

MOTHERS AS HYPERVIGILANTS AND FATHERS AS NURTURERS: THE  
MAINTENANCE OF GENDERED CARE WITHIN MEMOIRS BY  
PARENTS OF CHILDREN WITH COGNITIVE  
DISABILITIES

by

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## **DEDICATION**

For my twin sister, Anna: conducting this project has expanded my awareness of the ubiquitous inequalities sustained against people with disabilities in ways that have made me question my place within this topic. Even now, I wonder whether I made a critical error in not directly addressing the persistent ableism embedded in our structures and culture. I am so grateful and lucky to have gotten you as a partner in this life. You deserve a community of support.

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## TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS .....	v
ABSTRACT .....	vii
CHAPTER	
I. INTRODUCTION .....	1
II. LITERATURE REVIEW .....	4
Doing Gender Through Caregiving .....	4
“Good Mother” vs. “Bad Mother” .....	6
Blending the Breadwinner and Nurturer Identities .....	10
Gaps in Literature .....	14
III. THEORETICAL PERSPECTIVES .....	15
IV. METHODS .....	17
V. FINDINGS .....	21
Identities as Good Parents: Involved Fathers and Intensive Mothers .....	22
Involved and Nurturing Fathers .....	22
Hypervigilant Mothers and Mother Blame .....	28
Relationship with Child: Negotiations of Gendered Relationships .....	33
Making Meaning of Child’s Disability .....	33
Letting Go of Relationships Imagined .....	39
Relationship with Spouse: Contradictions of Choice and Gender Essentialism .....	42
VI. DISCUSSION AND CONCLUSION .....	51
BIBLIOGRAPHY .....	54

## **ABSTRACT**

Sociologists have demonstrated that familial caregiving is gendered, particularly in the context of heterosexual parenting. When parenting children with cognitive disabilities, research shows that parents typically perpetuate gendered divides of caregiving, with mothers often contending with unique societal policing. Due to cultural sanctions of intensive motherhood, mothers are often deemed individually responsible for the outcome of their child, an expectation which becomes further enforced when their children have disabilities. Alternatively, fathers of children with disabilities present characteristics encompassing both nurturing caregiving and traditional fatherhood. To further the understanding of gendered dynamics of caregiving for children with disabilities, I analyzed narratives of family caregiving within autobiographies written by parents of children with cognitive disabilities. Findings indicate that 1) mothers prioritize their identities as parents according to standards of intensive motherhood and fathers embrace identities as nurturers, 2) parents convey their relationships with their children through gendered lenses, and 3) relationships with their spouses illustrate that traditional divisions of familial care are maintained. I assert that these findings demonstrate that parents reproduce gender inequalities when caring for children with disabilities, despite parent narratives which may insist on maintaining an equitable division care. I conclude with implications and suggestions for future research.

## I. INTRODUCTION

Parents of children with cognitive disabilities fit into unique cross sections of discourse involving gender and caregiving. On one side, scholars contend that parents of children with cognitive disabilities perpetuate stricter divides of gendered parenting (e.g., breadwinner fathers and stay-at-home mothers), with mothers shouldering the responsibility of finding a ‘cure’ for their child’s disability (Tabatabai 2019; Douglas 2014; Brandon 2011; Sousa 2011; Blum 2007; Cohen and Petrescu-Prahova 2006). A different angle of this topic, though, shows that fathers of children with cognitive disabilities often emphasize and take pride in their identities as nurturing caregivers (Mitchell and Lashwicz 2018; Potter 2016; Bonsall 2014). Ultimately, however, these parents must navigate the complex sanctions of gendered parenting, a context which scholars show continues to be regulated by traditional gender norms.

Despite a societal push to include women in the public sphere and to break away from the imposed identities of stay-at-home mothers, heteronormative couples still contend with cultural expectations of hegemonic masculinity and emphasized femininity; particularly within the context of parenthood (Leader 2019; Hale and Latshaw 2015; Brandon 2011). Within workplaces that organize themselves around the assumption that men are natural providers and therefore will rarely have childcare responsibilities, fathers feel pressured to conform to traditional forms of masculinity (Boetcher et al. 2021; Eatough and Thackery 2018; Venter 2011). Alternatively, mothers are often subjected to societal scrutiny if they do not spend the expected amount of time caring for and worrying about their children, pressuring them to engage in intensive mothering (Hays 1996). As Hays (1996) discusses, intensive mothering involves putting a tremendous



amount of emotional labor into the care of your child, even if the mother is working outside the home. When there is a child with cognitive disabilities in the family, cultural expectations surrounding traditional gender norms can lag the progression towards a more progressive division of caregiving responsibilities.

Due to the assumptions embedded in the ideology of intensive motherhood, mothers of children with disabilities are told that to be good mothers they must engage in continual advocacy and intensive caregiving for their children (Tabatabai 2019; Sousa 2011). These types of expectations not only enforce the neoliberal ideology that disability is an individual and personal problem, but also furthers social and gender inequalities as this type of care work is expensive and time consuming. Fathers of children with disabilities, on the other hand, can be further pushed into the role of the breadwinner due to medical expenses (Boetcher et al. 2021; Wright et al. 2015; Venter 2011). Sociologists have conducted compelling research which examines mothers' and fathers' individual experiences in having a child with cognitive disabilities in the family; however, few studies have compared their experiences through critically examining the role gender plays within this context of parenthood. The present study fills this gap by analyzing how heterosexual mothers and fathers maintain heteronormative divides of gendered caregiving within the context of memoirs written by parents of children with cognitive disabilities. Using West and Zimmerman's (1987) lens of doing gender and Hays' (1996) paradigm of intensive motherhood, I show that memoir narratives simultaneously challenge and adhere to strict gendered divisions of care. I argue that although heterosexual fathers present themselves as significantly involved in childcare, these narratives are subverted by examples of mothers continually held responsible for the

managerial side of raising their child. Consequently, parent memoirs present a space where unequal sanctions of gendered parenting are maintained.

## II. LITERATURE REVIEW

### *Doing Gender Through Caregiving*

Past research has utilized West and Zimmerman's (1987) theory on doing gender to describe the systematic process by which gender is reproduced through social interactions (Coltrane 1989). One of the environments where performance of gender sanctions becomes most salient is within the division of household labor (Coltrane 1989; West and Zimmerman 1987). Within heteronormative families, mothers are most often expected, encouraged even, to take on more childcare responsibilities due to assumptions that women are natural nurturers (Hays 1996). Although the contemporary genre of women's self-help books in the workplace (Giuffre and Webber 2020) indicates the cultural shift towards encouraging women to enter and thrive in the public sphere, these encouragements still carry the weight of childcare responsibilities. Even while society has become more accepting of the caregiving father (Leader 2019), mothers are still expected to practice intensive mothering.

Among studies that research heteronormative families where the father does take on the role as the primary caregiver, there exists an underlying theme of heterosexual men continually repositioning themselves in dominant masculine positions (Borgkvist et al. 2020; Bach 2019; Latshaw and Hale 2015; Coltrane 1989). This finding is exemplified in instances where fathers indicate excluding themselves from certain caregiving tasks by highlighting that their wives are simply better at engaging in specific (e.g., managerial) childcare work (Borgkvist et al. 2020; Coltrane 1989). Coltrane's (1989) study on equitable parenting describes that in many instances fathers defaulted as the 'helper' to their wives, with their spouses continuing to be responsible for the major decision-

making regarding their child's development. This finding is echoed in Bianchi, Raley, and Wang's (2012) research using the time-use survey. In analyzing when fathers spent time doing childcare, their results indicate that major caregiving responsibilities typically involve leisure time with their children. Alternatively, mothers continue to be presented doing managerial tasks, like organizing doctor appointments, meeting with teachers, and doing physical caregiving tasks like getting children cleaned and dressed (Bianchi et al. 2012). These findings illustrate dominant forms of masculinity within the household because, while women continue to be responsible for the major developmental aspects of their children, fathers are absolved from engaging in those tasks.

Yet, it would be remiss to assume that 'doing gender' through caregiving is ultimately stagnant in nature. Many researchers have investigated how heteronormative parents have adapted the gendered nature of caregiving to accommodate women taking on more of a breadwinner role (Latshaw and Hale 2015; Johnston and Swanson 2006; Coltrane 1989). These changes, however, do not necessarily mean that the caregiver role and essentialized mother characteristics have been disregarded. As Latshaw and Hale's (2015) research shows, breadwinner mothers still find themselves taking on more childcare and caregiving than breadwinner fathers. In other families where the father identifies as the primary caregiver, mothers continue to take on a more managerial position within the household (Latshaw and Hale 2015; Bianchi et al. 2012; Coltrane 1989). These managerial positions may involve delegating housework and childcare responsibilities; alternatively, fathers may identify with more laid-back or fun activities (Choi and Lui 2015). These tendencies reassert gender essentialism by putting fathers in a position where they continue to defer to the mother being most familiar with domestic

labor, which reaffirms to mothers that they have lived up to societal expectations of being good mothers who make their children their priority.

