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**SHAPING OF MATERNAL IDENTITY THROUGH PARENTING
EXPERIENCES OF A CHILD WITH A DISABILITY**

by

Katlyn Lauren Martinez

A Thesis

Submitted to the
Department of Educational Services and Leadership
College of Education

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at

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Thesis Chair: Carmelo Callueng, Ph.D.

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Abstract

Katlyn Lauren Martinez

SHAPING OF MATERNAL IDENTITY THROUGH PARENTING EXPERIENCES OF A CHILD WITH A DISABILITY

2016-2017

Carmelo Callueng, Ph.D.

Master of Arts in School Psychology

The focus of the present study explored how maternal identity is influenced by parenting experiences of a child with a disability. By gaining insight on mother's experiences of raising a child with a disability, a deeper understanding of the psychological impact can be achieved. This research sought to understand how a mother's challenges, adjustments, and feelings in caring for a child with a disability have contributed to her self-concept. In-depth interview was employed to gather information on mother's view of self as well as how others view the mother in relation to parenting a child with disability. Qualitative analysis of data was used to extract themes that describe self-identity of mothers. Mother's reported both positive and negative experiences that impacted their self-perceptions and other's perception. A paradox exists between mothers' experiences of negative changes in self-esteem and personal growth in being the primary caregiver of their child with a disability. In contrast to the negative emotions mothers reported a greater sense of awareness and realization of strengths. In relation to other's perception of mother's identity, participants reported the inability to connect with others and difficulty maintain social and romantic relationships, but discussed the ability to form meaningful relationship with mothers who share similar challenges which served as a system of support.

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Chapter 1

The Problem

The anticipation of the birth of a child is an exciting time for an expecting mother. For many mothers, it is more than just a desire to be a parent- it is a fantasy that holds meaning for their identity, who they are as a person (Hauser, 2015). Mothers imagine what their babies will be like, who they will become, and idealize them to be perfect. Upon the realization that the mother's child has a disability, she no longer sees the endless potential of her perfect child, but instead she sees limitations and disability accompanied by pain, anger, and guilt (Berger & Foster, 1986; Mori, 1983). The unexpected diagnosis of a disability in a child can be marked as a significant stressful experience in a mother's life, it now challenges the expectations and future plans a mother had created for her child and her own life (Lichter, 2003). As the child develops and problems occur at every stage of development, overtime a cumulative burden presents itself in caring for a child with a disability (Lichter, 2003). Mothers make big changes in their lives and shift their priorities to accommodate their child's needs, which may have a psychological effect on them.

Mothers of children with disabilities report feeling a loss of identity, in giving up their careers and goals they lost a sense of who they were in trying to deal with the responsibilities of caring for their child's needs (Helitzer, Cunningham-Sabo, VanLeit, & Crowe, 2002). As they adapt to their child's neediness for care, cyclical feelings of uncertainty, guilt, and helplessness are endured by mothers. There is often a lack of support from relationships resulting in a sense of isolation and loneliness amongst mothers, who often feel that others are intolerant of the child's disability (Helitzer, Cunningham-Sabo, VanLeit, & Crowe, 2002). Although several quantitative studies

have documented that exhaustion and stress is common amongst parents who have children with disabilities, little attention has been directed at the impact of caring for a child with a disability can have on a mother's identity (Lichter, 2003). The loss of identity in mothers caring for a child with a disability is a relationship that needs to be further explored in order to understand its impact on identity and obtain knowledge on how to further provide support to mothers.

Purpose of the Study

The focus of the present study is to explore how maternal identity is influenced by parenting experiences of a child with a disability. This study will offer a comfortable space for mothers to freely express feelings and experiences endured throughout her role as a caregiver. By gaining insight on mother's experiences of raising a child with a disability, a deeper understanding of the psychological impact can be achieved. Qualitative investigation can expand knowledge on how raising a child with a disability can affect a mother's self-esteem and sense of self. Questions that will be explored include:

1. How do mothers perceive themselves in relation to parenting a child with disability?
2. How do others perceive mothers in relation to parenting a child with disability?

Significance of the Study

The importance of exploring parenting experiences from a maternal point of view is to understand the impact it has on her self-concept. The diagnosis of a child with a disability can be considered a traumatic event in a mother's life and this experience stresses the importance of understanding the psychological effect it can have on the

mother as the primary caregiver. Finding meaning in these experiences can aid psychologists in understanding the developmental effects of caring for children with disabilities. Each mother's narrative will give an insight into what she views as the most challenging parts of her role that have shaped her identity. This research seeks to understand how a mother's challenges, adjustments, and feelings in caring for a child with a disability have contributed to her self-concept. The in-depth interviews as the primary data gathering method in the study can provide the mothers an interactional setting that is characterized by candor, sense of support by the researcher. Mothers will also be able to elevate awareness and reflection of their unique parenting experiences.

Limitations

This qualitative study will involve four mothers who will share their parenting experiences of a child with disability through in-depth interview. The researcher recognizes that narratives of four mothers may not encompass views and experiences of all mothers of children with disabilities. Responses of mothers through in-depth interview are a vital part of this research; however, mothers' may have difficulty being vulnerable in an interview setting and may impact the results of this study. Moreover, mothers may fear judgment in their vulnerability. The conceptual definition of maternal identity for this study only refers to self and others' perceptions as they relate to parenting experiences of a child with a disability. Maternal identity consists of numerous factors but not all factors are explored in this present study. Maternal identity is not a static concept, it can be easily influenced and can vary from day to day. As such, this may be reflected in results of this study.

Assumptions

This study operates under the assumptions that mothers in this study are invested in the care and outcomes of their child's development. It is assumed that mothers are disclosing their experiences of parenting a child with a disability in an honest and sincere way. As this is a qualitative study, open-ended responses cannot be confirmed or tested and thus, it is claimed that responses provided by mothers during the interview are truthful disclosure of their full parenting experiences of a child with a disability.

Definition of Terms

Disability. A child with a disability can refer to a number of conditions which can include mental retardation, a hearing, speech, or language impairment, emotional disturbance, autism, traumatic brain injury, learning disabilities, or other health conditions that require the need of special education services (IDEA, 2004, U.S. Department of Education Services). In this study this term is used to represent any child who has one or combination of conditions listed above.

Maternal identity. The attachment to motherhood that is developed based on the interaction and bond between a child and others (Saffee, 1999). In this study this term refers to the way a mother views herself as well as how others view the mother in relation to parenting experiences of a child with a disability.

Sense of self. The way a person views oneself, which includes their qualities, attributes and ways of being that are characteristic to who they are (Markus, 1980). Sense of self in this study is used to represent a mother's perception of herself and the realization of themselves from having a child with a disability.

Overview of Study

Chapter 2 provides a review of relevant literature of themes related to the concept of maternal identity and mother's perceptions of raising a child with a disability. Chapter 3 describes the methodology and procedures used in this study in terms of setting and participants, the procedure of the study, interview guide used for this study, and strategies for data analysis. Chapter 4 provides a general analysis of themes constructed from interview responses and contains descriptive profiles of each of the three mothers. Finally, Chapter 5 provides a discussion of themes, implications, and recommendations for future research.

Chapter 2

Review of Literature

This chapter will discuss themes that are related to the concept of maternal identity. The concept of maternal identity will be explored through existing literature. Existing literature describes maternal identity as more than just a desire to have a child; it holds a more significant value to their life and identity. This chapter will present a comparison of mother's perceptions of their role as a mother and father's partial identification with their role. Current literature reported that maternal gatekeeping may be the reason mother's have taken on more of the burden of caregiving, preventing their partners from engaging in parenting practices that hold more responsibility; this is discussed further in this chapter. Several qualitative studies reported that mother's with children with disabilities experienced a significant amount of stress in their daily lives. The demands and inflexibility of their schedules in meeting the needs of their child, led them to make career and relationship changes that led to a loss of identity. This theme will be examined in this chapter. A synthesis of literature will conclude this chapter.

