of children with special needs are unable to let go of hopes that their children might someday become like their peers (Park & Chung, 2015). Most of the participants in this study did not hold on to hope that their child would be like their peers because of their types of special need. The participants felt at times it was unfair to experience the challenges they experience, unlike parents that do not have children with special needs.

In addition to feeling that their experience was unfair, parents experienced a variety of mixed emotions. Research reveals that parents often experience a range of emotions such as confusion, loss, disbelief, anxiety, despair, remorse, and grief when learning and knowing that their child has a special need (Price & Oliverio, 2016; Smith et al., 2015). Research also reveals that parents can experience love, hope, and joy with a child who has a special need (Price & Oliverio, 2016; Smith et al., 2015). Participants in this study experienced love and joy for their child with special needs but also experienced emotions around disbelief and grief. Findings in this study revealed that participants experienced being stressed, angry, stigmatized, confused, and in denial surrounding their child having a special need. Despite being trained as a social worker, many of the participants felt something internally were wrong with them because they had a child with special needs.

Many of these participants struggled and faced challenges as they parented their child with special needs. Park and Lee (2016) stated that experience in the ecological theory’s microsystem is affected by the direct interaction between parent and child.

Within microsystem, parents can be influenced by the way they interacted with their children. A parent’s view of their child and the child’s special need influences the interaction and activities they have with their child. Factors within the microsystem that might influence this interaction between a parent and a child are the parent’s personality, attitude, and ability to be flexible, and the specific special need of the child (Galasyuk & Mitina, 2018). Participants in this study discussed their level of interaction with their as a positive relationship, despite being stressed. Participants in this study shared their views on interacting with their children and how they tried to help their children experience normal activities. Trying to implement activities that are considered normal can at times become stressful and can leave parents feeling negative. Findings in this study did not suggest that participants viewed their children in a negative manner. While the participants did not view their children negatively, some appeared to struggle more than others with the child having special needs. This additional struggle could have been due to the type of special need of the child. Additional research is needed to understand specific types of special needs a child has, to determine if parents struggle more based on the type of special need. All participants in this study had children with special needs but the children had different types of special needs, such as Cerebral Palsy, Bronchomalacia, ADHD, Autism, Sickle Cell Anemia, Chaka Marie Toothe, Learning Disorder, and Epilepsy, however, examining these differences was not the purpose of this study.

I used the macrosystem of ecological theory to look at how experience is affected by the culture and messaging of a community around children with special needs. This experience can influence a parent. The culture of a community can influence how parents perceive their experiences with having a child with a special need. There is a need for future research around understanding the culture of a community and how it influences the parent while parenting their children with special needs. In this study, there were brief discussions with participants about how they interpreted the culture of their community around person's having special needs. Participants commented briefly in their discussion that their communities were accepting of persons with special needs, but the data does not reflect that the culture of the community was a significant influence on their ability to come to terms with having a child with special needs.

The culture and message in the macrosystem of ecological theory could influence a parent's experience depending on their child's particular type of special need. The culture and message in the macrosystem might include the amount and type of resources available to families. Services and resources depending on a family's geographical location could be limited; therefore, messaging within a community around special needs are important. Messaging is important because it would determine if the parent can obtain the support needed within the community to get access to the services and resources needed for their children. Research revealed that responsibilities shift beyond family members to the broader community so that families can obtain the services needed for their child (Muir, & Strnadova, 2014).

Theme 2: Balance of Home and Work Life

The essence of this theme is having to balance home and work life. The participants in this study found balancing home and work life to be a challenge in everyday life. This aligns with research that reveals caregivers spending around 30 hours a week engaging in caregiving responsibilities for their children with special needs (DeRigne & Porterfield, 2010; National Alliance for Caregiving, 2009). Not only are parents engaging in 30 hours a week in caregiving responsibilities, but they are also doing so while maintaining employment (National Alliance for Caregiving, 2009). Morris (2014) noted that a caregiver's employment is impacted by their caregiving demands. Findings from that study revealed that parents of children age 6–17 with special needs went to work and found work to be a form of respite to alleviate high stress levels while parents of children ages 0–5 worked less because the younger children required more medical treatments, doctor's visits, and other appointments. Parents also had a higher level of concern about their child being in the care of others at a young age in which caused them to work less (Morris, 2014). Shan, a participant in this study, found that work was too demanding when her child was younger. Her daughter required extensive care, so she quit her job to meet the demands of her daughter. Mae, another participant, found that her job was very demanding and stressful when attempting to manage caregiving duties for her daughter. Helen, a third participant, took leave from work for 8 to 9 months to care for her child. Helen's son required extensive treatment, care, and supervision when he was first born. Kay, Eva, Sue, Kelsey, and Kate did not work fewer hours but found themselves having to adjust their work schedules to adequately address the needs of their children more than parents of children without special needs. Findings in this study revealed that home and work life was a challenge for participants, but they tried hard to keep work at work and home at home.

When using the microsystem of ecological theory, I looked at what directly influences the parent as they parent their child with special needs. Self-care methods can influence the parent's direct interactions with their child. Balancing home and work for most individuals can be demanding and challenging. Social workers are trained to ensure they are self-aware and use self-care to ensure a healthy balance when working with vulnerable individuals and populations. Findings in this study revealed how participants over time engaged in self-care techniques in efforts to decrease their stress level with caring for their child with special needs. Participants expressed engaging in small activities of self-care when the opportunity presented itself to combat the stress they experienced. The participants in this study felt that small methods of self-care they engaged in worked for them.

The mesosystem of ecological theory encompasses the interaction of two microsystems (Bronfenbrenner, 1974). Within the mesosystem, the two microsystems that are linked that can influence the parent's experience are family and providers, specifically services and resources. Family members and services from providers can influence the parent's experience.

Findings in this study revealed participants having primary support from their husbands and minimal support from their extended family members. Hall and Graff (2011) noted that parents should not expect all their support to come from their spouse or partner although it is helpful if most of the support came from the spouse or partner. Discussion with most participants in this study revealed that extended family at times were unable to relate to them as a parent and understand the challenges they face.

Whitmore and Snethen (2018) noted that many family members state they are too scared to assist in caring for the child with a special need. Some participants in this study discussed their family members being scared to assist in caring for the child due to the level of care the child needed while other participants in this study had family members who either assisted with the care of the children or had family members who did not live in the area to assist.

Parents experience challenges and difficulty around meeting and ensuring their children’s overall needs. Many of the participants felt part of this need was to ensure appropriate supervision of their children due to their special need. Studies revealed that parents with children with special needs spend more time supervising their children than parents whose children do not have special needs (Axelsson & Wilder, 2014; Luijkx et al., 2017). Research shows that parents spend on average 2.1 to 2.8 hours more per day supervising their children with special needs than those parents of children who do not have a special need (Axelsson & Wilder, 2014; Luijkx et al., 2017). Findings in this study revealed that participants felt they had to provide 24-hour supervision for their children. Participants in this study found that ensuring supervision was challenging at times and difficult to manage when trying to find the balance of work and home but adjusted to ensuring supervision was appropriate.