*“Good Mother” vs. “Bad Mother”*

Research shows that parents of children with cognitive disabilities tend to perpetuate gendered divisions of traditional caregiving more so than parents of children without cognitive disabilities. Due to the amount of expenses that usually accompany having a child with disabilities, fathers may feel further pressured to maintain their role as breadwinners (Venter 2011). Mothers, on the other hand, are subjected to the expectation of prioritizing the care of their child over other aspects of their lives, which often involves intense emotional labor and advocacy (Becerra and Kibria 2020; Tabatabai 2019; Fisher and Goodley 2007). According to Hays (1996), when working outside the home, “intensive mothers” are expected to continually exert physical and emotional labor into the care of their child (p. 6); thus, a child’s failures are viewed as a reflection of the mother’s failure to parent and provide nurturing care. This emphasis on individual advocacy and self-sufficiency aligns with the cultural attitudes of neoliberalism, an ideology which tells mothers that only they know what is best for their child, and therefore only they can care for them (Reich 2014).

When mothering a child with disabilities, being a good mother means that mothers must seek out and understand exactly what is ailing their child and be able to find the right therapy or miracle cure. As Reich’s study (2014) indicates, neoliberal mothering expectations mean that mothers must be able to understand exactly what is wrong with their child and take the perfect steps to fix it. Mothers who place high value

upon medical-expert opinion, and adhere closely to the pathological view of disability, become frustrated when experts are unable to help them understand the cause of their child's problems (Fisher and Goodley 2007). Among those who are privileged enough to seek out other expert opinions, further emotional labor is exerted into this search for finding the perfect therapy for their child (Green 2007). Moreover, mothers who have a child with a cognitive, or invisible, disability are often the target of pharmaceutical industries trying to push the sale of psychotropic drugs to mend disruptive behavior (Blum 2007).

One of the complications when working closely and intimately with the medical industry is that it can subject mothers to a certain degree of medical scrutiny when they do not fulfill the societal expectations of a "Fit Mother" (Blum 2007:204). A Fit Mother is a mother who can independently care for their children and is not a perceived danger to the pathological idea of mothering (Blum 2007). Among mothers who both have a disability and are caring for a child with disabilities, heightened levels of medical policing are prevalent, underscored by the assumption that the mother's disability prevents them from being an adequate caregiver (Frederick 2017; Malacrida 2009). It is wrong, however, to assume that mothers who face increased societal scrutiny benignly lie down and internalize the judgement from others. To combat the imposed identity that they are unfit or bad mothers, many may fight back with narratives of their own (Tabatabai 2019; Malacrida 2009; Fisher and Goodley 2007). In Malacrida's (2009) study, many disabled mothers of children who also have disabilities highlight the positive aspects of their disability in helping them better anticipate their child's own needs. Being able to know exactly what your child needs is an important aspect to doing good

motherhood (Reich 2014; Malacrida 2009) and the ability to use their disability to their advantage helps reaffirm that they can care for their child.

Apart from being advocates within the medical system, mothers are also expected to advocate for their child within the school system, and more generally the public sphere. Becerra and Kibria (2020) emphasize how being vigilantes of the special education system allow mothers to negotiate their identities as good mothers and reaffirm to themselves that they are worthy of caring for their child with disabilities. As other studies have shown, advocacy is often expected and encouraged among mothers of children with disabilities (Tabatabai 2019; Cole, Hammond, and Munroe 2016; Sousa 2011; Doktor et al. 2009; Blum 2007; Fisher and Goodley 2007). This type of advocacy not only supports the neoliberal ideology that advocates for mothers to be independent caregivers, but also helps mothers transform an identity of being a bad mother to being a good advocate mother.

In their analysis of autobiographic books written by mothers of children with disabilities, Sousa (2011) explores how mothers negotiate their identities as good, intensive mothers through their narrative accounts within their books. Sousa (2011) argues that these mothers transform their imposed identities of being bad mothers by reclaiming their identities as good mothers through perpetual and individual advocacy. Thus, by engaging in intensive mothering they can confirm to themselves that they are capable caregivers. This finding is consistent with other studies, who have found that public advocacy allows for mothers to renegotiate the identity of being a bad mother because their child has behavior issues, to one of being a champion of their child (Becerra and Nazli 2020; Tabatabai 2019; Blum 2007). The emotional labor which this type of

advocacy requires is indicative of the underlying social narrative that tells women that performing good motherhood means constant self-sacrifice.

Perpetual advocacy can be tiresome and emotionally draining in and of itself and is usually a successful endeavor among those who have the privilege of class and time to do so. As Calton (2010) argues, memoirs by parents of children with cognitive disabilities do not include discussion of the vast number of resources they had at their disposal. Going to different therapies and seeking out different medical opinion is expensive (Hogan 2012), and a luxury only those in the middle to upper classes can afford (Calton 2010). Further, having to do this type of advocacy work is especially difficult for mothers who are immigrants, particularly when there is a language barrier between them and specialists. As parents are operating in a neoliberal culture which assumes mothers should be individually responsible for their children, mothers are subjected to scrutinizing mother blame if they are unable to get their child's needs met (Becerra and Nazli 2020; Tabatabai 2019). As one respondent indicates in Becerra and Nazli's (2020) study, many specialists in the special education system are not sympathetic to parents who cannot speak English, and most do not offer an official translator during meetings. Though this type of emotional labor comes from a place of love and devotion (Tabatabai 2019), this emphasis on mothers being the individual advocate of their children through intensive mothering is ultimately harmful to women who are unable to do this type of advocacy, and further exacerbates social and gender inequalities.

Despite the medical linear model of disability which emphasizes the deficit aspects of having a child with disabilities (Potter 2016), many researchers indicate that



these negative experiences are culturally derived, and do not impact the loving relationship these mothers share with their children. As Fisher and Goodley (2007) describe in their interviews with mothers of babies with disabilities, many mothers combat the medical linear model by focusing on the good aspects of their child's disability, and the loving relationship they share with their child. Other studies find that perceived stigma greatly impacts perceived burden (John and Roblyer 2017; Green 2007), causing some mothers to avoid seeking social support (Cole, Hammond, and Munroe 2016). Yet, despite the stigma experienced from the public sphere, mothers still express great pride in their children's accomplishments (John and Roblyer 2017) and emphasize their children's uniquely positive qualities (Tabatabai 2019; Fisher and Goodley 2007). Although having a child with disabilities may present some unique complications, these narratives indicate that most of these difficulties are strongly tied to the gendered expectation of intensive mothering under neoliberalism.

### *Blending the Breadwinner and Nurturer Identities*

There is little sociological research that specifically focuses on the experiences of fathers parenting children with disabilities. Many scholars assert that this is because the primary caregiver responsibilities often fall upon the mother due to gender norms attached to motherhood (Brandon 2011; Kingston 2007). Other scholars, however, indicate that while fathers' experiences are often yielded invisible, this invisibility does not mean that they do not care or are completely uninvolved in the caregiving rituals (Boetcher et al. 2021; Potter 2016). Despite quantitative data reaffirming the idea that mothers of children with disabilities disproportionately take on more caregiving,

qualitative data tell a more complex story of fathering children with disabilities.

Brandon's (2011) quantitative research on the impact of child's disability on employment among heterosexual married couples reveal that, when controlling for sociodemographic and economic variables, mothers were the only ones whose work hours were significantly impacted. On average, mothers worked 3 hours less per day than fathers, indicative that parents may further enforce gender norms when raising children with disabilities (Brandon 2011). Alternatively, in-depth interviews with fathers of children with disabilities signal that many of these fathers are not indifferent to the responsibilities of caring for a child with disabilities (Boetcher et al. 2021; Mitchell and Lashewiz 2018; Crettenden et al. 2016; Venter 2011). For instance, during face-to-face interviews, most fathers report making a concerted effort to reduce their hours at work so that they could help in caring for their child with disabilities (Boetcher et al. 2021; Venter 2011). In Venter's (2011) study on the impact of child's disability on employment, a large sample of the fathers expressed negotiating flexible hours with their employer so that they could help with caregiving. However, single parents and primary caregivers in Venter's study all identified as being the mothers, reflecting the results of Cohen and Petrescu-Prahova's (2006) quantitative research on gendered living arrangements among children with disabilities.

This discrepancy between what fathers report compared to what the quantifiable data shows may be partially due to the traditional gender norms which are saturated throughout the work environment. Despite the inclination for some workplaces to offer flexibility for people who have family members who need extra care due to a disability, the underlying assumption is that these liberties will not be utilized by fathers (Venter

2011). In Venter's (2011) study, these projected presumptions regarding father breadwinners made some fathers feel as if their coworkers no longer trusted them to get the job done; that they were weak links within a company perpetuating traditional norms of masculinity. Alternatively, other fathers highlight the rationality of maintaining traditional family division of labor. Because men *do* typically get placed in higher paying positions and receive higher paying jobs, many families choose a traditional family dynamic (i.e., father as breadwinner) due to both the extra care needs and the extra financial needs (Boetcher et al. 2021; Eatough and Thackeray 2018; Wright et al. 2015; Venter 2011). For some fathers, taking more time to care for children would negatively impact their finances, something that they depend upon for medical expenses (Wright et al. 2015). This earning power attached to traditional masculinity, coupled with the cultural expectations of intensive mothering, is one of the leveraging powers which may cause families of children with disabilities to lag in terms of progressing past hegemonic gender norms.