Maternal Identity

Orlee Hauser's (2015) research *The Cost of Maternal Identity* suggests many women often have a sense of maternal identity long before they give birth to their children. Women experience more than just a strong desire to become a mother, it is a longing that is tied to who they are as person, it holds meaning for their character as a whole. Mothers often describe their role as a mother as more than just duties of caregiving but holds weight in constructing their personal identity. Hauser conducted interviews with mothers and fathers asking questions regarding their parenting

experiences (2015). Several mothers described their role as mothers as being their whole identity in comparison to father respondents who look at their fathering role as a piece of their identity. Father respondents linked their identity to their occupations or as a breadwinner in the family. This partial identification as a father even held true for male participants who their primary role was caregiving for their children. For most fathers, they appeared to be less emotional about their role. Hauser (2015) also reported that a mother explained her role of being a mother as “her whole life and that she did not feel that before her child was born that she had been really living....” Hauser’s (2015) research emphasized a similar concept of this current study that maternal identity is valuable and can impact the shaping of a woman’s identity as a whole. The role of parenting to mothers encompasses their whole identity in comparison to fathers who only partially identify, mothers felt that their identities were enhanced as result of being a mother and provided them with more fulfillment psychologically than a paycheck from their jobs. Fathers did not share a romanticized vision of taking on a paternal role that represents who they are after or before the birth of their child, they feel more represented by their occupation. Mothers form an attachment with their children that is stronger than just maternal, it is a sense of power to mothers to hold all the responsibility of caregiving. This power was expressed as both a burden, in wishing fathers would take on more responsibility with the children, but at the same time a welcomed burden. One mother described it as “I love being a mom so I don’t mind doing it all” and another said “... I feel like I’ve taken on more responsibility than he has, because I feel I don’t know, I guess its just the mother thing to take care of the child and entertain. I feel like I do all of that myself.” This research emphasized how strongly mothers begin to develop a

maternal identity long before the conception of their child, the role of being a mother is a symbol for their whole character, stressing to further explore the possible impact of parenting a child with a disability can have on their identity.

Parenting Practices

Hauser's research (2015) found maternal gatekeeping to be at the root of mothers taking on the majority of responsibility with their children. Mothers in the study felt that their natural ability made them the better parent, leading them to take on a bigger role in parenting their child. This concept of gatekeeping is may lead fathers to be more involved in activities like playing with their children rather than more nurturing and caretaking activities because women take the lead. Women expressed the desire for their partner to take on more of the parenting labor, however maternal gatekeeping has kept fathers in this role of attaining to the less structured aspects of a child's development, like play. This questions if fathers would be nurturing if mothers allowed them this freedom?

In this current study mother's identity is being explored to identify if having a child with a disability can shape a mother's sense of self and have an influence on her development of identity. Helitzer, Cunningham-Sabo, VanLeit, and Crowe (2002) reported the demands of taking care of a child with a disability; the role of parenting a child with a disability has caused mothers to spend more time on activities in the home and less time focusing on themselves and socializing with other adults. Helitzer, Cunningham-Sabo, VanLeit, and Crowe's research study found that mothers of children with disabilities are not only taking on the role of nurturer, but professionals also expect them to take on the role of therapist and teacher. Mothers of exceptional children displayed a tendency to complain more often about mental and physical pain in

comparison to mothers of typically developing children. This study also found that mothers lacked the proper support to help them cope throughout the development of their child's life.

Stress

Parents of children with disabilities experience significantly higher levels of stress in comparison to those of typically developing children (Lichter, 2003). Several factors are associated to these increased levels. In addition to dealing with the overwhelming stress of the initial diagnosis and adjustment, families experience increased financial strain and the demand of providing additional care to meet the needs of their child (Crnic, Friedrich, & Greenberg, 1983). While the family may experience additional stress in dealing with the additional needs of the child, differences are present between members. Studies have found that mothers report feeling more stressed than fathers (Crnic & Booth 1991; Creasey & Reese 1996; McDonald & Almeida 2004; Herring, Gray, Taffe, Tonge, Sweeney, & Einfeld, 2006).). As discussed earlier in this section, mothers feel more overwhelmed by the stress they face in their daily lives in dealing with hectic schedules and trying to meet the needs of their child. In a two year longitudinal study conducted by Gerstein, Crnic, Blacher, & Baker (2009) using the parenting daily hassles measure (PDH) it was reported that not only did mothers endure greater daily parenting stress in comparison to fathers, but their level of stress grew significantly as the child developed into the preschool age. Stress levels of fathers did not increase over time.

This research provides further evidence to the continuous stress mothers feel in response to being a caretaker of their child with a disability. Mothers experiencing an

increase in stress levels over time suggests that they are facing greater challenges as their child grows older. A mother is meeting each stage of development of their child with new difficulty. Gerstein, Crnic, Blacher, & Baker (2009) infer that mothers may be suffering from higher levels of stress because parenting is a domain in life that mothers strongly identify with (2009). Stress is more salient to mothers because their role as a mother holds a stronger meaning for who they are. It is evident that there is a connection between parenting stress and maternal identity. The differentiation in parenting stress levels between mothers and fathers further illustrates that fathers identify themselves with role of being the provider for the family, and therefore do not take on as much stress in the caregiving.

Re-Occurring Grief

Re-occurring grief is a concept that both mothers and fathers of children with disabilities endure. It occurs when grieving the loss of the child parents once fantasized of before the child was born and at stages of development the child struggles to meet (Brown, 2016). Brown (2016) conducted an in-depth interview 6 mothers of children with intellectual disabilities to examine what factors cause re-occurring grief and why it continues to manifest throughout a child's development. Several themes emerged from the in-depth interview of the mothers, the first occurred during the initial diagnosis of the child's disability. The diagnosis of their child ignited feelings of shock and disbelief in confronting the realization of their child's disability. Following the initial stage of grief, a period of double mourning that pertains to the mother's grief for her own life and her child's life. One participant described double mourning as "the death of your hopes and dreams for that individual child...I would have been in my mid 40s and I'm thinking my

whole life all I'm going to do is care for this child, I'm never going to be able to accomplish anything, any of my own desires, any of my own dreams” (Brown, 2016).

The study indicated that this stage of double mourning was characterized by more intense feelings of sadness, depression, and anxiety. This description of double mourning closely identifies with the loss of identity mothers experience in dealing with the stressful demands of meeting the needs of their child. Alongside the diagnosis of their child’s disability, mothers may question what their future will look like in having a child that will require more time, attention, and resources. In adapting to the needs of their child mothers alter their professional plans, social relationships, future plans.

Re-occurring grief is triggered by societal factors such as exclusion. When mothers are not met with love and support from family and friends, mothers feel hurt, depressed, and hopeless as a result of the rejection. Mothers consider exclusion to be not a loss of relationship for the mother but for the child as well (Brown, 2016). Support is vital to mothers of children with disabilities and is essential to increased levels of happiness and better well-being as discussed in future exploration of literature.

Examining the stages of re-occurring grief a mother endures in raising a child with a disability is important to understand as it impacts a mother’s identity. This process of re-occurring grief is described as an adaptive process that entails the “gradual letting go of the double dreams and the constructing of a new reality for the child and themselves around the disability” (Brown, 2016). Mothers try to find a balance between letting go of the future they once imagined for themselves and child and adapting to a new normal that includes the child’s disability. Services can be more tailored address the triggers of grief and aiding mothers in coping strategies to address its reoccurrence.

Psychological Well-Being

As discussed in the previous section of this literature review, mothers of children with disabilities endure higher stress levels. (Taylor, Pallant, Law, and Howie's study reports children with disabilities are known to have higher rates of sleep disturbances in comparison to those of typically developing children (2013) Further, this study found that the sleep problems of children with disabilities can have a direct impact on the sleep habits of their mothers. These poor sleep habits contributed to poor mental health and well-being of the mother Sleep disturbance were found to increase the risk for anxiety and depression. In addition, this study researched the frequency to which mothers of school-aged children with disabilities were disturbed at night during sleep and how this impacted their maternal health. It was reported that 49% of mothers had children that required frequent night-time attention. In addition, 32% of mothers reported that they slept through the night without disturbances from their child less than 1 night per week. This study concluded that an increase in sleep disruption resulted in mothers reporting poorer quality of mental health, social functioning, and ability to meet the emotional needs of life roles (Taylor, Pallant, Law, & Howie, 2013). This research inferred that mother's experiences in raising a child with a disability can produce poor outcomes for their health. The findings in this study help to further understand the life experiences of a mother raising a child with a disability and the impact it can have on their quality of life. Understanding these experiences aids in the present study in exploring how maternal identity is shaped by having a child with a disability.

