

PARENTS OF CHILDREN WITH AUTISM: THE STIGMA AND EMOTION WORK
ASSOCIATED WITH NAVIGATING, ADVOCATING, AND MANAGING AUTISM

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ABSTRACT

This study analyzes the experiences of stigmatization and emotion work through the interview responses of eight parents of children with autism. Developing from Goffman's theories of direct stigma and associative stigma this research integrates Hochschild's emotion work as a way that parents respond to the stigmatization that they encounter. The results of this study indicate that some parents of children with autism perform suppressive emotion work in the way they respond to stigmatization and obstacles that occur when raising a child with special needs. In addition, stigma occurs in interactions with close friends and family members, creating issues of boundary-crossing. Parents of children with autism respond to stigma by educating those closest to them and normalizing the experiences of themselves and their child. In order to cope with the hardships of stigma, some parents also work to advocate, problem-solve, and build community beyond their immediate relationships.

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DEDICATION

I would like to dedicate my thesis to my beloved brother Payton. Without your incredible spirit and love, I would not have had the same childhood and I would probably not have written this thesis. I hope to see you again one day. This thesis is also dedicated to my amazing parents Curt and Heidi who were the inspiration behind my interest in this research. Thank you for your unwavering support and for consulting me in my research process.

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CHAPTER ONE: INTRODUCTION

The current study seeks to understand how parents of children with autism experience Goffman's associative stigma and how it relates to the advocacy they do for their child. Stigma is characterized by stereotypes and negative perceptions about an individual or groups that do not fit into or follow social norms. This study recognizes that parents of children with autism may experience stigma through their relationship with their child. Through interviews with parents of children with autism, I found that the stigma parents experience reaches beyond their association with their child and affects their lives directly through their closest relationships with family and friends as well as through the institutions they access on their child's behalf.

Additionally, I wanted to know the role that Hochschild's emotion work played in the parental response to stigma. Emotion work is described as self-regulation of emotion in social interactions and situations. Specifically, I wanted to know how parents emotionally worked through stigma in the navigation, advocacy, and management of their child's autism. I found that parents routinely make sacrifices by setting their emotions aside to work through the challenges that come with raising a child with autism.

The Center for Disease Control (CDC) defines autism spectrum disorder (ASD) as a developmental disability that can impair communication and behavioral health with varying levels of severity (CDC, 2018). Impairments of communication can include both verbal and nonverbal skills such as a lack of eye contact, trouble displaying or understanding emotions appropriately, and difficulties in social contexts or relationships. Another facet of autism involves repetitions of behaviors or a need for routine as well as a unique relationship with one's sensory environment (Autism Speaks, 2019). Autism encompasses a spectrum of severity that is dependent on how the disability affects the individual's life (CDC, 2018). As this disorder is

recognized as a spectrum, levels of ability vary widely from person to person (Autism Speaks, 2019).

Most diagnoses occur early in a child's life, placing an emphasis on early intervention services. Autism becomes evident in children when they fail to meet or are delayed in meeting developmental milestones. Signs of autism can be noticed as early as eighteen months of age; however, it is usually not diagnosed until the child is two years old. Autism is diagnosed through a behavioral assessment by a trained professional (CDC, 2018). Assessment cannot point to the cause of the disorder, but it can be indicative of what treatment needs to be done. While there is no cure, there are therapy services available to aid in modifying characteristics of autism (Autism Speaks, 2019).

Autism and its effects are important to research because of the increasing amount of new cases every year. In 2000, children that were born in 1992 had a 1 in 150 prevalence rate for autism. The most recent data from 2014 indicate that children born in 2006 had a 1 in 59 prevalence rate for autism (CDC, 2019). With a continually growing prevalence rate, more people will be affected by autism both directly and indirectly. While autism is becoming more well-known and researched, families are still affected by the stigma that surrounds the disorder.

The families of those with special needs like autism are often forgotten in literature, especially literature involving stigma. Growing up with a brother with autism that required a more severe level of care gave me a unique perspective into the lives within my own family, but I always wondered, "Is there anyone out there who knows what we are going through?" Through this thesis project I sought out the perspectives of other families who had children with autism, focusing on the viewpoint of parents. I chose to interview parents who had children with autism because I wanted to understand the extra work and true unconditional love that goes into raising

a child with autism. Specifically, I wanted to know how stigma affected the lives of these parents and how they emotionally worked through stigmatization.

Problem Statement

Parents of children with autism experience an associative stigma that can motivate them to enhance their child's life through navigating diagnosis and treatments and advocating for their child while performing the care and emotion work necessary to manage this process. Parents of children with autism encounter associative stigma through interactions in schools and in close relationships. As a result, parents combat the stigma of autism through engaging in emotion work throughout their child's life. This study focuses on the parents who are able to turn to advocacy as a way to counteract stigma.

The central goal of this research is to examine the relationship between the stigma and emotion work that parents of children with autism encounter. Parents of children with autism experience a dramatic life shift after receiving their child's diagnosis. The autism diagnosis attaches stigma to parents and their children, requiring parents to perform emotion work to change feelings of helplessness into competence. Parents then feel obligated to navigate, advocate, and manage their child's autism in order to ensure their child's successes.

This has been the experience of my own parents. My brother Payton had a severe form of autism that left him nonverbal, requiring constant supervision and care. To this day, I have never met anyone like him. My family was centered around his care and needs for most of my life. Unfortunately, he passed away in 2015. Having a brother with autism made for a unique family experience that was stressful, beautiful, frustrating, and rewarding. Through my experience, I became interested in family dynamics, specifically of other families that had children with

autism. In my examination of the literature thus far, I have found that there is a large amount of behind-the-scenes work that parents of children with autism must do.

Through interviews with eight parents of children with autism, I found that stigma is experienced in almost every relationship and institution regarding their child. While associative stigma from their relationship with their child is part of the equation, I also found that many parents experience direct stigma themselves regarding their parenting and their advocacy for their child. Parents emotionally work through the stigma by educating others, normalizing their own and their child's unique experiences, building community, isolating, and suppressing emotions in order to effectively advocate.

Additionally, the institutions necessary to the functioning of the families of a child with autism often fail in supporting the needs of children with autism. Respite services are understaffed and have a high turnover rate that make impossible to find someone qualified and available to care for a child with autism. Similarly, schools lack experienced special education staff and rely on parents to be educators to their child's teachers. The issues within these institutions place an added pressure on to be advocates for their children.

The issues that the following literature review and subsequent chapters will address include the stigma and emotion work that parents of children with autism experience throughout their child's life in the navigation of a diagnosis, advocating for their child, managing emotions in each of these processes.

Research questions that I will address in this research include the following:

- First, how do parents of children with autism experience associative stigma?
 - Does that relate to the advocacy they do for their child?

- What type of emotion work factors into how parents navigate their child's autism diagnosis, advocate for their child, and cope with the stress of daily life?
 - In particular, how does emotion work factor into parents' navigation, advocacy, and management of their child's autism?

The project seeks to bring awareness to and understand how both stigma and emotion work are prevalent throughout the span of navigating to an autism diagnosis, advocating for the child in various settings, and the continual emotion managing process involved with raising a child with autism. Through my research I have found that parents of children with autism not only experience an associative stigma, but also experience a direct stigma through judgment they receive about their parenting and advocacy. The direct stigma of parents comes from close relationships of friends and family as well as the institutions they require to aid them in caring for their child. Parents in this sample combat the stigma they experience through emotion work done by suppressing anger and frustration in order to effectively parent and advocate.

In the subsequent chapters, I will discuss existing literature and theories of stigma and emotion work. Next, I explain the methods I used to collect data and answer my research questions. Then, I work to analyze the themes that appeared in my analysis section and conclude the results of my study. Finally, I identify limitations of my research and issues that future research should address.

CHAPTER TWO: LITERATURE REVIEW

Theory

Parents often stand alone in the goals they set for their child and are made to put themselves through extensive emotion work and stigma to get adequate therapy, education, and other resources for their child. The issues of stigma and emotion work are intricately tied to each part of caring for someone with autism. To start, I will analyze the theory surrounding stigma and disability. In particular, I focus on why parents may experience stigma due to the lack of understanding and acceptance of people with disabilities in society. I argue that stigma of disabilities leads to an associated stigma of those caring for people with disabilities such as autism. Therefore, parents must perform emotion work as a response to stigma and throughout the process of navigating a diagnosis, advocating, and managing their own emotions.

Stigma

This section will address the theoretical focuses of stigma and emotion work as they relate to autism as a disability and parents' involvement in combatting stigma. Stigma is a social theory within sociology that breaks down how social interaction attaches stereotypes to deviance (Goffman, 1963). This constructed representation, made through social interaction, creates a "virtual social identity" of an individual without knowledge of that individual's character (Goffman, 1963). In other words, an assumption is made about someone based on a stereotype. In contrast, the "actual social identity" of an individual are the things known to be true about someone (Goffman, 1963). When someone is considered stigmatized, it means that they are perceived negatively even if they do not actually fall under the stereotype attributed to them. As a result of this attribution, the stigmatized person is thought to be inferior to those who fall into normative ideas of what it means to be a person (Abberley, 1987). My literature focuses on the

ways people with disabilities such as autism are stigmatized to be somehow less than other societal members.

Stigma is placed on those with attributes that set them outside of mainstream social norms. If someone is deviant from the norm, it places them in a position vulnerable to stigma. At first, stigma was associated with visible physical disorders or deviances. However, it is now applied to invisible deviances or stereotypes as well. “Today the term is widely used in something like the original literal sense, but it is applied more to the disgrace itself than to the bodily evidence of it” (Goffman, 1963: p. 1-2). While autism is not a physical disability, the behavioral issues that are present in many people with autism are often the most stigmatizing.

Stigma about autism varies on a spectrum just like the disorder itself. People with more severe autism may act out aggressively, potentially hurting themselves (Bessette Gorlin et al., 2016) or others during reactive behaviors, contributing to a stigma of violence. Those with milder forms of autism may be given a stigma through an inability to understand social contexts or maintain friendships. Additionally, those with milder forms of autism may be expected to have a gifted ability that is unmatched by anyone without autism (John et al., 2018). However, those attaching stigma to people with autism are often misinformed and could be swayed by certain myths about autism (John et al., 2018). This type of ignorance has immense consequences for how people with autism and their families are viewed by society.

Some parents even believe that stigma about autism is present throughout society. A survey of parents of children with autism found that ninety percent of parents “think that most or some (as opposed to only a few) of the general public believe that a child with ASD will never hold a job, marry, or live independently” (Kinnear et al., 2016: p. 946). Other prevalent opinions include that people with autism cannot be a good friend, are mentally ill, dangerous,

intellectually challenged, and that their autism was caused by how they were parented (John et al., 2018). Stigma surrounding characteristics of autism isolates those with autism and their families (Gray, 1994) and creates a focus on the medicalization of autism.

The fact that autism is categorized as a disorder or disability also has serious implications. Abberley (1987) notes that disability is treated much more like a medical issue rather than a social issue. The medical model looks at disability as something biological that needs fixing. It sees the disability as part of the person, an “embodiment” that is both physical and identifying. On the contrary, the social model views disability as a product of the social environment. To become socially just for people with autism, the societal focus needs to change from medical intervention to intervention through avenues of social justice (Siebers, 2008).

Social justice for children with autism is an ongoing process that is most often carried out by their parents or caregivers through advocacy (Boshoff et al., 2016). Parents may advocate for social justice for their children with the main goals of inclusion and acceptance into mainstream society. In this way, parents act as the primary facilitators of communication for the child and work to provide equity so that their child may be treated fairly (Boshoff et al., 2016). They advocate in schools and even with their own friends and family members in order to change perceptions from those based in stigma to those manifested in acceptance. If societal views became more socially just, disabilities would not be as limiting.

As a result of the intricate involvement in their child’s life, parents of children with autism can experience what Goffman calls a “courtesy stigma” (1963). Courtesy stigma, otherwise known as associative stigma (Gray, 2002) is attributed to people who have close relationships with those who are widely stigmatized. By having this close relationship to a deviant person, the label of deviance carries over to the nondeviant person as well. Even the

parent-child relationship is “obliged to share some of the discredit of the stigmatized person to whom they are related” (Goffman, 1963: p. 30). When someone takes on an associative stigma, they are portrayed as a normal identity, but are given access to the associated deviance through their relationship with the stigmatized person (Birenbaum, 1970). People with associative stigma are also able to act as a barrier of “normalization” between the stigmatized person and those without stigma (Goffman, 1963). For example, parents may no longer want their child to play with a child with autism. As a result, parents of the child with autism could feel embarrassed and frustrated for their child (Francis, 2012). In this way, parents of children with autism take on the impacts of the stigma of autism without experiencing it directly.

Emotion Work

The second theory that I utilize in this research is emotion work. Hochschild (1979) defines emotion work as managing or acting out emotion. Emotion work is a type of self-regulation that requires thoughtful processing of emotions or non-emotions. “Emotion, it is argued, can be and often is subject to acts of management. The individual often works on inducing or inhibiting feelings so as to render them ‘appropriate’ to a situation.” (Hochschild, 1979: p. 551). In this way emotion work is a performative social task done in social interaction where emotions are produced (Pugliesi & Shook, 1997). A technique of emotion work closely linked with the experience of parenting a child with autism is the cognitive technique. Cognitive work involves a conscious effort to change the feelings one has about a thought or idea (Hochschild, 1979). In the instance of parenting a child with autism, parents often have to change the way that they think about their child’s future after receiving an autism diagnosis (Singh, 2016). They may have envisioned a fully developed future for their child, but now they must reimagine it through cognitive emotion work.

In particular, the type of emotion work that parents of children with autism work with is suppression. Suppression is when “the cognitive focus is on an undesired feeling which is initially present” (Hochschild, 1979: p. 561). With suppression, a person talks themselves out of feeling a certain way. The feeling may still be present, but the focus is on changing how one feels in order to quash the immediate presence of that emotion. In finding out their child is diagnosed with autism, many parents find themselves in a place of despair, grieving for the life that they thought their child would have had (Fernandez-Alcantara et al., 2016). In order to maintain their family, parents often must suppress this undesired grief and move forward to help their child.

Evocation is another type of emotion work that can be done by parents of children with autism. Evocation is when “the cognitive focus is on a desired feeling which is initially absent” (Hochschild, 1979: p. 561). A general instance of this would be if someone actively worked themselves up to a feeling. The feeling being worked towards is missing, but the individual focuses on this emotion until they finally feel this way. It’s almost a “fake it ‘til you make it” form of emotion work. Evocative emotion work can happen when parents are evolving into advocates for their child. Many parents may feel uncomfortable asserting themselves into situations where they have to be critical of other people and establishments. Through evocation, parents work to change their feelings of uncertainty into feelings of competence.