However, the workplace is not the only context where hegemonic forms of masculinity are perpetuated. In some cases, fathers used traditional masculinity to rationalize their caregiver responsibilities with their children. For instance, one father in Venter's (2011) study indicated that their wife did most of the caretaking responsibilities simply because they were better at it. Alternatively, other fathers who identify as both the breadwinner and caregiver, emphasize this trait of being hard workers, both within employment and in insuring that their children's needs are met (Boetcher et al. 2021). The former dictates a type of masculinity that hinges upon the essentialized notion that mothers are naturally more adept at caring for children; yet the latter also has undertones

of traditional masculinity through being the family provider. Other fathers were able to maintain their identity of traditional masculinity by emphasizing taking a more relaxed role in caregiving (Boetcher et al. 2021) as well as discussing how they taught their children life lessons through sports and outdoor activities (Mitchell and Lashewicz 2018). Through emphasizing the ways they helped their children with disabilities learn how to play sports, these fathers are able to identify as the nurturing caregiver and remain confident in their masculinity.

Similar to research that focuses on mothering children with cognitive disabilities, a prevalent theme throughout the literature on fathers highlights the many positive experiences fathers have in parenting a child with disabilities. In Potter's (2016) study, a few fathers rejected the deficit narrative perpetuated by the medical model of disability, instead focusing on the amount of joy caring for a child with disabilities has brought into their lives. Thackeray and Eatough's (2018) research show that many fathers choose to primarily focus on the rewarding aspects of fathering children with cognitive disabilities despite the expectations of traditional masculinity weighing on fathers. Being able to connect to their children through play (Mitchell and Lashewics 2018) or through humor (Potter 2016) highlights how many emphasize this need to connect and support their children in various ways, despite the data that indicate fathers' lack of time spent with children with disabilities.

Identifying with a nurturing role and attaching one's identity to being a good father (Potter 2016) may act as a method of redoing gender (Connell 2015) as it contradicts traditional forms of masculinity. Therefore, although parents raising children with cognitive disabilities may further enforce gendered divisions of household labor,

these findings are also indicative that raising children with disabilities gives fathers a space to redo masculinity into a caregiving which places value on being a nurturer.

### *Gaps in Literature*

Most of the sociological research surrounding the gendered nature of parenting children with disabilities focuses on the experiences of mothers. Despite the criticism many scholars have vocalized regarding the invisibility of fathers' experiences raising children with disabilities (Lashewiz and Mitchell 2018; Potter 2016; Venter 2011), quantitative data indicates that caring for children with disabilities is still gendered (Brandon 2011; Cohen and Petrescu-Prahova 2006). Further, mothers have higher expectations of being the primary nurturer and caregiver if their child has disabilities (Becerra and Kibria 2020; Tabatabai 2019; Sousa 2011; Fisher and Goodley 2007). There has been little sociological research which has compared the experiences of mothers and fathers raising children with disabilities and much less that has critically examined the gendered connotations of these experiences. This study fills this gap within the literature by analyzing 10 autobiographical books written by self-identifying mothers and fathers of children with cognitive disabilities and compares the experiences their narratives convey.

### III. THEORETICAL PERSPECTIVES

The theoretical perspective of doing gender (West and Zimmerman 1987) will be utilized to understand the differences (or similarities) in the portrayals of mothers' and fathers' experiences in caring for a child with disabilities. Along with the perspective of doing gender, I will also utilize Connell's (2010) lens of redoing gender to account for ways in which mothers and fathers may depict breaking traditional gender norms within their narratives. Coupled with the theoretical perspectives of doing/redoing gender, I will use the theoretical perspective of intensive mothering, a term coined by Hays (1996) to describe the phenomenon of women being pressured to engage in continual emotional labor because of the assumption that they are natural caregivers. These perspectives will be used to understand the depictions of motherhood and fatherhood within autobiographical narratives, and the influence of gender within these experiences.

Previous research indicates that fathers of children with cognitive disabilities may challenge traditional gender norms, identifying and embracing their role as the nurturing father (Boetcher et al. 2021; Carol 2016; Bonsall 2014). Alternatively, while some might embrace this new identity of being nurturing caregivers, some scholars contend that many fathers are still policed by expectations of being the family breadwinner (Boetcher et al. 2021; Wright, Crettenden, and Skinner 2015). As West and Zimmerman (1987) indicate, gendered division of labor is where traditional gender norms become most salient, and essentialized characteristics are attached to men and women. Identifying as a nurturing father, however, is a method of redoing gender by combatting these imposed identities. Analyzing autobiographical books written by mothers and fathers through the doing/redoing gender lenses will add further knowledge to contexts where these assumptions

unfold, and where parents may work to break from these traditional gender norms.

Hays' (1996) theoretical framework surrounding intensive mothers has been used across multiple studies that analyze mothers' experiences caring, and advocating, for their child with disabilities (Becerra and Kibria 2020; Frederick 2017; Sousa 2011; Malacrida 2009; Blum 2007). According to Hays (1996), even though women are encouraged to join the workforce, mothers still face the dilemma of balancing childcare and employment. This complication is in part due to the hegemonic ideals surrounding femininity, and the societal assumption that women are natural nurturers. Under these cultural expectations, women are expected to continually make the care of their child their priority, to make motherhood their primary identity, and to constantly work on advocating for their child (Hays 1996). This framework of the intensive motherhood will be used alongside the doing/redoing gender frameworks to understand how mothers and fathers individually define and engage in nurturing their child with disabilities, and the way traditional gender norms may influence their experiences.

#### IV. METHODS

To analyze the presentation of gendered caregiving within families of children with cognitive disabilities, I conducted a qualitative content analysis on 10 memoirs by parents of children with cognitive disabilities. Qualitative content analyses are unobtrusive methods that allow the researcher to understand how different ideas or cultural nuances are portrayed within a certain medium (Moran 2016; Stokes 2012; Boero and Pascoe 2012). Analyzing autobiographical books using qualitative methodology allows themes to emerge within these writers' narratives (see Sousa 2011) and uncovers how mothers and fathers of children with cognitive disabilities interpret their perceived experiences.

As past literature describes, memoirs written by parents of children with disabilities reveal ideologies perpetuating the gendered behavior of intensive mothering (Sousa 2011), the way fathers create meaning in fathering children with disabilities (Bonsall 2014), and how the ability to provide for a child with special therapies is a luxury of the middle-upper classes (Calton 2010). The present study demonstrates how gendered caregiving influences how parents create meaning of their experiences caring for and raising a child with cognitive disabilities. I explored the following research questions: 1) How do mothers and fathers portray their experiences caring for children with disabilities? 2) What are the differences and similarities of their experiences, and do these experiences have gendered connotations?

Ten books were carefully selected for this project. While the original intent was to limit the sample to books published within the past 5 years, it was difficult to find relevant books written by fathers of children with cognitive disabilities within that time



span, so I ended with a sample of 10 books spanning from 2009-2020. There are 5 books written by mothers and 5 books written by fathers. The books are:

- *Half a Brain: Confessions of a Special Needs Mom* (2020) by Jenni Basch
- *A Life Beyond Reason: A Disabled Boy and His Fathers Enlightenment* (2020) by Chris Gabbard
- *Raising a Rare Girl* (2020) by Heather Lanier
- *Loving Tiara* (2019) by Tiffani Goff
- *Don't Squeeze the Spaceman Taco: Lessons Learned from My Son with Autism* (2019) by Kelly Jude Melerine
- *Loving Lindsay: Raising a Daughter with Special Needs* (2017) by Linda Atwell
- *Becoming a Seriously Happy Special Needs Mom: 21 Steps to Finding Your Happy Place* (2016) by Linda Bennett
- *An Uncomplicated Life: A Father's Memoir of His Exceptional Daughter* (2015) by Paul Daugherty
- *No Greatness without Goodness: How a Father's Love Changed a Company and Sparked a Movement* (2014) by Randy Lewis
- *The Boy in the Moon* (2009) by Ian Brown

The criteria for including these books were that they had to be written by either a self-identifying father or self-identifying mother and had to have an autobiographical component to their narratives. I began looking for my sample by googling “books for parents of children with disabilities” and clicking through the first few webpages that came up in the search results. There were many websites which recommended books for parents of children with cognitive disabilities; these websites included “10 Parent-

Approved Books for Parenting Kids with Disabilities,” “10 Best Books for Parents of Children with Special Needs,” and Amazon’s top 20 books for parents of children with disabilities. I included books which were recommended more than once across these websites and chose the rest based on book recommendations from Amazon and Goodreads. To narrow the sample down further, I googled each book that had not been recommended by multiple websites to see if they had any notoriety elsewhere; many of the books within this sample have articles written about them, recorded interviews with the author, or have received an award.