As primary caregivers, mothers have been identified as being more vulnerable to the stressors of raising a child with a disability (Armeli, Gunthert, & Cohen, 2001). In

combination with disability-specific stress, there are general life-stressors including divorce, death, financial hardship that are typical life transitions that mothers must also cope with (Armeli, Gunthert, & Cohen, 2001). Mothers can experience both positive and negative outcomes in raising a child with a disability, some describing their experience to be more stressful and filled with anguish but marked with joy and strength (Kearney and Griffin, 2001). Happiness is an emotion that has been correlated to health and functioning (Diener, 2000). Findler, Jacoby, and Gabis (2016) examined factors that contributed to the happiness of mothers of children with a developmental disability. This study included great diversity of disability amongst the children, children ranging from ages 3 to 7, and a range of disabilities including autism, an intellectual disability, cerebral palsy, etc. This study examined the differences amongst mothers who adapted to the long-term stress of raising a child with a disability and experienced positive outcomes leading to their overall happiness in comparison to mothers who struggled to adjust and found difficulty in adapting and experiencing happiness. Attachment, social support, stress, and guilt were examined risk factors related to raising a child with a disability were measured in this study to determine its impact on a mother's happiness (Findler, Jacoby, & Gabis, 2016). This study utilized several scales: Subjective Happiness Scale, Perceived Stress Scale, Handicap Related Events Checklist Symptom Severity Measure, Experiences in Close Relationships Scale, and the Multidimensional Scale for Perceived Social Support. Results of this study found that higher levels of happiness resulted from lower levels of attachment, avoidance, anxiety, perceived general stress, and guilt, and greater levels of social support (2016).

Findings in this study stressed the existence of social relationships as a source of support for mothers of children with developmental disabilities. The presence of satisfying social relationships is an essential part of coping for mothers of children with disabilities and is congruent with higher levels of happiness. Mothers of children with disabilities often cut out social relationships for lack of time and understanding from others isolating themselves. This sense of loneliness and absence of support contributes to a mother's loss of identity. This direct correlation with happiness emphasizes the need of relationships for support in mothers' of children with disabilities. Lower levels of guilt indicated in this study were related to higher levels of happiness. Mothers of children with disabilities are can suffer from intrusive thoughts of regret, these feelings as concluded in this study can contribute to poorer psychological well-being. Conclusions from this study provide further understanding into the factors that contribute to a decreased feeling of happiness in mothers of children with disabilities. Stress, guilt, and shortage of support significantly impacted a mother's psychological well-being providing us with further understanding of the factors that shape a loss of maternal identity in mother of children with disabilities.

Challenges

Mothers reported that their child's problem behavior limited the places they could go with their child (Johnson, O'Reilly, & Vostanis, 2006). Public settings such as restaurants and movie theaters were avoided for some families because their child's problem behavior pose difficulty when surrounded by others. Mother's felt restricted as to what activities their families could participate in because their child's problem behaviors could be wrongly misinterpreted by others. Needing to plan activities around

the child's disability imposed a negative impact on the other children in the family. One participant stated, "We can't do the simplest of things" (Johnson, O'Reilly, & Vostanis, 2006). The worry of their child engaging in the problem behavior in public often prevented families from going out due to the reason that problem behavior is more difficult to manage outside of the home. This limitation of lifestyle is a factor that contributed to loss of identity. Not having the ability to freely participate in activities with the community can result in mother's feeling restricted and secluded.

This limited lifestyle also translated to personal lives of mothers. Planning to go out to engage in social opportunities was challenged by their inability to be flexible and arrange plans in needing to make arrangements for child care with someone who could handle the heavy demands of their child's behavior. The challenges in finding someone willing to watch their child was a reoccurring problem for some mothers, ultimately leaving them unable to leave the house. These challenges left mother's feeling emotionally isolated. Mother's reported feeling like other mothers could not relate to their challenges, this feeling lead to a loss of identity in mothers (Johnson, O'Reilly, & Vostanis, 2006).

Further, some mothers found solace in ensuring that they participate in activities outside of the home for themselves in order to maintain a social network, such activities included employment or volunteer work. The need to participate in activities for themselves outside of the house is a concept discussed in Project Bien Estar further in this section. A child with a disability requires constant attention, therefor, mothers give up elements of themselves that were important to them to be more available to their child resulting in a loss of identity.

Adaptation Differences Between Mothers and Fathers

The birth of a child is a life transition that requires the ability for parents to adapt in order to accommodate the needs of their newborn child. The diagnosis of a disability further emphasizes the need to adapt for both parents. Parents must grieve the loss of their fantasized child and adapt to the idea of having a child with a disability. Adaptation is essential in meeting the physical and emotional needs of their child's disability, a key component in establishing a practical lifestyle and coping (Pelchat, 1989). Parents redefine their roles in the family to provide necessary care for their child, which as discussed in this present research can result in a loss of identity for mothers. In meeting the demands of caring for a child with a disability tremendous stress is put on both parents. Pelchat, Levert, and Bourgois-Guérin (2009) explored the adaptation process of mothers and fathers of children with cerebral palsy from four different levels: the individual, parental, marital, and extra familial levels. The study examined the similarities and differences of perceptions mothers and fathers while describing the transformation process that occurred to adapt to the needs of their child with a disability.

In this study interviews were conducted with the mothers and fathers and the PRIFAM clinical model of the adaptation or transformation process was used to provide insight on the dynamic that exists amongst the family and individual after the birth of a child with a disability as well as the family's influence on the child's disability and the influence of the disability on the family (Pelchat, Levert, & Bourgois-Guérin, 2009). One of the themes identified from their research study was reoccurring grief experienced by mothers and fathers. Grief often accompanied new or unexpected difficult situations. Mothers and fathers described different experiences of grief. Mothers reported feeling

grief more intensely and directed their guilt and anger inward. Mothers became so focused on their child, relationships with their partner and themselves suffered. This diminished attention on relationships as discussed in this present study contributes to a lack of support and a loss of identity. Fathers experienced their grief and guilt on an individual level, but repressed their emotions engaging in avoidance behaviors like focusing on work.

Pelchat, Levert, and Bourgois-Guérin (2009) also found that mothers tended to express their lack of time differently than fathers. Mothers expressed raising a child with a disability resulted in an increase of responsibilities that resulted in the need to reevaluate their careers. Fathers did not report making the same adaptations. Mothers tend to take on more adaptive strategies in order to meet the needs of their child. Changes that mothers make in order to adapt to their child's disability create a lasting impact on a mother's identity because she is giving up parts of herself. It is important to highlight this conclusion in the differences in adaptive strategies mothers and fathers engage in, concluding that mothers engage in adaptive strategies that alter major aspects of their life that define who they are.

In addition, strengths existed at the marital level. Mothers and fathers described having skills that complimented the skills that the other person did not possess, displaying an adaptive strategy employed from both parents. However, mothers were the only ones in the interview to discuss the tension that existed in the marriage. Communication strategies were more often employed by mothers than fathers. Mothers in the study expressed, "the fathers' lack of communication and openness about the situation created a sense of isolation, raised questions, and caused unease. Mothers felt trapped by their

daily workload, which meant that they no longer had time for their partner.” Though fathers struggled to communicate, both mothers and fathers perceive the quality of marital support as a major factor contributing to their well-being. Results from this study further concluded the feelings of isolation mothers of children with disabilities feel in raising a child with a disability, but it also stressed the importance of support for both mothers and fathers (Pelchat, Levert, & Bourgois-Guérin, 2009). Communication is an essential adaptive strategy for both mothers and father to feel supported.

Mothers and fathers in the study viewed difficult situations in a positive way as a challenge or new experience. Perceiving the situation as a challenge provides the opportunity for coping and personal growth (Lazarus & Folkman, 1984). This finding indicated perception of the situation to be a predictor of positive or negative experience of raising a child with a disability. This demonstrated the effect of a change in perception, it can greatly impact experience in raising a child with a disability. Subjective experience is discussed further in the synthesis of research.

It is important to understand the impact of raising a child with a disability from a variety of levels. While mothers most often take on the role of primary caregiver, they are often accompanied by a partner and additional children in the family. Partners play a significant role as a source of support to the mother and involvement in meeting the needs of their child. Knowledge of the adaptation process of both the mother and father leads to further comprehension of the kind of support that mothers and fathers need while adjusting to their child’s disability and establishing their sense of normalcy in their life. Highlighting these differences brings attention to the variety of services to address both mothers’ and fathers’ needs. In addition, there is a fuller understanding of how mothers

and fathers can compliment each other in areas they may struggle with further aiding the transformation process a family undergoes in adjusting to the life of a child with a disability.