Understanding Parents’ Work

Caring for a child with autism requires constant emotional and intellectual work battling the stigma parents can experience. This section marks out three distinct parts of parental work that are present in current literature: navigation of the autism diagnosis and treatments, parental

advocacy in schools and within circles of family and friends, and the management of emotion work involved with combatting stigma.

Navigation

Navigating an autism diagnosis can be a long, tough, and grueling process. While autism is becoming more well-known, there are many myths surrounding the causes and diagnosis of this disability. The causes of autism have been widely debated in popular media. In a study of lay person causal beliefs of autism, it was found most people believed that autism was caused either by parenting, genetics, supernatural, or medical/chemical factors (Gulyn & Diaz-Asper, 2018). Although beliefs varied for a number of reasons, the beliefs of both parenting and genetics directly placed blame on parents of children with autism.

When navigating this initial diagnostic process, parents can run into beliefs like these from family, friends, and neighbors. While parents of children with autism often turn to autism therapists for advice about their child (that is, if they are able to access that treatment), a study found that around 12% of parents turn to family and friends instead (Gibson et al., 2017). However, parents most likely turn to their close relationships prior to seeking out diagnosis and services, making the value of these relationships much greater than those already receiving professional help. If family and friends believe that autism could be caused by parenting or genetics, this can create an associative stigma that could be internalized by a parent.

The theories surrounding causes of autism can place blame on parents in a number of ways. For instance, if autism is caused by genetics, parents could face blame or guilt for their interaction of genes that caused their child's disability. If autism is due to environmental factors, parents could feel as though it was their parenting that led to their child's autism. Each of these

theories creates a stigma about parents' involvement in causing autism. As a result, some parents push back by looking for external causes.

For example, to combat this stigma, vaccines make for an easy scapegoat. Since vaccines are practically mandated, parents also can redirect blame on the medical institution rather than feeling parental guilt. In this way, parents who believed vaccines caused their child's autism could project the stigma elsewhere. While no parent should feel responsible for their child's autism, it is important to recognize that vaccines do not cause autism and are integral to proper health care.

Although vaccinations are not the cause of autism, there are still many people that believe otherwise. Andrew Wakefield, the researcher that first posited that vaccines could cause autism, has been denounced from the medical community and can no longer practice medicine due to his unethical research practices (Hussain et al., 2018). However, there have even been celebrity endorsements of this theory. Jenny McCarthy claimed that her son had only exhibited symptoms of autism after being given routine vaccinations (Hussain et al., 2018). Despite the overwhelming evidence against this theory, there are still parents that put their child and others at risk of contracting previously eradicated diseases by refusing vaccinations. Because of the widespread misinformation surrounding causes of autism, some parents monitor their children closely after vaccinations for symptoms and blame vaccines for signs that were likely there prior to the vaccinations (Bearman, 2010).

When parents begin to notice signs of autism, they start to discover that the autism diagnosis is often inaccessible. Parents often notice the signs that their child is different and seek the help of doctors. However, doctors are usually hesitant to offer an autism diagnosis, using the excuses "he's just a boy" or "he needs to grow up" (Singh, 2016: p. 1110). In situations like

these, parents have to manage their emotions (potentially suppressing anger or frustration) in reaction to stigma from doctors and instead be strategic about getting a diagnosis as it is typically required in order to get treatment. However, specialists have long waiting lists and are only truly accessible to families with higher educational backgrounds or socioeconomic statuses (Singh, 2016).

Accessing a diagnosis may be difficult, but finding accessible therapies and treatments are even harder. Finding appropriate treatment and therapy requires parents to fill in the blanks on their own. Post-diagnosis, autism becomes the “focal point” of the family (Cohen, 2002), making the pursuit of services a top priority. Therapies and intensive schooling have waiting lists of their own and are accessible only to those who can find and afford them (Singh, 2016). Still, there is a growing campaign to begin intervention early (Cohen, 2002), making it more discouraging for those struggling to access services. Accessibility issues can cause parents to feel incredibly frustrated as they fight for their child’s future.

In order to locate services, parents also need to process the autism diagnosis and what it means for their child. Many parents imagine their child’s life as part of the normative experience. When they had just given birth to the child, they were not thinking about their child missing developmental milestones or questioning how they will have to do things differently for their child. Rather, parents need to perform evocative emotion work by re-orienting themselves to what life will be like with a child with autism. While finally getting a diagnosis may grant some relief, parents often need to reframe their mindset from one of despair of a life-long condition to hope for some sort of independence for their child (Singh, 2016).

Beyond the navigation for their child’s diagnosis, parents also have to navigate the stigma facing their child and themselves. This stigma can come from schools, family, and friends.

Within schools, teachers may be understanding of students with other disabilities, but have difficulties adapting to students with autism. Sometimes parents even feel as though schools would rather not have their child attending. Their child is seen as a burden on the school rather than just a student (Broady et al., 2017).

Autism can also be a burden on close relationships. Friends and family relationships are often abandoned as a result of misunderstandings of autism. Parents in Gray's study report feeling that other parents just do not get it (Gray, 1994). One study found that family and friends of children with autism told parents a variety of things that stigmatized both parents and their children. In one case, a child with high-functioning autism was not recognized as having a real disorder by a family member as "there's nothing wrong with him" (Broady et al., 2017: p. 228). Behaviors were seen as a phase that could be outgrown. Other parents were told that they just needed to discipline their child more (Broady et al., 2017). Rather than educating family and friends who misunderstood autism, parents decided to withdraw from these relationships. The emotion work of advocating even amongst family and friends was deemed to be too much for parents, leading them to cut off the relationships and focus on advocating for their child in other arenas.

Advocacy

Advocacy comes in a variety of different forms, impacting both on an individual and social level. Parents of children with autism may use advocacy as an avenue to enhance their child's agency. Advocacy in families with autism can involve anything from meeting with their child's teacher, being the voice for their child at a doctor's visit, or even educating close friends and family about their experience with autism. Advocating for a child with autism does not come without its difficulties. Advocacy is a "life-long, persistent and all-encompassing challenge"

(Boshoff et al., 2016: p. 788). On the individual level, a challenge of parental advocacy is to perform the emotion work needed to carry out advocacy.

In order to advocate, parents need to work on their emotions to suppress feelings of anger and frustration in order to effectively advocate for their child. This suppressive emotion work requires pushing down negative feelings and replacing them with more appropriate emotions (Hochschild, 1979). Becoming an advocate can be emotionally draining because it involves taking on an additional role while trying to fulfill all of the other important roles in their lives (Boshoff et al., 2016). Advocacy can be taxing on a parent, making it crucial that parents perform the proper emotion work to become persuasive advocates for their children.

In order to effectively advocate, parents of children with autism have to work towards the emotions of competence and confidence. Parents can be passionate about making sure their child has everything they need, but they need to use the expressive technique of emotion work to make their outward emotion match their inner feelings (Hochschild, 1979). Some parents may initially have fervor for their child's acceptance, but experience evocation—the focus of a deficient feeling—when it comes to the confidence to go through with the advocacy. For example, parents may desire the feeling of competency to speak to their child's school board, but that feeling may not be with them to start. The performance of emotion work is necessary to not only feel confident to advocate, but to combat the stigma present in public arenas.

Schools are the first public arena that a child encounters, making parental advocacy almost inevitable due to the inadequate education that children with autism often receive. Stigma is established in schools through the deficient follow-through of federal policies regarding special education. The Individuals with Disability and Education Act (IDEA) “mandates that all eligible children (including children with autism) have the right to a free and appropriate

education that meets their unique individual needs” (Singh, 2016: p. 1112-1113). Although an autism diagnosis guarantees eligibility for adequate schooling services through IDEA, children’s needs are not always met. Parents often have to work their way through people, paperwork, and meetings in order to get the school to perform at the level their child needs (Singh, 2016). Schools enhance stigma by making it difficult for children with disabilities to achieve. In turn, parents must fight for their child’s educational rights. The stigma present in schools also carries over into the private arena of friends and family due to misunderstandings surrounding the child’s autism.

In Broady et al.’s (2017) study of people who were the primary caregivers for those with autism, they found that extended families and friends were unsupportive of the child and passed stigma onto the family. Other parents who were previously friends with a family prior to an autism diagnosis would be rejected because they were afraid of the child’s behavior. Extended families of the child with autism would not help in babysitting or offer emotional support to the family due to the stigma they felt surrounded the child’s behaviors. Friendships also deteriorated because friends of the family did not want to be around the child with autism (Broady et al., 2017).

Advocacy is difficult to achieve when public and social support systems both buy into the stigma surrounding autism. Parents often take the stigma that was enacted towards their children personally (Broady et al., 2017). However, parents can still advocate for their child within their close relationships if they wish to reduce this stigma. Parents may perform cognitive emotion work through suppression by replacing anger towards a stigma with a want for their child to just be seen as a person. Singh found that parents shape “personhood” by accentuating the great qualities of their child with autism (Singh, 2016: p. 1115). They gently advocate to those around

them that their child's autism is a "difference and not a disability" (Singh, 2016: p. 1115).

Advocacy directs stigma away from autism and allows for this personhood to be developed.

As a result of parental advocacy, the child with autism is humanized and able to get the proper care, education, and treatments they require. Parents also benefit from advocacy through using it as a coping mechanism to gain control over a diagnosis and life path that they believed was out of their control. Parental advocacy has greater societal implications as well. Even if a parent is just advocating for their own child, their actions help to make sure that other parents do not have to go through the same stigmatizing process (Boshoff et al., 2016).

Management

In the context of unsupportive family and friends, parents of children with autism must learn to manage several things on their own, including their relationships and emotions. Navigating and advocating for a child's needs can be very draining. Therefore, it is important for parents to balance their family's, child's, and their own needs to maintain their family (Boshoff et al, 2016). This incredible responsibility can put parents, especially mothers (who take on the primary caregiver role), at a higher risk of depression (Moes et al, 1992). One study found that some of the biggest risk factors for depression in mothers were if mothers thought they could not afford autism therapy services and if their child had more problem behaviors (Taylor & Warren, 2012).

Parents of children with more severe behaviors often have the hardest time with isolation. They feel like they have nothing in common with parents of non-disabled children because they are constantly worried about their child injuring themselves or others. In Gray's study, many parents felt like they were unable to leave home to meet friends because it was so difficult to find someone to watch their child (Gray, 1994). Besides the isolation from external relationships,

parents of children with severe autism can feel isolated from their own child. Children with more severe forms of autism may have little to no verbal communication skills so parents have an even harder time understanding their child (Bessette Gorlin et al., 2016).

As a result of this incredibly stressful parenting situation, parents turn to different coping mechanisms to maintain family functioning. As mentioned previously, advocacy is one way that parents both cope with and manage their lives (Boshoff et al., 2016). When parents advocate, they see themselves as being educational and proactive. Broady found that parents' love for their child motivated them and helped them to cope with any stigma they experienced (Broady et al., 2017). Gray's study on parental coping found that other coping strategies included using services, relying on family support, religion, individualism (creating identities separate from autism), and withdrawal. However, it was discovered that none of these coping strategies worked better than the others (Gray, 1994).

Instead because so many of the families in Gray's (1994) study used special autism services as their main coping mechanism, parents thought this service to be the most successful for them no matter what other strategies they used. However, if the child experienced more severe signs of autism, parents found it much harder to cope. In the follow up to this study, parents overall learned to better cope with their child's autism. Some parents were receiving psychological treatment through therapy or medication to help deal with the stress and anxiety of raising their child (Gray, 2002).

In addition, external emotional support outside of the family has been shown to return eventually. Gray (2002) found that over time, extended family members—like grandparents—became more understanding of their grandchild's diagnosis. As a result, parents felt less of a familial isolation and more acceptance of their child. Parents also became less embarrassed of

their child's public outbursts. They did not feel the stigma as much or at least no longer cared about it. However, they did begin to worry more about their child's future as they reached adolescence and adulthood (Gray, 2002).

In light of this research, I seek to add greater understanding about how parents in the Fargo-Moorhead area experience emotion work and stigma in navigating to a diagnosis, advocating for their child, and managing their lives. The methods chapter will cover information about how the study will be conducted with regards to the research plan, participant selection, and data analysis. By interviewing parents of children with autism, I was able to more deeply comprehend the experiences of emotion work that parents must engage in to aid their child in combatting stigma.

CHAPTER THREE: METHODS

Purpose and Goals of Research

This research project was meant to obtain insider knowledge from parents of children with autism about their experiences surrounding stigma and emotion work. The goal of this research was to gain a better understanding of the stigma that these parents encounter and learn about the emotion work they experience through each step of navigating, advocating, and managing their child's autism. The research project helps to better understand the struggles of a mostly ignored and forgotten population. It is important that these parents have a voice outside of their usual advocacy for their child so that societal changes can be made to better adapt to the needs of individuals with autism.

To reiterate, my research questions are as follows:

- First, how do parents of children with autism experience an associative stigma?
 - Does that relate to the advocacy they do for their child?
- What type of emotion work factors into how parents navigate their child's autism diagnosis, advocate for their child, and cope with the stress of daily life?
 - In particular, how does emotion work factor into parents' navigation, advocacy, and management of their child's autism?

Research Design

For this research, I collected qualitative interviews with parents of children with autism. Qualitative interviews were the chosen method of this research because it allowed me to obtain conversational data by building and maintaining relationships with participants (Rubin & Rubin, 2012). I used this method as a way to answer my research questions, because it provides a space through which I engaged in in-depth discussions with my participants about how they navigate

their experiences with their child and the institutions and resources available for them to care for their child.

Interviews focused on parents' experience of stigma and the emotional work attached with caring for a child with autism. The interview guide (see Appendix A) is organized in a way to guide parents through a narration of their experiences. The three main categories that are addressed are navigation through a diagnosis; autism advocacy in schools and close relationships; and how parents manage and cope with the emotional hardships of caring for a child with autism. Only two of the participants come from the same family, the analysis will reflect discrepancies and similarities of this data.

In addition to the interviews, participants were asked to fill out a short questionnaire (see Appendix B) regarding demographic information that includes: household income, race/ethnicity, gender, number of children living in the household, number of children with autism living in the household, and marital status. This data is only used in the research to identify variances within the research group. For instance, participants of this study all identified as white and with the exception of one participant, all were women.