For this study, I did not include faith-based books, books written by both parents, or books that were specifically written as a self-help books for their child’s behavioral issues. I chose not to include books about accepting one’s child through faith because I wanted to analyze gender within these narratives without a salient religious mindset as the backdrop to these experiences. Further, books that approach the experience of having a child with cognitive disabilities specifically through religion may be too dissimilar from other types of experiences. Books written by both parents were excluded because I want to specifically compare the experiences and advice from mothers to the experiences and advice from fathers. This reasoning was also why I did not include self-help books specifically geared toward helping your child with emotional or behavioral difficulties. I want to highlight that all the parents in these books identified as being in a heterosexual marriage with a partner, therefore these books represent a very small slice of the vastly lived experience of parenting children with disabilities. I highly suggest that future research should seek to understand how queer or nonbinary identifying couples portray their experiences parenting children with disabilities.

I first began open coding all 10 books. Esterberg (2002) delineates the process of coding qualitative data. When engaging in open coding, the researcher is simultaneously immersing themselves in the data and taking detailed notes (Esterberg 2002). After I finished open coding the books, I began focused coding, a system which involves dividing your notes into specific categories, or codes, and analyzing the overarching themes (Esterberg 2002). For this component I created a table which consisted of different codes I conceptualized based off my initial process of open coding. Anytime parents described their caregiving tasks I coded these into ‘descriptions of childcare.’ Descriptions of their child were coded into ‘relationship with child,’ and ‘feelings toward child’s disability.’ Specific positive descriptions were coded into ‘description of child’s value.’ Descriptions of ‘leisure time’ were also included and were conceptualized as instances where parents described playing with their child or included their child in their own unstructured downtime. Any instances where parents described blaming themselves for any perceived misfortune to befall their child I coded into ‘internal blame.’ Any instances where parents expressed perceiving blame from others, I coded into ‘external blame.’ The present findings represent the most prominent and overarching themes which emerged from this coding process.

## V. FINDINGS

Throughout these memoirs, mothers and fathers navigate their identities as caregivers to their children using narratives which imply that gender ideals of parenting continue to perpetuate their presentations of caregiving. Notably, however, fathers illustrate defining themselves as good fathers under terms which challenge traditional dictates of masculinity. Yet, mothers perpetually represent ideals of heightened femininity through acting out intensive motherhood and being hypervigilant of their child's disability. Further, while fathers define themselves as nurturing caregivers, in many instances this identity is continually subverted by traditionally masculine conceptions of fathering responsibilities. These findings demonstrate that although current expectations of fathering masculinities might be shifting, mothers of children with disabilities are still policed by societal expectations of good motherhood. I argue that contemporary discourse around heterosexual parenting still privileges traditional divisions of childcare, particularly within the context of having a child with disabilities. Despite distinctive challenges to traditionally gendered caregiving within memoir narratives, parents continually frame their experiences in a way that places the burden of emotional and managerial caregiving onto women.

*Identities as Good Parents: Involved Fathers and Intensive Mothers*

Involved and Nurturing Fathers

*“If I couldn’t be a great scholar, at least I could be a great father to August. I would make caring for him as profoundly beautiful as I could”* (Gabbard 2017:103).

Gabbard (2017), is one of the fathers among the five books who framed his identity around being a nurturing caregiver to his child with disabilities. This identity of fathers embracing the nurturing role is one consistent with the paradigm of “new” fatherhood, a cultural expectation which shifts the demands that men uphold masculinity through being distant breadwinners, to one which places high value on fathers who are both breadwinners and involved nurturers to their children (Bach 2019:351). These new cultural expectations allow heterosexual men to embrace the identity of being a nurturing provider without fear of substantial societal retribution. However, as Borgkvist, Crabb, Elliott, and Moore (2020) contend, these new fathering premises do not necessarily render equitable caregiving. As their findings indicate, fathers appear cognizant of the necessity of equitable parenting, however, many continue to privilege their breadwinner identity over their parental one (Borgkvist et al. 2020). Within this sample of memoirs written by heterosexual fathers, the authors display reflections of dismissing traditional ideals of masculine fatherhood, preferencing their identities as involved and nurturing fathers. This facet of their identity, however, is perpetually underscored with reassertion of their masculinity through falling into a helper role when describing their relationships with their children and wives. Notably, then, for some there is a discrepancy between how

they identify and how they portray their caregiving responsibilities. I suggest that the instances where fathers describe characteristics of embracing nurturing caregiving typically associated with intensive motherhood (see Blum 2007; Hays 1996) are areas where fathers ‘redo’ their gender roles in contrast to traditional provider ones, presenting a masculinity whose identity prioritizes the needs of their children.

Several fathers depict feeling guilty about not spending enough time with their children (Brown 2009; Melerine 2019). Brown (2009), one of the fathers who depicts an equitable division of care between him and his wife, expresses perpetual self-retribution for being unable to keep his son living with them at home. After years of discussing whether they should put their son in a home for people with disabilities, Brown and his wife finally make the difficult decision when realizing the emotional toll caregiving has taken on them both. Brown (2009) tells his readers:

*Every time he [Brown’s son] comes to mind I remember that we couldn’t keep on with him, and my hands and chest go cold; I think about how long it has been since I saw him last and when I will see him next...calculate the number of days he has been away, feel okay or reprobate about the number... (P. 244)*

This dialogue is illustrative of the importance Brown places on his role as a nurturing caregiver in his son’s life. Here, not only does Brown depict acute guilt for being unable to keep his son with them at home but expresses urgency that he does not go too long without visiting him again. In narrating his feelings of shame regarding his ability to care for and spend time with his son, Brown demonstrates an embracement of

his identity as a nurturing and vigilant caregiver, challenging traditional presentations of fathering masculinity.

Similarly, Melerine (2019), the only father who identifies as a stay-at-home father, berates himself for not being around his son enough to understand the source of his headaches, hypothesizing that these migraines are causing his son's violent behavior. In this excerpt, Melerine reflects:

*My gut feeling told me that Cade was suffering from migraines or other severe headaches. Convincing doctors that a special needs child is in pain requires persistence. Unfortunately, when it comes to children with disabilities, doctors are quick to label everything as behavioral problems. (2019:5)*

In this quote, Melerine presents acute concern for his child's illness and orients himself the expert who knows his child well. This feeling is emulated in another narrative, where Melerine indicates that he "beat [himself] up over how long Cade has been suffering with headaches," alluding to the fact that he doubts his abilities as a good parent (2019:10). These dialogues challenge the view that heterosexual fathers raising children with disabilities do not identify with their caregiver role. While these narratives indicate grappling with complex feelings over their role in their child's life, Melerine (2019) and Brown (2009) both place high emphasis on their identities as good parents around not only being actively present in their child's lives, but also being able to anticipate and understand their needs.

There are also explicit descriptions of physical caregiving within these fathers' narratives (Brown 2009; Gabbard 2017; Melerine 2019). Although Bianchi's, Raley's, and Wang's (2012) analysis of the time use survey indicate that fathers are less likely to engage in physical caregiving tasks than mothers, Eatough's and Thackery's (2018) research indicates that disabled children often necessitate fathers engage in physical caregiving responsibilities. Notably, within this sample, the more severe the child's disability, the more fathers engaged in physical and solo caregiving responsibilities. In one excerpt, Melerine (2019) explains his reasoning when he realizes the cause of his son's severe behavior:

*The funny thing is I didn't need a degree to figure that out. I just needed to be a parent. My focus on Cade shifted back to what I believed to be migraines. By tracking his headaches the common triggers were pointing to allergies...By observing Cade I began to sense the moments that a headache was approaching. When these subtle cures presented themselves, I gave him an over the counter migraine pill and it actually made a difference. (P. 38)*

Here, Melerine frames his identity as a good caregiver around being vigilant of his child's needs, a finding typically associated with intensive motherhood (see Tabatabai 2019; Sousa 2011; Blum 2007). Brown (2009) echoes this fixated concern for his child's wellbeing, describing how every morning he sat their son down and checked his limbs, to ensure that nothing was wrong. Gabbard (2017) also describes reading literature on how to care for children with disabilities, specifically commenting that there are very few



books written for father caregivers. Further, Gabbard indicates doing physical caregiving activities like bathing, dressing, and brushing their teeth in the morning and evening as part of their routines, emphasizing that he finds these activities as integral to forming a relationship with his son. Thus, Gabbard's identity as a good father incorporates qualities that dismantle traditionally masculine conceptions of caregiving.