When parents learn that their child has a special need, they often seek services or resources to assist them with their child. Participants in this study acknowledged their ability to obtain services due to their profession. Findings in this study revealed that participants used their knowledge and training from their profession of social work to access services to mitigate their stress levels. There are some studies that found some parents having an issue with obtaining resources and services for their children (Muir & Strnadová, 2014; Tetreault et al., 2014). These studies discovered that locating resources was difficult for most families to obtain due to a lack of transportation and a lack of providers to perform the services (Muir & Strnadová, 2014; Tetreault et al., 2014). Zapella (2016) conducted a study that had different results and noted that parents accessed services and found the services beneficial to meet the needs of their children. Parents may have found services beneficial and easy to access due to their geographical location and community in which they live. If parents live in rural areas versus a suburban area, parents may find that the services are limited and access to the services are limited. Future research could consider parent's accessibility to services and resources for their children with a special need while living in a rural or suburban area. Findings in this study revealed that participants accessed services and resources. Three participants in this study lived in urban areas where they could easily access services. The other participants lived in rural areas, and either went outside of their rural area or researched and located the local services in their rural area. Participants in this study utilized their knowledge as a social worker and personal resources to obtain services from providers that their children needed.

The exosystem of ecological theory pertains to the linkages that may exist between two or more settings that may affect the parent but may not affect their child (Bronfrenbrenner, 1974). A parent's ability to take respite services can influence their parental experience. Respite services may or may not have an impact on the parent's child but can have an influence on parents' experiences. The availability and quality of respite care services can influence parents' experience even though they are not directly involved. Studies show that parents engaging in respite allows parents to sleep and regenerate their reserves so that they experience some sense of normalcy (Dyches et al., 2016; Nankervis et al., 2011). Studies show that parents struggle at times with seeking respite for their children because they do not know if they can trust the individual to take on the task of caring for and meeting the needs of their children (Ling et al., 2015; Whitmore & Snethen, 2018; Virdun et al., 2015).

Discussion with participants in this study revealed they did not utilize respite services often. Most participants in this study felt the need to supervise their children because of the level of care the child needed. Many participants in this study also perceived the need to care for their children on their own because family was either not around or did not show interest to assist. Participants did not want to place a burden of care for their children upon anyone, and they faced uncertainties around knowing if the level of care from someone else would be the same level of care they provide to their children. Kvarme et al. (2016) revealed that parents of children with special needs spent less time away from their caregiving duties compared to parents of children without special needs. Findings in this study revealed that one participant expressed the possibility of seeking respite services but was unsure if the individual chosen could meet the needs of her child.

The chronosystem of ecological theory looks at an individual's development overtime within their environment (Bronfenbrenner, 1995b). The development of children can influence a parent’s perception and experience of and with their children overtime. Helen knew immediately that her child would have a special need whereas Mae, Kate, Shan, Kelsey, Eva, Kay, and Sue knew their children identified with having special needs during their toddler years. That development trajectory changed their experience and expectations. Having a medically fragile baby is a different experience developmentally than having a child diagnosed later in life. Abu-Ras (2018) notes that children who have identified special needs such as psychological, physical, and intellectual may go undiagnosed for years. Studies note that parents’ experiences could be at risk for emotional and psychological distress and face difficulties dealing with life daily (Al-Qaisy, 2012; Khamis, 2007; Mendenhall & Mount, 2011; Woodgate et al., 2012). As the children aged, their needs changed.

Looking at the child’s development and growth can help parents understand that their child may require some additional care, time, resource, and services. Children that are not growing physically, emotionally, and socially may require that the parent take on more responsibilities of caregiving duties to and for the child more than it would for children that are developing along the typical continuum. Participants in this study had children with special needs and the children’s level of care required parents to take on more caregiving duties for their child. Participants in this study realized that their children were not meeting milestones and were not developing like children without special needs and felt that they would have to take on primary care for their children for many years.

Limitations of Study

Several limitations have been identified. First, the scope of this study was limited to eight social work participants who have children with special needs. The social workers who volunteered for this study may be different from other social workers who may have experiences with having children with special needs and did not participate. It is likely that the social work parents that chose to participate in this study were ready to open up and talk about their experience. Secondly, social media was the primary source used to recruit participants. Social media sites can reach a vast number of people, but there could have been social workers with children with special needs that do not have social media accounts. These social workers potentially were not targeted and could have provided insight into their experiences of having children with special needs. Thirdly, participants completed three interviews. However, the two follow-up interviews asked for clarification of the 1st interview versus engaging in more conversation around the phenomena of study in all three interviews. Prolonged engagement could have been enhanced by engaging in more discussion with participants in addition to asking participants to clarify previous responses in the additional interviews. Lastly, this study only interviewed women that were social workers with children with special needs. Themes produced may or may not transfer to men because of gender role expectations and gender socialization.

Recommendations/Future Research

One recommendation for future research is to look at parents differing level of accessibility to services and resources for their children with a special need while living in a rural or suburban area. Some participants in this study that lived in urban areas had resources that were readily accessible and available to help them meet the needs of their children, while participants that lived in rural areas mostly had to travel outside of their area for services. Secondly, further research should consider looking at the culture of a community and how it influences the parent while parenting their children with special needs. Several participants in this study lived in communities where the culture was sensitive in offering services and resources that would allow parents to meet the needs of their children. Other participants that did not live in communities where services were scarce used their knowledge on how to obtain services to meet the needs of their children. Thirdly, future research should consider the emotional and mental health of social work parents that have children with special needs while actively working in the social work field. Participants in this study found that they had challenges dealing with their emotions, feelings, and thoughts as they parented their children. While participants were facing these challenges, many of the participants continued to work with families to help them address the issues they faced with their families. Fourthly, only mothers that were social workers participated in this study, but future research could show a father’s perception and interpretation around his experience with having children with special needs. The fifth consideration for future research is to look at the different experiences of parents related to the specific special need. The sixth consideration for future research is to look at other professions to understand what the influence on experience would be to see if these themes are transferrable to other groups. Lastly, prolonged engagement was a limitation. Future research may use longitudinal data to see how the experience changes over time.

Implications

Participants in this study shared their experiences around their challenges and difficulties with having children with special needs. An implication from the findings may be the need to educate extended family members about the level of support needed for parents as they experience challenges and difficulties related to parenting a child with special needs. This may improve clarity and help family members understand why serving as reliable resources may include emotional support and respite services to allow the parents an opportunity to rejuvenate.

Findings in this study produced knowledge around how participants experienced with having a child with special needs. This education knowledge can be used to inform administrators, specialists, counselors, and the profession of social work on ways to create strategies and interventions to aid workers in addressing their feelings, thoughts, and emotions around parenting their children with special needs. This knowledge can inform the social work profession about the importance of building a supportive system that assists social workers in parenting children with special needs emotionally, physically, mentally, and financially.

Conclusion

The purpose of this qualitative research study was to gain insight into the lives of social workers with children with special needs. Phenomenology was the best approach to allow these social work parents an opportunity to express their stories and for me to gain insight into their lived experiences. Findings from this study revealed social work parents struggles, challenges, and difficulties around their perception and interpretation of their children having a special need. Coming to terms and balancing home and work life with a child that has special needs can be challenging. This study may help parents to look at their environment and understand what influences them. I anticipate that the social work profession may benefit from this research and the findings could be used to inform others on how to become more effective in building supports, services, and resources for families with children with special needs.

References

Abu-Ras, W., Saleh, M., & Birani, A. (2018). Challenges and determination: The case of palestinian parents of children with disabilities. *Journal of Family Issues*, *39*(10) 2757–2780.

Algood, C. L., Harris, C., & Hong, J. S. (2013). Parenting success and challenges for families of children with disabilities: An ecological systems analysis. *Journal of Human Behavior in the Social Environment*, *23*(2), 126-136. doi: 10.1080/10911359.2012.747408.

Algood, C. L., Hong, J. S., Gourdine, R. M., & Williams, A. B. (2011). Maltreatment of children with developmental disabilities: An ecological systems analysis. *Children and Youth Services Review*, *33*, 1142–1148.

Allen-Meares, P., Hudgins, C., Engberg, M. and Lessnau, B. (2005). Using a collaborator model to translate social work research into practice and policy. *Research on Social Work Practice*, *15*(1), 29-40.