Participants and Recruitment

Participants for this project included parents of children with autism. I had begun my research with the intention to interview parents with children between the ages of five and twelve to focus on the experiences of parents with children in elementary school. I chose this age range because parents would likely not have experienced interactions with schools until their child is at least five years old. However, this age range of participants was difficult to access, so I expanded my age parameters and ended up with a range of children between four and twenty-five years old. Although this was not the intended age range, I was still able to ask questions of parents

with older children to reflect on their experiences and I asked those with younger children about their worries for the future.

The sample size was eight participants and I believe that data saturation was achieved. Saturation is only achieved “when gathering fresh data no longer sparks new theoretical insights” (Charmaz, 2014: p. 213). In other words, new data reiterates already established conceptual categories and fails to offer new features of existing data. I found several themes repeated across participants and no new themes emerged after extensive interviews. Although, eight participants may not allow for a wide external validity, there may be some internal validity (Maxwell, 2013) that matches experiences of parents of children with autism from prior literature.

Recruitment first came from contacting an autism agency in the Fargo-Moorhead area. I had worked at this agency and had contact with the operations manager. She was the initial contact with potential participants via an email script (see Appendix C) that I prepared. By contacting participants through the operations manager of this agency, the agency and its patients were protected from any potential outside risks of confidentiality. Participants also contacted me to be a part of the study to ensure voluntary and uncoerced participation. Since recruitment from the agency only resulted in one participant, I reached out to other agencies that worked with children with autism and support groups for parents of special needs children in the area. Sampling from support groups yielded four additional participants. I also utilized snowball sampling, asking participants if they have suggestions for other people who might like to participate in my study, this made up the rest of my sample, for a total of eight participants. Pseudonyms were used to protect the identities of these participants.

Demographics

Table 1

Demographic Information

Name	Gender ID	Race	Income	Marital Status	Adults in House	Adults Working	Children in Home	Children with Autism in Home
Elaine	Woman	White	76-100k	Married	2	2	4	2
John	Man	White	51-75k	Married	2	2	4	2
Holly	Woman	White	51-100k	Married	2	2	1	1
Caitlin	Woman	White	51-75k	Divorced	1	1	3	1
Beth	Woman	White	Over 100k	Married	5 (2 parents, 3 kids)	5	3 (adult children)	1
Rebecca	Woman	White	51-75k	Married	2	2	1	1
Tessa	Woman	White	N/A	Married	2	1	2	1
Anna	Woman	White	76-100k	Married	2	2	1	1

Through a short demographics survey, I was able to learn specific details about my participants' backgrounds. In my sample of eight participants, all identified as White/Caucasian and with the exception of one participant, all were women. Incomes ranged from \$51,000-over \$100,000 per year. Only one participant was divorced, but she continued a coparenting relationship with her ex-spouse. The average number of children living in a participant's household was about two children. In this sample, only one family had two children with autism living in the same household, the rest only had one child with autism.

It is important to note the connections between participants as these are relevant to later analysis. Elaine and John are married to one another and have four children, two of which have diagnoses on the autism spectrum. Caitlin had recently started a support group for parents of children with a variety of needs prior to being interviewed. Holly had attended one of the meetings for this group and decided to be interviewed at the same time with Caitlin. Holly and

Caitlin were the only participants that were interviewed together. Lastly, Beth and Rebecca had each ran their own support groups for parents and merged together to create a non-profit for those with children with special needs.

Data Analysis

The data analysis portion of this research project was conducted through interview transcription and coding. Transcripts were sent to participants to allow them to retract or add responses to their own interviews. This process ensured that participants had agency in the research process through member checks so that conclusions would not be taken out of context (Maxwell, 2013). When transcripts were sent back to participants, I asked some follow up questions and if they had wanted to redact anything they had said. Participants clarified my questions, but no one asked for any redactions.

The coding of interview data was done through the process of categorizing responses through summarizing, coding, sorting, comparing, and including different perspectives (Rubin & Rubin, 2012). Memos were also kept throughout the interview, transcription, and analysis processes to help me retain memory of the interview that may not be present in the transcript. This helped me to engage with my theoretical approaches in relation to the data I collected. The first step in analysis was initial coding or drawing out items of interest line by line from the transcripts. I utilized Microsoft Word to make comments next to each quote that I felt pertained to my research questions. Next, focused codes were made to make out descriptive categories to compare and contrast themes. I went back through my transcripts a second time to pick out recurring topic that were brought up in the interviews. Lastly, axial coding was done to turn the descriptive categories into conceptual categories and to create a structure to link concepts together (Charmaz, 2014).

CHAPTER FOUR: ANALYSIS

In this analysis, many themes emerged as integral to documenting the experiences of parents of children with autism. These themes are organized into major categories to help me address my primary research questions:

- How do parents of children with autism experience an associative stigma?
 - Does that relate to the advocacy they do for their child?
- What type of emotion work factors into how parents navigate their child's autism diagnosis, advocate for their child, and cope with the stress of daily life?
 - In particular, how does emotion work factor into parents' navigation, advocacy, and management of their child's autism?

The major categories include parenting processes and stigma, emotion work with family and friends, normalization practices, problems with school and care, and coping strategies. Each category includes 3-4 themes (see chart below) which highlight the complex ways in which parents navigate the challenges of managing stigma as they engage in the emotion work necessary to support their children and themselves. Below is a chart of the organizational categories that structure my analysis and discussion of the primary themes that emerged in my interviews. I used these categories to guide the organization of this chapter.

Table 2

Table of Themes

		Thematic Sections				
		<i>Parenting Processes and Stigma</i>	<i>Emotion Work with Family and Friends</i>	<i>We're Just Like Everybody Else: Normalization Practices</i>	<i>Problems with School and Care</i>	<i>Coping Strategies</i>
Themes	Relief and Naming	Managing Stigma in Friendships: The Virtue of Empathy		Just Being a Parent	Moving	Advocating for Others
	Grieving	Managing Stigma with Family: The Challenges of Boundary-crossing		Just Being a Kid	Difficulty Finding Services	Problem-Solving Now, Emotion Processing Later
	Bad Mom	Educating Others: Resetting Boundaries and Setting Expectations		Relating to Their Child through Empathy and Shared Humanity	Good Experiences with School/Daycare	Building Community
		Isolation		School Misunderstandings and Miscommunication		

Parenting Processes and Stigma

In navigating to a diagnosis, parents in my study experienced relief and grief at finally having a name for what their child was going through. Throughout this process, parents tried to maintain their composure, but had to perform emotion work in mourning the loss of the expectations they had for their child while working to accept the new normal of what their lives would become. Being able to put a name to what their child was experiencing ended up feeling like a weight lifted for some parents, but for others receiving a label added weight to their shoulders. As parents became adjusted to their new lives, mothers in this sample began to experience the stigma of being a “bad mom.” They were judged for how they parented as well as how they advocated while adjusting to their new role as a mother to a child with autism.

Relief and Naming

Elaine had been worried about a diagnosis more severe than autism. Elaine had seen how Down Syndrome and schizophrenia had affected her own extended family members and worried that her children would face similar challenges. When she had spoken with a doctor about assessing her first son for disabilities, she was concerned by the questions the doctor was asking her:

I was a little worried because once I started listening to the questions she [the doctor] was asking us I guess I got a little...worried because we also—my uncle on my mom's side has schizophrenia and so I guess that triggered in my mind so when I heard it wasn't that I was super relieved... I think the first time—like I said it was kind of a relief because at least it wasn't schizophrenia...which is stupid because that's manageable as well, but when you see someone devastated by it, you know, it takes a toll on you.

The diagnosis of autism aided Elaine to see her child's future as manageable. She felt reassured that although caring for a child with autism would be difficult, the burden may be less than what she had seen from her uncle with schizophrenia. Being able to have the label of autism excluded the possibility of other worries she had and allowed her to have a better sense of her son's future.

Rebecca's son exhibited signs of autism differently than most, making it hard for her and her son's doctors to reach the correct diagnosis. While Rebecca's son had been developmentally advanced for his age, he rapidly changed in front of her eyes:

He kind of disappeared on us. He was advanced in almost everything and then all of a sudden, he was gone. He just wasn't there anymore. So, they thought he had like cancer or a tumor or something horrible where he was gonna die. And then we went through almost six months of trial and diagnosis to figure out that he had autism.

After experiencing the trauma of thinking she was going to lose her child, Rebecca was relieved to accept an autism diagnosis and even saw it as something manageable.

On the other hand, Beth and Tessa's articulated a sense of relief with having a name for what their child was experiencing and being able to seek services to help them. Beth's son had been diagnosed with epilepsy as a newborn and had struggled with seizures his whole life. However, Beth felt that the diagnosis did not encompass all of the different behavioral traits she noticed in him. However, having constant seizures overshadowed some of those traits and made it hard to get to an autism diagnosis. When asked about the range of emotions she experienced when finding out that her son had autism Beth said:

I think our experience—or mine personally was a little bit different than probably a lot of people because we already had this very stressful, very emotional life experience of him starting to have seizures as an infant. So now I have all of these—we're constantly watching for him to meet milestones, we were constantly, you know in like fight or flight when he would seize, and he had lots of seizures so that was part of it. And then there was all this quirky stuff. So if you said he had epilepsy, it didn't explain what he had so I was actually relieved when he got an autism diagnosis, because I'm like, "Okay, that explains it," then I didn't have to feel like I had to do this big spiel about what needs he had. I could say, "Well he has a kitchen spoon because he has autism," you know, kind of a thing. So, for me it was not—I wasn't shocked, I was kind of just relieved that we could call it something.

Having the label of autism allowed Beth to summarize why her child had quirks or did things differently than other children. Rather than delving into long-winded conversations to explain her son, she felt reprieved in being able to identify his diagnoses.

Tessa also experienced relief in finding a name for what made her son different. However, her main sense of comfort came from qualifying for services. Having a name for what her son experienced not only gave her a linguistic tool to help her understand her son's experiences, but it also enabled her to gain access to resources. Her son had been diagnosed with a speech delay at first and like Beth, she felt there were more developmental issues beyond his language. Tessa had come across autism when doing her own research and asked her son's speech therapist about it, but was told, "No, I don't think he has autism, I've worked with kids with autism. I just think he's stubborn." Still Tessa continued to have her son reassessed and came back with a diagnosis of Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) before he eventually qualified for an autism diagnosis.

Although she was surprised that her son did not get an autism diagnosis right away, she was satisfied after each diagnosis because they still qualified for services. However, having an autism diagnosis helped her to feel more secure in being able to get services as her family moved for various jobs. Additionally, having researched autism prior to her son being diagnosed helped her to prepare her for the sadness mixed with relief both her and her husband felt at having a son with autism.

Grieving

Tessa had found comfort in receiving her son's autism diagnosis to secure services for him, but she felt sad at the officiality of the diagnosis. She had been taking him to therapies for a while at this point and had it in her mind a while before he was officially diagnosed that he had autism, but the diagnosis "sealed the deal." Tessa felt that her husband took it a little harder because while he was involved in his son's therapies, having a name for what was going on made it feel more real to him. Grieving the loss of expectations for their child acknowledges that there

is a stigma to having an autism. In this way, parents internalize neurotypical values as achievable milestones but are crushed when they realize that their child might not be able to obtain those goals (Singh, 2016).

The reality of the autism diagnosis for Beth's son began with the satisfaction of being given a name for his behaviors, but Beth still mourns the lifelong repercussions of the diagnosis. She told me about a time when she had gone shopping for ties for her son and broke down in the middle of the store because she realized that her son would never be able to drive. When parents mourn their child's diagnosis, they are typically grieving the loss of the neurotypical life they had expected for their child (Fernandez-Alcantara et al., 2016). Elaine described a similar feeling of grief that she felt for both of her children with autism:

But, I think you go through...you go through a weird stage because at the same time it's kind of like—as a parent, as a mom especially when you're pregnant you focus on—“Okay as long as they have ten fingers, ten toes, and are healthy I'm happy.” And then later to—you know, you have this dream of, “Okay, what are they going to be when they grow up” and this and that and, when they are diagnosed it is...it's a blow because you just see all the hurdles that are—extra hurdles that are gonna be put in their place. And...it's just hard. So, you kind of—you realize “Okay, my kid's not gonna be that perfect kid,” which is stupid because no kid is perfect to begin with [laughs]. But it just, you know, you go kind of through a mourning phase of what—the death of what you thought was going to be your kid's life. But at the same time, it opens so many opportunities—I think a lot more now, especially with [youngest child] than when I had [oldest child].

Elaine highlights how there are certain normative experiences that parents expect for their child. Receiving a diagnosis of autism can mean giving up those normative ideals and expectations, making it seem like a loss of their child's future (Singh, 2016). Although Elaine eventually began to see her sons' diagnoses as an opportunity, she had to work to get that emotional state by first going through the grieving process. Caitlin also spoke about grieving her child's abilities: "I was devastated, angry, and confused and I'm still confused because I don't know—you know, nobody's gonna answer the question, 'Will he talk? Will he be able to get married? Will he be able to graduate?' I still want those things." Caitlin still wants her child to meet those neurotypical milestones but recognizes that some things may be out of reach.

On the other hand, Anna and Holly were able to accept their children's diagnoses more easily. Anna grew up with a brother with autism, so she did not experience the grieving process to the extent of some other parents: "...from my perspective, it wasn't like all devastating. I mean it was still—you are devastated because, you know, 'Is my child every going to be able to do A, B, and C? Is he ever going to have a full sentence come out of his mouth?' You know, that sort of questioning." Anna was still upset because the future is so uncertain of what her child is going to be able to do, but she did not see it as a tremendous loss. Likewise, Holly's experience with her own disability also helped her to be more accepting of what her son's life would be like:

...I have muscular dystrophy, so I grew up as a kiddo with differences and stuff. And like I don't have the expectations in life that most people—or I didn't have those going forward with [son] it was just like, "You're gonna be a cool kid no matter what." And then I run some state councils for people with disabilities so I've seen people with some severe, severe mental disabilities on councils and stuff with me that I don't think it's such a—to me it wasn't like, "Ugh his everything is over," because I don't have those

expectations, he doesn't need to graduate and get married. It was so different for me that I never felt like I grieved or was sad about it. Because I—especially because as soon as she said that—I pretty much accepted it at that [club] meeting. Like, “Yup, that's what it's going to be,” so that's how it was for me.

Holly's unique perspective allowed her to move past the emotion work involved processing grief. Being that she had lived with a disability throughout her life, she already knew what having a disability entailed and felt comfortable with her son not achieving certain neurotypical expectations.

