

## **ABSTRACT**

HUNT, ANDREA NICOLE. Caregiving for Children with Disabilities: Effects on Parental Employment and Mental Health. (Under the direction of Theodore N. Greenstein and Maxine P. Atkinson).

Previous research demonstrates that caregiving for children with disabilities affects parental employment (Porterfield 2002; Powers 2003) and mental health (Keller and Honig 2004; Sloper and Turner 1993). Specifically, mothers are more likely than fathers to be the primary caregivers of children with disabilities, which results in lower levels of employment and higher levels of psychological distress (Cuskelly, Pulman and Hayes 1998; Kagan et al. 1998; Leiter et al. 2004; Lewis et al. 2000; Lukemeyer et al. 2000). My research adds to the existing literature on families and disabilities by using multilevel, longitudinal data from the 2001 panel of the Survey of Income and Program Participation (SIPP) (U.S. Census Bureau 2005). I examine the effects of a child's disability on employment and psychological distress to gain a better understanding of how parents balance work and family when their children may have extraordinary caregiving needs.

I begin by extending an economic model of family life to focus more specially on racial differences in employment among mothers of children with disabilities. The multilevel growth models suggest that maternal employment is affected by a child's disability and that this varies by race. African American mothers of children with disabilities have the highest initial hours of paid employment, but decrease at a steeper rate over time, controlling for education and family income. The presence of younger children reduces employment for all mothers with a greater effect for mothers of children with disabilities. However, having older children (e.g., teenagers) also reduces employment for mothers of children with disabilities, but does not have the same effect for mothers of typical children. Thus, the presence of a

child with disabilities in a household has a negative and prolonged effect on maternal employment.

Next, I use a life course development perspective and estimate a series of dyadic multilevel growth models that compare the employment trajectories of parents of children with disabilities and parents of typical children. The findings suggest that the gap in initial hours worked is larger between parents of children with disabilities, showing that gender moderates the initial hours of employment, but does not affect employment over time. Racial effects for mothers are insignificant or only minimally significant when fathers are added to the analysis. The only significant racial difference in paternal employment occurs with white fathers of children with disabilities, who see a reduction in employment over time especially if their child has more severe disabilities.

The last analysis is guided by Pearlin et al.'s (1990) stress process model and examines whether parents of children with disabilities have higher levels of psychological distress and if this relationship is mediated by employment. The findings from the multilevel models suggest that a child's disability significantly affects parental levels of psychological distress, with mothers of children with disabilities having the highest rates of psychological distress. The only significant racial difference in psychological distress for mothers of children with disabilities occurs as the severity of the child's disability increases. Specifically, nonwhite mothers of children with disabilities have higher rates of psychological distress compared to white mothers of children with disabilities when controlling for the severity of the child's disability. Employment reduces psychological distress in all parents (i.e., role enhancement) while quitting a job or reducing hours due to caregiving demands (i.e., role strain) also reduces psychological distress in mothers with a

greater reduction for mothers of children with disabilities. I conclude by suggesting that being employed may not be the most important factor to consider, but rather that job quality is. Mothers may have more of their identities invested in caregiving; thus, when employment is incompatible with caregiving, their psychological distress increases.

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Caregiving for Children with Disabilities: Effects on Parental Employment and Mental Health

by  
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## **DEDICATION**

For the parents (and other caregivers) of children with disabilities in Wake County, NC – your love and dedication inspired this project and taught me how to be a good caregiver.

## **BIOGRAPHY**

Andrea Nicole Hunt was born in Coffeyville, KS and attended Field Kindley High School.

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I would like to thank my husband, Chris, who has been on this academic journey with me for twelve years. Not only has he supported my intellectual growth, but he opened his heart and home to my cousin Derek when he needed a place to live. This is a testament of

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## CHAPTER 1: INTRODUCTION

Work-family research is a growing body of interdisciplinary literature and is one of the most widely studied topics in family sociology. It draws attention from scholars and lay people alike because it is an area where gender relations are amplified and implicated in the reproduction of inequality. Recently, Lachance-Grzela and Bouchard (2010) reviewed a decade of research on work and family to show that despite gains in employment, women continue to do the “lion’s share of housework.” While not included in Lachance-Grzela and Bouchard’s (2010) decade review, research on parents of children with disabilities points to an even more traditional division of labor with mothers as the primary caregivers even if they are in paid employment (see Kagan, Lewis, and Heaton 1998; Leiter et al. 2004; Lewis, Kagan, and Heaton 2000; Lukemeyer, Meyers, and Smeeding 2000).