In some instances, though, fathers presented characteristics perpetuating the provider role associated with traditional fathering masculinity (Brown 2009; Daugherty 2015; Gabbard 2017; Lewis 2014; Melerine 2019). Concerned for his son's future, Lewis (2014) spends years creating a movement within his workplace to ensure that his son, and others with disabilities, will have a means to survive when he is no longer able to provide for him. This goal derived from Lewis's (2014) concern that he would never be able to save enough to support his son throughout his entire life:

*How can I ever save enough to ensure that our child won't end up on the streets after we're gone? Will he be safe? Who will worry about him? I know all parents with a child with disabilities share the same prayer: to live one day longer than our children. (P. 48)*

Even though Melerine (2019) made a conscious decision to be a stay-at-home dad to their son, he indicates feeling the need to do extra tasks when everyone is away to prove he is not a "slacker," (p.142). In these examples, Lewis and Melerine both present inner struggles of their identities as adequate providers. Lewis solved this conflict by

creating jobs for people like his son; Melerine, even as he embraces his nurturing identity, tries to compensate for not having a job by doing more errands.

These father narratives regarding their identities as good fathers illustrate the continual renegotiation of gendered fatherhood. Even as fathers challenge traditional notions of fatherhood through expressing nurturing tendencies, there is also indication that pressures to conform to masculinity through being a provider, for some, are still underscoring their identities as good caregivers. Andreasson and Johansson (2016), in their analysis of father bloggers, note that willingness to engage in nontraditional forms of fatherhood does not necessarily mean that fathers do not perpetuate a hegemonic masculinity. Similarly, in their inquiry of father caregivers, Thackery and Eatough (2018) contend “that a thread of masculinity runs through” the ways fathers denote caregiving responsibilities of children with cognitive disabilities (p.187). In the context of this study, father caregivers center their good father identities around their abilities to care for and center their children, representing a ‘redoing’ of masculine roles through caring for children with disabilities. However, when describing their insecurities in their provider role, fathers engage in a dominant form of masculinity, as described by West and Zimmerman (1987). Like the fathers in Thackery and Eatough’s (2018) analysis, these narratives demonstrate that fathers’ identities balance both the nontraditional and traditional roles of their caregiver status, indicative of the cultural push for fathers to be more involved in nontraditional masculine care. In illustrating a redoing of their masculine identities, though, there continues to be little discussion on gender neutral identities of parenting (see Boettcher et al. 2020; Andreasson and Johansson 2016).

## Hypervigilant Mothers and Mother Blame

*“The standards for good mothering are impossibly high, and few people encourage women to invent unconventional paths” (Lanier 2020:117).*

As fathers grapple with their identities around masculine fatherhood, mothers consistently maintain caregiving femininity. As literature suggests, mothers of children with disabilities often formulate their identities as good mothers under societal expectations that they either find a cure for their child’s disability or mediate the disability through therapy intervention (Tabatabai 2019; Douglas 2014; Sousa 2011; Blum 2007). I use the term ‘hypervigilant’ here to describe mothers’ acute vigilance of their children through continual surveyance of their child’s disability and symptoms. Even as some mothers present awareness of the unequal ideals of caregiving perpetuated onto women (Lanier 2020; Goff 2019; Bennett 2016) all mothers in this sample emulate ideals of intensive motherhood as part of their identities as good mothers. From initially looking for a diagnosis, to designating themselves as their child’s therapist, being the primary caregiver of their children is immediately salient in their identities as their child’s parent (Atwell 2017; Basch 2020; Bennett 2016; Goff 2019; Lanier 2020;). Goff (2019), a mother to three children, one of which has a cognitive disability, describes orienting herself not only as a primary caregiver, but also as the expert of her child’s disability. Goff (2019) writes:

*As her mother and as her constant companion, I could sense things about her medical state that couldn't be measured or verified; I just knew how she was feeling or responding to a treatment even though she couldn't verbally tell me. (P. 78)*

In this narrative, Goff frames motherhood as synonymous to understanding one's children completely, to the point where Goff believes that she can comprehend her daughter's symptoms better than medical expertise. Whether Goff's assessment of her daughter is true or not, insisting that she is the expert of her child because she is a mother is consistent with the Hays's (1996) intensive mothering paradigm. Thus, under these heightened cultural ideals, Goff negotiates her status as a gendered caregiver through emphasizing her achievement of motherhood through total understanding of her child's needs.

Similarly, Bennett (2016) tells her readers that "[a]s new parents, our intuition, or parent radar system started alerting us to problems," when explaining her initial realization of her son's disability (p.16). Bennett's use of the term "parents" more broadly encompasses gender neutral caregiving. The implication is that parents possess essential characteristics that are critical for child rearing. This "radar system," also implies that there is a biological component to caregiving, language which some scholars contend can absolve some from caregiving responsibilities under the assumption that caregiving is inherent to women (Borgkvist, Crabb, Elliott, and Moore 2020).

However, mothers also discuss feeling as if they have little choice but to engage in this intensive caregiving labor. When trying out different therapies and caseworkers to

help with her daughter's disability, Lanier (2020) describes her initial interpretation of what disability motherhood entails:

*[w]ith a gripping sense of duty, I internalized the messages that I needed to become three therapists inside one mother... I read out of a sense of duty that couldn't fail her. (P. 94)*

Within this description, Lanier hints that the current systems of care created a mother identity which demanded she engage in continual labor to help her child's disability. Being unable to execute these therapies meant that she would fail being a caregiver to her daughter. Like Lanier, Basch (2020) states that:

*Over time I became a surrogate physical therapist, occupational therapist, speech therapist, doctor, neurologist, radiologist, and teacher. I had to become an expert to advocate for my child. (P. 101)*

For Basch, identifying as her child's expert and teacher are an outcome necessitated because of the perpetual need to advocate for her daughter. Tabatabai (2019) argues that mothers of children with disabilities often perpetuate privileged and neoliberal motherhood, but they often do so because of the unwelcoming environment for people with disabilities. In response to the perceived unequal resources and care allocated to their disabled children, mothers often counter with maternal activism (Douglas 2014; Sousa 2011; Doktor et al. 2009; Blum 2007). The experiences presented by mothers in

this sample indicate that inadequate systems of care create the gendered expectation that mothers engage in heightened feminine caregiving. Where fathers of children with disabilities may grapple with identities as providers and nurturing caregivers, mothers of children with disabilities must navigate an environment that demands their continual labor of feminized care.

Under watchful societal scrutiny, mothers also express lingering guilt that they may have caused their child's disability (Atwell 2017; Basch 2020; Bennett 2016; Lanier 2020). Basch (2020) writes, "[e]ven though I felt needlessly guilty for being the parent with screwed-up antigens, I felt a huge sense of relief. I didn't eat the wrong food or exercise too aggressively" (p. 65). Through writing that she felt "needlessly guilty," Basch conveys that she understands that she is not to blame for her child's disability. In indicating her "relief," however, Basch reveals that she still feels partially responsible for producing a disabled child.

Similarly, Lanier (2020) also explicitly expresses wondering if it was her fault that her child was born without a fourth chromosome. When Lanier asks an expert in their field about the cause of her daughter's chromosomal deletion, she reflects:

*[i]t turned out I was wondering, oh just slightly, if I'd done something, oh just something, to make my daughter have a deletion on her fourth chromosome... After all this time, I still wondered... My belief in a person's responsibility for wellness ran decades old... I later learned that plenty of mothers ask this same question, even when we know the science... Maybe we subliminally carry the long history of maternal blame. (2020:167)*

Lanier, however, is particularly aware of the policing of women through perpetual mother blame. Her indication that “we...carry the long history of maternal blame” is indicative that she is cognizant of the mother blame paradigm, even as she feels its policing presence in how she processes her child’s disability. These narratives contrast starkly with father accounts, whose identity as good fathers do not include continual questions as to whether they were proximate cause of their child’s disability. Although Lanier (2020) is the only mother who explicitly attributes societal mother blame for her internal guilt, the prevalence of this continual questioning of their role in their child’s disability represents the gendered policing of caregivers. For mothers, their identity as good mothers rely on being able to expect and cater to the needs of their child, while having their culpability continually scrutinized.

In contrast to father narratives, mothers convey their identities as good caregivers strictly under the cultural dictates of ‘good motherhood,’ presenting traditionally gendered childcare behavior. These identities correspond to good mothering ideologies in several ways. In claiming to possess essential parental characteristics, for instance, mothers cultivate an environment that places the burden of childcare onto women. Further, in detailing their identities as caregivers around managing their child’s doctor, therapy, and education appointments, they showcase the gendered practice of mothers being primarily responsible for the outcome of their children. As Hays (1996) contends, the cultural environment for good mothering demands that mothers be primarily responsible for the children under the conditions that mothers, and women, are naturally fit for childcare. To navigate the unequal expectations of childcare, and contend with an ableist environment, mothers of children with disabilities internalize the message that

they must act as their child's activist (Tabatabai 2019; Douglas 2014; Sousa 2011; Doktor et al. 2009; Blum 2007; Fisher and Goodley 2007). Additionally, Douglas (2014) reminds us that the policing eye of mother blame has shifted from directly blaming mothers for birthing children with cognitive disabilities, to blaming them if they do not 'cure' their child's disability. The prominent theme within this sample indicates that mother's identities of intensive mothers are an outcome of perpetual expectations of unachievable motherhood and ableist attitudes towards disability. In sum, fathers may be allowed the flexibility to bend identities of masculine fatherhood, but mothers continue to shoulder the weight of idealized femininity and motherhood.