Loss of Identity

Project Bien Estar was an intervention program aimed at aiding mothers with coping skills to help throughout the daily challenges of their lives associated with raising a disabled child (Cunningham-Sabo, VanLeit, & Crowe, 2002). The program consisted of six weekly group sessions with a therapist and two individual sessions with an occupational therapist. Participants shared their experiences and provided emotional support to one another, the aim was for mothers to discuss problems in their daily routines and make a collaborative effort to solve them. Several themes emerged from the sessions with the mothers, one of them reflecting upon their self image was feeling overwhelmed. Mothers reported feeling very overwhelmed; their days filled with juggling multiple tasks at once leaving them scarce amount of time for themselves and a constant feeling of anxiousness. In addition, a theme of social isolation was present amongst women. Several lacked close relationships, the absence of friendship or romantic partners in their lives due to unavailability of time to develop these relationships and a response to the sense of intolerance of their child's disability. Loss of identity, having uncertainty, and no goals for their future were themes discussed by participants. Many of their lives were transformed by the responsibility of a child with a disability, resulted in loss of sight of their personal goals and independence. One participant said "I was always pretty self-sufficient...I guess there is a mourning of a loss in all of that and I thought about what was it that I lost. And it was me. My job, my identity, part of me

wasn't there anymore." They altered parts of their life that defined them, abandoned their careers and goals for their future. Their perceptions of themselves have changed and parts of their identity are lost. This study demonstrated that mothers may lose parts of their identity in trying to support a child with a disability. Sacrifices made included giving up their careers or cutting back on their work hours, not engaging in healthy self care behaviors, or refrain from establishing meaningful relationships in their lives in order to cope with their demanding daily routines. All these choices were made in order to support their child, and had an impact on their self-image.

Lichter (2003) explored the challenges and experiences of 12 mothers of preschool aged children with disabilities in an in-depth interview. Their perceptions of their self-identity were examined to determine what kind of effect raising their child has had on their identity. When discussing sense of self, participants described the event of having a child with a disability as a detour in their life. They described their lives and experience of motherhood to be vastly different in comparison to other mothers. This often produced a feeling of loneliness and inability to relate to others around them because their challenges were so different. One participant shared "It's unnerving, that you live and breathe every minute for him, I mean every minute and in that way don't take time for yourself enough, because you are still thinking about the rest of your family too". As a result of having a child with a disability, participants shared that several components of their lives changed. Though all the mothers shared they had to alter several components of their lives as a result of raising a child with a disability they also cited having a greater sense of awareness of themselves, their strengths, and their experiences. This intense experience of making their child's life their life resulted in a

change in attitude, their views of priorities and life had shifted. Mothers had difficulty imagining what their future could look like because so much of their lives were centered on living for one person.

Synthesis

Project Bien Estar was a research study that greatly contributed to the well-being of several participants in the study. It allowed mothers to become stronger advocates for themselves and their children, by making small changes in their challenging daily routines to improve their well-being (Cunningham-Sabo, VanLeit, & Crowe, 2002). Listening to the details provided by participants were useful in closely examining the challenges and needs of mothers, this being a benefit of conducting qualitative studies. This particular study was beneficial in identifying that caregivers need support programs centered on expression of stress in their daily schedules. Addressing personal needs will strengthen self-image and encourage small changes that can impact the quality of care provided to their child. In this current study, a similar interview structure was conducted to explore the details of a mother's identity. Details were crucial in investigating the changes in identity that occurred as a result of parenting a child with a disability. "The Cost of Maternal Identity" also conducted through interviews, emphasized the role that motherhood has in shaping a woman's identity, this research is important in exploring how identity can be impacted when the child is not meeting milestones in their development. Its incorporation of fathers in the study allowed for a comparison in views amongst mothers and fathers. There was a clear distinction in how mothers viewed their role as an entire part of their identity, shedding light on this current research as to why mothers' sense of self is so greatly impacted by parenting a child with a disability.

“Caring For Children With Learning Disabilities Who Present Problem

Behaviors: A Maternal Perspective” provided an in-depth understanding to the challenges mothers and families face in raising a child with a disability. Mothers often feel restricted to the activities they can participate in because it is more difficult to control their child’s problem behavior when outside of the home environment. These restrictions presented in the social relationships mothers have because there are many challenges in finding proper childcare services leaving them inflexible to make plans with others and leave the house. This research provided an understanding to the several challenges mothers resulting in a sense of isolation. This sense of isolation may be a major contributing factor in a mother’s loss of identity. Not only did this research report on the difficulties mothers faced but coping strategies that mothers used to combat their negative emotions.

A longitudinal study by Gerstein, Crnic, Blacher, & Baker (2009) provides valuable research over the span of two years. A strength of this study was its ability to measure several relationships. The conclusion was that mothers experience increased levels of stress throughout a child’s development. This study attributed mother’s increased stress levels to a mother’s close identification with the role of being a mother. In comparison, fathers’ associated themselves more strongly with the role of provider which may have resulted in lower stress levels. These findings are meaningful in understanding how the role of caregiving as a mother is representative of their identity.

Lichter (2003) emphasized several points of this current study such as loss of identity. Exploring the personal narratives of these mothers was a display of the relationship between sense of self and having a child with a disability. This research

provided a greater understanding into the feelings and processes that a mother went through, it incorporated a discussion of a wide range of experiences from pre conceived expectations of having a child, dealing with the diagnosis of their child, and what their view of their future looked like. This current study will focus solely on the relationship between maternal identity and having a child with a disability, keeping it more specific to one area of a mother's experience. The study was far more in depth than the other two studies discussed, focusing on several aspects of the mother's life, this provided a plethora of data, however it can be difficult to generalize all the data that was provided.

Finder, Jacoby, and Gabis (2016) examined the factors that are related to higher levels of happiness amongst mothers of children with disabilities. Researchers indicated a mother's subjective experience as a limitation that could impact the discussion data provided by mothers. Happiness is a subjective emotion that varies depending on the positive and negative experiences of raising a child with a disability. Challenges and difficulties in raising a child with a disability differ depending on the circumstance of each child's disability, this ultimately impacting a mother's experience. Similarly in this current study a mother's subjective experience can be seen as a limitation. Mother's experiences are not all the same, generalizing results from mother's subjective experience of raising a child with a disability can be difficult as it is not a representation of the whole population. Pelchat, Levert, and Bourgois-Guérin further examined subjective experience (2009). The positive perceptions mothers and fathers had toward making changes to meet the needs of their child contributed to the well-being of the family. Seeing the child's disability as a challenge to overcome was a useful adaptive strategy in comparison to parents who choose to engage in avoidance behaviors. Each experience of

raising and adapting to a child with a disability is subjective and can be heavily impacted by the positive or negative perceptions each parent chooses to embrace.

Chapter 3

Method

Setting and Participants

Target participants of the study were mothers of children who have a disability. The sample size of this study was 3 mothers. Participants were recruited through email with the assistance of the organization leader of Asperger Autism Spectrum Education Network (ASPEN) of Monmouth County as key informant. Participants were chosen through chain referral sampling; however ensuring diversity of demographic characteristics. Demographic profile of the mothers and children is included in the final report of the study. Participants are described in terms of gender, age, ethnicity, socio-economic status and disability of their child.

In-Depth Interview

This research employed an in-depth study into mothers' views of herself as well as how others view the mother in relation to parenting experiences of a child with a disability. Participants were asked a series of open-ended questions in relation to their experience in raising a child with a disability. Each interview used the following guide questions to explore deeper into the parenting experiences of mothers.

1. How do you view your role of being a mother?
2. Tell me about your experience in finding out about your child's disability.
3. Tell me about how your role as a caregiver has impacted you as a person.
4. Tell me about your experience in adjusting to meet the needs of your child.
5. How has this experience changed your view about yourself?
6. Tell me about what you have heard from other people regarding your being a mother to your child.

7. Can you tell me about your experiences in dealing with professionals?
8. Can you tell me about your expectations for your future?