Al-Natour, M., Amr, M., Al-Zboon, E., & AlKhamrah, H. (2015). Examining collaboration and constrains on collaboration between special and general teachers in mainstream schools in Jordan. *International Journal of Special Education*, *30*(1), 1-14.

Al-Qaisy, L. (2012). Mothers' stress in families of children with mental handicap. *Asian Social Science*, *8*(2), 80-85. doi:10.5539/ass.v8n2p80

American Psychological Association. (2017). *Parenting*. Retrieved from: https://www.apa.org/topics/parenting

Amr, M., Al-Natour, M., Al-Abdallat, B. & Alkhamra, H. (2016). Primary school teachers' knowledge, attitudes, and views on barriers to inclusion in Jordan. *Journal of Special Education, 31*(1), 67-77.

Antopooulou, P., Killian, M., & Forrester, D. (2017). Levels of stress and anxiety in child and family social work: Workers' perceptions of organizational structure, professional support and workplace opportunities in Children's Services in the UK. *Child Youth and Services Review, 76*, 42-50. doi:org/10.1016/j.childyouth.2017.02.028

Asen, E., Dawson, N., & McHugh, B. (2001). *Multiple family therapy: The Marlborough Model and its wider application*, London, UK: H. Karnac (Books).

Avramidis, E. (2010). Social relationships of pupils with special educational needs in the mainstream primary class: Peer group membership and peer-assessed social behaviour. *European Journals of Special Needs Education*, *25*(4), 413-429, doi:10.1080/08856257.2010.5135550.

Avramidis, E. (2013). Self-concept, social position and social participation of pupils with SEN in mainstream primary schools. *Research Papers in Education, 28*(4), 421-442. doi: 10.1080/02671522.2012.673006

Avramidis, E., & Norwich, B., (2002). Teachers' attitudes towards integration/inclusion: A review of the literature. *European Journal of Special Needs Education*, *17*, 129-147.

Axelsson, A. K. & Wilder, J. (2014). Frequency of occurrence and child presence in family activities: A quantitative, comparative study of children with profound intellectual and multiple disabilities and children with typical development. *International Journal of Developmental Disabilities, 36,* 13–25.

Bachman, S. S. & Comeau, M. (2010). A call to action for social work: Minimizing financial hardship for families of children with special health care needs. *Health & Social Work, 35*(3), 233-238.

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behavior problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*(4/5), 217–230.

Barlow, J.H., Powell, L.A., Gilchrist, M. & Fotiadou, M. (2008). The effectiveness of the training and support program for parents of children with disabilities: A randomized controlled trial. *Journal of Psychosomatic Research, 64*, 55–62.

Baydik, B. & Bakkaloglu, H. (2009). Variables that predict the sociometric status of the students with and without special needs at lower socioeconomic level. *Theory and Practice in Egitim Bilimleri*, *92*(2), 401-447.

Booth, A., C. Carroll, I. Ilott, L. L. Low, and K. Cooper. (2013). Desperately seeking dissonance: Identifying the disconfirming case in qualitative evidence synthesis. *Qualitative Health Research 23,* 126–41.

Brandon, P. (2007). Time away from “smelling the roses: Where do mothers raising children with disabilities find the time to work? *Social Science & Medicine*, *65,* 667–679. doi:10.1016/j.socscimed.2007.04.007

Breitkreuz, R., Wunderli, L., Savage, A., & McConnell, D. (2014). Rethinking resilience in families of children with disabilities: A socioecological approach. *Community, Work, and Family, 17*(3), 1–20.

Brehaut, J.C., Kohen, D.E., Raina, P., Walter, S.D., Russell, D.J., Swinton, M. (2004). The health of primary caregivers of children with cerebral palsy: How does it compare with that of other Canadian caregivers? *Pediatrics, 114,* 182–191.

Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities*, *24*, 33–49.

Broomhead, K. E. (2013). 'You cannot learn this from a book': Pre-service teachers developing empathy towards parents of children with special educational needs (SEN) via parent stories. *European Journal of Special Needs Education, 28*(2), 173-186. doi:10.1080/08856257.2013.778109

Bronfenbrenner, U. (1970). *Two worlds of childhood: US and USSR*. New York, NY: Russell Sage Foundation.

Bronfenbrenner, U. (1974). Developmental research, public policy, and the ecology of childhood. *Child Development, 45*(1), 1–5.

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32*, 513–531.

Bronfenbrenner, U. (1979). *Ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.

Bronfenbrenner, U. (1994). Ecological models of human development. In T. Husen & T.

N. Postlethwaite (Eds.), *International encyclopedia of education, 2*(3), 1643–1647. Oxford, England. Elsevier Sciences.

Buck, A. A., & Neff, L. A. (2012). Stress spillover in early marriage: The role of self-regulatory depletion. *Journal of Family Psychology, 26*, 698–708.

Burton, P. & Phipps, S. (2009) Economic costs of caring for children with disabilities in Canada. *Canadian Public Policy, 35*(3), 269–290.

Cankaya, O. & Korkmaz, I. (2012). Grading of primary school teachers 'classroom teachers' gifted education. *Ahi Evran University Journal Kirsehir Education Faculty Journal*, *13*(1), 1-16.

Centers for Disease Control and Prevention. (2013). *Developmental disabilities*. Retrieved from http://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html

Ceylan, R., & Aral, N. (2016). The opinions of classroom teachers and normally developing children on inclusive practice. *International Online Journal of Educational Sciences, 8*(2), *12-22.* doi:*//dx.doi.org/10.15345/iojes.2016.02.002*

Coffey, M., Dugdill, L., & Tattersall, A. (2004). Stress in social services: Mental well-being, constraints and job satisfaction. *British Journal of Social Work, 34*, 735-746.

Cole, L., Crettenden, A., Roberts, R., & Wright, A. (2016). The experience of sole mothers balancing paid work with care for a child with a disability. *Australian\ Journal of Social Issues, 51*(3), 317-339.

Creswell, J. W., Shope, R., Plano Clark, V. L., & Green, D. O. (2006). How interpretive qualitative research extends mixed methods research. *Research in the Schools, 13*, 1–11.

Creswell, J. W. (2013). Qualitative inquiry & research design: Choosing among five Approaches (3rd ed.). Thousand Oaks, CA: Sage Publications.

Creswell, J. W., and D. L. Miller. (2000). Determining validity in qualitative inquiry. *Theory into Practice 39*, 124–30.

Crettenden, A., Wright, A. & Skinner, N. (2014). 'Mothers caring for children and young people with developmental disability: intent to work, patterns of participation in paid employment and the experience of workplace flexibility'. *Community, Work & Family, 17*(3), 244–267, doi:10.1080/13668803.2014.923816.

Crnic, K., & Low, C. (2002). Everyday stresses and parenting. In M. H. Bornstein (ed.), *Handbook of parenting, vol. 5: Practical issues in parenting* (2nd ed., pp. 243–267). Mahwah, NJ: Lawrence Erlbaum Associates.

Cronin, S. & Becher, E.H. (2015). What is stress? How do parents experience it? *Parenting stress: Understanding experiences, contexts and responses*. University of Minnesota.

Cuskelly, M., Pulman, L., & Hayes, A. (1998). Parenting and employment decisions of parents with a preschool child with a disability. *Journal of Intellectual & Developmental Disability, 23,* 319–332. doi:10.1080/13668259800033801

Cummins, R. (2001). The subjective well-being of people caring for a family member with a severe disability at home: A review. *Journal of Intellectual & Developmental Disability, 26,* 83–100. doi:10.1080/13668250020032787

Dapudong, R. (2013). Knowledge and attitudes towards inclusive education of children with learning disabilities: The case of Thai primary schools teachers. *Academic Research International, 4*(4), 496-512.