#### *Relationship with Child: Negotiations of Gendered Relationships*

##### *Making Meaning of Child's Disability*

*"Having Fiona gifted me with maternal intelligence that was beyond logic" (Lanier 2020:112).*

A central theme within this sample of parent autobiographies revolves around parents coming to understand, and accept, their child's cognitive disabilities. Therefore, these narratives emphasize the creation of meaning within the relationship they share with their children. Simultaneously, these parents challenge the deficit view of disability, yet several also fall into the trap of finding value in their children through emphasizing ways they have 'overcome' their disability, thus perpetuating ableist attitudes onto their children. Many scholars note that parents of children with disabilities perpetuate ableist



narratives in perceiving disability as synonymous to deficit, yet simultaneously use their voices to attempt to transform cultural attitudes towards disability (Boettcher 2020; Tabatabai 2019; Frederick 2017; Piepmeier 2012; Fisher and Goodley 2007). Piepmeier (2012), for instance, offers a critical analysis of parent memoirs, illustrating that parents' emphasis on grief reinforces negative views of disability. Within the present sample, mothers and fathers convey similar attitudes. Notably, there is a gendered dynamic woven throughout their meaning-making process, particularly in the depicted relationships with their children.

In coming to view and accept their child outside of the medical-deficit narrative, mothers depict doing so through the process of intensive motherhood (Atwell 2017; Basch 2020; Bennett 2016; Goff 2019; Lanier 2020). Basch (2020) and Lanier (2020), for example, both emphasize coming to understand their child outside of the deficit lens of disability through doing research and helping their children through their different therapies. Basch (2020) reflects that her daughter “is not inferior, just different,” after realizing that she appreciates the different experience of caregiving raising her daughter has allowed her to pursue (p. 218). Lanier (2020) writes that her daughter has taught her “another way to parent,” one which does not expect her child to become independent of her care (p.160). Similarly, Bennett (2016) depicts that it was her continual observation of her son that made her realize that Ryan seemed to be happily enjoying life with a disability. Yet, Bennett (2016) continually uses language that implies that her son's disability puts him at an inferior status. She advises her readers that they need to see children as more than their disabilities:

*I thought Ryan would be sitting in a corner, sucking his thumb for the rest of his life. Today he is more independent, funny, and intuitive than I could have imagined.... We [mothers] need to challenge our kids the same way we do our typical kids. (Bennett 2016:23)*

Bennett (2016) implies that there is a hierarchy to disabilities, indicating that her son's independence makes him better off than those with disabilities who may not have the capabilities to act as independently. And within this dialogue, she notes that it was her abilities as a mother which cultivated his independence and that all mothers must do the same for similar outcomes. This emphasis on cultivating independence among children with disabilities is a narrative often charged to mothers, bound closely with the norms of neoliberal motherhood (see Tabatabai 2019; Douglas 2014; Sousa 2011). In these cultural constraints, a mother's relationship with her child is tied to acts of intensive motherhood. Similarly, Atwell (2017) presents a perpetual adherence to the medical model of disability, exemplifying pride in her daughter when she showcases her ability to 'overcome' her disability through the caregiving Atwell provided. The perpetual theme of viewing their children's values within the context of their active caregiving responsibilities is indicative that their relationship with their children is still largely tied to managing their child's disability.

In contrast, fathers highlight forming a relationship with their child through leisure and playtime. Although three of the fathers also emphasize forming a relationship with their children in the context of their caregiving responsibilities, these experiences continue to be coupled with narratives of leisure time and play (Brown 2009; Daugherty

2015; Gabbard 2017; Melerine 2019). This finding is consistent with several studies regarding care time fathers spend with children, with and without disabilities (Lashwicz and Mitchell 2018; Lee and Hofferth 2017; Bianchi et al. 2012; Coltrane 1989). Bianchi, Raley, and Wang (2012), for instance, delineate that fathers are more likely to incorporate solo childcare time into their leisure activities. By itself leisure time in childcare does not equate a dominant form of masculine caregiving. However, when this practice accounts for most, if not all, caregiving responsibilities, fathers continue to perpetuate masculinity that inadvertently shifts the managerial components of caregiving onto women (see Coltrane 1989).

Thus, even while fathers highlight their integral roles in raising their children, these are subverted by dominant patterns of parenting that adhere to traditional forms of masculine fatherhood. Cultivating a positive lens of their child's disability within the context of leisure activities, a context which mother memoirs specifically lack, displays a continuation of gendered divisions of care (Brown 2009; Daugherty 2015; Gabbard 2017; Melerine 2019). Daugherty (2015), for instance, opens his book with descriptions of teaching his daughter to ride a bike. In this scene, he metaphorically compares her finally being able to ride a two-wheeled bike without help to parents having to eventually let go of their children when they are old enough. Daugherty hints that raising his daughter is like typical experiences of caregiving but does so within the context of teaching his daughter to ride a bike, a sports activity. In another chapter, Daugherty discusses the struggles he contended with in accepting his daughter's diagnosis with Down syndrome. He describes that within the year after her birth, he would pick her up at the end of the day and dance her around the room:

*My sadness was large. My need to protect against it was overwhelming. So I hugged for dear life, just to feel good about something. If I hugged Jillian hard enough, maybe the Down syndrome would go away. Please give your love to me. At the end of each day, my daughter performed therapy on me. She danced with me around the room. (Daugherty 2015:59-60)*

In this quote, Daugherty depicts trying to understand and make meaning of his child's disability through dancing with her each evening during her first year of life. Similarly, Gabbard (2017), who began deconstructing his deep-rooted ableism when his son was born with cognitive disabilities due to medical malpractice, describes coming to accept his son's disabilities as a spiritual journey. He describes instances of taking his son on jog with him in his stroller around the neighborhood and playing mini ball games with his son at home. Their game involved Gabbard shooting balls and yelling 'goal!'. Gabbard writes that, "[t]his had become our sport, our way of playing ball together" (2017:51). Like Gabbard, Brown (2009) also describes making sense of his son's disability through moments of leisure, whether it be reading to his son, taking him on kayaking trips, or making up their own language together.

Likewise, even though Melerine (2019) challenges traditional organizations of caregiving more conspicuously through identifying as a stay-at-home father, he also indicates engaging in the most leisure time with his son. This contrasts with the memoirs written by mothers who identify as primary, stay-at-home caregivers, and who indicate few instances spending time with their child doing leisure activities. Alternatively, Melerine (2019) depicts connecting with his son through movies they watch together.

Melerine tells his readers that, “[i]n many ways Cade and I were a lot like the duo from the film [*Shrek*]. He was the big, misunderstood green guy and I was his loyal companion” (2019:67). He implies that he and his son’s relationship is more like a friendship, with Melerine acting as both his caregiver and his closest friend. These illustrations of meaning making with their children through play and leisure shift slightly from the strictly caregiving perspective presented in the books written by mothers. Through underscoring their meaning making of their child’s disability through intensive and hypervigilant caregiving, mothers highlight their presentation of feminine caregiving. Meanwhile, fathers’ emphasis on leisure activities fashions a masculinity that, although still involved in caregiving, continues to perpetuate a masculinity focused on caregiving through leisure.

Throughout these accounts, both mothers and fathers produce gendered presentations in how they come to view their child’s disability outside of the limiting constraints of the medical model. Further, several of them indicate their spouses displaying the same gendered behavior in creating a relationship with their child (Basch 2020; Bennett 2016; Brown 2009; Daugherty 2015; Goff 2019; Lewis 2014). Although Goff (2019) hints at discontent that her husband does not engage in more managerial caregiving, she overshadows this idea by asserting that when he is home, he always taking their children out to play. Similarly, the other books contain little critique regarding this problematic division of care. In viewing these presentations through West and Zimmerman’s (1987) doing gender paradigm, these parent-child relationships depict a continuation of binary practices of childcare. Further, using Hays’ (1996) framework of intensive motherhood, we see mothers centering the development of their child where

control of their child's outcome takes precedent over play and leisure time. Several scholars contend that fathers of children with disabilities are heavily involved with their children's lives, asserting that studies on heterosexual parents of children with disabilities often render fathers invisible (Eatough and Thackery 2018; Lashewicz and Mitchell 2018; Potter 2016; Wright et al. 2015; Bonsall 2014). The findings within this sample support these scholars' argument but shows that the methods in which fathers and mothers are involved and create a relationship with their children perpetuates the cultural narrative that women are primarily responsible for caregiving. I argue that the present study is where we can see why quantifiable data show that mothers of children with disabilities continue to be more involved in routine childcare. Although fathers do identify as involved parents, they continue to defer to caregiving with the context of leisure.

### Letting Go of Relationships Imagined

Though these parents attempt to create a new narrative of disability outside of the deficit one, there are instances where parents grapple with moving past the image of the child they envisioned before realizing their child's disability. The image of the child they imagined often involves essentialized characteristics of gendered relationships between parent-child dyads. In these depictions, parents project their gendered assumptions surrounding typical parent-child relationships.