The number of U.S. families raising children with disabilities is growing, and their experiences balancing work and family are different than families with typical developing children. This dissertation seeks to extend the existing body of research on work and family by examining a different family context. In particular, I ask: How do the needs of children with disabilities affect parental employment and how does this vary by race? Secondly, do parents of children with disabilities have higher rates of psychological distress and does employment mediate this effect? I study these broad research questions in three different chapters using multilevel, longitudinal data from the 2001 panel of the Survey of Income and Program Participation (SIPP) (U.S. Census Bureau 2005). In this introductory chapter, I begin with an overview of the historical changes in women’s labor force participation and corresponding division of household labor, and the variations across families. Next, I extend

this literature to families of children with disabilities to show how caregiving affects parental employment and mental health.

## **WOMEN'S LABOR FORCE PARTICIPATION**

In the preindustrial economy, production and social reproduction were based on the household unit with more than 90 percent of people living on farms (Laslett and Brenner 1989; Mintz and Kellog 1988). Families were entirely self-sufficient. For example, fathers were property owners, regulated economic activities, and had broad responsibilities for the children while mothers had the primary responsibility for the daily needs of all household members and contributed to the productive activities of the household. With the development of industrial capitalism, the household unit was no longer the source of production. The bourgeois family became the propertied class who controlled the means of production while the new middle class consisted of professionals and salaried workers (Wright 1980).

Among the new middle class, a highly differentiated division of labor appeared where men worked in the public sphere and women were hidden in the private sphere. Hartmann (1976) suggests that some type of division of labor is universal throughout human history. However, the notion of separate spheres that emerged in the early nineteenth century became the “ideal type” for families and obscured historical differences by race and class. For example, working-class married women contributed economically through domestic work, casual labor, and by taking in boarders (Laslett and Brenner 1989; Mintz and Kellog 1988; Padavic and Reskin 2002). African American women worked 11 to 13 hours a day on plantations along with taking care of their own families during slavery (Thistle 2006), and physically hard labor in the fields continued under sharecropping.

The shift from an agricultural to an industrial economy not only increased the demand for male factory workers, but many poor, young white women filled these positions (Mintz and Kellogg 1988; Spain and Bianchi 1996). African American married women, on the other hand, were primarily employed as private domestic workers, which illustrates how the intersection of race and gender kept them in low-paid work (Thistle 2006). During the Depression, men experienced high levels of unemployment and women were seen as a threat to men's economic livelihood. This reinforced the need for married women to remain in the home and was a byproduct of upper class concerns towards family stability. For married women during this time, domestic identities were resolute even after industrial changes in the labor market. This may be attributed to the role of childcare in women's lives, which men assisted with prior to the development of the wage labor system.

The expansion of the service sector throughout the mid-twentieth century and an increase in professional/white-collar employment opportunities drew in many African American married women with young children. Older married white women returned to paid labor after raising their children while younger middle-class white women remained in the home. Middle-class white women, especially those with college degrees, joined paid labor in the latter half of the twentieth century. By 2005, 59.3 percent of all women were in the labor force with 68 percent of all married mothers of children under 18 in some type of paid employment (U.S. Census Bureau 2012a, 2012b). While women's labor force participation slightly decreased, the percent of married mothers of children under 18 in the labor force increased to 69.8 percent by 2009 (U.S. Census Bureau 2012b). The U.S. Census Bureau (2012a) projects steady labor force participation rates for women throughout 2018.

## **DIVISION OF HOUSEHOLD LABOR**

Changes in labor force participation have been more dramatic than changes in the division of household labor. Despite married women being increasingly likely to share the breadwinning role, they continue to do most of the household labor (Greenstein 2000; Padavic and Reskin 2002; Raley, Mattingly, and Bianchi 2006; Sayer 2005; Tichenor 2005). Studies do show that men are increasing in their household labor over time, specifically in their childrearing responsibilities (Bianchi 2000; Bulanda 2004; Craig 2006). Nonetheless, women still do about two-thirds of routine household tasks (i.e., housework) (see Coltrane and Shih [2010] and Lachance-Grezela and Bouchard's [2010] for a discussion) that they balance with paid employment and caregiving. The empirical findings in the work-family literature point to several well-documented predictors of household labor.