In both Holly and Anna's cases, there was less emotion work involved in accepting the diagnosis and grieving the lives they had anticipated for their children. They had already experienced stigma of disability in their own lives, so they did not feel like there was a huge burden being added to their shoulders. On the other hand, parents who had not had the same experience with stigma felt an additional strain on their lives by grieving the expectations they had previously held for their child as well as worrying about the stigma their child would experience in the future. However, emotion work is needed in situations beyond grieving a neurotypical life. Parents also perform emotion work in response to stigma generated by the people they are closest to.

While parents find relief in having a name for their child's behaviors and grieve the milestones their child may not achieve, they try to find understanding in what life will be like for their child and themselves. At the same time, family and friends of the child with autism are attempting to understand the diagnosis as well. They may have intentions to help and support their friend or family members with the autism diagnosis, but misconceptions of what parents should do and how autism manifests in a child cloud their perceptions and make it difficult to

understand unique family struggles. Ultimately, they respond with suggestions that are more stigmatizing than helpful to the parents of the child with autism. In turn, parents in this sample perform emotion work to be able to defend stigma of their parenting as well the ways that they advocate for their child.

Bad Mom

One theme that came up in almost every interview was what I call the “Bad Mom.” I identify the “bad mom” as the mother as opposed to the “bad parent” because my sample consisted of mainly women and only women addressed this theme in their interviews. The “bad mom” has two parts to it. In the first part, the *bad mom* is meant to reflect how parents are perceived when their children with autism demonstrate behavioral issues. Typically, parents experienced stigma from friends or family, or even from strangers that made them feel as though they were being a bad parent. Some parents were even called out on it directly. This experience highlights the way the women participants in my study experience not only an associative stigma, but feel they are stigmatized as a result of their experiences as a mother of a child with autism.

Elaine mentioned on several occasions that she felt judged by others and her own family for her children’s behavior. For instance, she felt that because her kids had more mild traits of autism people would attribute their behavior to their parents spoiling them rather than autism:

And then also, like I said with my kids being more high functioning it’s also very frustrating because: A. people don’t believe you because they think, “Oh they’re just being brats,” or “You just spoil them,” or—in which case it’s not the truth.

The behaviors of Elaine’s children do not have anything to do with how they are parented, but Elaine still takes on a stigma of being a bad mom. While hearing judgement from others is one

thing, hearing you are a bad mother from your own family hurts on a whole other level. Elaine noted that family gatherings can be especially difficult because she is not only defending herself and her children but is also trying to maintain a good relationship with her family. Some things that she has heard while with her family include: “Oh, they’re just misbehaving because you allow them,” “They’re spoiled brats,” and “They need to be spanked.” Judgement around how children with autism were disciplined was a common experience of other parents as well. Rebecca’s mother-in-law had told her she thought if Rebecca’s son were spanked or disciplined more harshly, he would not have autism. However, autism cannot be spanked out of a child.

Even when families are supportive, they can still say hurtful things that make mothers question their parenting. Anna’s family was supportive of her, but she still was judged about her parenting priorities:

That’s a tough one because, even though they’re supportive, he still has antisocial tendencies or behaviors and there is kind of judgment of “Well if you laid down the law better, he wouldn’t be eating with his fingers.” And I’m like, “Well there’s more going on in that. You know, it’s motor issues and this whole other realm of stuff.”

In each of these instances, parents were told their child behaved poorly because of their bad parenting. Examples like these are the reason there still is stigma surrounding autism and parents of autism. Attributing a child with autism’s behavior to how they are parented stigmatizes both the child and the parent and makes it difficult for either of them to feel accepted.

The second part of the bad mom trope is what I like to call—and what Elaine quoted it as—is the “Karen.” This is something that most of the moms in this sample were aware of and very wary of becoming. According to Dictionary.com, a Karen is a

mocking slang term for an entitled, obnoxious, middle-aged white woman. Especially as featured in memes, Karen is generally stereotyped as having a blonde bob haircut, asking to speak to retail and restaurant managers to voice complaints or make demands, and being a nagging, often divorced mother from Generation X.

The moms in this sample were not exactly worried about being a Karen because they wanted to speak to the manager, they were worried of being labeled a Karen when advocating for their child. The stigma they experience by being a Karen is not so much associative stigma from being a mother to a child with special needs, rather the stigma is placed directly on them as women. Francis (2012) also found that parents experienced a duality of stigma or having both direct stigma from the blame of being a bad parent as well as the associative stigma of their proximity to their stigmatized child. Mothers were also found to be the ones taking on the majority of the blame for anything that stigmatized their child (Francis, 2012). Similarly, my sample of mostly women also felt the blame of being a bad mom along with the associated stigma of having a child with special needs, but with the added feature of additional stigma for the advocacy they do for their children.

Moms in this sample utilized emotion work to combat the stigma of being a Karen. Each mom worked to suppress feelings of anger and frustration when advocating for their child's needs. Instead of using their passion to fuel their advocacy, they took a step back and evaluated how they may be perceived prior to taking action. Elaine chose to process her emotions to calm herself in order to not be seen as a "bitch":

Obviously, you don't wanna overstep your bounds and you don't wanna be looked at like, you know, "Oh god, this mom's a Karen. She's gonna come and complain about absolutely everything." So, you kind of have to weigh things and say okay. I like to take

some time to process before I shoot my mouth off because I can shoot my mouth off [laughs]. And you really do have to process, “Okay, is this just because this is my kid or is this because it’s truly an autism thing”... but being an advocate is hard because you don’t wanna be looked at like, “Oh, here comes that bitch again,” but at the same time you definitely want to be heard so I think you have to...you really have to be careful and pick your battles.

Tessa also felt a need to think of how her actions will affect relationships if she were to advocate with her anger or frustration. She worries about how she might be perceived as well, thinking that building a reputation of being emotional will deter people from working with her family in the future:

Yeah, I feel like I’m always trying to educate or...I feel—this is almost like a politician sometimes, like I feel like I have to be careful to what I say to some people because I might need that relationship later on down the line. It sounds so manipulative and I don’t mean it to be manipulative and I try to be sincere with all my relationships. But, I’m really careful not to try to get emotional and burn bridges over a parent-teacher conference or things like that because I may need those people later down the line too. Or I don’t want to develop a reputation of being *that* mom and nobody wants to work with us.

Tessa plays out the scenario of what is the worst that could happen if she advocates based on emotion or if she advocates based on logic. However, emotion and logic are not mutually exclusive. All parents in this sample expressed how they were just trying to do the best that they can for their children and sometimes emotions can help to get a point across. Beth tries to think rationally through her advocacy but wants to be understood from her perspective. When people

do get frustrated with her as she says, “Goll’, here comes [Beth], she’s such a bitch,” she tries to help them to see the perspective of an advocate. However, she has tried to be less emotional so she “can do a little bit more advocating with my cortex as opposed to my amygdala.” Ultimately, she has to suppress her emotions to not be stigmatized as a bitch.

The mothers in this sample are worried about how they will be perceived by others when advocating for their child. Each time they assert what they want for their child to care providers, teachers, and even family members, mothers perform suppressive emotion work by pushing down the anger and frustration they have experienced with their child’s needs not being met. Suppressive emotion work is done by focusing on the undesired feeling that is present at first and working to replace it with the desired emotion (Hochschild, 1979). Mothers in this sample do suppressive emotion work by dismissing the initial anger that they may have and attempt to replace it with calm reasoning. Rather than act on their emotions, mothers attempt to think rationally to solve the problem for their child.

Additionally, the experience of being an advocate mother carries a stigma. They do not want to be seen as a Karen. Part of this worry or stigma may come from what the role of a mother entails. With traditional gender roles, we tend to think of mothers being more involved in raising their children with the father taking on more of an extraneous role as a provider or breadwinner (Lorber & Farrell, 1991). Because of this role that we expect of women as mothers, they are often the parent most intertwined in their child’s day-to-day care (Francis, 2012), therefore they are the ones who notice problems that need advocacy.

However, being a mother may only be part of the equation. Would men have the same concerns about being the male equivalent of a Karen when advocating for their child? I think that men may still fear overstepping boundaries like many of the women in this study, but I am

unsure if they would face the same stigma and backlash. When men advocate for their child, they are seen as being protective because they are idealized when they are involved in their child's lives (Francis, 2012). However, women are not idealized in the same way because of the societal expectations for motherhood. Additionally, when women use emotions in power inequalities like in advocacy, they are more likely to be seen as irrational or too emotional (Bernardez 1987).

Parenting in the context of advocacy mean facing social stigma not only from the actual fighting of stigmatization, but also from the backlash of standing up for their child. While mothers in this sample experienced a duality of stigma, parents also combatted difficulties in relationships with friends and family. These relationships where stigma seemed to appear the most and have the greatest effect on parents and their child with autism.

Emotion Work with Family and Friends

For parents in this sample, relationships with friends and family can be incredibly stigmatizing and draining. Friends and family are supposed to be the ones who love and support you no matter what. But when it comes to having a child with autism, these are the relationships are sometimes the most stigmatizing. Parents of children with autism have to work to help their friends and family to understand how autism affects the functioning of their own family. The labor of explaining autism, their parenting, and battling stigma involves performing emotion work to suppress frustration and anger in attempts to maintain their most basic relationships. As a result of their extensive labor, parents seek isolation to avoid experiencing stigma.

Managing Stigma in Friendships: The Virtue of Empathy

In terms of friendships, most parents had little to say about how their relationships with their friends had changed since having a child with autism. I think that this may be due in part to how friendships change when people become parents in general. Parents have less time to spend

with their friends because of the responsibilities of their new family. This is the case for many parents in this study, but with the added complexity of managing the stigma of autism. Stigma is based in a lack of understanding. As mentioned in the literature review, stigma is placed when assumptions are made based on a stereotype (Goffman, 1963). When assumptions are constructed out of a stereotype, any actions that resemble the stereotype are validated when others witness the stigmatized person doing them. The stereotype that parents of children with autism face is that they are overprotective, looking for sympathy, or that they do not have it as bad as they make it out to be.

In Caitlin's case, her friend assumed that she was worrying too much about her son: "My neighbor who was supposed to be my friend, I kept telling her, you know, 'This is my fourth kid, I'm telling you something is off,' and she just kept saying, 'Oh, he'll grow out of it. You worry too much. You worry too much.' That was rude." Rather than listening and trying to understand Caitlin's situation, this friend minimized her concerns and assumed that this was an overreaction. In this way, Caitlin was misunderstood as being an overprotective mom when she was actually just seeking support from her friend.

Other participants raised concerns about their friends understanding their situation as well. Elaine mentioned that she did not particularly like talking to her friends about her children on the spectrum because she was worried that they would pity her. She preferred to talk to other parents of children with autism because they can more easily understand what was going on. This feeling is common amongst parents of children with autism as Gray also found that there was a collective feeling of other parents just not understanding (2002). In this example, Elaine was not seeking sympathy, but rather empathy from other parents. Sympathy is stigmatizing because it fails to acknowledge and humanize the experience of being that parent by only

associating autism with its difficulties. Parents in this sample want empathy from others, in other words, they want to be heard and understood without judgement (Thieda, 2014). When Elaine talks to other parents with kids on the spectrum, she is able to voice her concerns and connect to those parents without judgment because they have those same experiences.

Beth's experience is similar in that her friends do not always understand the level of care that her son requires. She was in grad school for speech language pathology when she had noticed that something was off with her son's development. He had been diagnosed with epilepsy as an infant, but he had some quirks that epilepsy just could not explain. Beth asked her friends in grad school to evaluate him and they were "horrified" by the experience. Beth explained that her friends were great about assessing him and helping with therapy, but "they just don't understand what it was like to be us, you know. It took a long time for us to find people who really understood what it was like to be us and what it was like to try to function." While her friends were supportive, there was still stigma present due to their misunderstanding.

However, one of Beth's friends offered support in a way that many other participants struggled to find: by watching her child. Beth's friend watched her son as an infant while Beth was attending grad school. Unfortunately, the stress of his constant seizures proved to be too much for her. One day she wrote Beth a letter saying that she would no longer be able to care for her child. She was overwhelmed and was unable to run her daycare while Beth's son continued to have medical emergencies. Beth greatly empathized with her friend and is still good friends with her, even though a situation like that could have caused their friendship to end. This friend could have not allowed Beth's son into her daycare in the first place, but she chose to help her in one of the only ways that she could. By caring for Beth's child, this friend was given more insight into life with a child with special needs.

Managing Stigma with Family: The Challenges of Boundary-Crossing

Misunderstandings with family often lead to boundary-crossing, which I define as a form of stigmatizing behavior done by family or friends that bridges the line of helping to hindering. Previous literature has focused on the blaming that parents of children with autism experience from their families (Farrugia, 2009), but boundary-crossing is a new concept that helps to explain how misunderstanding in familial relationships stigmatizes parents of children with autism. Many times people outside of the immediate family will offer advice, help, or even an invitation with good intentions to aid the family of a child with autism, but will cross the boundary of support and end up hurting the family and neglecting the needs of the child. Elaine, John, Beth, Rebecca, and Tessa all had families that were supportive of their children with autism, however, there were (and still are) some misunderstandings between parents of autism and their family members. For instance, some families went as far as helping to find resources for these parents, but they could not understand what daily life with the behaviors of autism entailed.

For instance, Elaine's family likes to go on family trips, but her sons can get overstimulated with noise and other sensory issues. In order to prevent or cope with the stimulation, her sons will need to go off on their own or be in a quiet space for a while to process everything. Instead of accepting the need to have time alone, Elaine's family dismisses her sons' needs: "I think in my family it's very much, 'Oh, suck it up,' but I think they have a hard time with that portion, not the diagnoses, but the understanding of what that diagnoses is." This type of boundary-crossing with family members was common in my sample. Parents or extended family of the respondents would be supportive from a distance, but when it was time for family get-togethers, they did not always make concessions for demands that come with having a child with autism.

Tessa's in-laws also took part in boundary-crossing. Tessa described her in-laws as always wanting to be going and doing things when they had family over, but Tessa's son was easily overstimulated by the family gathering and the activities they had planned:

I was eight months pregnant with my second kid and I said, "Can we just stay home? You guys can go miniature golfing and I'll just stay home. It's no big deal, my feelings won't be hurt." And my mother-in-law is like, "No, you *have* to come. You *have* to come." And I'm like, "Ugh, it's like right before nap time!" You know, and then being autistic he was just like all over the place and crying and throwing fits and so I literally spent the whole time in the clubhouse with the screaming, tantrum-ing kid while everybody else—So that's what I'm saying. Like, they understood it, and they respected it to as much as they could, but they did understand—like setting limits on what my kid needs and we can do with setting those boundaries has taken a while after the diagnosis, I guess.