De Boer, A.A., Pijl, S.J., & Minnaert, A. (2011). Regular primary schoolteachers' attitudes towards inclusive education: A review of the literature. *International Journal of Inclusive Education, 15*(3), 331-353.

Demir, M.K., & Acar, S. (2011). Experienced classroom teachers' views on introductory. *Kastamonu Education Faculty Journal, 19*(3)*, 719-732.*

Denzin, N. & Lincoln, Y. (2005). Introduction: The discipline and practice of qualitative research. In Norman Denzin & Yvonna Lincoln (Eds.), *The SAGE handbook of qualitative research* (pp.1-32). Thousand Oaks, CA: Sage Publications.

Denzin, N. K. & Lincoln, Y. S. (2015). *The sage handbook of qualitative research*. Thousand Oaks, CA: Sage Publications.

DeRigne, L., & Porterfield, S. (2010). Employment change and the role of the medical home for married and single-mother families with children with special health care needs. *Social Science & Medicine, 70*, 631-641.

DeRigne, L. & Porterfield, S. (2017). Employment change among married parents of children with special health care needs. *Journal of Family Issues, 38*(5), 579–606.

Diaconescu, M. (2015). Burnout, secondary trauma and compassion fatigue in social work. *Revista de Asistenţ\ Social*, anul XIV, nr. *3*, 5763.

Dollard, M., Winefield, A., & Winefield, H. (2003). *Occupational stress in the service* *professions*. London: Taylor and Francis.

Donalek, J. G. (2004). Demystifying nursing research: Phenomenology as a qualitative research method. *Urologic Nursing, 24*, 516–517.

Dowling, M. and Dolan, L. (2001). Families and children with disabilities: Inequalities and the social model. *Disability and Society*, *16*(1), 21-35

Dupre', M. (2012). Disability culture in social work. *Social Work Education*, *31*(2), 168–183.

Dyches, T. T., Christiensen, R., Harper, J.M., Mandleco, B., & Roper, S. O. (2016). Respite care for single mothers of children with Autism Spectrum Disorders. *Journal of Autism Development Disorders, 46*, 812-824. doi:org/10.001007s10803-015-2618-z.

Edwards, B., Higgins, D., Gray, M., Zmijewski, N., & Kingston, M. (2008). *The nature and impact of caring for family members with a disability in Australia* (Research Report No. 16). Melbourne: Australian Institute of Family Studies.

Edwards, J. R., & Rothbard, N. P. (2000). Mechanisms linking work and family: Clarifying the relationship between work and family constructs. *Academy of Management Review, 25,* 178–199.

Earle, A. & Heymann, J. (2012). The cost of caregiving: wage loss among caregivers of elderly and disabled adults and children with special needs. *Community, Work & Family, 15(*3), 357-375

Fenning, P., & Rose, J. (2007). Overrepresentation of African American students in exclusionary discipline: The role of school policy. *Urban Education, 42*(6), 536-

559.

Feizi A, Najmi B, Salesi A, Chorami M, & Hoveidafar R. (2014). Parenting stress among mothers of children with different physical, mental, and psychological problems. *Journal of Research Medical Sciences, 19,* 145-52.

Finzi-Dottan, R. & Kormosh, M. B. (2016). Social workers in Israel: Compassion, fatigue, and spillover into married life. *Journal of Social Service Research*, *42*(5), 703-717, doi: 10.1080/01488376.2016.1147515

Frederickson, N. L., & Furnham, A. F. (2004). Peer-assessed behavioral characteristics and sociometric rejection: Differences between pupils who moderate learning difficulties and their mainstream peers. *British Journal of Educational Psychology, 74,* 391-410.

Fong, R. & Furuto, S. (2001). *Culturally competent practice: Skills, interventions and evaluations*. Allyn & Bacon, Needham Heights, MA.

Ford, M. T., Heinen, B. A., & Langkamer, K. L. (2007). Work and family satisfaction and conflict: A meta-analysis of crossdomain relations. *Journal of Applied Psychology, 92*, 57–80.

Forde, H., Lane, H., McCloskey, D., McManus, V. & Tierney, E. (2004). Link family support – an evaluation of an in-home support service. *Journal of Psychiatric and Mental Health Nursing, 11*, 698–704.

Freudenberger, H. (1974). Staff bumout. *Journal of Issues, 30*(1), 159-165. Doi**:** 10.1111/j.1540-4560.1974.tb00706.x

Freudenberger, H. J. & Richelson, G. (1980). *Bum-out: The high cost of high* *achievement.* Garden City, NY: Doubleday

Earle, A. & Heymann, J. (2012). The cost of caregiving: Wage loss among caregivers of elderly and disabled adults and children with special needs. *Community, Work & Family, 15*(3), 357-375.

Eisner, E.W. (1991). *The enlightened eye: Qualitative inquiry and the enhancement of Educational practice*, New York, NY: Macmillan.

Galasyuk I.N. & Mitina O.V. (2018). Parental attitude in families with a special child. *Psychological Science and Education*, *23*(4), 102-111. doi:10.17759/ pse.2018230410.

Gallagher, S., & Whiteley, J. (2012). The association between stress and physical health problems in parents caring for children with intellectual disabilities is moderated by children's challenging behaviors. *Journal of Health Psychology, 18*(9), 1220-1231. doi:org/10.1177/1359105312464672.

Gallagher, S. & Hannigan, A. (2014). Depression and chronic conditions in parents of children with and without developmental disabilities: The growing up in Ireland cohort study. *Research in Developmental Disabilities, 35*, 448-454. doi:10.1016/j.ridd.2013.11.029.

Gauvin, M. & Perez, S. (2007). The socialization of cognition. J.E. Grusec & P.D. Hastings (Eds.), *Handbook of Socialization: Theory and Research*. 588-613. The Guilford Press, New York, NY, USA.

Gibbs, G. R. (2008). *Analysing qualitative data*. Los Angeles, CA. Sage Publications.

Giorgi, A. (1985). Sketch of a psychological phenomenological method.

Phenomenology and psychological research, 8–22.

Gordon, M., Rosenman, L., & Cuskelly, M. (2007). Constrained labour: Maternal employment when children have disabilities. *Journal of Applied Research in Intellectual Disabilities, 20*, 236–246. doi:10.1111/j.1468-3148.2006.00325.x

Gottlieb, J., & Semmel, M. (1980). Among mainstreamed mentally retarded children. *Journal of Developmental Psychology, 9*, 396-404.

Gouin, J.P., de Estrela, C., Desmarais, K., & Barber, E. T., (2016). The impact of formal and informal support on health in the context of caregiving stress. *Family Relations, 65*, 191-206.

Grady, M. D., & Cantor, M. (2012). Strengthening the professional selves of social workers through the lens of self-psychology. *Smith College Studies in Social Work, 82,* 401–417.

Grandey, A. A., & Cropanzano, R. (1999). The conservation of resources model applied \ to work–family conflict and strain. *Journal of Vocational Behavior, 54,* 350–370.

Green, S.E. (2007). ‘We’re tired, not sad’: Benefits and burdens of mothering a child with a disability. *Social Science and Medicine, 64*(1), 150-163.

Greene, R.R. & Kropf, N. P (2014). Caregiving and care sharing: A life course Perspective. *Journal of Gerontological Social Work, 58*(7), 703-705.

Gresham, F. M. (1982). Misguided mainstreaming: The case for social skills training with handicapped children. *Exceptional Children, 48(5),* 422-430.