Procedure

A number of steps were taken before participants were recruited to participate in the study. An electronic IRB application was submitted to the Rowan University Office of Research Compliance. Once approval of the IRB was achieved, prospective participants were contacted to discuss the possibility of participating in the study and to determine if they meet inclusion criteria for the study. Email addresses of participants were obtained from the leader of the ASPEN organization of Monmouth County. Given the study is based on a small sample size, representativeness of the demographic characteristics of the mothers (e.g., race, gender, socio-economic status) and their children (e.g., age, gender, and type of disability) were considered to more or less endure diversity of the sample. After prospective participants were identified through chain referral sampling an email was sent by the researcher to introduce the study and obtain participant's consent to be interviewed. Upon receipt of consent, a schedule for interview was arranged. The researcher met with each participant in a mutually agreeable location to conduct the in-depth interview for approximately an hour and with possible follow-up through phone. Though guide questions were prepared for the interview, the researcher used probing to be able to clarify responses as well as gather more information that will give broad picture of parenting practices of each mother in relation to her sense of self. As this is an open-ended interview, questions may change as the interview progresses. Responses were recorded through the use of an iPhone device and stored on a locked laptop. Immediately following the interview, responses were

transcribed into a written transcript stored on a locked computer. Access to responses was only be granted to the principal and co-investigator.

Analysis

The primary goal of this study was to gather information on the feelings, attitudes, and experiences of mothers that are developed within their role of parenting a child with a disability. A verbatim transcription of mothers' responses was used to identify patterns amongst responses. The researcher reviewed the transcript and identified key words and phrases and evolved them into themes (Lichter, 2003). Analysis of data was organized into positive and negative themes.

Chapter 4

Results

The three participants were mothers of children with disabilities who consented to be interviewed for this study. This chapter contains descriptive profiles of each of the three mothers. Mother's feelings and experiences are organized in two categories, those contributing to view of self as perceived by her and as perceived by others. Themes were constructed from patterns identified in key words and phrases in mother's responses. A verbatim disclosure of mother's responses are included within themes. A general analysis of themes was done comparing the themes that emerged from individual interview data. Mothers are referred to as Participants #1, #2, and #3 to ensure confidentiality.

Participant #1

Participant 1, aged 60, is a mother of two children who resides in a middle class suburban town. Her younger son now 24 years old, was diagnosed with Asperger's at age 10 and is currently living in her home; her daughter, age 29 is married and living in another state. She has been married to her husband for 33 years and maintains a household income of 95, 000 dollars annually. Participant 1 has obtained some college education and is currently employed as a full time Library Assistant in an elementary school in her district. Interview with participant 1 was conducted by the researcher in a public library for approximately 1 hour.

Self-perception. Participant 1 identified her role of being a mother as an advocate for her son. From the time her son was diagnosed with Asperger's syndrome, she has been advocating for her son to accommodate his needs in both school and employment. Her son's school district refusing to accommodate his disability, transformed her from a

usually a soft-spoken and easy-going woman, to an out spoken voice for her child. These changes in her identity, in advocating for her son, negatively impacted her self-esteem. Participant 1 made several changes in her life to be able to her son's condition. She lost sight of personal goals and found it difficult to maintain social relationships. As a result of her experience in raising a child with a disability, Participant 1 discussed factors that contributed to her personal growth. Several themes emerged from the interview that have impacted Participant 1's view of self, these themes are identified and presented in detail below.

Theme 1: Making sacrifices. Participant 1 discussed her experiences of raising a child with a disability that led her to making sacrifices to support her son's condition. Quitting her job was necessary in order to have the time available to find professionals to accurately diagnose her son's disability. Her son's diagnoses experience provided the family with many challenges both emotionally and financially. For over a year, professionals failed to diagnose her son with the proper Asperger's diagnosis. Worsening of his symptoms prompted by medications caused her son to become violent. Desperate to find the proper care for her son she quit her job in order to bring him to various physicians outside of the state. Inadequate insurance left the family responsible for the cost of \$500 weekly medical visits to several professionals, these costs placed a great amount of stress on the family. Devotion to her son's condition derailed her from her plans of going back to school. Participant 1 reported that making these sacrifices were crucial to her son getting the proper diagnosis and services he needed to improve his condition. The district she was formerly employed for refused to hire her back for her position as a result of fighting the school district to provide her son with services in the

classroom in which she reported feeling depressed. Making sacrifices was identified by additional participants as the result of being overtaken by the needs of a child with a disability.

“I had to stop work, because I needed to be home when he got home from school. At the time I was fine, I was happy to give up my job because it was what I had to do to help my child. I think it kept me back a little bit because it wasn’t an option for me to go back to school, which is ideally what I would have liked to have done. Financially, it put us in very bad spot because we needed benefits. But I had to what I do to because of the way life turned out. I was working in that district and they didn’t hire me back because I was fighting that system, so it was depressing.”

Theme 2: Negative impact on self-esteem. Advocating for the needs of their children was reported by all 3 participants. Participant 1 strongly identifies her role of being a mother as being an advocate for her son. She reports acting out of character, transforming into a mean person. The constant fighting for services negatively impacted the self-esteem of participant 1.

“I feel like I had to start getting mean to get him the services he needed and it’s not in my nature. The wild mother would have to come out way too many times and I was never really comfortable with that but it’s just what you have to do. And I think I’m a people pleaser and I want people to like me and I realize due to my advocacy I’m hated probably by many.”

Theme 3: Personal growth. Realization of strengths amongst mothers of children with disabilities was a reoccurring theme in this study. Participant 1 discussed the

positive impact of her experiences, feeling that it made her a more compassionate individual. Gaining knowledge from her own experiences in raising a child with a disability impacted her professionally and personally. Participant 1 identified strengths as a result from her experience in raising a child with a disability.

“I always up until a couple years ago worked in special education and I don’t think back when I was working with people with disabilities I was as comfortable as I am now. I definitely am more comfortable now and it definitely gave me a better understanding not to blame the children, even sometimes when you feel like parents could be doing more you never really know what’s going on at home. It’s made me better as a person and in work.”

Theme 4: Inability to connect with others. Participants in the study reported both a loss of social relationships and a strengthening of relationships among mothers who shared similar experiences in raising a child with a disability. Participant 1 struggled with openly discussing her son’s diagnosis of Asperger’s. She did not feel comfortable confronting many of her friends and as a result lost social relationships. Previously employed at the school her child once attended, many of her relationships at her work suffered as the result of being a strong advocate for her son within the school. She described an inability to connect with other mothers who did not share similar challenges of raising a child with a disability.

“It was nerve-racking, at the time that I lost most of my friends, I didn’t tell any people. There were rumors going around, so except for a couple of friends I never did catch up with those other friends I left behind at that time.”

Theme 5: Ability to connect with others. Participant 1 described her experience in connecting with other mothers of children with disabilities to be very therapeutic for her. The Asperger Autism Spectrum Education Network served as a strong support system where she felt instantly accepted. She reported that she benefited tremendously from connecting with other mothers who understood her challenges more than anyone else. The relationships she built from this group have continued to support her till today.

“I developed life long friends from ASPEN. We did a lot of classes and support groups, we did really well with that. Everyone there really just gets it, it’s a strong system of support.”

Others’ perception. Participant 1 experienced mixed support from the relationships in her life, both social and family. A strengthening of relationships exists among mothers who have children with disabilities, however participant 1 felt unsupported by some friends and family. Blame and judgment are identified in her experience in raising a child with a disability. Opposition from professionals in the school district resulted in a continuous battle in advocating for her son’s needs. She describes a disconnect that exists between others who cannot identify with the difficulties of raising a child with a disability. Themes in relation to self as viewed by others are discussed in this section.

Theme 1: Blame. Participant 1 received mixed reactions from family. Her family did not understand that her son’s disability could not be cured through professional help. Family placed blame on her for not seeking additional services to control her son’s behavior. Participant 1 feels the weight of her family’s criticism and misses the unconditional love her parents once provided her with before they passed

several years ago. She contributes this lack of support and blame to the inability of others to relate to her challenges in raising a child with a disability.

“My husband has a lovely family, his parents are still living and he has a brother. Him and his wife, as much as they want to get it, they don’t get it. I think were still getting blamed, that we’re not doing enough. They blame the psychiatrist and the therapist. They think they should be doing more. They are still judging me, that I’m still doing something wrong. Do this, do that. Until you are living it, you really can’t understand. With family it’s been rough. My parents are gone now but they were extremely supportive. My parents totally got it, unconditional love. I have no siblings, I was an only child so we just deal.”