Atwell (2017) tells her readers that she is disappointed with her and her daughter's relationship, writing that, "we [Atwell and Lindsey] had not developed the rapport I'd dreamed a mother-daughter relationship should have- more like the one I

shared with my mom” (2017:203). Throughout the book, Atwell indicates frustration that she and her daughter are not close like she thinks mothers and daughters should be and reveals that this resentment had occurred from the moment she found out about her daughter’s disability. For Atwell, accepting her daughter also meant releasing her previous image of what she considered ideal mother-daughter relationships. Within this depiction, Atwell conveys that her image of the ‘perfect’ child involved the crafting a daughter who was not only nondisabled, but also confirmed her essentialist views of gender. Like Atwell, Goff (2019) emphasizes that her role as a caregiver (through volunteering at schools and being there for her children) define her relationship as a mother to her children, saying that she does not want to be like her mother. Only Lanier (2020) makes a point to emphasize not wanting to know the gender of her baby beforehand because she did not want to project gendered assumptions onto her child.

Brown (2009), Daugherty (2015), and Gabbard (2017) also describe grappling with the relationship with their child they thought they would have based on their perceived gender. Daugherty states that he feels he must let go of the image of walking her down the aisle or seeing her off to her first big school dance. In this detail Daugherty is projecting what he views as being the typical gendered relationship between fathers and daughters, a projection he feels he now must let go because of her disability. Similarly, Brown (2009) and Gabbard (2017) each envision assumptions about their relationship with their children based around the gendered the father-son dyad. Brown (2009) indicates buying his son his first “big boy” clothes even though they are too big for him, writing that it may be the only “male ritual” he passes down (p. 42). When

hearing the doctor's assumption of his son's gender, Gabbard immediately launches into a vision of what he daydreams he and his child's relationship will be:

*Knowing it would be a boy, I began to dream about the things we would do. We would backpack in the High Sierras, where, camping in the wilderness, we'd drink in an ocean of stars while sitting beside a fire. We'd go to baseball games at AT&T Park, where I'd teach him to root for the Giants and against the archrival Dodgers, the way my dad had done.... (P. 13).*

In these narratives, parents present idealized visions of what they thought their children would be like based on essentialized gender characteristics. The process of creating meaning of their child's disability, therefore, involves cultivating a new narrative which releases what they thought their relationship would be. West and Zimmerman (1987) observe that to 'do' gender means to create differences between women and men which are perceived to be essential to each gender. These perceived differences act to validate social organization, enforcing the belief that the socially created categories of men and women necessitate different treatment. As Kane (2006) demonstrates, heterosexual parenting is often a space where the gender binary is first enforced through parental ideals of the characteristics 'girls' or 'boys' should mimic. My study shows that parents of children with disabilities use their child's perceived gender to signify the expected relationship they believe they will, and should, have. For parents, a child with cognitive disabilities disrupts the idealized image of the child they imagined through their child's gender. These instances reveal the complex relationships between parents and



their children with disabilities. On the one hand parents perpetuate ableist and heteronormative assumptions onto their children through their expectations of what constitutes ‘normalcy.’ On the other hand, parent narratives also create a space where new meanings of disability outside of the deficit one can be forged. And overlapping these nuances are gendered divides which perpetuate binary divisions of familial care.

*Relationship with Spouse: Contradictions of Choice and Gender Essentialism*

*“There were times when I felt like his life was easier than mine because I was doing all the heavy lifting. Of course, that feeling went both ways” (Bennett 2016:41).*

Throughout these narratives, mothers and fathers highlight their identities as good caregivers through their involvement in their child’s lives and their cultivation of a close relationship with their child. Although mothers follow stricter norms of femininity in their depictions, fathers present themselves redoing traditional forms of masculinity in many instances. West and Zimmerman (1987) and Risman (2009) both delineate gender as a set of interactions that are enforced at the structural level and reproduced through individual dynamics. Within these memoirs, parents appear both cognizant of gendered sanctions of caregiving, yet continually reinforce traditional caregiving rituals when describing their reasoning behind their division of care.

Although fathers often underscore their active involvement in caregiver activities, and mothers highlight their partner’s critical assistance in raising their children, mothers are depicted in managerial roles (Atwell 2017; Basch 2019; Bennett 2016; Brown 2009;

Daugherty 2015; Goff 2019; Lanier 2020; Lewis 2014). As Coltrane (1986) and Bianchi, Raley, and Wang (2012) discuss, most of the childcare undertaken by women in heterosexual relationships often comprises doing the managerial work with men acting as more of a ‘helper’ within their dynamic. There are several reasons for this behavior that scholars debate, but most of them attribute this behavior to ideals surrounding intensive motherhood (Hale and Latshaw 2015; Bianchi et al. 2012; Hays 1996). According to Hays (1996), cultural ideals surrounding good motherhood often bind women to the view that they are solely responsible for the outcome of their children, even as the metaphorical doors of liberation and choice appear to be sprung wide open. Although several parents appear to be cognizant of the unfair expectations placed upon women and mothers, they continue to shift back into traditional modes of caregiving through underscoring the critical role choice and spousal characteristics plays in their decisions of caregiving responsibilities.

As if to explain her hypervigilant role in her child’s life, Bennett (2016) indicates that, “[e]very mom is thinking about the health of their child from the moment they are expecting” in describing the different responsibilities she undertook to find a diagnosis (p. 15). In this instance, Bennett implies that it is the natural, singular tendency for mothers to be concerned for their children, and therefore the labor they engage in when caring for children with disabilities is something that naturally accompanies motherhood status. While none of the other mothers directly imply that engaging in this much work is something that mothers should do, they continue to designate themselves as ‘momager’ of their child’s welfare through making calls to insurance companies, scheduling doctor’s

appointments, and attending school meetings (Lanier 2020; Basch 2019; Goff 2019; Atwell 2017).

Among the memoirs written by fathers, several of them indicate that their spouses undertake a majority of the managerial aspects of their children's care (Brown 2009; Daugherty 2015; Gabbard 2017; Lewis 2014). Interestingly, however, fathers do indicate the unfair treatment of mothers and women. Most of this discourse revolves around their disdain that women used to be blamed for birthing children with disabilities. When his wife has difficulty making insurance claims, Gabbard (2017) tells his readers:

*To them, Ilene was a mother whose child had a disability that must have stemmed from drug or alcohol abuse or some other bad behavior during pregnancy. Because of this supposed moral failing, she must have done something to cause August to be the way he was. His impairments provided them with an opportunity for mother shaming. To them, these problems disclosed her lack of love, willpower, and maternal dedication. (P. 111-112)*

In discussing how their son's disability provided a channel through which staff could inflict "mother shaming," Gabbard (2017) illustrates his awareness of the social inequities perpetuated against mothers. Lewis (2014) describes how mothers used to get blamed for birthing children with autism because of supposed child neglect. In reflecting on this inequality, however, he also highlights that she had been exceptionally caring and nursed him until he was one. Thus, rather than broadly critiquing the culture as Gabbard (2017) does, Lewis (2014) instead denotes that his spouse was caring and nurturing,

continuing to imply his spouse's individual responsibility for child rearing. Similarly, Brown (2009) attributes his spouse's perpetual guilt for their child's disability to being because he came from her body, and not because of societal implications. Although Brown (2009) and Lewis (2014) are clearly aware of the internal blame experienced by mothers, they both continue to look at this issue through an individual lens, without investigating the cultural implications.

In undertaking most of the managerial caregiving responsibilities in raising their children, several mothers emphasize that it was their personal choice to engage in this dynamic. Some indicate this decision was because their husbands have steadier incomes, and some denote that they and their spouse simply shared differing perceptions of necessary caregiving. Lanier (2020) writes:

*Because I now only taught half-time, I became the primary manager of Fiona's complex medical calendar... I called our health insurance on my off-days, fought incorrect bills, and set up appointments for early intervention. (P. 81)*

However, Lanier (2020) highlights that she had not initially imagined herself falling into the traditional family division of caregiving when she first married. In Lanier's (2020) case, she views her primary dedication to her daughter's medical care as a production of necessity, particularly as the bills for her daughter's treatment are substantial. Like Lanier (2020), Basch (2020) attributes traditional division of caregiving to necessity. Though Basch expresses resentment that she is the one who must tirelessly stay at the hospital by herself through her daughter's medical procedures, she also

defends her husband by reminding herself that he is dealing with a different struggle because of the need that he continues to work to pay the medical bills. Echoing Brandon's (2011) findings on the division of caregiving, these examples demonstrate that decisions in division of care might often hinge upon work flexibility. This dependence on work flexibility is also echoed in Brown's (2009) and Gabbard's (2017) accounts, both indicating that they needed the dual earner income to afford their children's medical expenses.