Tessa's in-laws likely had good intentions of trying to include her family, but they failed to understand what Tessa's son needed in that moment. She had attempted to advocate for her son but was shut down when she tried to remove herself and her son from the situation.

Boundary-crossing is a tricky part of navigating family situations. Families of kids with autism want their extended families to be a part of their child's life, but it is an added hurdle when family gatherings or activities means compromising the care and needs of the child with autism. On the other hand, tending to the needs of someone with autism often means compromising relationships with family and friends.

Beth has had to compromise some of her own familial relationships because the care that her son requires. When she is able to visit her family, she has to bring her son and she feels like

her family does not understand how difficult it is to care for him or to find someone to care for him:

...My sisters might want to do something on the spur of the moment, I'm like, "I can't do that." Or if I go home and I—kinda have to bring [son] wherever I go. I can't just leave him with anybody, especially now when he's a man. The people who might be watching him are smaller or whatever and it's just trickier than that. So, and they don't—I don't think they grasp the complication that is his care, you know.

Not understanding how complicated caring for someone with autism can be just as stigmatizing as not understanding the diagnosis itself.

While autism is a lifelong disability, it is sometimes difficult for family to distinguish between autistic behavior and the behavior of a bad kid. Additionally, one of the stigmatizing parts about autism is that it is an invisible disability. There are not clear physical indicators of what it looks like to have autism. What is visible about autism are the behaviors connected to it. However, those behaviors can also be associated with being an uncontrollable kid or having permissive parents. In response to stigma that friends and family place on the family of a child with autism, parents often choose to educate those closest to them as a form of advocacy for their child.

Educating Others: Resetting Boundaries and Setting Expectations

Educating family, friends, and teachers was a significant theme in how my participants discussed the management of their relationships with others outside of their home. Educating others was a way that these parents mediated the stress that the stigma of autism carried for the family, and it provided a way to respond to the boundary-crossing they experienced from many of their well-intentioned family and friends. Most parents spoke of at least one moment where

they felt the need to defend their child or explain their parenting by educating family or friends. By educating, I do not necessarily mean describing basic characteristics of autism, rather educating is done to spell out why their child is the way they are and why traditional modes of parenting just do not work for children with autism. Parents educate to eliminate misinformation and bring awareness to their family's situation (Broady et. al, 2015). Educating is a way to reset boundaries by clearly identifying what is stigmatizing to families of children with autism.

For instance, John found himself having to explain to his father what it meant for his son to have autism. "My dad has asked me multiple times if it's something they can grow out of or...I don't think he gets it that, you know, it's something they have to live with and we can teach them how to handle things and that's the best we can do." In this instance, John's dad did not understand what autism was or how it manifested in his grandchildren. Rather, he chalked their behavior up to a childhood phase. John educated his father by letting him know that autism was something lifelong and needed to be treated with therapy techniques instead of traditional discipline. He also advocated in defense of his child's behavior by assuring his father that his son was not a bad kid but was acting out a response that was beyond his control.

Holly had a similar experience in educating when her mom called Holly out for not having her four-year-old son potty-trained. Holly responded by acknowledging that while there are priorities in parenting, potty-training is not a priority when there are other developmental issues that are more concerning. Holly also educated her father-in-law when he could not understand why his grandson did not want to eat Thanksgiving dinner. Holly knew her picky son would not eat if he were served a Thanksgiving meal, so she gave him something he would like instead. She educated her father-in-law by telling him that her son was fine eating his Uncrustable sandwich and not partaking in the dinner.

Educating can also take the form of correcting language or perspectives. Tessa spoke about a time when her husband's brother made a joke about taking the 'short bus.' Some school districts use smaller busses to transport students with disabilities. Tessa's brother-in-law had made this joke without realizing that Tessa's son took a short bus to preschool every day. Tessa was obviously hurt and was sure to inform her brother-in-law about how insensitive his joke was to her family. She also has caught her sister saying the "R" word and has asked her to adjust her language.

Other times, educating can mean letting friends and family know the level of care that their child with autism needs. Beth realized that she needed to educate her family in order to succeed in watching out for her son. One time, Beth had attended a large family gathering with her son and had asked the group she had been talking with if they could watch him while she went to the bathroom. While she was in the bathroom, he snuck out of the house which was a scary ordeal for all involved. Beth said that she learned from this incident that she has to assign one person to watch him rather than a group so there is some responsibility attached for that minute that she takes her eyes off of him and goes to the bathroom.

This type of preemptive planning is an important part of the education process. Caitlin exemplified the way some parents established boundaries and set expectations for social interaction. She was meeting a friend at McDonald's with her son and she explained to her friend, "a lot of the times he has about ten to fifteen minutes when we go to a new place where he's going to have a meltdown. We'll go to the bathroom and I sit with him and I wait." Being that this friend was not familiar with autism, Caitlin wanted to warn her that there would be a meltdown, to help her understand that this was not something unusual. She set clear expectations to not surprise her friend and to prevent stigmatization of herself and her son. The importance of

setting expectations is critical for families with a child who responds differently to certain social situations.

Educating family and friends can be a tedious and uncomfortable experience for family and friends but achieving understanding and reducing stigmatization can be a beautiful thing. Rebecca reaped the benefits of educating by helping her sister-in-law and her children adapt to playing with Rebecca's son:

...My sister-in-law in my husband's family would do anything for him. Most of them understand him and like—her kids were raised to know, “We're quiet when [son] comes over, if it's too loud he'll hit you.” “If you're in his face, he'll hit you, and it's not because he doesn't love you, it's because he can't handle noise.” And now, he goes in that house and because those kids were raised that way, he'll say, “Let's run,” and they'll run and yell and scream and play and when it gets too much, he'll say, “All done noise! All done noise!” And they play just fine.

Again, we see the power of establishing boundaries and expectations. Rebecca was able to help create an environment with her sister-in-law where her son was free to play with his cousins and have his needs met by the children if he ever felt overstimulated. In this way, Rebecca's educating helped to normalize the experience of being overstimulated and needing a break to her nieces and nephews. This has also allowed her son to have friends within his own family, making the family gatherings and experiences much easier and more enjoyable.

Educating can be a powerful way to help family and friends to better understand the child with autism and their parents. However, it can be incredibly exhausting to have to explain away stigma in these relationships. Parents in this sample sometimes choose between educating and isolating. Either they maintain their relationships with the chance of being stigmatized or they

withdraw and shelter themselves through isolation. Each way involves variable sacrifices to their wellbeing with no real way to involve themselves in difficult relationships without being hurt.

Isolation

Constantly battling stigma from friends and family can leave parents feeling very lonely. Being judged for their parenting or their child's behavior often leads parents to defend themselves and their child in their relationships with family and friends. This results in parents retreating from social relationships (Broady et. al, 2015). Parents in this sample often feel like they are alone, but they are mostly alone because they disconnect themselves from relationships where other people do not understand their situation. Rather than put themselves and their child out there to face stigma or get hurt, parents in this sample withdraw from relationships with friends and family.

Because of the intensive care and attention that a child with autism requires, isolation is a consequence of the focus and attention on what that child needs. Parents discussed their experiences of isolation as something that helped them manage having a child with autism. Reasons for isolating included not having time to maintain relationships, not being able to find care for their child, and wanting to prevent themselves and their child from experiencing further stigmatization.

For instance, Rebecca had to quit her job as a fulltime hairstylist and shifted to working odd hours cutting hair and doing overnights at her second job just so she could take her son to all of his therapy appointments during the day. She was basically alone in trying to get her son's needs met, meeting her own basic needs was set aside. This left her incredibly drained and without any extra time for other relationships:

I would take him to therapy, sleep in the therapy waiting room. He would go to therapy and we would go home, and I was emotionally exhausted, physically exhausted and pretty much alone because I had no time for anybody.

Rebecca centered her life around her son and made incredible sacrifices just to see him improve. Her dedication to her son's needs practically ended her social life, but without rearranging her entire work schedule, her son would not have been able to receive therapy.

Tessa discussed how much she focuses her efforts on her son, which leaves her with little time for friends. She recently went to a conference to learn a new type of reading curriculum so she could try to adapt it into a usable resource for her son and his teachers. Tessa said that its things like attending that conference that people have a hard time understanding. Taking time to take a child to therapy or go to learn more about how to help them is difficult to understand because not many people realize the effort that parents of children with autism need to put in in order to help their child improve.

While isolation can be out of necessity, it is also a choice for some parents. Disengaging from public life as a family prevents judgement from others. Parents in this sample disconnected from social relationships because missing out was easier than dealing with the potential meltdowns of their child and subsequent judgment from other people. Parents miss their social life, but they recognize that sometimes it is just easier to stay home. Holly summed it up best as the "FOMO of life," or the fear of missing out. Being isolated allows for parents to manage their child and the stigma they encounter because they are in a controlled environment. Having control over the environment ensures that their child will not run away, hurt someone or themselves, or place the family in a position experience stigma. Tessa put it best as:

I feel like we're not a very social family just because of the autism, because it's just easier for us to stay home or just do stuff with the family a lot because my husband and I can manage—we know how to manage everything.

Rather than attempting to get a babysitter or finding some other arrangement so Tessa and her family can be social more often, she chooses to isolate because it is more manageable.

Anna has experienced similar management issues with stigmatization. When her son was younger, she had to use a kid leash with him to make sure he did not run away from her in public. Having a child with autism can attract some attention in public but having a child on a leash is guaranteed to garner looks. However, using the leash was a last resort. Instead, Anna would isolate with her son and just do errands by herself or have her husband to them for her. Although Anna was never confronted by anyone when she took their son out with the leash, she definitely felt the judgment of others with the side glances that she got. Using a leash helped Anna to keep her child safe, but she internalized the stigma that she felt from the looks that came her way and ultimately decided to remove herself and her son from that situation.

Rebecca isolated to prevent misunderstandings and avoid further stigmatization of her child and herself. As her son got older, he tended to play and react more physically than he had as a young child. She recalled a few times that her son hit another kid, making the other kid's parent upset all while she was trying to calm and correct her son. Rather than going through explaining what she needed to do to help her child not to hit, she isolated from other families so they would not experience stigma:

But the older he got, he got more swatty, he got more hitty, and he wasn't super nice to everybody's kids. It took us a long time to figure out how to work with him with other people's kids. And you get, "Your kid hit my kid!" "Your kid pushed my kid!" and like,

“Yup! And I’m trying to talk to him about it right now.” Like, “I can’t just turn around and spank him. It doesn’t do anything, doesn’t teach him anything. I need to explain to him why that’s not okay, or I need to figure out why he hit your kid.” So, we just kind of isolated.

Isolation is complex because parents in this sample do want to feel understood. However, empathy from others is not always achievable. In isolation when parents seek out support from those who do not understand, they have to censor information so that they will not be pitied or further stigmatized and misunderstood. One way that parents help to bridge the gap for others to empathize for them and their child is to make their situation relatable to others. Normalizing their experiences helps parents to subtly emerge from isolation by defending their child and themselves in an easily understandable way.

We’re Just Like Everybody Else: Normalization Practices

Normalization was a common theme that emerged with parents in this sample. Normalization is a way to educate others about their own or their child’s experience by turning their experiences into relatable scenarios and emotions. While normalization educates others, it is different from educating because it is how parents attempt to assimilate themselves and their child with autism into the normative experience. Goffman notes that those who have associated stigma act as the barrier of normalization between the person with stigma and the public (1963). However, the parents in this sample act as more of a filter to bring normalcy to their child’s experiences and their own. I termed this theme “normalization” because some parents advocated for themselves or their child to in their interviews by either attributing their experience to part of just being a parent, associating their child’s experience to just being a child, or equating their

child's reactions and emotions to something they feel themselves. Through normalization these parents were making their own and their child's unique life experiences appear less unique.

Just Part of Being a Parent

Parents normalized their own experiences during their interviews by attributing parenting a child with autism to be similar to parenting a child without autism. In other words, they downplayed some of the struggles they experienced in order to be more relatable. For instance, Elaine felt like she was always questioning if her parenting was good enough:

No matter what you do it's the wrong thing. So, you never know, "Am I doing the right thing?" So, I—that's a tough question because I think it's the same for any parent, not just one with kids on the spectrum.

While other parents might also question their parenting skills, by saying that "it's the same for any parent," Elaine minimizes her own parenting efforts. Parents of children with autism go above and beyond what most parents have to do for a neurotypically developing child. Advocacy is a key point where parents of children with autism feel like any other parent. What is ironic is that advocacy is a critical point where parental experiences diverge. While most parents advocate for their children at some point, they do not face the same stigma that parents of children with autism do.

When I asked Elaine and John "How does being an advocate make you feel?" they both normalized their experiences to those of any other parent:

I don't know if it makes you feel different than any other parent. I mean even if you don't have a child on the spectrum, you're still gonna advocate for your child. (Elaine)

Like a dad. We...I mean we were...I don't know. I don't think of myself as an advocate.

I think of advocates as going out and speaking to groups and, you know, making a bigger difference. I'm just trying to be a dad and raise my kids. (John)

These parents do not see a difference between being an advocate for their child and being an advocate for a child with autism. For them, it is just part of being a parent. Similarly, Caitlin felt as though she did not go through any emotional changes when she became an advocate for her child, rather she said, "I think when you become a mom it just happens." Caitlin had other children before she had her son with autism, so she had already felt like an advocate.

In these responses, it is clear that becoming a parent was the catalyst to begin advocacy. However, not all parents view what they do for their children as advocacy. For instance, John defines advocacy as doing some sort of public speaking and making a difference for multiple people. Elaine and Caitlin identified themselves as advocates, but their advocacy was deeply tied to when they became parents. These responses are attempts to normalize the experience of parenting someone with autism. By saying that advocacy is just part of being a parent, these parents normalize the lengths they go to make sure their child is doing well in school or is receiving adequate care. While they might not be going out and speaking publicly to groups of people on behalf of their child, they are advocating to friends, family, and teachers in ways that other parents do not have to. I do not think that these parents felt a stigma in speaking about their advocacy during their interviews, but these responses come across as normalizing the change and involvement that being an advocate entail.

Just Part of Being a Kid

In addition to some of my participants normalizing their experiences as parents, two parents normalized their children's experience of autism by relating their experiences to other

children. Normalization in these instances involves replacing their child's unique experience with a general experience that all children go through. It is a way to make their child seem more like other children.