### **Time Availability**

Coltrane and Shih (2010) suggest that as women's and men's employment increases, the time spent on housework decreases, which supports a time availability hypothesis. Cunningham (2007) found that when women work more over time, husbands perform a greater share of the housework compared to husbands with wives who have shorter employment histories. Further, he found that husbands increase housework when their earnings are comparable to their spouses'. Gough and Killewald (2011) examine how both men and women increase their household labor when unemployed, whereas spouses of those who are unemployed decrease their housework. Unemployed wives, however, increase their household labor more than unemployed husbands, suggesting that time availability in conjunction with gender ideologies may affect reallocation of housework.

## **Gender Ideology**

Gender ideology or attitudes about gender roles is a consistent predictor of the division of household labor (Coltrane and Shih 2010; Cunningham 2007; Davis and Greenstein 2009; Greenstein 1996; John and Shelton 1997; Thompson and Walker 1989). Presser (2003) and Acker (2006) both argue that the gap in housework narrows with husbands doing more and wives doing less housework when both spouses make similar incomes and have similar gender ideologies. Wives' egalitarian beliefs about gender also reduce the overall amount of housework that is done within a household so that both husbands and wives do less household labor and/or outsource it to service workers. This may not necessarily be the case for wives who are senior partners or primary breadwinners. Atkinson and Boles (1984) and Tichenor (2005) suggest that gender is more salient than earnings and that higher-earning wives are unable or unwilling to use their incomes to alter the power imbalance in the household. This demonstrates how deeply engrained the gender division of labor is within marriages.

## **Variations by Race**

African American couples tend to have more equal divisions of household labor than whites (Davis and Greenstein 2009; John and Shelton 1997; Kamo and Cohen 1998), although African American women still perform more household labor than African American men. Penha-Lopes (2006) suggests that this is due, in part, to early socialization into household chores as a child and expected competence in these tasks. That is, the African American men in her sample report high involvement with housework as children with little gender differentiation between assigned tasks. Research also attributes the smaller gap in

household labor in African American couples to more egalitarian gender ideologies, lower rates of male employment, and similar earnings (John and Shelton 1997; Spain and Bianchi 1996; Vespa 2009). Glauber and Gozjolko (2011) found that even African American men with traditional gender ideologies use egalitarian work-family arrangements as they are often faced with lower rates of employment or underemployment. The research on race and work-family illustrates that while household labor is still gendered, there are variations across families with decisions about work and family occurring within different familial contexts.

### **PARENTS OF CHILDREN WITH DISABILITIES**

The carework for children with disabilities is situated within larger transformations in the meaning of disability and public policies and practices regarding care. There has always been some way of identifying children who are “different” (Johnson 2006) with responses to this varying across time and place. For example, the welfare discourse in the nineteenth century shifted towards children and a child-saving orientation that was characterized by a social control agenda shaped largely by middle-class women’s expectations of a proper family, a scientific approach to childcare, and a focus on true motherhood and domestic purity (Gordon 1994; Mintz and Kellog 1988). For children with disabilities, the focus was on “curing” impairments caused by bad mothering through the institutionalization of children with disabilities and the medicalization of disability (Braddock and Parish 2001).

Responses to caring for children with disabilities were further exacerbated by threats of eugenics throughout the late nineteenth and early twentieth century and an even greater reliance on institutional care during periods of economic downturns such as the Great Depression. By the 1950s, however, attention shifted away from blaming mothers for their

child's disability, and public policies of deinstitutionalization reinforced family care (Seltzer and Heller 1997). Disability activists and organizations criticized the medicalization of disability and worked towards an independent living movement. The passing of the Americans with Disabilities Act of 1990 (ADA) was a culmination of the efforts of disability activists and prohibits discrimination on the basis of disability in employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications (U.S. Department of Justice 2005). While the legal statutes outlined in the ADA are a sign of the changing ideas towards disability, social policies still do not adequately address caregivers who often provide long-term care for children with disabilities.