Grutter, J., Meyer, B., & Glenz, A. (2015). Social exclusion in integration classes: a matter of opinion? Psychology in Education, *62*(1), 65.

doi:10.2378/peu2015.art05d

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The handbook of qualitative research* (pp. 105–117). Thousand Oaks, CA: Sage.

Güleryüz, Ş. O. (2009). *In relation to peers of disabled students continuing integration education Assessment of the problems they meet*. Unpublished master's thesis, Selcuk University, Konya.

Gupta, A., & Singhal, N. (2004). Positive perceptions in parents of children with disabilities. *Asia Pacific Disability Rehabilitation Journal*, *15*(1), 22–35.

Ha, J.-H., Hong, J., Seltzer, M. M., & Greenberg, J. S. (2008). Age and gender differences in the well-being of midlife and aging parents with children with mental health or developmental problems: Report of a national study. *Journal of Health and Social Behavior*, *49*, 301–316.

Hall, H. R., & Graff, J. C. (2010). Parenting challenges in families of children with autism: A pilot study. *Issues in Comprehensive Pediatric Nursing*, *33*(4), 187–204.

Hall, H. R., & Graff, J. C. (2011). The relationships among adaptive behaviors of children with autism, family support, parenting stress, and coping. *Issues in Comprehensive Pediatric Nursing*, *34*, 4–25. doi:10.3109/01460862.2011.555270.

Harney, P. A. (2007). Resilience processes in context: Contributions and implications of Bronfenbrenner’s person-process-context model. *Journal of Aggression,* *Maltreatment, and Trauma, 14*(3), 73–87.

Harris, H. (2008). Meeting the needs of disabled children and their families: some messages from the literature. *Child Care in Practice, 14*(4), 355–369.

Hartley, S. L., Papp, L. M., Blumenstock, S.M., Floyd, F., & Goetz, G. L. (2016). The effect of daily challenges in children with autism on parents' couple problem-solving interactions. *Journal of Family Psychology, 30*(6), 732–742.

Hasting, P., Utendale, W. & Sullivan, C. (2007) The socialization of professional development. In: Handbook of Socialization: Theory and Practice, 638-664. The Guilford Press, New York, NY, USA.

Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., & Krauss, M. W. (2001). The development of children with disabilities and the adaptation of their parents: Theoretical perspective and empirical evidence. *Monographs of the Society for Research in Child Development, 66*, 6–21.

Head, E. (2009). The ethics and implications of paying participants in qualitative Research. *International Journal of Social Research Methodology, 12(*4), 335–344.

Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behavior and emotional problems in toddlers with pervasive developmental disorders and developmental delays: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research, 50*(12), 874–882.

Hess, A. (2002). Secondary trauma: How working with trauma survivors affects therapists. *Clinical Social Work Journal, 30*, 293–309.

Hess, R. S., Molina, A. M., & Kozleski, E. B. (2006). Until somebody hears me: Parent voice and advocacy in special educational decision making. *British Journal of Special Education, 33,* 148–157.

Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, *9*, 125–137.

Hiranandani, V. (2005). ‘Towards a critical theory of disability in social work’. *Critical Social Work*, *6*(1), 1-21.

Holden, G. W. (2010). Childrearing and developmental trajectories: Positive pathways, off-ramps, and dynamic processes. *Child Development Perspectives, 4*(3), 197–204.

Home, A., Carter, I., Scarth, S. & Warren, R. (2015). Working together in special needs parenting: An innovative research dissemination project. *Social Work & Social Sciences Review, 17*(3), 6-19. doi: 10.1921/12503170302.

Ho, K. M., & Keiley, M. K. (2003). Dealing with denial: A systems approach for family professionals working with parents of individuals with multiple disabilities. *The Family Journal: Counseling and Therapy for Couples and Families, 11*(3), 239–247.

Hornby, G. (1992). A review of father’s accounts of their experiences of parenting children with disabilities. *Disability, Handicap, & Society*, *7*(4), 363-374.

Howe, D. (2004). Relating theory to practice. In M. Davies (Ed.), *The Blackwell companion to social work* (2nd ed., pp. 82-87). Oxford, England: Blackwell.

Humphrey, K. (2006, July 31). *How do social workers help the families of children with* *disabilities?* Retrieved from: http://www.helpstartshere.org/health-and-wellness/disabilities/how-do-social-workers-help-the-families-of-children-with-disabilities.html

Hwang, Y.S & Kearney, P. (2014). Mindful and mutual care for individuals with developmental disabilities: A systematic literature review. *Journal of Child Family Study, 23*(3), 497–509; doi:10.1007/s10826-012-9707-9

IFSW. (2014). A global definition of social work. *Chance, 6,* 96-100.

Issurdatt, S. & Whitaker, T. (2013). Keeping parents in the driver's seat. *Journal of Human Behavior in the Social Environment*, *23,* 118–125.

Janesick, V.J. (2011). *Stretching exercises for qualitative researchers*. Thousand Oaks, CA. Sage Publications.

Jinnah, H. A., & Stoneman, Z. (2008). Parents' experiences in seeking child care for school age children with disabilities – Where does the system break down? *Children and Youth Services Review*, *30,* 967–977. doi:10.1016/j.childyouth.2007.11.020

Kabasakal, Z., Girli, A., Okun, B., Çelik, N., & Vardarlı, G. (2008). Mainstreaming students, peer relations, and peer abuse. *Dokuz Eylül University Journal of Buca Education Faculty, 23,* 169-176.

Kalliath, P., Hughes, M., Newcombe, P. (2012). When work and family are in conflict: Impact on psychological strain experienced by social workers in Australia. *Australian Social Work*, *65*(3), 355-371. doi: 10.1080/0312407X.2011.625035

Kalliath, P. & Kalliath, T. (2013). Work-family conflict and its impact on job satisfaction of social workers. *British Journal of Social Work, 45***,** 241-259. doi:10.1093/bjsw/bctl25

Kalliath, P. & Kalliath, T. (2014). Work-family conflict: Coping strategies adopted by social workers. *Journal of Social Work Practice, 28*(1), 111–126. doi.org/10.1080/02650533.2013.828278

Kalliath, P., Kalliath, T., & Chan, C. (2015). Work–family conflict and family–work conflict as predictors of psychological strain: Does social support matter? *British Journal of Social Work, 45*, 2387–2405. doi:10.1093/bjsw/bcu079

Kargın, T., Acarlar, F., & Sucuoğlu, B. (2003). Integration of teachers, administrators and parents determination of opinions on their applications. *Special Education Journal, 4*(2), 55-76.

Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of Advanced Nursing, 34*(5), 582–592.

Kersh, J., Hedvat, T. T., Hauser-Cram, P., & Warfield, M. E. (2006). The contribution of marital quality to the well-being of parents of children with developmental disabilities. *Journal of Intellectual Disability Research*, *50*, 883–893.

Khamis, V. (2007). Psychological distress among parents of children with mental retardation in the United Arab Emirates. *Social Science & Medicine, 64,* 850-857.

Klein, M. D., Cook, R. E., & Richardson Gibbs, A. M. (2001). *Strategies for including children with special needs in early childhood settings* Albany, NY: Delmar-Thompson Learning Inc.

Koster, M., Pijl, S. J., Nakken, H., & Houten, E. V. (2010). Social participation of students with special needs in regular primary education in the Netherlands. *International Journal of Disability, Development and Education, 57(1),* 59-75. doi:10.1080/10349120903537905

Krull, J., Wilburt, J., Henneman, T. (2014). The social and emotional situation of first graders with classroom behavior problems and classroom learning difficulties in inclusive classes. *Learning Disabilities: A Contemporary Journal,* (*12)*2, 169-190.