For example, Elaine normalized her son's experience of feeling different from others to me and also to her own son. She had mentioned that her son is a part of an autism group, but has friends outside of the autism group:

...[My child] is one of those kids...that can be part of the autism group, but also be part of another group, but I think he puts on airs in other groups, because in his words, he doesn't want to feel different. And that's any teenager. I mean I felt weird [laughs] when I was a teenager so that's any kid, but I think for him it's kind of compounded because he knows he has autism and that he is different. I mean I keep telling him that everybody is different [laughs].

Elaine explains that although her son feels different, all teenagers feel different—she even felt different at that age. Although he recognizes that he has a disability that legitimately makes him different from other people, Elaine normalizes her son's experience by saying that “everybody is different.” This is not to minimize her son's struggles with autism, but rather to reassure him that this is a normal experience and he should not feel self-conscious about his differences.

Rebecca also normalized her son's experiences by relating them to his age. Her son has trouble communicating when something is too much for him or when he needs to be alone. Because of his difficulty communicating, he will sometimes act out aggressively. Rebecca normalizes her son's experiences by emphasizing that he is just a kid:

It's because he can't tell people when he's had enough and he needs space, so he pushes, and hits and people get mad. They don't give him the benefit of the doubt where he's not

always trying to be the bad guy. Sometimes he's a turd, he's nine, he's a kid. There are definitely times that he is just being a turd [laughs].

Rebecca's desire for her son to get the benefit of the doubt reinforces the point that her son can engage in bad behavior at times without his autism being an identifying factor. Her son is not acting out because he is a bad kid, rather he acts out because autism hinders him from being able to communicate his needs. Since he cannot always communicate when enough is enough, he is stigmatized as the "bad guy." However, Rebecca normalizes his experience by identifying his behavior with his age instead of his diagnosis.

Both of these parents refer to their child's traits of autism as experiences of just being a kid or a teen. You cannot always separate a child's experience from the experience of being a certain age. However, there is some normalization of the experience of the child going on in these messages. I think any parent would normalize the experience of their child—I have even heard my own mom do it. If you have heard any parent groan about their child being a toddler or a teenager, you have seen this normalization happen. It reminds us that children are learning how to be people and struggle with that process. I see this normalization as a form of advocacy in the responses above because Elaine and Rebecca are relating the experience of their child with autism to the experience of any other neurotypical child. By saying their child with autism is like any neurotypical child of the same age, they are subtly—and probably even subconsciously—removing stigma associated with what it means to be a child with autism. In this way, normalization creates a narrative of "personhood" for the child with autism to be accepted for their differences (Singh, 2016).

Relating to Their Child through Empathy and Shared Humanity

The last piece of normalization involves the parent relating to their own child's experiences. Empathy becomes a powerful tool for parents to normalize their child's experiences, as well as their own experiences as parents. Parents in this sample related to how their child felt in different situations and used that understanding to make their child's experiences feel more normal. Elaine did this when she had talked about her son feeling different as a teenager as previously mentioned. Her son had told her he felt weird and different and she said that she felt weird as a teen too. Elaine normalized the experiences of both her sons again when she acknowledged their social awkwardness: "... my kids are high-functioning and like I said, academically, they're smart, but socially they are extremely awkward, but I am too." These responses are similar in that Elaine relates qualities in her sons to what she has also experienced or what she still experiences now.

Elaine again put herself in the shoes of one of her sons when explaining the toll that group projects take on him. She had advocated on his behalf to get him out of group projects at school when they got to be too much for her son:

...when every single one of the classes are nothing but group projects that's another time you kind of have to step in and advocate and say, "No, we gotta find something else because it's just too overwhelming." It would be overwhelming for me.

By saying that something her child finds overwhelming would be overwhelming for her as well, Elaine normalizes her son's emotions. If just one person says something is difficult for them, it may seem as though they are the only one experiencing difficulties. However, by utilizing common humanity—as Elaine did—the person suffering is able to see that they are not alone in the problems they face (Neff & Faso, 2014). Since Elaine let her son know that she found group

projects overwhelming, she created a bond between them of a shared problem, rather than something he was experiencing on his own. Had Elaine's son gone to a teacher on his own and explained his feelings, he may not have been taken seriously, but having his mother on his side made his experience more legitimate.

John also empathized with his son and accepted the autism diagnosis. He even felt like he could see a lot of his son's characteristics in himself:

I can see a lot of traits that [oldest child] had that I had growing up. I was very quiet, very...I got down on myself quite a bit. So, I think there's—to a certain extent—I have a lot of the...I'm on the spectrum somewhere I would guess, just no diagnosis.

John normalized the experience of his son by recognizing how he felt growing up and empathizing with how his son must feel now. Rather than emphasizing the differences between him and his son, John acknowledged his son's perspective and link his son's experiences with his own. In this way, John normalizing his son's traits by claiming that he sees those traits reflected in himself.

Likewise, Caitlin normalized the experience of her son by actually projecting her own emotions onto him. She had been worried that her son would feel like he was different when he entered a general education classroom, so she had asked his teachers to hold off and keep him in the special education classroom. However, Caitlin said, "I came to realize that I was projecting how I feel and well I'm not him." Although Caitlin's emotions did not match her son's she normalized that experience by putting herself into his perspective. When she realized that he did not feel different at all, she backed off, validating his actual emotions about the situation.

Parents in this sample that related to their children had responses ranging from feeling weird or awkward as a kid, empathizing with how they're child might be feeling, and even self-

diagnosing through recognizing similar traits in themselves to traits in their children. By admitting that teenage years were awkward or that she does not have the best social skills, Elaine normalizes the experiences of her sons by putting a neurotypical face to those feelings. In the same way, Elaine saying that group projects are overwhelming or Caitlin worrying about her son feeling different places a sense of normalcy on the problems that their children are facing. In this way, parents utilize normalization to educate on what might otherwise be stigmatizing experiences for their children.

While normalization helps to reduce stigma in some areas, other difficulties arise when barriers of accessibility prevent the child with autism from getting services they need. Parents in this sample experienced difficulties with being able to find and access care as well as complications with school communication.

Problems with School and Care

Resources for children with autism are hard to come across, and when parents in this sample had access to them, they found that some services were inadequate. Some parents even moved to the Fargo-Moorhead area from hours away to be able to receive services or be in a school district that was equipped to care for their child. Even when respite services were acquired or the school was ready for their child, parents perceived a lack of experience from respite staff and teachers.

Moving

Finding resources can be the hardest part about having a child with autism. Without having the proper care or schooling, caring for someone with autism can become incredibly difficult. In order to access some of these resources, three parents in this sample moved so that they could better provide for their families.

Holly had been living in a North Dakota town four and a half hours away from Fargo when her son was first diagnosed with autism. She knew there was limited resources for her son, but the final straw for her was when they were unable to see a speech therapist because there was only one therapist for four hundred families. Sometimes the speech therapist would move or get replaced, sometimes they would need to reschedule due to illness, but either way they would be faced with a six month wait before Holly's son could see anyone for therapy. Ultimately, they moved to the Fargo-Moorhead (F-M) area to have access to more services.

Caitlin moved to the F-M area from a Minnesota town an hour away due to an inadequate special education program at her son's school district. She described the program as "a retired daycare lady who took the special ed kids for a *walk*. That's it." There was no real adaptation for individual needs taking place, rather special education was neglected. So, Caitlin packed up her family to find a better education system. Beth also wanted better services for her child, so she moved from a neighboring town in the area to be closer to services and her graduate school. However, moving does not always solve the problem of finding or maintaining therapies, services, and schooling as the Fargo-Moorhead area has its own issues in each of these areas.

Difficulty Finding Services

Many of the parents in this sample struggled with finding daycare and respite services. Respite services are a form of assistance that cares for people with functional needs for an amount of time (Harper et. al, 2013). Respite can be provided by a variety of people, but in the case of the participants in this sample, it was provided through trained respite workers provided through different agencies in the area. Funds for respite care may be paid for by parents on their own or through avenues within the private or government run respite agency (Robertson et. al,

2011). It often takes the place of daycare services as children with autism may require more one-on-one care than a daycare is able to provide.

Both Elaine and Caitlin had their sons kicked out of daycare because the daycare was unable to adapt to their children's special needs. Elaine's son had wandered out of sight of the daycare staff, so they thought it was unsafe for him to be a part of the daycare. She found it difficult to find someone to take care of her son because he did not qualify for respite services but was not able to find a daycare that could adapt to his needs. Caitlin's son was also kicked out of daycare because they required that he have one-on-one respite staff with him, but they could not find anyone to provide care for him. Although Caitlin's son did qualify for respite, a big obstacle in care currently is finding qualified people to work in respite care.

When Holly and Caitlin were asked about respite care, they said it was such a hurdle to find a really good respite care provider, and when they could find someone, they leave, move, or graduate college. A respite worker may have built a strong bond with a child, but only work in respite for a short period of time. From my time working at a local autism agency, I know that respite work has incredibly high turnover rates and most respite agencies in the area are constantly hiring. Having a strong bond with a care provider only to have them leave is difficult for a child with autism and their parents. Children with autism thrive with routines, but to have that routine broken when they have to find a new respite provider every few months can be detrimental. Beth even puts in extra work when respite care might be unavailable. She makes connections and recommends people to interview to work through a respite agency in her home or she will make alternate plans and have other family members step in to care for her son.

Beth and Rebecca especially know the difficulty of trying to fill the gaps in care. Rebecca is down to only one respite worker who comes to her house to care for Rebecca's son. She is

supposed to have 68 hours per month covered by respite care through her respite agency, but only half of those hours are being filled. Rebecca thinks that part of the reason people are not seizing the opportunity to work with her child is because she believes he is past the age with whom most respite workers want to work. Although her son is only nine years old, Rebecca says, “When he was littler, it was easy to get respite because he was cute and little.” Rebecca figures that children who are smaller and younger are easier to work with.

Beth has also found that attempting to get respite care has been harder as her son has gotten older: “So, the same issues we had when [son] was three, we had when he was twenty-five and it sucks worse now because people aren’t jumping at the chance to babysit an adult that still needs incontinence care and help with feeding and all of these other things.” While the difficulty of finding care due to age is more stigmatizing of the child with autism than the parent, respite is something that provides parents with relief of their care duties; therefore, not being able to get respite puts them at an incredible disadvantage.

Even when parents have access to respite, it puts them in a vulnerable position to trust someone else with their child and to open up their home to strangers. Caitlin has had terrible experiences with respite providers. One worker vaped in her house while working with Caitlin’s son. Another time, Caitlin had to call the police because a respite worker had lost Caitlin’s child. While respite does provide relief to parents, it can be nerve-wracking to leave their children with someone who they may not trust.

Trust with respite workers and families with special needs is also incredibly important due to the sensitive work environment of the family’s own home. Beth was open to allowing respite workers into her home because she knew having those extra hands around would help to improve her family’s functioning. However, she recognized that it was a difficult process to

adapt to strangers or acquaintances being in her home. For instance, with two young daughters in her home, she decided she did not want to have any male staff in the house. More issues have come up throughout the years when people she knew through her job or her daughters' school wanted to work through the respite agency.

And so then now we're running into—people from this department want to work at [respite] and I'm like, "Okay do they come work at our house?" which makes it uncomfortable for me if I'm there teacher or [daughter] if she's their classmate. Even [daughter] is like, "Do I know who that is?" and they're just in the middle of your private life and it's like, "Oh crap, I forgot my underwear on the bathroom floor." Or whatever it might be.

The people providing respite care are around during some of the most private times in members of a family's lives, making it awkward for both the worker and the family. Beth said that they could be around when someone gets hurt, a parent dies or gets sick, and the respite provider is right there in the middle of everything. Acknowledging the uniqueness of the situation, Beth said, "[It's] uncomfortable for them too. But it's just having extra people that in the midst of your private life and I still think that is still the hardest pill to swallow, although we've all adapted pretty well." Respite workers are exposed to a sensitive work environment not only physically in someone's home, but also emotionally because of the value of the work they provide to people with autism. Parents appreciate respite care, but the process to have and maintain workers within your own home and caring for a vulnerable child is emotionally exhausting in itself. However, not all experiences with care were difficult.

Good Experiences with School/Daycare

Most of the parents in this sample felt that their relationship with schools, daycare, or respite services were good and strong. I asked all the participants: “Who do you feel is the person initiating communication or relationship building, you as a parent or your child’s teacher?” This question had not originally been a part of my interview schedule ended up being integrated into every interview because it was surprising to me how good relationships were between parents and school employees. For instance, Caitlin told me that her son’s teacher even babysits for her sometimes. However, when I posed the question of who initiates contact, almost all parents said that they were the ones doing the most initial communication and relationship building. While it is wonderful that parents in this sample are so involved in their child’s care, it is clear that parents being the main communicators can indicate that there is some miscommunication happening at school. Almost every parent had experienced a rough patch of a year or more at their child’s school where teachers or school staff were miscommunicating or misunderstanding the child’s school plan.

School Misunderstandings and Miscommunication

Since autism involves such a range of characteristics, schools need to adapt to each child to allow them to learn in the best way that they can. However, miscommunication between the school and parents can hinder the child’s learning and their behavioral growth. Elaine experienced difficulties with the schools when she had her son reevaluated for disability accommodations but found that teachers were not reading his accommodation plan that was created based on his diagnosis since his diagnosis had not been done through a formal state evaluation. Once they settled that disagreement, everything was good for a while and her son had an excellent resource teacher. However, the teacher left the next year and Elaine and John were

left in the dark. They had no idea who to contact to talk about their son. At this time, their son was experiencing behavioral issues, so it was very difficult for them and their son.

In addition to miscommunication, many of the parents felt that their child's teachers or staff were inexperienced with autism. For instance, because Elaine and John's son is tall for his age, one of his teachers "thought he was too aggressive or was scared because he was taller than she was, but he wasn't anywhere close to her." John agreed that any negative interactions that happened between them and the school was because "they don't understand what's going on with kids with autism." Having inexperienced staff is incredibly frustrating for these parents because parents already have to educate their friends and family about autism, and they have to educate their child's educators.

Tessa also experienced special education staff who had not worked with autism before her son attended middle school:

So, we were sort of their baptism by fire so to speak when it came to special education of autism and it didn't work very well... And it was just really frustrating because I felt like we were just in this cycle, like [son] would have a bad behavior and then their lack of education and their inappropriate response to it would up the behavior and it would just be going round and round in circles.