The literature on the work-family divide for parents of children with disabilities is an extension of the larger body of work-family research. Many of the same theoretical (e.g., role conflict and role enhancement) and methodological approaches are fundamental to this research. However, the nature of caregiving is different in that parents of children with disabilities face unique challenges as they balance work and family. What effect does this have on parents? Research consistently demonstrates that caregiving for children with disabilities affects parental employment (Porterfield 2002; Powers 2003) and mental health (Keller and Honig 2004; Sloper and Turner 1993).

### **Employment**

Mothers are more likely than fathers to be the primary caregivers of children with disabilities, which results in lower levels of employment (Cuskelly, Pulman and Hayes 1998; Kagan et al. 1998; Leiter et al. 2004; Lewis et al. 2000; Lukemeyer et al. 2000). Mothers who are able to work full-time often have informal networks (e.g., older siblings, grandparents,

neighbors) that provide one-on-one care for their child since childcare and/or appropriate educational and skills development programs are difficult to find (Brandon 2000; Malsch, Rosenzweig, and Brennan 2008). Even when at work, parents have to be available if their child has a mental or health issue since doctor appointments are usually only available during work hours. This difficulty in balancing work with the extraordinary caregiving needs of children with disabilities is why many mothers who are able to work find low-paid and low-skilled jobs that are often restricted to a few hours a day, for example, in clerical work or transcription (Shearn and Todd 2000). Mothers view this kind of employment as convenient for their caregiving demands and choose these types of jobs because there tends to be some flexibility in the event that their child is injured or becomes ill at school or has a medical appointment (Cuskelly et al. 1998). Mothers of children with disabilities do not necessarily return to work as their children enter school. The extraordinary caregiving demands do not end as children get older; rather they change as children “age out” of services and families are faced with the growing needs of older children (Heller, Hsieh, and Rowitz 1997) which are out of sync with typical life course transitions.

### **Psychological Distress**

For some parents of children with disabilities, it is the nature of caregiving itself and for others it is striving to achieve a balance between work and family that increases the levels of psychological distress (Bailey and Smith 2000; Hogan 2012; Litt 2004). Because they are more likely to be primary caregivers, mothers of children with disabilities tend to have higher levels of psychological distress than fathers (Johnson, O’Reilly, and Vostanis 2006; Leonard, Johnson, and Brust 1993). To alleviate psychological stress, parents rely on coping strategies

(e.g., distancing, use of self-control, blaming, and passive acceptance) and social support. The availability of resources (e.g., income and employment) may also affect the appraisal of a stressful situation. Employment has been found to be an important factor for parental adaptation to stressful situations and employed mothers exhibit lower levels of psychological distress (Knussen and Sloper 1992; Thyen, Kuhlthau, Perrin 1999). Litt (2004), however, cautions against generalizing about the effects of employment, suggesting that the *type* of employment may actually increase or decrease psychological distress.

## **STRUCTURE OF DISSERTATION**

This chapter reviews the historical changes in women's labor force participation and division of household labor. I draw attention to variations across families and extend this literature to families of children with disabilities to show how caregiving affects parental employment and mental health. Chapters 2, 3, and 4 are analytic chapters with empirical examinations of these data. Chapter 5 is a conclusion of the results with a discussion of the limitations of this research and areas for future research.

In Chapter 2 ("Study 1"), I develop a gender/race economic model and compare employment outcomes over time for mothers of children with disabilities and mothers of typically developing children. I suggest that maternal employment is affected by a child's disability status and the severity of the disability, and that this effect varies by race. Further, I argue that married mothers with more education are more likely to work full-time regardless of their child's disability status. The findings from the multilevel growth models support my hypotheses and show that maternal employment is affected by a child's disability and that this varies by race with African American mothers of children with disabilities having the

most initial hours of paid employment, but decreasing at a steeper rate over time than other mothers in the sample, controlling for education and family income. The results suggest that education does not have the same effect for all mothers in the sample. Mothers of children with disabilities work more initial hours as their education increases compared to mothers of typical children who only see a substantial increase in hours when they receive a graduate/professional degree. Yet, education is not significant over time. I conclude by suggesting that fathers' employment should be simultaneously examined with mothers' to gain a more complete understanding of the effect of a child's disability.