Kvale, S. (1983). The qualitative research interview: A phenomenological and a hermeneutical mode of understanding. *Journal of Phenomenological Psychology, 14*(2), 171.

Kvarme, L.G., Albertini-Fruh, E., Grekke, I., Gardsjord, R., Halvorsrude, L., & Linden, H. (2016). On duty, all the time: Health and quality of life among immigrant parents caring for a child with complex health needs. *Journal at Clinical Nursing, 25*, 362—371. doi:org/101111//jocn.13056

Lambert, S. J. (1990). Processes linking work and family: A critical review and research agenda. *Human Relations, 43*, 239–257.

Lambert, E., Pasupuleti, S., Cluse-Tolar, T., Jennings, M. & Baker, D. (2006). 'The impact of work-family conflict on social work and human service worker job satisfaction and organizational commitment: an exploratory study'. *Administration in Social Work, 30*(3), 55–74.

Lee, G. K. (2009). Parents of children with high functioning autism: How well do they cope and adjust? *Journal of Developmental and Physical Disabilities*, *21*, 93–114.

Lee, Y. & Park, H. (2016). Becoming a parent of a child with special needs: Perspectives from Korean mothers living in the United States International *Journal of Disability, Development and Education*, *63*(6), 593–607. doi.org/10.1080/1034912X.2016.1154139

Leiter, V., & Krauss, M.W. (2004). Claims, barriers, and satisfaction: Parents' requests for additional special education services. *Journal of Disability*, *15*(3), 135-146.

Leiter, V., Krauss, M. W., Anderson, B., & Wells, N. (2004). The consequences of caring: Effects of mothering a child with special needs. *Journal of Family Issues*, *25*, 379–403.

Levine, K. A. (2009). Against all odds: Resilience in single mothers of children with disabilities. *Social Work in Health Care*, *48*, 402–419.

Lightfoot, E., & LaLiberte, T. (2006). Approaches to child protection case management for cases involving people with disabilities. *Child Abuse & Neglect*, *30*(4), 381–391.

Lim, H.B., & Chia, K.H. (2017). From teachers and family to community: What supports is available for our children with special needs. *European Journal of Special Education Research*, *2*(4). doi:10.5281/zenodo.569049

Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic Inquiry*. Beverley Hills, CA. Sage Publications.

Lindo, E., Kliemann, K. R., Combes, B.H., & Frank, J. (2016). Managing stress levels of parents of children with developmental disabilities: A meta-analytic review of interventions. *Family Relations, 65,* 207–224. doi:10.1111/fare.12185

Ling, J., Payne, S., & McCarron, M. (2015). Parental decision making on utilization of out-of-home respite in children's palliative care: Findings of qualitative case study research a proposed new model. *Child: Care, Health, and Development, 42*, 51-59. doi:org/10/1111/cch.12300

Lonergan, B. A., O'Halloran, M. S., & Crane, S. C. (2004). The development of the trauma therapist: A qualitative study of the child therapist's perspectives and experiences. *Brief Treatment and Crisis Intervention, 4,* 353-366.

Luijkx, J., van der Putten, A. A., & Vlaskamp, C., (2017). Time use of parents raising children with severe or profound intellectual and multiple disabilities. *Child: Care, health and development*, *43*(4), 518–526. doi:10.1111/cch.12446

Ma, J. L. C., Wong, M. M. C., Wan, E. S. W. & Wong, T. Y. (2013). Experiencing multiple family groups in a Chinese context: The clients' perception of it's helpful and unhelpful impact. *Journal of Social Work Practice, 27*(1), 47-62. dx.doi.org/10.1080/02650533.2012.706217

Ma., J. L. C., Wong, M. M. C., Wan, E. S. W. & Wong, T. Y. (2011). *An alternative way of helping Chinese parents with parenting difficulties: Learning from the participants' feedback on the multiple family groups in Hong Kong, social work with groups, 34*(2), 158-174. doi:10.1080/01609513.2010.543345

Marc, C. & Osvat, C. (2013). Stress and burnout among social workers. *Revista de Asistenţ Social*, 121-130.

Marshall, M.N. (1996) Sampling for qualitative research. *Family Practice*, *13*, 522-525.

doi.org/10.1093/fampra/13.6.522

Mason, C. A., Goldman, S. E. (2017). Facilitated individualized education planning: The state of implementation and evaluation. *Journal of Disability Policy Studies, 27*(4), 212–222. doi:10.1177/1044207316660828

Mauro, T. (2016, May 27). *What is special needs?* Retrieved from: http://www.verywell.com/what-are-special-needs-3106002

Marshall, M.N. (1996). Sampling for qualitative research. *Family Practice, 13*(6), 522-526. doi.org/10.1093/fampra/13.6.522

Mawdsley, H. P., & Hauser-Cram, P. (2012). Mothers of young children with disabilities: Perceived benefits and worries about preschool. *Early Child Development and Care*, *183*, 1258–1275. doi:10.1080/03004430.2012.719896

McNulty, M. A. (2003). Dyslexia and the life course. *Journal of Learning Disabilities*, *36*, 363–381.

Mendenhall, A., & Mount, K. (2011). Parents of children with mental illness: Exploring the caregiver experience and caregiver-focused interventions. *Families in Society: The Journal of Contemporary Social Services*, *92*, 183-190. doi:10.1606/1044-3894.4097

Miles, M.B., Huberman, A.M., Saldaña, J. (2014). *Qualitative data analysis: A methods sourcebook*. Thousand Oaks, CA: SAGE Publications.

Minjarez, M. B., Mercier, E. M., Williams, S. E., Hardan, A.Y. (2013). Impact of pivotal response training group therapy on stress and empowerment in parents of children with autism. *Journal of Positive Behavior Interventions, 15,* 71–78.

doi:10.1177/1098300712449055

Minou Michilin, P. & Juarez-Marazzo, S. (2001). ‘Ableism’. Social work practice with individuals with physical disabilities. G.A. Appleby, E. Colon, & J. Hamilton (Eds.), Diversity, Oppression and Social Functioning: Person-in-Environment Assessment and Social Functioning and Intervention. 179-194. Needham Heights, MA: Allyn & Bacon.

Morris, L. A. (2014). The impact of work on the mental health of parents of children with disabilities. *Family Relations: Interdisciplinary Journal of Applied Family Studies, 63*, 101–121. doi:10.1111/fare.12050

Moseley, A. & Tierney, S. (2005). Evidence-based practice in the real world. *Evidence and Policy, 1*(1), 113-12.

Mount, N. & Dillon, G. (2014). Parents’ experiences of living with an adolescent diagnosed with an autism spectrum disorder. *Educational & Child Psychology*, *31*(4), 72-81.

Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage Publications.

Muir, K. & Strnadová, I. (2014). Whose responsibility? Resilience in families of children with developmental disabilities, *Disability & Society*, *29*(6), 922-937. doi:10.1080/09687599.2014.886555.

Murphy, N.A., Christian, B., Caplin, D.A. & Young, P.C. (2006). The health of caregivers for children with disabilities: Caregiver perspectives. *Child*, *33*(2), 180–187.

Murray, S. (2007). Families care of their children with severe disabilities in Australia. *Community, Work, & Family, 10,* 215–230. doi:10.1080/13668800701270141

Nankervis, K., Rosewarne, A., & Vassors, M. (2011). Why do families relinquish care? An investigation of the factors that lead to relinquishment into out-of-home respite care. *Journal of Intellectual Disability Research*, 55, 422-233. doi:org/10/11111/j.1365-2788.201101389.x

National Alliance for Caregiving. (2009). A focused look at caregivers of children with special needs. Retrieved from http://www.caregiving.org/pdf/research/Report_Caregivers_of_Children_11-12-09.pdf.