Theme 2: Lack of support from professionals. The participants in the study reported the need to constantly advocate for their children in response to inefficient support from professionals in and outside of school. Participant 1 experienced a direct push back from her son’s school, refusing to accommodate his needs in the classroom. Professionals in the school placed blame on her for son’s behavior, attributing her son’s Asperger’s to be the result of failing to discipline her child. She reflects on her experience with professionals to be a painful constant battle.

Those years were painful, my husband and I can’t even look at the letters sent to teachers and the school district just begging other people for help. There was a lot of pushback from the district; they really didn’t want to deal with it. He really didn’t have trouble in school but he just shut down and they didn’t want to deal with it. They didn’t want him at the district and they tried to blame me. They tried to blame me for his behaviors, as if it was like a discipline thing, saying we

weren't disciplining him or different things. It was bothersome, constantly fighting. At the time he would leave the classroom go to the main office and pick up the phone and call me and beg me to bring him home and he ended up sitting in the school office playing with Legos in the fifth grade it was ridiculous."

Participant #2

Participant 2, aged 55 years old is a divorced mother of two children who is employed as a full time Paraprofessional at an elementary school in her district. Her youngest son now 22 years old was diagnosed with Autism at 6 years old and continues to suffer from Encephalitis. Her oldest daughter is 27 years old and was diagnosed with Bipolar Disorder when she was 20 years old and is currently struggling with an eating disorder. She resides in a middle class suburban community with her daughter and son. She maintains a household income of \$60,000 dollars and has obtained some college education. Interview with participant 2 was conducted by the researcher in a public library for approximately 1 hour.

Self-perception. Participant 2 described her role of being a mother as being a supporter of her children and an advocate. She takes pride in her role as a mother of a child with a disability and does not let the opinions of others impact her. She fully accepts her son for who he is and is unapologetic of her son's disability. Participant 2 describes herself as being strong minded and will fight for the needs of her child, even if that means she has to be nasty with others. She exuberates a strong sense of resilience in response to the many demands of raising a child with Autism, constantly describing her need to push forward and keep going. Though her son is high functioning and has made significant progress in working to become an independent individual his recent diagnosis

of Encephalitis has caused him to digress, compromising his memory and speech, causing him to become more dependent on her. Her son requires her constant attention.

Providing support for her son solely falls on her shoulders due to her husband's refusal to accept his son's disability. This demand has caused her to feel overwhelmed with stress and forces her make sacrifices such as limiting her personal activities such as dating and social outings. The experiences of raising a child with a disability have had a significant effect on the self-esteem of Participant 2. She reports feeling defeated at the end of the day and doubting her ability to being a good mother for her children.

Theme 1: Making sacrifices. Participant 2 reported needing to limit social outings and personal activities a result of the overwhelming responsibility her son's disability required. She has been divorced for 7 years and reports that dating is not an option for her because of unpredictability of her son's needs. She expresses doubt that there will be a partner that will accept her son and the burden of responsibilities paired with his disability. Participant 2 is dedicated to the needs of her son and as a result has made sacrifices in her personal life to be more available to her son.

I have to limit my personal activities. I just don't make plans. If I want to make plans I have to make many arrangements. I don't date, I've been divorced almost 7 years. Who wants to date someone who has a package with them? Most people my age their children are getting of college so they have their freedom. I could call you up 10 minutes before we have to go out to dinner and say I can't go because he's having a bad day so I just don't even bother. I have just accepted that he is going to be with me till I take my last dying breathe, and that's ok.

Theme 2: Negative impact on self-esteem. The responsibilities of being the primary caregiver of a child with a disability are accompanied by intense emotions for Participant 2. She describes feeling exhausted and sad. She repeatedly doubts her role as a mother and is uncertain if she is doing enough for her child. She is overcome with emotion at the end of the day and often breaks down in response to the stress of her role.

Right now we are living in hell, there can't be a worse place right now. I do beat myself up a lot. At the end of the day I go to bed and I cry myself to sleep almost every night. I think did I handle that right, did I do enough of a good job today. I worry myself a lot.

Theme 3: Personal growth. While Participant 2 struggles with the intense burden of being the primary caregiver for her child she reports feeling stronger as a result of her experiences. Similar to the other participants in this study Participant 2 describes personal growth from her experience. Her intense feelings of sadness and stress are accompanied by resiliency. She refuses to feel bad for herself and dwell on her harsh circumstances. She attributes the demands of taking care of her child as just being part of the job of being a mother. She emphasizes the need to keep moving forward and push herself to be better and fight for her son and other children she assists in her profession as a Paraprofessional to children of learning disabilities.

It's hard when both my children are having bad days and are having issues, it's hard. But I just do it because they need me. I just go with whatever I have to do to make both of them happy and calm. I am very stressed, but why complain about it? I have to be strong. I will never let him see me cry. I don't want him to ever think that anything he does is his fault and as frustrated as I get I don't ever

let him see that side of me. People say I don't know how you do it and I just say, I just do it. I don't know how I do it, but I do it the best way I know how, that's all I can offer. Some days go better than others, some days it's like a total shit show. But when I fall asleep I think, ok, I get another chance at this tomorrow to be better.

Others' perception. Participant 2 described feeling judgment from other mothers in response to her son's behavioral outbursts in public. She reported mothers not wanting their children to associate with her son on the playground because of his behavioral issues and because he did not engage in play like other children. Faced with judgment however, she did not let the opinions of others affect her view of her self. She expressed that confronting other mothers of her child's condition was therapeutic for her and allowed her to further accept his condition. In congruence with the other participants in this study she feels that if you do not have a child with a disability its difficult for others to empathize with your experiences and there is a disconnect as a result.

Theme 1: Strained relationships. Refusal of her ex-husband to accept his son's disability led to the dissolution of their marriage. For several years he did not offer support for their son and did not make an effort to understand his son's condition. The constant fighting between Participant 2 and her husband created tension in the home and had a negative impact on both of their children resulting in their divorce.

The stress of dealing with my son definitely impacted our marriage. My ex-husband was unsupportive. He did not understand our son at all and did not have the patience to try to understand him. He was in denial. I think he went to one IEP meeting and was nasty and asking stupid questions. Every man wants the son

that can play baseball in the backyard. Our marriage became so bad, he verbally abused us. It affected my children. My son wanted him out of the house. He said I can't take the yelling, I don't want him here. And that's when it became clear to get a divorce. So I have done everything for him. I went to all the meetings at school and I got him services he needed.

Participant #3

Participant 3, aged 46 years is a mother of 3 children residing in a suburban community. Her oldest son is 18 years old and was diagnosed with Asperger's at the age of 10, her youngest daughter is 14 years old, and middle son is 16. She has obtained a bachelor's degree from a 4-year college and is currently employed as a full time Front Desk Coordinator at an athletic facility and maintains a household income of \$96,000. She has been divorced for 6 years and is in a committed relationship with an Education Lawyer. Interview with participant 3 was conducted by the researcher at her place of work for approximately 2 hours.

Self-perception. Participant 3 defines her role as a mother as one that has undergone a transformation over the last 10 years. She identifies her role as being an advocate for her son and the voice for what he needs. For many years she feels she failed to support his needs in forcing him to meet the demands of the school and conform to the standards of a typical child. She described herself as being a tyrant, pushing her son to work at the same pace as other children instead of accepting his differences. Similar to Participant 1 and Participant 2 in this study, she reported becoming a mean person with a hard demeanor that did not exist before the diagnosis of their child. The constant

pressure from school professionals and Participant 3 led her son to threaten suicide at age 11. This incident served as the catalyst to her transformation. She became more aware of her son's needs, listened to what he wanted and recognized the limitations of his disability. Participant 3 reports to have become a better individual who is more loving; she now believes she is truly an advocate for what her sons needs are rather forcing him to meet the demands and expectations of others. Lack of support and constant disagreement over how to parent their son resulted in a divorce. She attributes her son's disability to the cause of her divorce; however there is a theme of personal growth that will be further discussed in this section.

Theme 1: Acceptance. Participant 3 struggled to accept her son's disability and its limitations. She desperately wanted her to son to fit the image of the popular children at school, therefore refused to openly acknowledge her son's condition with other mothers. Through refusing to acknowledge her son's disability this hindered her ability to meet his needs. Rather than accommodating his limitations she put immense pressure on him to succeed to the level of other peers at school. She accepts fault in herself for her inability to initially support her son's disability.