Tessa had said that middle school years were tough for a number of reasons but having teachers that were inexperienced with autism related behaviors made it that much more difficult.

Rebecca felt a similar lack of experience with her son's teachers that made them fearful of integrating him into the classroom:

I think with some of the younger teachers they're scared. They're not sure how to think out of the box, every body's stuck in this little box—if he doesn't fit in there, how am I

supposed to integrate him? Well you may have to stretch your box, make it square or a rectangle I don't know.

Rebecca was especially upset when she went to a parent-teacher conference with her son's general education teacher and was told, "To tell you the truth, I don't know why you're here. I don't really know your child." Later, Rebecca was able to get in contact with her son's special education teacher to find that her son was in fact a part of that general education teacher's class, but because he has a para (an educational assistant to help children in special education navigate learning in a general education classroom (National Education Association, 2019)) she chose not to interact with him. This was a stigmatizing interaction because Rebecca does want her son to be integrated but having a teacher that did not interact with him was denying him the opportunity to be truly integrated.

Another example of the inexperience of school staff comes from Anna, who has had to pick up her child from school on multiple occasions because he plays sick to get out of doing schoolwork. She said she understood the school's concern the first time, but when he continued to get away with it each time after that Anna became frustrated that no one was catching on to his behavioral issue. By allowing him to go home, they were enabling this type of behavior and inconveniencing Anna by having her leave work to take care of him when he was not actually sick.

Since inexperience appears to be such a common problem with school staff, parents advocate through preparing teachers, respite providers, and family for problems that may arise. Parents in this sample meet with teachers and school staff typically a few times a year to go over individualized education plans. Some parents meet with their child's teachers even more, sometimes as much as a few times a week.

The first year her son was at school, Rebecca came in and watched him with his teachers and even offered suggestions about what they should do that Rebecca knew would work. Similarly, John said that he and Elaine prepare for problems in advance by letting the teachers know what their children are like and how they can prepare for different behaviors. Tessa has also advocated by preparing teachers and even regularly talks to her son's coaches on his athletic team to make sure everything is going alright.

However, parents can only do so much when schools make big decisions regarding special education. An issue that came up in a couple different interviews was the new plan for a D-level school for Fargo Public Schools. A D-level school would be for children who have special needs and an individualized education plan that require them to not be integrated into a general education classroom. Rather than being within the buildings of the school district, a D-level school would offer children with behavioral issues placement in a separate building. Other levels of education plans besides the D-level allow for placement inside a general education classroom for varying times, but the placement ultimately depends on what the parents and the school decide is best for the child (Beyer, 2019). Students who are considered D-level generally do not spend any time in a general education classroom. Instead, they are given individual attention to meet their needs in a special education classroom. As Rebecca explained to me in Fargo schools, students in levels C through A are progressively more integrated into a general education class dependent on their abilities.

Fargo has planned to create a D-level school to keep D-level students and those with severe behavioral challenges apart from the general student population. The school board has faced backlash from parents about children attending the school facing stigmatization (Olson,

2019). These are also the concerns of parents in this sample. Holly worried that segregating students with more severe behavioral issues would be incredibly stigmatizing:

Yeah, it's just gonna be putting them over there, "those kids with the behavioral problems" and there's gonna be a stigma created around the behavioral kids. That's what I'm afraid of. It is relabeling. It's putting labels back on...

Holly had felt like there had been progress made in destigmatizing people with disabilities but having a school to segregate D-level students from general education students would reverse any progress. Rebecca was especially against the Fargo school system and even turned down the opportunity to live in the Fargo school district so that her son would not be in their special needs program. Although her son is considered a C-level student, she worries that Fargo will not have enough D-level students to be able to fill a separate school. If this were the case, she thinks that Fargo might pull C-level students into the D-level school to fill the building.

Fargo has since finalized plans to begin construction on an addition to an existing elementary school building to provide a D-level setting (Olson 2019). Even though this is not a separate building, having a separate addition dedicated to students with behavioral issues could still garner stigma from other general education students in the building.

When parents are not busy worrying about the services and schools their child is a part of, they attempt to emotionally work through the problems they experience by utilizing coping strategies. Trying to navigate resources and stigma can be incredibly draining, yet parents still find ways of coping that help them to emotionally process while simultaneously solve the difficulties that their child faces.

Coping Strategies

Parents in this sample deal with a myriad of problems related to having a child with autism. In response to these problems, parents used emotion work to come up with coping strategies to get through the challenges of daily life with a child with autism. Coping strategies included advocating for others, problem-solving, and building community.

Advocating for Others

Although advocacy can be incredibly stigmatizing, parents in this sample emotionally work through the stigma to become empowered to advocate not only for their own child, but for others as well. For instance, Tessa admitted that she did not have the time to advocate in ways that would influence legislation, but she felt that she needed to stand up for anyone experiencing oppression:

I feel like in some ways I'm hopefully being an advocate for not just kids with autism, but with other people who just don't fit any of our traditional molds in general or expectations how like a typical person should be. I feel like I have the obligation to stand up for those people as well, like race, gender, all of those things, just because I know what it's like—not me personally—I know what it's like to have a family member that doesn't get accepted for who they are, if that makes sense.

Being a mom to someone with autism opened Tessa's eyes to other lenses of people who are not acknowledged the same everyone else. Tessa wants for everyone to be accepted. Although she is not able to advocate for others on a larger platform, she does so on an interpersonal level.

Beth has advocated at the interpersonal level as well as on larger platforms. She feels that advocacy can be intimidating for some people, but not for her. She recognizes that in order to have her son's needs met, he needs to have a strong advocate. However, not everyone is prepared

for the job. Beth wants to be that advocate for someone when they do not have someone there to step up to the plate for them. She posits that “every time I have to advocate for something for him, I feel like I’m advocating for someone else who doesn’t have a strong advocate.” Even though she wishes to be an advocate for others, Beth acknowledges that advocacy is draining in every sense of the word:

If you can take one thing out of your study is that parents of children with special needs have to fight for everything at a time where their emotional resources, their mental resources, their physical resources, their financial resources, all of their resources are either taxed or tapped out completely. They have to fight more fights more often and longer and harder than the average joe while they’re still parenting that child. So, it’s exhausting to think about, and I think, “Well, if I have a little stamina to do it, I’m gonna do it because someone else doesn’t.” Or because someone doesn’t have someone fighting for them is probably more of it.

The stamina for advocacy that Beth has carries over into her career as a speech language pathologist. She had not always dreamed of having this career, but she had known going into school that she wanted to work with kids. As she finished grad school, her son started exhibiting signs of autism. At that same time, she was working to help develop autism curriculum for classrooms. It was through this job that she was able to learn more about autism and recognize the symptoms in her own son. Beth emerged herself in the world of autism through her life and career because she wanted to learn as much as she could to help her son and others.

Rebecca also was led to her career because of her child. Before having her son, Rebecca was a hair stylist who did not take her career too seriously. However, after her son was born, she realized the importance of advocacy and decided to pursue it as a career. She took online classes

to get her two degrees and now works at a non-profit for people with disabilities. She absolutely loves her job and how she is able to help people with special needs. Having her son completely changed Rebecca's career path. Immersion in the advocacy world was a way for both Beth and Rebecca to cope with the emotion work that advocating for their own children requires. By doing work that contributes to the lives of others, they can work through their own problems by finding solutions to help their clients.

Problem-solving Now, Emotion Processing Later

Emotion work persists in coping strategies by putting off emotions to take care the problems at hand. Since children with autism may have behaviors at a moment's notice or problems with different infrastructures like school, respite, or their medication, parents need to act quickly to solve problems. Often that means finding a solution before they have time to react or process what happened. When I had asked Caitlin how she responds to obstacles in her child's care she said: "Go home and watch him. [laughs] Is that what you mean? Like if there's no daycare or no school?" While I clarified that I meant to ask about how she emotionally works through obstacles, the blunt message in her response is that parents do whatever they have to do get through the problem quickly—emotional processing is pushed to the side.

After clarifying my question, Caitlin acknowledged that part of the problem-solving process happens before the problem ever appears. This could mean that the emotion work is done in the worrying about what might happen:

but to me it feels like...anticipating problems that are going to happen before they happen without him knowing that they could have happened and fixing them before he has to run through them...But it really feels like almost like a bodyguard in a way. Just trying to,

you know, anticipate problems, address them if you can, and when you can't, be there to deal.

Anticipating problems acts as a coping strategy for parents because it helps them to avoid worrying by doing preparation. By preparing for something that may or may not happen, Caitlin works through the emotions associated with problems before and after they happen. Emotion work is done in the moment by suppressing worry or frustration to work through a problem, but coping is what takes place in anticipation and after fixing problems.

John tries to focus on the things he can fix. Although he does not consider himself to be an emotional person, he still gets frustrated and angry. Rather than acting on those emotions, John suppresses them to target how he can help his sons to improve. For instance, his son had been having meltdowns at school around the time that I interviewed John. Although John was upset that his child was having a rough time at school, he did his best to put his emotions aside and help his child to work through the issues he was having.

Rebecca also tries to push off emotions but acknowledges that bad days still happen:

On a bad day I crumble, but generally you just crumble for a minute because then you have to get back up and fix it. And then you just gotta figure out the plan like, "Okay this is what the problem is, this is what has to be the outcome." I don't care how we get there, but this is what we have to figure out. And then you just have to pull the pieces out like Jenga block until you get to the top part.

Rebecca imagines what the outcome needs to be to find the solution. Figuring out some problems is a process, but she tries her best to work through the Jenga puzzle. Anna utilizes a similar technique to solve problems for her son. While she panics at first, she tries to work through those emotions to calm herself and think through what needs to be done. Her mantra is "it always

works out in the end and there's always the resolution because I can't think of anything that hasn't resolved to be fine in the end." By thinking about what the end result will be of the preparation work she does for her son, she is able to get through difficult times.

Beth has done preparation work through adapting her family to having respite care workers in their home. She knew that this was a necessary step in alleviating some of the care concerns for her son, but her family was hesitant about having strangers in their home:

I might have been a little further ahead with accepting people to come into our home, but no one wanted people to come into our home. And I had to say, "Listen guys, we need help and if we don't have that we're not going to be functioning," you know. And so, we have people still to this day—anytime I have to train someone new to work inside the home it's like everyone hates it, but at the same time we know it's something that our little village needs. We need to have extra workers in the village.

Beth's family eventually saw the need for respite care and came around to having other people help to care for their family member. Building a community of care as Beth has is not only important for the functioning of the family, but the well-being of its members as well. Although not all parents in this sample required respite for their child with autism, many sought supports externally through other avenues. Most commonly, this was created through utilizing existing support groups or creating their own with other families of children with special needs.

Building Community

Parents in this sample looked to build community through support groups as a way to give themselves the opportunity to experience true empathy from others going through the same things as them. While they still isolated from some social situations, having a support group allowed parents to break isolation without experiencing stigma. Support groups not only gave

parents the freedom to vent their concerns, but also granted the chance to learn from other parents like them as well as the option to educate on their own terms and without fear of stigma.

Three parents in this sample ran support groups and others attended support groups or had their children involved in similar activities. In Caitlin's initial research of her son's diagnosis she turned to online forums, and Facebook support groups. In one of those Facebook groups, Caitlin responded to another mom's question, eventually got to know her and they decided that they wanted to start a support group together. Since Caitlin does not have much family support, she sees the support group as a great way to find resources and make connections with other parents to build support networks. She even made an agreement with another mom in the group that they would help each other out by learning to watch each other's kids.

Holly is a member of Caitlin's support group. Having a disability herself, she thinks her experience of finding support is different from other parents because she had grown up always seeking out likeminded support. Rather than having to go through the emotion work of working to divulge information and trust in outside support networks, support groups are what she had relied on for most of her life. To Holly, support groups are a necessity that just come with any differences that someone may experience.

However, seeking support is a relatively new experience for most parents in this sample. Some parents sought support for their children and ended up finding support for themselves along the way. For instance, Elaine found refuge in a local group that puts on events for teens with autism. While her child is participating in the activity, she speaks with the other parents there:

We kinda gather and that's a good place where we can kind of decompress and we feel like we don't have to pretend we're something we're not and that would be one of those

times and we can talk...but yeah, we can kind of talk and say, “Hey do you have any suggestions?” or “What can I do about this?” or...so that’s a good resource for parents but also kinda where you can relax and not feel judged.

Her son’s group is a place where Elaine feels accepted and is able to talk freely about her son. She does not feel the same way when speaking to parents that do not have kids on the spectrum. When Elaine has talked to parents that do not have experience with autism, she feels like they think she is looking for pity. However, sympathetic or pitying responses can be stigmatizing to a parent of a child with autism who is just seeking understanding.

Tessa actually found understanding from her classmates in graduate school. Her program required a lot of writing, so naturally she wrote about her son. Tessa’s classmates would ask her how her son was and showed a genuine interest in his care. After school she found other parents asking her questions and decided to start a blog. Tessa partly started the blog to get out of having the same conversations about her son over and over, but also because she felt other people might benefit from her experience. For instance, she said wish she had had someone to tell her what a medication change would be like.

Similarly, Beth and Rebecca started their support groups because they wanted to be able to give support to others and to create a communal sense of belonging. Beth had been going to a support group run by her friend and decided to take over when her friend could not manage the group anymore. Beth’s reasoning for taking on this responsibility was: “I can’t have people do this without supports like I had to. I don’t want them to learn how to do it by themselves when I had to struggle through it so part of it turned out to be support for me too.” Beth wanted to support other people, but she also recognized that continuing the group would support her as well.

Rebecca had started a support group with a friend who had a child in therapy with Rebecca's son. They decided to start a support group for individuals with special needs because they felt that labeling a support group as just for autism or Down Syndrome was too confining. They wanted to be able to support people who had just started out in their journey or maybe could not get a diagnosis, so they kept a broad focus with special needs in mind. Eventually, Beth and Rebecca met and decided to combine their groups to be able to reach the most amount of people and share resources. Although they started their support groups separately, they eventually found each other and created a non-profit support network.

In this chapter I discussed how parents in this sample struggle with the daily invasion of stigma into their lives. Whether they are stigmatized by their association with their child with autism or through the direct stigma of the judgment they experience because of their parenting and advocacy, parents do their best to educate, normalize, and work through problems using emotion work. Parents used educating, isolation, normalization, and coping strategies to work through the difficulties of stigma regarding being perceived as a bad parent, the burden of stigma in relationships, and the adversities of battling institutions of school and respite to meet the needs of their child. In each problem they faced, parents in this sample fought against the stigma they experienced by utilizing emotion work.