National Association of Social Workers. (2017). Code of ethics of the National Association of Social Workers. Washington, DC: National Association of Social Workers.

Naveed, S., Naveed, S.R. (2013). Job burnout process and its implications in HRM practices: A case study of trainee doctors in public health organization. *Asian Journal of Business Management*, *5*(1), 113-123. Retrieved from http://www.maxwellsci.com/print/ajbm/v5-113-123.pdf

Neeley-Barnes, S., & Marcenko, M. (2004). Predicting impact of childhood disability on families: Results from the 1995. *National Health Interview Survey Disability supplement: Mental Retardation, 42,* 284–293.

Neff, L. A., & Karney, B. R. (2007). Stress crossover in newlywed marriage: A longitudinal and dyadic perspective. *Journal of Marriage and Family, 69,* 594–

607.

Nelson-Gardell, D., & Harris, D. (2003). Childhood abuse history, Secondary traumatic stress, and child welfare workers. *Child Welfare*, *82*, 5–26.

O'Connell, T., O'Halloran, M., & Doody, O. (2013). Raising a child with disability and dealing with life events: A mother's journey. *Journal of Intellectual Disabilities, 17*(4), 376–386.

Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children With intellectual disability. *Journal of Intellectual Disability Research*, *45*, 535–543.

Oşvat, C. (2013). The social protection of children with disabilities and their families: A case study of the Bihor County. *Revista de Asisten]\ Social*, *1*, 23-31.

Palkovitz, R., Marks, L.D., Appleby, D.W. & Holmes, E. K. (2003). Parenting adult development: Contexts, processes, and products of intergenerational relationships. L. Kuczynski (Ed)., *Handbook of dynamics in parent-child relations,* 307-323. Thousands, CA: Sage Publications.

Papp, E. & Racz, A. (2016). How professionals in the social system and child protection perceive their profession. *cta Universitatis Sapientiae - Social Analysis, 6*(1), 71-91.

Pardeck, John T. (2015). "An ecological approach for social work practice. *The Journal of Sociology & Social Welfare, 15*(2), 133-141.

Park, H. J., & Chung, G. H. (2015). A multifaceted model of changes and adaptation among Korean mothers of children with disabilities. *Journal of Child and Family*

Studies, 24, 915–929.

Park, H. J. & Lee, Y. (2016). Becoming a parent of a child with special needs: Perspectives from Korean mothers living in the United States. I*nternational Journal of Disability, Development and Education*, 6*3*(6), 593–607, doi.org/10.1080/1034912X.2016.1154139

Parish, S.L. (2006). Juggling and struggling: A preliminary work– life study of mothers With adolescents who have developmental disabilities. *Mental Retardation, 44*(6), 393–404.

Parish, S.L. & Cloud, J.M. (2006). Financial well-being of young children with disabilities and their families *Social Work, 51*(3), 223–232.

Patchner, L.S., (2005). Social work practice and people with disabilities: Our future selves. *Advances in social work*, *6*(1), 109-120.

Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd *ed*.). Thousand Oaks, CA: Sage Publications.

Peterson, E. R., Schmidt, J., Reese, E., Lee, A. C., Carr, P. A., Grant, C. C., & Morton, S.M.B (2014). “I expect my baby to grow up and be a responsible & caring citizen” What are expectant, parents’, hopes, dreams, and expectations for their unborn child? *Australian Institute of Family Studies, 94*, 35-44.

Pijl, S. J., & Frostrad, P. (2010). Peer acceptance and self- concept of students with disabilities in regular education. *European Journal of Special Needs Education*, *25*(1), 93-105. doi:10.1080/08856250903450947

Price, M. & Oliverio, P. (2016). The cost of raising a special needs child after divorce.

American Journal of Family Law, *30*(1), 25-31.

Ponterotto, J.G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology*, *5*(2), 126-136. doi:10.1037/0022-0167.52.2.126.

Rayner, M., & Moore, P. S. (2007). Stress and ameliorating factors among families with a seriously ill or disabled child. *E-Journal of Applied Psychology*, *3*(1), 86–93.

Repetti, R. L., Taylor, S. E. & Seeman, T. E. (2002). Risky families: family social environments and the mental and physical health of offspring. *Psychological Bulletin*, *128*, 330–366.

Romano, E., Tremblay, R., Boulerice, B. & Swisher, R. (2005). Multilevel correlates of childhood physical aggression and prosocial behaviour. *Journal of Abnormal Child Psychiatry*, *33*, 565–578.

Rose, K. K., Barahona, D., & Muro, J. (2017). Peer perceptions of students receiving pull-out services in elementary school: A multi-age study. *International Journal of Inclusive Education*, *21(*4), 376-388. doi: 10.1080/13603116.2016.1197323

Rosenberg, S., Zhang, D., & Robinson, C. (2008). Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics*, *121*, e1503–e1509.

Rosenzweig, J. M., Brennan, E. M., Huffstutter, K., & Bradley, J. R. (2008). Child care and employed parents of children with emotional or behavioral disorders. *Journal of Emotional and Behavioral Disorders*, *16*(2), 78–89. doi:10.1177/1063426607312538

Rosenzweig, J.M., Brennan, E.M., & Ogilvie, A.M. (2002). Work-family fit: Voices of parents of children with emotional and behavioral disorders. *Social Work, 47*(4), 415-424.

Rosen-Reynoso, M., Porchel, M., Kwan, N., Bethel, C., Thomas, V., Robertson, J., Hawes, E., Foley, S., Palfrey, J., (2016). Disparities in access to easy-to-use services for children with special health care needs. *Maternal Child Health.* doi: 10.1007/s10995-015-1890-z

Rudestam, K.E. & Newton, R.R. (2015). *Surviving your dissertation: A comprehensive guide to content and process* (4th ed). Thousand Oaks, CA: Sage Publications.

Russell, F. (2003). The expectations of parents of disabled children. *British Journal of Special Education, 30(3),* 144–149. doi:10.1111/1467-8527.00300

Sadioğlu, Ö., Bilgin, A., Batu, S., & Oksal, A. (2013). Classroom teachers' problems with integration, anticipations, and recommendations. *Theory and Practice in Educational Sciences, 13*(3), 1743-1756.

Salston, M., & Figley, C. R. (2003). Secondary traumatic stress effects of working with survivors of criminal victimization. *Journal of Traumatic Stress, 16*, 167–174.

Saraç, T., & Çolak, A. (2012). In the process of mainstreaming primary education teachers Opinions and recommendations on the problems they face. *Mersin University Education Faculty Journal, 8*(1), 13-28.

Schuiringa, H., Van Nieuwenhuijzen, M., Orobio de Castro, B., Matthys, W. (2015). Parenting and the parent–child relationship in families of children with mild to borderline intellectual disabilities and externalizing behavior. *Research in*

Developmental Disabilities. doi.org/10.1016/j.ridd.2014.08.018

Scott, E. K. (2010). “I feel as if I am the one who is disabled”: The emotional impact of changed employment trajectories of mothers caring for children with disabilities. *Gender & Society, 24*, 672–696. doi:10.1177/0891243210382531

Seligman, M. & Darling, R. B. (2009). *Ordinary families, special children: A systems approach to childhood disability* (3rd ed). New York, NY: The Guilford Press.

Shannon, P., & Agorastou, M. (2006). Identifying children with developmental disabilities receiving child protection services: A national survey of child welfare administrators. *Families in Society, 87*(3), 351–357.