At the time as a mother in that role I definitely thought the teachers were overreacting and they didn't know what they were talking about. I was that mom that thought this is my precious baby and nothing could be wrong with him. So I definitely took offense. It was really hard to hear my child is not perfect. I struggled with it because in my eyes they are perfect. That was hard to hear something is wrong. We just thought sometimes the teachers expected too much. My biggest mistake as a mom was being more worried about the stigma of him

being moved to another class because of his limitations. I was so worried about what everybody else wanted for him that I stopped realizing the effect of what it was doing to him. I was so demanding and I would scream at him to do the work because it was what the school wanted from him. I let the school put those demands on him and then I placed those demands on him then he went to school and the school was demanding him. He continued to struggle to meet those demands and expectations.

Theme 2: Personal growth. Participant 3 reports undergoing a major transformation as a result of parenting experiences of raising a child with a disability. In response to the stress of constantly fighting the school to prevent her son from being moved into a self contained classroom she developed a tough and nasty demeanor. The school placed expectations on her son and she also reinforced those demands at home often yelling and fighting with him to complete work that was out of his range of abilities.. This pressure led her son to threaten suicide. Her son's breakdown was the catalyst to her transformation. She became aware that though she thought she was supporting her son's needs she was breaking him down instead of building him up. As a result, she softened and accepted her son for his limitations and served to be the voice of his needs. Rather than responding with frustration to her son she showed him support with love and praise. She reports experiencing tremendous growth as a person from the events in her life.

There was so much turmoil in me, in our house, in our home, arguing and yelling. When it got so terrible for your son to want to kill himself that it was devastating. He thought no one loved him. I learned a lot as a parent. I definitely went

through my own personal journey. Up until that changing point of him saying he wanted to kill himself I was definitely concerned about the teachers, worried about what the principal and the vice principle thought and I just wanted him to be successful and happy and I was very demanding on him. I made a huge transformation. I took a complete step back. I learned and grew and realized he was different. A light bulb went off. I was forgetting to stop and smell the roses. I love him of course. But the hugs stopped and I was so angry and irritated, he was difficult. I was calmer I was more supportive of him being and I would say I'm so proud of you. He was like, 'You are mom?' I did a 180, he didn't know I was proud of him. It was all about building him up and being a complete support system, although I thought I was up until that point, it was a support system with huge demands, yelling at him and losing my temper out of frustration. I was different. I gave him more praise than I had ever given and he became happier.

Theme 3: Inability to connect with others. Participant 3 reported that many people thought she was under the illusion that nothing was wrong. She discusses the same inability for others to understand the turmoil she was going through that Participant 1 and Participant 2 disclosed. She describes her experience as a nightmare that other people cannot understand unless they too have a child with a disability. There is a silent struggle that occurs for parents of children with disabilities as described by Participant 3.

People thought I was pretending nothing was wrong with my son and acting like nothing was wrong. But people just didn't know what was going on behind closed doors. I was in a horrible nightmare in some way. Its hard for you to understand the magnitude of how difficult it really was when you have a child who is

screaming and crying and not happy and the school is calling all the time its overwhelming. You just want your child to be happy and the school to not be calling you, you want the Brady Bunch family.

Others' perception. Participant 3 reported feeling societal pressure and judgment from other parents. She indicated that many other people were ignorant to the battle she was experiencing that no one knew about. She reported that the experience of raising a child with a disability separates you from other mothers who cannot relate to your struggles. Participant 3 made aware the stigma placed on children with disabilities and the effect it can have on their parents. She discusses that she was very fearful of judgment of her and her child, this fear silenced her and prevented her from openly discussing her son's disability.

Theme 1: Societal pressure and stigma. Participant 3 feared the stigma that would be placed on her son if she was open to other parents about her son's diagnoses with Asperger's. She refused to say his condition out loud fearing that others would instantly stigmatize him. Participant 3 greatly feared the disapproval of others. She reports living in this bubble where she did not acknowledge her son's condition in front of other people. Internalizing her son's diagnoses proved to not be beneficial for her or her son's success.

Socially I tried to fly under the radar for a while when he was young, act like there wasn't a problem with my child. Starting out not wanting the label we didn't tell maybe they wont notice and we realized early on that wasn't the approach because it wasn't helping him. I wanted to stay in my happy little bubble. We

didn't tell anyone for a long time. We just said we would handle it we didn't want the stigma and to have other people judge him, but of course they figured it out. I was so quiet I didn't want to say it out loud if I said it out loud it was like our son was so different.

Theme 2: Strained relationships. Participant 3 reported that her divorce was due to constant disagreement with her ex-husband over how to parent their child. Her ex-husband did not provide her with the support she needed. She discussed that parents of a child with a disability need to operate as a team, but her and her ex-husband did not and had opposite approaches. It was difficult for their marriage to succeed because they functioned as separate units than a partnership, often undermining the advice by provided by professionals on how to parent their son. Lack of support within the marriage is a repeated theme in this study. Similar to Participant 2, Participant 3 reported that she did not receive the support she needed in raising a child with a disability this led to a divorce.

I'm divorced, and the reason I am divorced, very happily divorced, is because we could not meet in the middle. A big part of the marriage not working out was the difficulty of fighting about our son. I needed him to be on board with me and he wasn't. You have to have parents on the same page. I hate to say it but one of the biggest reasons we are divorced is because we weren't on the same page. I went to every meeting so he didn't hear all the stuff. My husband and I did not make it because we were complete opposites with how to handle our son. I was iron fist and he was completely the good cop. We constantly fought; he would give him no boundaries and let him do whatever he wanted to make him happy. Part of the reason it was so hard, he was completely soft. No rules whatsoever. Just let him

do whatever he wants, if he doesn't want to do the homework don't let him do it. It was such an opposite approach that made me even harder and stronger and tougher on him. It was not a team approach and we didn't make it.

Themes In Relation to View of Self and Self As View by Others

Table 1

Summary of the Themes in Relation to View of Self as Perceived by Self and Others

| Participant | Themes | |
|-------------|--|--|
| | <i>Self-Perceptions</i> | <i>Others' Perceptions</i> |
| 1 | Making sacrifices Negative impact on self-esteem Personal growth Inability to connect with others Ability to connect with others | Blame Lack of support from professionals |
| 2 | Making sacrifices Negative impact on self-esteem Personal growth | Strained relationships |
| 3 | Acceptance Growth | Societal pressure and stigma Strained relationships |

Chapter 5

Discussion, Conclusion, and Recommendations

This qualitative study explores the impact of raising a child with a disability on a mother's self-identity. In-depth interviews of three mothers who served as the primary caregiver for their child with a disability were conducted to gather experiences, challenges, and views that impact their own self-identity or others' perceptions of mother's self-identity. In this chapter, themes found in the previous chapter are discussed further in detail to understand the impact of participants' experiences on their self-identities.

Self as Perceived by Mothers

Each mother in this study discussed the increase of responsibilities and stress that accompanied raising a child with a disability. Participants 1 and 2 reported making sacrifices in their lives to devote their time supporting the demands of their child's disability. These sacrifices included giving up career and education goals and personal and romantic relationships to meet their child's needs. These results are consistent with Cunningham-Sabo, VanLeit, and Crowe (2002) research findings that women refrain from establishing meaningful relationships and alter parts of their lives that defined them in order to adjust to the demands of their child's disability.

A transformation of character was reported by mothers. Mothers in this study report negative changes in their self-esteem as a result of transforming into an angry, frustrated, and unpleasant person in fighting for the needs of their child. Participants reported negative changes in self-esteem, doubting their parenting skills, and feeling they were not doing enough for their child. Sadness and frustration accompanied these

feelings of doubt. As discussed by Findler, Jacoby, and Gabis (2016), mothers of children with disabilities are plagued with intrusive thoughts of regret that contribute to changes in self-esteem, happiness, and poorer-psychological well-being. A paradox exists between mothers' experiences of negative changes in self-esteem and personal growth in being the primary caregiver of their child with a disability. In contrast to the negative emotions mothers reported a greater sense of awareness and realization of strengths. Participants reported a strong sense of resiliency in dealing with the overwhelming stress of their child's disability. Mother's choses not to dwell on the difficult circumstances of their life and continued to push forward and keep fighting for their child. These results are congruent to research that suggests mothers experience both positive and negative outcomes, both tremendous stress and anguish, but characterized with joy and stress (Kearney and Griffin, 2001). Though mothers had to cope with the tremendous burden of meeting the demands of their child's disability, mothers report a greater sense of awareness of themselves, their strengths, and their experiences (Lichter, 2003).