In Chapter 3 ("Study 2"), I begin with the assertion that employment trajectories of mothers and fathers are often interdependent. Guided by the family life course development perspective, a series of dyadic multilevel growth models are estimated that compare the employment trajectories of parents of children with disabilities and parents of typically developing children. I expect to find that the child's disability status and severity of disability predict the difference in hours worked between parents. I contend that mothers of children with disabilities are more likely to reduce their hours of paid employment because of specific caregiving demands than fathers of children with disabilities and parents of typical children. The findings in this chapter suggest that parents of children with disabilities have lower rates of employment over time compared to parents of typical children, with mothers of children with disabilities having the lowest rates of employment. The gap in initial hours worked is larger for parents of children with disabilities, suggesting that gender moderates initial levels of employment, but does not affect employment over time for parents of children with

disabilities. I conclude by connecting this research with the stress process and asking whether employment mediates the stress process.

In Chapter 4 (“Study 3”), I ask why some caregivers fare worse than others. I extend my findings from Chapters 2 and 3 by examining whether parents of children with disabilities have higher levels of psychological distress and if this relationship is mediated by employment. Using a stress process model, I argue that the child’s disability acts as a primary stressor increasing levels of psychological distress among parents of children with disabilities. I expect to find gender and racial differences in psychological distress, test whether employment mediates the stress process, and consider the severity of the child’s disability as a secondary stressor. The findings from the multilevel models suggest that a child’s disability does affect parental levels of psychological distress with mothers of children with disabilities having the highest rates of psychological distress. As expected, employment reduces psychological distress in all parents. However, quitting a job or reducing hours because of caregiving also reduces psychological distress. I conclude with a discussion of how job quality might affect psychological distress in working parents.

Chapter 5 reviews the findings in the three analytic chapters and reiterates my contributions to the literature on work and family. I discuss the findings in relation to the stalled gender revolution, address the major limitations of these data, and suggest areas for future research in caregiving. I conclude by arguing that research on work and family should be extended to different family contexts and that to advocate for the cared-for we must advocate for the caregiver (Kittay 2002).

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## **CHAPTER 2 (STUDY 1): EMPLOYMENT OF MOTHERS OF CHILDREN WITH DISABILITIES**

Nearly 2.8 million families in the United States are raising a child with disabilities (Wang 2005), and children with disabilities are now more likely to reside with their families than in any other time in history. How is maternal employment affected by raising children with extraordinary caregiving needs? The literature has yielded inconsistent results. Powers (2003) suggests that having a child with a disability exerts similar effects on maternal employment as having a young child, while others have found that married mothers of children with disabilities remain out of full-time employment across their children's life span (Lefley 1997; Porterfield 2002; Seltzer and Heller 1997). This chapter adds to the work-family literature by demonstrating how the caregiving needs of children with disabilities affects maternal employment over time by using a nationally representative longitudinal sample. My goal is to demonstrate how certain contexts of women's unpaid care work alter their employment trajectories while also conveying the importance of racial differences among women.

### **LITERATURE REVIEW**

Women have always contributed to the production and social reproduction of the household (Hartmann 1976; Laslett and Brenner 1989). Historical patterns illustrate vast differences in women's paid employment by race and class with African American women experiencing higher rates of labor force participation over time (see Mintz and Kellog 1988; Spain and Bianchi 1996; Thistle 2006). More recent trends highlight the growing importance of employment for *all* women with children, especially mothers of young children whose

rates of labor force participation have fluctuated somewhat over time (Cohany and Saks 2007). By 2009, 70 percent of mothers with children under the age of 18 were in the labor force with nearly 58 percent of mothers of infants working for pay (U.S. Census Bureau 2012). A closer examination by race reveals that African American mothers have the highest rates of labor force participation until their youngest child reaches the age of 14. This is the only point in which labor force participation rates of white and Asian mothers with children less than 18 years surpasses African American mothers.

Gerson (2010) suggests that while most men prefer to define themselves as the breadwinner even in dual-earner families, African American men face additional obstacles in establishing their breadwinner identity because of constricted job opportunities, low wages, low educational attainment, and high incarceration rates. Moreover, the educational gains of African American women and their entry into upper-tier service sector work have provided them with a clear economic advantage in the labor market compared to African American men (Thistle 2006). These fathers may then compensate for a lack of paid employment with other contributions to the family such as childcare (Spain and Bianchi 1996). The combination of constrained economic opportunities and having children with extra caregiving needs encourages African American fathers of children with disabilities to use their fathering role as a way to successfully transition to adulthood.