Alternatively, Goff (2019) indicates choosing to be a stay-at-home mom because she felt like she had not been a good enough mother to her children:

*Society was always telling women to be smart, have a career, your children will be proud of your accomplishments, but in reality, it didn't feel like that. I had been a crappy mom to Tabitha for the past four years, and it was time for a change. (P. 34)*

Therefore, Goff's decision to stay at home rested on her perception of good motherhood, even as she reframes her decision as her personal choice. Further in the book, Goff insists that her husband always takes the kids on outings, while downplaying the fact that he does not attend any school meetings or doctor appointments because of work. Goff (2019) writes that her husband "wants me to stop doing so much and I want him to do more" to explain their responsibilities (p. 114). Here, Goff highlights that she and her husband engage in this traditional dynamic of caregiving out of choice, emphasizing that even though she does a substantial amount of caregiving, he wishes that

she would do less. In this instance, Goff reframes their division of labor as a production of choices, and not outcomes of cultural expectations of femininity and masculinity.

Though Goff hints at her wish that her husband will do more, she also overshadows this sentiment by indicating that she perhaps does more than he would like; thus, their division of work is attributed to personal preference. Similarly, Bennett (2016) suggests that she and her spouse disagreed on his role in caregiving activities, yet ultimately concludes in saying that their disagreement boiled down individual perceptions on caregiving needs.

Bach (2019) suggests that the emphasis on choice may be how couples contend with gendered divisions of care. Reframing these acts as personal preference, rather than one sanctioned by gendered expectations, may be a method for heterosexual couples reclaim their autonomy. In doing so, they shift the emphasis away from the role of traditional assumptions of feminine and masculine occupations in informing their choices. Whether this analysis is true regarding these parents' experiences, the traditional division of care continues.

In denoting that their caregiving decisions are out of choice and necessity, some parents also intertwine personal traits and characteristics to explain their spouse's caregiving behavior (Brown 2009; Daugherty 2015; Lewis 2014). Brown (2009), for instance, notes that his wife threw herself into organizing therapies and doctor's appointments upon first receiving the diagnosis. He writes, "[y]ou couldn't survive as the parent of a handicapped child if you weren't organized, and my wife was," explaining how she placed therapy tools on every floor of their house (Brown 2009:35). Like Brown,

Daugherty (2015) also praises his spouse's organization skills. Daugherty (2015) also admits not being as involved in his daughter's caregiving:

*So I was not always a gold-medal dad. I would be standard issue. I wasn't going to be Gibraltar. Gibraltar was Kerry's department...Jillian would be Kerry's life work. Any pressure Kerry felt was for Jillian to do well, even to thrive. Kerry assumed total responsibility for Jillian's success or failure. She knew she couldn't cure Jillian's Down syndrome. She could help Jillian overcome it. (P. 47)*

Although Daugherty admits not being a "gold-medal dad," he still emphasizes being "standard issue," implying that this behavior is typical and normal for familial divisions of labor. In attributing their spouse's managerial roles in their child's care to personal characteristics, Brown (2009) and Daugherty (2015) both absolve themselves of engaging in these tasks. As Borgkvist, Crabb, Elliott, and Moore (2020) assert, implying that their wives are better equipped for these organizational tasks suggests that there is a biological component of caregiving that some possess, and others do not.

Lewis (2014) highlights that it is not in his nature to worry like his wife; it was her 'nature,' not his, to persistently document everything when they found out their son has autism. Similarly, both Lanier (2020) and Basch (2020) describe their husbands as people who are not prone to worry, and justify their lack of worry as the reason their husbands do not do any additional research on their child's disability like they do. Continuing to contribute their individual parenting tasks to personal biology relieves spouses from engaging in tasks outside of the traditional dynamics of gendered

caregiving. Whether mothers genuinely believe that their spouses are not naturally predisposed to engage in managerial childcare, their narratives are illustrative of the continual reproduction of gendered divisions within their relationships.

Several scholars document the continuation of traditional familial caregiving through mothers taking on the role of the ‘manager’ and fathers acting as the ‘helpers’ (Crabb et al. 2020; Andreasson and Johansson 2016; Latshaw and Hale 2015; Bianchi et al. 2012; Coltrane 1989). Hays (1996), in their discussion of intensive motherhood, eloquently summarizes the cultural treatment of child rearing:

Men, apparently, cannot be relied upon to provide the same level of care. There is an underlying assumption that the child absolutely requires consistent nurture by a single primary caregiver and that the mother is the best person for the job. (P. 8)

None of the books within this sample directly indicate that mothers should be the primary caregiver of children. However, the continual presentations of mothers as responsible for the organizational component of childrearing, a responsibility which is both physically and emotionally taxing, upholds gender inequality in the context of caregiving. Heterosexual mothers and fathers are not only producing childcare but are engaging in the regular production of strict gender divides (West and Zimmerman 1987). Individual parents, though, are not solo actors within the cyclical routine of binary care. As several authors indicate, the current system of care often necessitates reverting to traditional forms of familial care as men are usually placed in higher paying positions



(see Brandon 2011). Yet, framing these routines as personal characteristics consequently ignores the social policing of mothers and perpetuates unequal divisions of labor.

## VI. DISCUSSION AND CONCLUSION

These memoir accounts illustrate a negotiation of parents' gendered position in caring for children with cognitive disabilities. Previous literature documents that parents of children with disabilities can exacerbate binary divisions of gendered care (Hofferth and Lee 2017; Brandon 2011; Cohen and Petrescu-Prahova 2006). However, scholars contend that research on caregiving has rendered the experiences of fathers caring for children with disabilities invisible, highlighting the different ways fathers are involved in the caregiving process (Mitchell and Lashewicz 2018; Potter 2016; Bonsall 2014). The findings in this study show that although some parents of children with cognitive disabilities are aware of the gendered constraints of caregiving, mothers particularly continue to be policed with cultural expectations of heightened femininity. Fathers, on the other hand, appear to present a blending of both traditional conceptions of masculine fatherhood and nontraditional fatherhood.

West and Zimmerman (1987) state that 'doing gender' is a result of negotiated gendered interactions, a fluid experience which is saturated within our social systems. Additionally, Hays (1996) frames intensive motherhood as a cultural phenomenon resulting from neoliberal ideals of motherhood. Under both paradigms, women and mothers continue to be bound within expectations of care that are near impossible to achieve unless they maintain an exceptionally privileged status. According to Coltrane (2018), the genre of memoirs written by parents of children with disabilities represents a very privileged group. Likewise, the present sample has little intersectional implications as all parents within these books are white and are still able to access therapies for their children even though they struggle financially. This privilege may have allowed the

women in these memoirs to engage in intensive motherhood, while fathers are able to engage in caregiving responsibilities without worrying too much about being unable to provide for their families.

Nevertheless, these narratives illustrate that this sample of parents of children with disabilities present reproductions of binary divisions of care. Although fathers emphasize their valued identities as their child's caregiver and nurturer, these narratives were often subverted in their descriptions of caregiving tasks and their reasoning behind this division. As Latshaw and Hale (2015) suggest, mandates of intensive motherhood may create a parent dynamic where mothers act as gatekeepers to their child's care, thus hindering fathers from undertaking additional managerial caregiving. However, continuing to highlight essentialized characteristics as the reasoning behind their responsibilities demonstrates that several parents are still policed by binary assumptions of caregiving. There is no way to understand the effects of these books or how readers perceive the advice; however, as Piepmeier (2012) and Sousa (2011) contend, these narrated experiences might be influential for parents who seek advice on parenting children with cognitive disabilities.

Green (2015) suggests that approaching parenting from a communal perspective may help eliminate unequal divisions of care. As researchers like Brandon (2011) and Venter (2011) suggest, unequal divisions of care are perpetuated within larger, gendered systems, who operate on the neoliberal assumption that women are better equipped to individually shoulder caregiving responsibilities. As these memoirs indicate, the hostile environment for disabilities means that parents', particularly women's, burden of care is heightened so their children can access the care they require. Further research should

explore other contexts where gendered division of caring for children with disabilities is reconstructed, particularly in the context of queer parenting. These memoir narratives demonstrate that while fathers of children with disabilities may be allowed to renegotiate a new presentation of fathering masculinity, mothers are still expected to labor in ideals of intensive mothering.

Because all 10 books were written from the point of view of different families, there is no way to understand the full scope of their caregiving dynamic. As this was content analysis, I cannot generalize the impact these books have on the audience. Further, the experiences presented within these narratives represent a very small minority as these authors are white and in heterosexual relationships. Future research should focus on familial caregiving dynamics which represent more diverse experiences. For instance, Shandra and Penner's (2017) research on disability and care to others demonstrates that, contrary to cultural perceptions on disability, people with disabilities engage in caregiving as much as people without disabilities. Research on gendered caregiving should focus on caregiving dynamics among those who perceive themselves as having a disability. My study adds to the literary gap on caregiving and disabilities in highlighting that even as families may present themselves as engaging in equitable caregiving, fathers perpetually shift managerial responsibilities onto mothers. If we are to create an equitable space for both mothers and people with disabilities, we must collectively address and reshape our cultural image of what good caregiving looks like and move forward with a communal intention in mind.

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