Self as Perceived by Others

Each mother experienced blame from others through some relationship in their life. Blame was most commonly sourced from professionals, family, and parents in the community. Mothers felt that others were identifying them as the cause of their child's difficulties. Participant's experienced negative and positive experiences with professionals. Each participant reported tension with the school district failing to acknowledge and understand needs and limitations of their child, the constant fighting created significant stress in their lives. Mother's reported that the feeling of blame placed

on them from family and other mothers contributed to a sense of isolation. As discussed by Lichter (2003), mothers have a tendency to put the blame on themselves for causing their child's disability; this feeling is further compounded by pressure from society leading to an increased sense of isolation among mothers. Participants described a disconnect that exists between parents who cannot empathize with their challenges of raising a child with a disability. Each participant felt that their experiences in raising a child with a disability made it difficult to connect with others. This feeling often prevented them from openly discussing their child's condition, but led to seeking out the support from mothers with similar experiences. Lichter (2003) supports this finding, reporting that mothers find their experiences to be significantly different in comparison to mothers of typical children, this often produced a feeling of loneliness and inability to relate to others around them

Participants 2 and 3 reported a lack of support from their marital spouses in response parenting their child. Spouses were lacked the ability to understand the limitations of their child's disability and did not provide support in meeting the needs of their child. Increased tension and fighting over parenting practices led to the failure of their marriages. Each participant emphasized the need for parents to operate as a team in order to support one another and their child. These results are consistent with research findings that men are less likely to use adaptive strategies to meet the needs of their child. Lack of communication from fathers creates a sense of isolation among mothers and unease in the marriage leading to marital problems (Pelchat, Levert, & Bourgois-Guérin, 2009).

Conclusion

Positive and negative experiences of parenting a child with a disability can impact self-identity of mothers who are the primary caregivers of their child. They reported significant changes in their lives: giving up goals, divorce, loss of ability to connect with others, and refraining from creating meaningful relationships. Negative experiences impacted self-esteem and self-identity. Mothers reported transforming into an angry and unpleasant person as a result of their experiences. Mothers were not comfortable with the person they became in fighting for their child's needs. Mothers were proactive and devoted themselves to their children and made them the focus of their lives. This devotion leads to loss of identity as a result of sacrifices made. Mothers reported that despite their extraordinary circumstances, mothers were able to recognize personal strengths obtained from their experiences. Mothers form a new identity and discuss being more resilient, a strong voice for the child, and have an enhanced sense of compassion for others. It is evident that mothers are constantly adapting to their circumstances and new challenges. With these challenges came painful emotions, but there is still the presence of happiness and ability to find joy in their lives. Personal growth is evident in each participant.

Each participant felt that their experiences in raising a child with a disability was a transformative experience for them. Mothers described their experiences as a journey. Their daily lives are compounded with stress and frustration, but mothers adapt to these circumstances because it is their role as a mother. Their dedication to their child is due to the responsibility they feel as a mother to their child. Their unique parenting experiences present the challenge of connecting with others. Blame and judgment create a barrier to

creating meaningful relationships with others, this results in social isolation. Societal pressure and stigma create a sense of fear in mothers to openly discuss their child's disability. Mothers in this study developed a support system with other mothers of children with disabilities at school or through community organizations. Mothers identified their relationships formed with mothers with similar experiences created a place of instant acceptance and empathy. The positive and negative experiences in interacting with others contributed to a loss and a gain for mothers.

Implications

Through qualitative exploration, the impact of raising a child with a disability can be further understood in order to accommodate the needs of mothers. Mother's experience a significant amount of stress in responding to the overwhelming responsibilities of a child with a disability. Services are needed to better assist mothers in understanding the needs of their child and assisting mothers in implementing the kinds of services their child needs. Mothers are often informed of their child's diagnosis of a disability and not provided with subsequent resources in how to cope with their child's disability or put a plan in place to support their child's needs. Educating mothers and providing resources and professionals can help mothers create a plan of action for their child to ensure the best possible outcome for their child. Mothers will be able to cope more effectively and experience less stress in response to the responsibilities of their child's disability. These services can be provided through professionals in the medical community and through child study team members in school districts. Networking is an important component of providing necessary services for children with disabilities and can serve to aid mothers.

Participants in this study stressed the need for partners to be unified and supportive of each other in parenting a child with a disability. Failure to communicate and implement adaptive strategies to meet the needs of a child's disability creates tension and imbalance in the relationship and can often lead to divorce. Both mothers and fathers need to implement adaptive strategies to support their child and each other. Parents and families experience a significant amount of stress in dealing with the challenges of raising a child with a disability, this emphasizes the need for counseling services for couples to strengthen their relationship and address issues within their marriage.

Recommendations

The goal of this study is to further the understanding of the experiences, challenges, and feelings of mothers of children with disabilities. The results in this study are limited to the three participants. The small sample size limits the generalization of these findings. Further research with larger sample size is needed to generalize the experiences of mothers of children with disabilities. All three participants were Caucasians and belonged to middle class income families. Further exploration of mothers from various socio-economic and racial backgrounds are to obtain a broader view of mother's understanding and views of self.

References

- Berger, M. & Foster, M. (1986). Applications of family therapy theory to research and interventions with families with mentally retarded children. In Gallagher, J.J. & Vietze, P.M., Eds. *Families of handicapped persons*. Baltimore: Brooks. Pp. 251-260.
- Bourke-Taylor, H., Pallant, J. F., Law, M. and Howie, L. (2013). Relationships between Sleep disruptions, health and care responsibilities among mothers of school-aged children with disabilities. *J Pediatric Child Health*, 49: 775–782.
- Creasey G. & Reese M. (1996). Mothers' and fathers' perceptions of parenting hassles: associations with psychological symptoms, non-parenting hassles, and child behavior problems. *Journal of Applied Developmental Psychology* 17, 393–406.
- Crnic K. A. & Booth C. L. (1991). Mothers' and father's perceptions of daily hassles of parenting across early childhood. *Journal of Marriage and Family* 53, 1042–50.
- Crnic K. A., Friedrich W. N. & Greenberg M. T. (1983). Adaptation of families with mentally retarded children: a model of stress, coping, and family ecology. *American Journal of Mental Deficiency* 88, 125–38.
- Gerstein, E. D., Crnic, K. A., Blacher, J., & Baker, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research*, 53(12), 981-997.
- Hauser, O. (2015). I love being a mom so I don't mind doing it all: The cost of maternal identity. *Sociological Focus*, 48(4), 329-353.
- Helitzer, D. L., Cunningham-Sabo, L. D., Vanleit, B., & Crowe, T. K. (2002). Perceived changes in self-image and coping strategies of mothers of children with disabilities. *OTJR: Occupation, Participation and Health*, 22(1), 25-33.
- 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 delay: associations with parental mental health and family functioning. *Journal of Intellectual Disability Research* 50, 874–82.
- Johnson, R. F., O'Reilly, M., & Vostanis, P. (2006). Caring for children with learning disabilities who present problem behaviors: a maternal perspective. *Journal of Child Health Care*, 10(3), 188-198.
- Keller, D., & Honig, A. S. (2004). Maternal and Paternal Stress in Families With School-Aged Children with Disabilities. *American Journal of Orthopsychiatry*, 74(3), 337-348.

- Lichter, J. M. (2003). Mothers of preschool children with developmental disabilities: Their experiences, development, and self-concept.
- Markus, H. (1980). The self in thought and memory. In D.M. Wegner, & R.R.
- McDonald D. A. & Almeida D. M. (2004) The interweave of fathers' daily work experiences and fathering behaviors. *Fathering: Special Issue: Work/Family Issues for Fathers 2*, 235–51.
- Vallacher (Eds.), *The self in social psychology*. New York: Oxford University Press.
- Oyserman, Elmore, Smith (2012). Self, self-concept, and identity. M.Leary & J. Tangney (Eds). *Handbook of self and Identity*, 2nd Edition (pp 69-104).
- Saffee, Christal L., *Maternal Identity in Previously Infertile and Never Infertile Women* (1999). Masters Theses. Paper 459. Sec. 300.8 Child with a disability.