### **Maternal Carework for Children with Disabilities**

There is a growing body of literature on carework for children with disabilities and maternal labor force participation (see Heller, Hsieh, and Rowitz 1997; Kagan, Lewis, and Heaton 1998; Leiter et al. 2004; Lewis, Kagan, and Heaton 2000; Lukemeyer, Meyers, and

Smeeding 2000). A recurring theme within this research is that disruptions or postponement of maternal employment results from atypical caregiving requirements, increased time needed for carework, and lack of appropriate childcare for children with disabilities (Brandon 2000; Cuskelly, Pulman and Hayes 1998; Jinnah and Stoneman 2008; Shearn and Todd 2000). Parish and Cloud (2006) and Powers (2001) suggest that other characteristics such as the severity of the child's disability, maternal disability status, and maternal education have stronger effects on maternal employment than the child's disability status. Nonetheless, most research on the effects of a child's disability on maternal employment uses women's marital status as the basis for comparison. For example, wives' employment is reduced by having a child with disabilities, but studies on female-headed households have yielded inconclusive findings likely due to the measure of child disability used (Powers 2003). Research on racial differences between married women is less common. Salkever (1982) and Wehby and Ohsfeldt (2007) found that a child's disability reduces white married mothers' employment, but did not have the same effect for nonwhite married mothers. Wehby and Ohsfeldt (2007) attribute this racial difference to maternal characteristics rather than the child's disability.

In general, the experience of carework for children with disabilities often becomes a "career" for female caregivers that span their life course (Lefley 1997; Seltzer and Heller 1997). Their employment levels remain below those of other mothers as long as their children continue to reside in the home. Carework for children with disabilities does not necessarily end as their children get older, but rather simply changes as new needs arise (Heller et al. 1997; Hooyman and Gonyea 1995; Lewis et al. 2000; Shearn and Todd 2000). It is not uncommon for mothers in a variety of situations to postpone employment while their

children are young and return to the labor force when their children enter school. For example, Porterfield (2002) found little difference in hours worked between mothers with children under six regardless of the disability status of their child. However, the findings were different for mothers of older children (15-19) with disabilities who were less likely to work full-time compared to mothers of older typically developing children. Thus, mothers of older children with disabilities continue to reduce their employment compared to mothers of typical children.

Regardless of race, caregiving for a child with disabilities requires specialized knowledge that is usually associated with professional work and not necessarily traditional mothering (Leiter et al. 2004; Traustadottir 1991). For example, Litt (2004) and Traustadottir (1991) both describe how mothers of children with disabilities feel like they are “on-call” 24 hours a day while they coordinate services, advocate for educational needs, and deal with behavioral issues. Carework for a child with disabilities is constructed in relation to an exaggerated form of “intensive mothering” and mothers may wonder if they are doing enough for their children (Ardenall 2000; Hays 1996; Hochschild 1989). Mothers often experience blame for their child’s disability, which perpetuates their own use of ‘intensive mothering.’ As one mother describes, “I’m doing what I’m doing. . . . I’m probably not doing enough. . . . I had to have someone else [their family counselor] tell me . . . ‘Okay, you *are* doing enough. You are doing what you are supposed to do and more’” (Blum 2007:211).

African American mothers have the additional burden of establishing themselves as a “good mother,” an identity that has long been denied to them. Like other racial/ethnic groups of mothers, their ideas of good mothering are often rooted in the ideology of intensive

mothering which stresses the importance of placing their child's needs above their own (Elliott, Powell, and Brenton forthcoming). Jacobs, Lawlor, and Mattingly (2011) suggest that Black mothers have to cross racial boundaries to establish a common identity as a mother. This boundary crossing establishes a common ground as mothers try to effectively access resources needed to support their child with disabilities.