Shannon, P., & Tappan, C. (2011a). Identification and assessment of children with developmental disabilities in child welfare, *Social Work, 56*(4), 297–305.

Shannon, P., & Tappan, C. (2011b). A qualitative analysis of child protective services practice with children with developmental disabilities. *Children and Youth Services Review, 33*(9), 1469–1475.

Shearn, J., & Todd, S. (2000). Maternal employment and family responsibilities: The perspectives of mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 13*, 109–131. doi:10.1046/j.1468-3148.2000.00021.x

Sherman, A., Trisi, D., & Parrott, S. (2013). *Various supports for low-income families reduce poeverty and have long-term positive effects on families and children*. Retrieved from: https://www.cbpp.org/sites/default/files/atoms/files/7-30-13pov.pdf

Sices, L. (2007). *Developmental screening in primary care: The effectiveness of current practice and recommendations for improvement*. Washington, DC: The Commonwealth Fund.

Smith, J., Flowers, P., & Larkin, M. (2015). *Qualitative psychology: A practical guide to research methods.* Los Angeles, CA: SAGE Publications.

Stevanovic, P., & Rupert, P. A. (2009). Work-family spillover and life satisfaction among professional psychology. *Professional Psychology: Research and Practice, 40*(1), 62–68.

Stoesen, L. (2005). Children with disabilities: A family affair-working with families is a 'Dance of Partnership'. *National Association of Social Workers, 50*(3), 1-4.

Story, L. B., & Repetti, R. (2006). Daily occupational stressors and marital behavior. *Journal of Family Psychology, 20*, 690–700.

Streubert, H. J., & Carpenter, D. R. (2002). *Qualitative research in nursing: Advancing the humanistic imperative* (3rd ed.). Philadelphia, PA: Lippincott Williams & Wilkins.

Stuckey, H. (2015). The second step in data analysis: Coding qualitative research data. *Journal of Social Health and Diabetes, 3*(1), 7-10.

Sumer, H. C., & Knight, P. A. (2001). How do people with different attachment styles balance work and family? A personality perspective on work–family linkage. *Journal of Applied Psychology, 86*, 653–663.

Tétreault, S., Blais-Michaud, S., Marier Deschênes, P., Beaupré, P., Gascon, H., Boucher, N., & Carrière, M. (2014). How to support families of children with disabilities?

An exploratory study of social support services. *Child & Family Social Work, 19*(3), 272-281. doi: 10.1111/j.1365-2206.2012.00898.x.

Thompson, G. & McFerran, K.S., (2015). “We’ve got a special connection”: qualitative analysis of descriptions of change in the parent–child relationship by mothers of young children with autism spectrum disorder. *Nordic Journal of Music Therapy*, *24*(1), 3–26. doi:org/10.1080/08098131.2013.858762

Thyer, B. A. & Pignotti, M. (2010). Science and pseudoscience in developmental disabilities: Guidelines for social workers. *Journal of Social Work in Disability & Rehabilitation*, *9*, 110–129.

Tong, H.C., Haig, A.J., Nelson, V.S., Yamakawa, K.S., Kandala, G. & Shin, K.Y. (2003). ‘*Low back pain in adult female caregivers of children with physical disabilities’, Archives of Pediatric & Adolescent Medicine*, *157*, 1128–1133.

Ungar, M. (2011). The social ecology of resilience: Addressing contextual and cultural ambiguity of a nascent construct. *American Journal of Orthopsychiatry*, *81*(1), 1–17.

Unwin, P, F., Joy M. Rooney, J, M., Osborne, N. & Cole, C. (2017). Are perceptions of disability changed by involving service users and carers in qualifying health and social work training? *Disability & So*ciety, *32*(9), 1387-1399, doi:10.1080/09687599.2017.1322498

Vanegas, S. B. & Abdelrahim, R. (2016). Characterizing the systems of support for families of children with disabilities: A review of the literature. *Journal of Family Social Work*, *19*(4), 286–327. doi.org/10.1080/10522158.2016.1218399

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany, NY: Albany State University of New York Press.

Varcoe, L. & Boyle, C. (2014). Pre-service primary teachers' attitudes towards inclusive education, *Educational Psychology*, *34*(3), 323-337. doi:10.1080/01443410.2013.785061

Virdun, C., Brown, N., Phillips, J., Luckett, T., Agar, M., Green, A., & Davidson, P.M. (2015). Elements of optimal pediatric palliative care for children with young people: An integrative review using a systematic approach. *Collegion*, *22*, 421-431.

Vural, M., & Yıkmış, A. (2008). The mainstreaming of classroom teachers' adaptation of teaching Determination of studies. *Abant İzzet Baysal Journal of Education*, *8*(2), 141-159.

Walker, A., Alfonso, M.L., Colquitt, G., Weeks, K., & Telfair, J. (2016). ‘‘When everything changes:’’ Parent perspectives on the challenges of accessing care for a child with a disability. *Disability and Health Journal*, *9*(1), 157-161. doi.org/10.1016/j.dhjo.2015.06.002

Wang, M., Mannan, H., Poston, D., Turnbull, A. P., & Summers, J. A. (2004). Parents' perceptions of advocacy activities and their impact on family quality of life. *Research and Practice for Persons with Severe Disabilities, 29*, 144–155.

Westman, M., & Etzion, D. (2005). The crossover of work-family conflict from one spouse to another. *Journal of Applied Social Psychology, 35*, 1936–1957.

Whitmore, K. E., & Snethen, J. (2018). Respite care services for children with special healthcare needs: Parental perceptions. *Journal of Special Pediatric Nursing, 23*. doi:org/10.1111/jspn.12217

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research, 18*, 1075–1083.

Woodgate, R. L., Edwards, M., & Ripat, J. (2012). How families of children with complex care needs participate in everyday life. *Social Science & Medicine*, *75,* 1912-1920. doi:10.1016/j.socscimed.2012.07.037

Woodgate, R. L., Edwards, M., Ripat, J.D., Borton, B. & Rempe, G. (2015). Intense parenting: A qualitative study detailing the experiences of parenting children with complex care needs. *Biomedical Pediatrics, 15,* 1-15. doi:10.1186/s12887-015-0514-5

Zapella, E. (2016). Being a parent of a child with a disability in Italy: From diagnosis to starting school. *Scandinavian Journal of Disability Research*, *18*(3), 200–209. doi.org/10.1080/15017419.2015.1063543

Zavirsek, D. (2009). Social work with adults with disabilities: An international perspective. *British Journal of Social Work*, *39*(7), 1393–1405.

Zavirsek, D. (2014). Time for recognition: People with disabilities today. *Social Dialogue*, *9(*3), 4-5.

Zechella, A.N. & Raval, V.V. (2016). Parenting children with intellectual and developmental disabilities in Asian Indian families in the United States. *Journal of Child Family Studies*, *25*, 1295–1309. doi:10.1007/s10826-015-0285-5.

Appendix A: INTERVIEW PROTOCOL

Demographics:
Gender
Age
# of years as a social worker
# of years working with children with special needs
# of children you parent with special needs
Type of special needs the child has

1. Describe your experiences as a parent with a child with special needs?
    a. What is your interaction like with your child with special needs?
    b. How has the school system impacted your experience parenting your child with special needs?
    c. How have other family members influenced your experience parenting a child with special needs?
    d. Describe for me the culture/role of the community surrounding supporting you as a parent with children with special needs?
2. Describe your experiences as a social worker?
    a. How has your training as a social worker influenced your parenting of a child with special needs?
    b. What has your experiences been like being a professional social worker navigating service systems in the parental role?
    c. How do you maintain a work-home life balance as a social worker and a parent with children with special needs?
3. Is there anything else I need to know from you in order to understand your experience?