CHAPTER FIVE: CONCLUSIONS

Through my interviews and the subsequent surfacing of themes, I have made connections between the stigma that parents experience and the emotion work that they perform in response. Connections included parents suppressing anger and frustration in order to advocate for their child and their own parenting practices. Additionally, parents emotionally worked through their own struggles of grieving their child's diagnosis, feeling like an inadequate parent, and feeling isolated to educate family and friends and build community for themselves. Although research on parents of children with autism has previously focused on the stigmatization of parents through their relationship with their child, few studies have acknowledged the direct stigmatization that parents also experience. Furthermore, my study has filled a gap in research about how parents emotionally process both an associative stigma and a direct stigma and the concept of boundary-crossing in familial relationships

Previous studies have acknowledged the immense emotional development that parents must undergo when learning and understanding their child's autism diagnosis (Singh, 2016). Other studies also account for the stigma that parents take on from their children (Gray, 2002) and how they experience direct stigma themselves from realizing the blame they feel from their own parenting (Francis, 2012). My research also delved into the relationships that presented the most stigma for parents of children with autism. While previous research like Broady et. al (2017) brushed the surface of difficulties within friendships and families, my research expanded on the stigmatization of parenting that frequently inhabits the relationships of parents of children with autism. My study tied themes of emotion work and stigma into a theoretical process to help better understanding of what parents of children with autism go through.

Goffman's stigma and Hochschild's emotion work connect in the data presented through my interviews in how parents experience each phenomenon. My first research question asked how parents experienced associative stigma and how it related to their advocacy, but that limited my view to how parents navigated stigma in general. As I came to learn about parents' relationships with their friends and family as well as institutions, I saw that parents also experienced direct stigma in being judged for the way they parented as well as how they advocated. As parents navigated this stigma, they worked to solve the problems at hand, but also to emotionally work to process what they were experiencing.

Additionally, I asked what type of emotion work parents perform and how it factors into their navigation, advocacy, and management for their child's autism. Through the interviews I found that parents typically perform emotion work as they encounter problems and stigma in their daily lives. While they may not realize the emotional sacrifices they are making, parents most often perform suppressive emotion work to set their emotions aside to work through problems. However, more research is needed to fully understand both stigma and emotion work of parents of children with autism.

Limitations and Future Research

Due to the time constraints and difficulty finding participants, this study is limited to a small sample size. Although the small sample size is a limitation of this study, my goal was to provide more depth of understanding about how parents of children with autism engage in the emotion work it takes to advocate and care for their child. While many of the experiences of stigma that participants noted is backed by current literature, my study is the only one to question how parents perform emotion work. Therefore, the connections made between stigma and

emotion work are nuanced and further research should be done to see if emotion work performance in response to stigma is common among parents of children with autism.

My study theoretically saturated the experiences of being a mother to a child with autism, but the experience of being a father in this situation needs further research. In my initial research for the literature of this study, fathers were typically in the minority for participants in similar studies. Having the perspective of both parents would allow for more distinctions to be made between their experiences. Although the Fargo-Moorhead area lacks diversity, research should be done to reflect the experiences of parents of different races, ethnicities, as well as financial backgrounds. Some of the experiences would likely remain the same, but to have additional stigma due to race and class could exacerbate these issues.

REFERENCES

- Abberley, P. (1987). The concept of oppression and the development of a social theory of disability. *Disability, Handicap & Society*, 2(1), 5-19. doi:10.1080/02674648766780021
- Allen, H. (2017). Bad mothers and monstrous sons: Autistic adults, lifelong dependency, and sensationalized narratives of care. *Journal of Medical Humanities*, 38(1), 63-75. doi:10.1007/s10912-016-9406-4
- Bearman, P. (2010). Just-so stories: Vaccines, autism, and the single-bullet disorder. *Social Psychology Quarterly*, 73(2), 112-115. doi:10.1177/0190272510371672
- Bernardez, T. (1988). *Women and anger: Cultural prohibitions and the feminine ideal* Stone Center for Developmental Services and Studies, Wellesley College.
- Bessette Gorlin, J., McAlpine, C. P., Garwick, A., & Wieling, E. (2016). *Severe childhood autism: The family lived experience* doi:https://doi.org/10.1016/j.pedn.2016.09.002
- Beyer, E. (2019,). Fargo superintendent moving ahead with plans for school for students with behavioral disorders. *Inforum* Retrieved from <https://www.inforum.com/news/education/3291104-Fargo-superintendent-moving-ahead-with-plans-for-school-for-students-with-behavioral-disorders?fbclid=IwAR0F-oAwsPiO08Aip7I2h-8KwAice27xoRE9PdBNnv7g1KdodhfD0nnkhTY>
- Birenbaum, A. (1970). On managing a courtesy stigma. *Journal of Health and Social Behavior*, 11(3), 196-206. doi:10.2307/2948301
- Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2016). Parents' voices: 'why and how we advocate'. A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder. *Child: Care, Health and Development*, 42(6), 784-797. doi:10.1111/cch.12383
- Broady, T. R., Stoyles, G. J., & Morse, C. (2017). Understanding carers' lived experience of stigma: The voice of families with a child on the autism spectrum. *Health & Social Care in the Community*, 25(1), 224-233. doi:10.1111/hsc.12297
- CDC. (2019). Data & statistics on autism spectrum disorder. Retrieved from <https://www.cdc.gov/ncbddd/autism/data.html>
- Cohen, S. (2002). *Targeting autism: What we know, don't know, and can do to help young children with autism and related disorders*. Berkeley and Los Angeles, California: University of California Press.
- Dictionary.com. (2020). What does karen mean? Retrieved from <https://www.dictionary.com/e/slang/karen/>
- DSM-5 criteria. (2019). Retrieved from <https://www.autismspeaks.org/dsm-5-criteria>

- Ekas, N., Timmons, L., Pruitt, M., Ghilain, C., & Alessandri, M. (2015). The power of positivity: Predictors of relationship satisfaction for parents of children with autism spectrum disorder. *Journal of Autism & Developmental Disorders*, *45*(7), 1997-2007. doi:10.1007/s10803-015-2362-4
- Fernández-Alcántara, M., García-Caro, M. P., Pérez-Marfil, M. N., Hueso-Montoro, C., Laynez-Rubio, C., & Cruz-Quintana, F. (2016). *Feelings of loss and grief in parents of children diagnosed with autism spectrum disorder (ASD)* doi:https://doi.org/10.1016/j.ridd.2016.05.007
- Francis, A. (2012). Stigma in an era of medicalisation and anxious parenting: How proximity and culpability shape middle-class parents' experiences of disgrace. *Sociology of Health & Illness*, *34*(6), 927-942. doi:10.1111/j.1467-9566.2011.01445.x
- Gibson, A., Kaplan, S., & Vardell, E. (2017). A survey of information source preferences of parents of individuals with autism spectrum disorder. *Journal of Autism & Developmental Disorders*, *47*(7), 2189-2204. doi:10.1007/s10803-017-3127-z
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall, Inc.
- Gray, D. E. (1994). Coping with autism: Stresses and strategies. *Sociology of Health & Illness*, *16*(3), 275-300. doi:10.1111/1467-9566.ep11348729
- Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability*, *27*(3), 215-222. doi:10.1080/1366825021000008639
- Harper, A., Dyches, T., Harper, J., Roper, S., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of Autism & Developmental Disorders*, *43*(11), 2604-2616. doi:10.1007/s10803-013-1812-0
- Hochschild, A. R. (1979). Emotion work, feeling rules, and social structure. *American Journal of Sociology*, *85*(3), 551-575. doi:10.1086/227049
- John, R. P. S., Knott, F. J., & Harvey, K. N. (2018). Myths about autism: An exploratory study using focus groups. *Autism: The International Journal of Research & Practice*, *22*(7), 845-854. doi:10.1177/1362361317714990
- Kinnear, S., Link, B., Ballan, M., & Fischbach, R. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism & Developmental Disorders*, *46*(3), 942-953. doi:10.1007/s10803-015-2637-9
- Lorber, J., & Farrell, S. A. (1991). *The social construction of gender* Sage Newbury Park, CA.
- May, C., Fletcher, R., Dempsey, I., & Newman, L. (2015). Modeling relations among coparenting quality, autism-specific parenting self-efficacy, and parenting stress in mothers

- and fathers of children with ASD. *Parenting: Science & Practice*, 15(2), 119-133.
doi:10.1080/15295192.2015.1020145
- McKenna Gulyn, L., & Diaz-Asper, C. (2018). Exploring perceptions of blame for autism spectrum disorder. *Journal of Developmental & Physical Disabilities*, 30(5), 587-600.
doi:10.1007/s10882-018-9604-2
- Moes, D., Koegel, R. L., Schreibman, L., & Loos, L. M. (1992). Stress profiles for mothers and fathers of children with autism. *Psychol Rep*, 71(3), 1272-1274.
doi:10.2466/pr0.1992.71.3f.1272
- National Education Association. (2019). Who are paraeducators? Retrieved from <http://www.nea.org/home/67057.htm>
- Neff, K. D., & Faso, D. J. (2015). Self-compassion and well-being in parents of children with autism. *Mindfulness*, 6(4), 938-947.
- Olson, D. (2019,). Lewis & Clark elementary expansion for students with behavioral challenges moves ahead. *Inforum* Retrieved from <https://www.inforum.com/news/education/4789147-Lewis-Clark-Elementary-expansion-for-students-with-behavioral-challenges-moves-ahead>
- Pugliesi, K., & Shook, S. L. (1997). Gender, jobs, and emotional labor in a complex organization. *Social Perspective on Emotion*, 4, 283-316.
- Robertson, J., Hatton, C., Wells, E., Collins, M., Langer, S., Welch, V., & Emerson, E. (2011). The impacts of short break provision on families with a disabled child: An international literature review. *Health & Social Care in the Community*, 19(4), 337-371.
- Siebers, T. (2008). *Disability theory* The University of Michigan Press.
- Singh, J. S. (2016). Parenting work and autism trajectories of care. *Sociology of Health & Illness*, 38(7), 1106-1120. doi:10.1111/1467-9566.12437
- Taylor, J., & Warren, Z. (2012). Maternal depressive symptoms following autism spectrum diagnosis. *Journal of Autism & Developmental Disorders*, 42(7), 1411-1418.
doi:10.1007/s10803-011-1375-x
- Thieda, K. (2014). Brene brown on empathy vs. sympathy. Retrieved from <https://www.psychologytoday.com/us/blog/partnering-in-mental-health/201408/brene-brown-empathy-vs-sympathy-0>
- What is autism spectrum disorder? (2018). Retrieved from <https://www.cdc.gov/ncbddd/autism/facts.html>

APPENDIX A: INTERVIEW QUESTIONS

1. How did you discover that your child had autism? Was it initially from diagnosis or from your own research?
 - a. [If there wasn't a clear response]: Tell me what the process was like for getting your child diagnosed with autism
 - b. How many doctors did you see before getting a diagnosis?
 - c. Have doctors ever dismissed your judgments or thoughts about your child having autism?
 - i. What type of work did you do outside of the doctor's office to come to an autism diagnosis?
 - d. [summarize some of the emotions that you heard and then ask]: How did you manage the range of emotions that come with caring for a child with autism?
2. What kind of support did you get from family or friends in attempting to get your child diagnosed?
 - a. What were the reactions of your family when you voiced concerns about your child's development?
 - b. What were the reactions of your friends when you voiced concerns about your child's development?
 - c. How did you respond to unsupportive or negative reactions?
3. How did your family and friends react to hearing that your child had autism?
 - a. How have your close relationships changed since your child started exhibiting signs of autism?
 - b. How have you emotionally worked through those changes?
 - c. Have you ever had to be an advocate for your child due to misunderstandings among family and friends?
4. What is it like to be an advocate for your child?
 - a. Do you feel like you were an advocate prior to having your child?
 - b. What caused you to begin your advocacy?
 - c. What was the emotional process like for you to become an advocate?
 - d. How does being an advocate make you feel?
5. Tell me about your experience with the school that your child attends
 - a. Have you ever had any negative interactions with staff or school administrators regarding your child's schooling?
 - b. How often do you have meetings with the school about your child?
 - c. What are the relationships like between you and the staff that works with your child?
6. How do you manage the range of emotions that come with caring for a child with autism?
 - a. What coping strategies do you use?
 - b. How do you respond to obstacles that come in the way of your child's care?
 - c. Does your marital or co-parenting relationship function as a coping mechanism?

APPENDIX B: DEMOGRAPHICS QUESTIONNAIRE

Please circle which term best describes your gender identity:

Man

Woman

Other: _____

Prefer not to answer

Please check all boxes that best describe your racial/ethnic identity:

<input type="checkbox"/>	Caucasian/White
<input type="checkbox"/>	African American/Black
<input type="checkbox"/>	American Indian or Alaskan Native
<input type="checkbox"/>	Hispanic
<input type="checkbox"/>	Asian
<input type="checkbox"/>	Other:

What is your annual family household income?

1. Less than \$20,000
2. \$21,000 to \$50,000
3. \$51,000 to \$75,000
4. \$76,000 to \$100,000
5. Over \$100,000
6. Prefer not to answer

What is your current marital status?:

Single

Married

Divorced

Widowed

How many adults are live in your home? _____

How many adults residing in your home work outside of the home? _____

How many children are currently living in your household? _____

How many children diagnosed with autism are currently living in your household? _____

APPENDIX C: EMAIL DRAFT

Hello,

You are invited to participate in a study of parents of children with autism. My name is Paige Stark and I am a Master's student in the Sociology Program at North Dakota State University. I am working with my graduate advisor, Dr. Christina Weber in the Department of Sociology and Anthropology. As part of my requirements for graduation I am doing a study of the challenges that parents of children with autism face and how they manage their emotions in response. Since I am a sister to someone with autism, I thought it would be interesting to learn from the perspective of parents about what raising a child with autism is actually like.

To participate in this study, you must be a primary caregiver of a child with autism. Your child can be anywhere between the ages of five and twelve for you to qualify for the study.

Participation will include taking part in an interview and short survey. Interviews will take between 45 minutes to 2 hours, but can be stopped at any time. I will ask questions about your experiences with your child's diagnosis process, your experiences with advocating for your child, and how you manage your caregiving experiences. As compensation for completing an interview and survey, you will be given a chance to win a \$50 Target gift card.

Please contact me at paige.stark@ndsu.edu or 320-760-2066 if you are interested!

Thank you!

Paige Stark