Ideologies of caring and motherhood blur the distinction between caring about (i.e., loving) and caring for (i.e., the actual carework) children with disabilities (Dalley 1988; Lewis et al. 2000; Traustadottir 1991). Qualitative research (Dowling and Dolan 2001; Lewis et al. 2000; Scott 2010) suggests that white middle-class mothers, in particular, often experience a complex sense of personal sacrifice due to diminished aspirations. Since they are unable to develop other areas of their lives and do not have equal assistance from other family members (i.e., men), mothers counterbalance their carework with the assertion that they are sacrificing themselves, their time, and their efforts for their children. These mothers often frame this sacrifice within a discourse of "choice" (Dowling and Dolan 2001; Lewis et al. 2000) while lower-class mothers see their caregiving as just one part of their day-to-day struggle for survival (Traustadottir 1991).

### **Conceptual Framework**

Much of the literature on the effects of a child's disability on maternal employment has been atheoretical (e.g., Powers 2001, 2003) or based on economic theories of the family (see, for example, Brandon 2000, 2007; Porterfield 2002). Similar to Brandon (2000, 2007) and Porterfield (2002), my research starts with an economic perspective of family decision-

making about labor market and household activities. However, I expand on a pure economic model to illustrate how gender and race shape experiences with paid and unpaid labor.

Economic models of the family are based on four main principles: 1) the allocation of time; 2) investment in human capital; 3) household production decisions; and 4) a view of the family as encompassing both consumer choice and household production decisions (Berk and Berk 1983). The basic premise is that adult family members make rational decisions that maximize family well-being. The immediate sources of family well-being are “household commodities”, which are transferred into “household production functions” by household members combining their time with market goods and services. According to Becker (1981), this is accomplished most efficiently through specialization, or a separate spheres model, since men are able to maximize their market work because of their greater earnings potential while women reduce their labor force participation to care for children. The theory assumes that mothers are the natural choice for unpaid care work because they have less human capital, earn less, and experience more discrimination in the workforce (Becker 1981). If this is correct, it then becomes more efficient for mothers to do most, if not all, of the care work and work part-time or remain out of the labor force altogether, especially if they have children with extraordinary needs. For example, families of children with disabilities often need caregivers with a more specialized knowledge of nursing skills, special education, and behavioral management (Brandon 2000; Dowling and Dolan 2001; Litt 2004). This can be difficult to find in market-based childcare so mothers may reduce labor force participation to care for their child or opt for in-home care if financially feasible.

Critics (e.g., Blau, Ferber, and Winkler 1998; Fenstermaker 1985) have argued that economic models of the family ignore gender, in particular, how gender affects power and inequality. Responses to these criticisms center on the notion that the well-being of the head of the household depends on the well-being of other members. In other words, Becker (1981) considers the head of the household to be altruistic and the well-being of the other members becomes a new commodity that needs to be maximized. Fenstermaker (1985) proposes a way to reconceptualize household production where household goods and services are being produced in addition to the production of gender. Households deal with allocation problems just like “small factories” that try to maximize output in the least costly manner (Becker 1981). By framing household labor as producing gender, Fenstermaker (1985) transforms Becker’s (1981) conception of households as “small factories” into “gender factories.” Gender becomes a critical unit of analysis within families because of the underlying gendered expectations about the allocation of time in the home and workforce. However, Fenstermaker (1985) uses universal notions of gender, neglecting how poor and minority women have different experiences with the gender division of labor than middle-class white women.

Collins’ (2000) theoretical work on African American families sheds light on the power relations and material inequalities that constitute oppression at the macro-level (e.g., racism, capitalism, and patriarchy as systems of power) to show the interconnections of race, class, and gender in the lives of Black women. The labor market experiences of African Americans have diverged significantly from the breadwinner/homemaker model upon which economic theories of the family are based. Becker’s (1981) assumptions about the efficiency

of specialization, or separate spheres, does not account for the race and gender inequality in the labor market or the inability of African American men or women to adequately maximize their market work. As such, African American families have historically experienced more fluidity between the public and private sphere, which shows how race and gender both shape the meanings and practices of paid and unpaid labor.

### **Research Questions and Hypotheses**

A gender/race economic model raises several empirical questions about maternal care work. First, how do the needs of children with disabilities affect maternal employment? Secondly, how does this effect vary by race? To address these questions, I derive hypotheses that compare mothers of children with disabilities and mothers of typically developing children, and a hypothesis that focuses on differences amongst the sample of mothers of children with disabilities. While the presence of children may affect all mothers' employment, the fundamental argument in this research is that caregiving for a child with disabilities has a greater impact on maternal employment than caregiving for a typical child and that this impact varies by race. African American married mothers have higher rates of labor force participation than other married mothers (Cohany and Sok 2007) partly due to the lack of well-paid employment opportunities for African American men. Based on these trends, I expect to find that:

*Hypothesis 1: Controlling for the number of residential children and their ages, married mothers' employment is negatively affected by their child's disability status and this effect is greater for white mothers than for African American mothers.*

Parish and Cloud (2006) suggest that maternal education may be a stronger predictor of maternal employment than children's disability status. Economic models would suggest

that investment in human capital allows for the maximization of earnings potential. Mothers who have invested considerable time and resources on their own education may then be less likely to reduce their hours of employment to provide unpaid carework. Human capital, conceptualized as investment in education and skills, becomes a resource for those wanting paid employment and can directly influence opportunities in the labor market and within families. If investment in human capital provides leverage when it comes to allocating tasks, then I expect to find that:

*Hypothesis 2: As married mothers' education increases, the number of hours worked per week increases regardless of their child's disability status.*

It may be that when mothers have an increased education and more human capital, fathers help provide childcare or these families have the ability to purchase childcare to substitute mothers' care. Conversely, if the findings do not support the hypothesis then one could speculate that normative expectations about gender still affect married women's labor force participation rather than investment in human capital.

The last hypothesis focuses only on mothers of children with disabilities. As stated above, I expect to find that having a child with disabilities affects maternal employment and that this effect varies by race because of the employment opportunities available to African Americans. Leiter et al. (2004) found that mothers whose children have more severe conditions are more likely to reduce their paid employment and provide more hours of carework. However, I expect that this varies by race given the difference in economic opportunities and availability of resources to support a child with more severe disabilities. Children with more severe disabilities need more specialized therapies, home modifications,

and adaptive equipment that often carry out-of-pocket expenses even with public health care coverage (Parish and Cloud 2006). Parents have to find ways to balance the extra costs and hours of care work needed for children with severe disabilities. Since African American married mothers have higher rates of labor force participation than other married mothers and African American married men have lower rates of labor force participation than white men, I expect to find that:

*Hypothesis 3: As the severity of the child's disability increases, maternal employment decreases for white mothers but increases for African American mothers.*

To summarize, I am comparing mothers of children with disabilities and mothers with typically developing children. Based on these comparisons, I expect to find that married mothers' employment is affected by their child's disability status and that this effect varies by race due to the racial differences in labor force participation rates. Most mothers return to work or increase their hours of employment as their children get older (Porterfield 2002; Waldfogel 1997). However, I expect that this is not the case for mothers of children with disabilities because of their time out of the labor force and the continued caregiving needs of their children. I expect to find that married mothers with more education are more likely to work full-time regardless of their child's disability status. The final hypothesis compares only those married mothers of children with disabilities to see if there are racial differences in how the severity of the child's disability affects maternal employment.

## **DATA AND METHODS**

Family researchers are increasingly interested in studying processes of change. Yet, most research uses cross-sectional analysis or cross-lagged panel designs with two waves of

data (Acock et al. 2005). Videon (2005) suggests that the problem with cross-sectional data are that predictors and outcomes are examined simultaneously, which weakens the causal assertions that can be made about family processes. Further, using two waves of data only allows for a comparison across two specific time points, but does not fully illustrate causal mechanisms or developmental trajectories. Contemporary methodologists suggest at least three waves of data for a more reliable analysis of rates of change over time (Acock et al. 2005; Singer and Willet 2003). My research improves on the existing literature by using short-term longitudinal data spanning a three year period to compare employment trajectories over time between mothers of children with disabilities and mothers of typically developing children.

The Survey of Income and Program Participation (SIPP) is a continuous series of national panels designed to measure the effectiveness of existing programs and to estimate future costs and coverage of government programs (U.S. Census Bureau 2005). SIPP content is built around “core” questions on income, labor force participation, program participation and eligibility, and general demographics. “Topical modules” are asked throughout the panels to provide additional information for analyses. SIPP utilizes a multi-stage stratified sample of the U.S. civilian non-institutionalized population. Imputation procedures are employed to reduce the bias of survey estimates and are based on the assumption that data are missing at random within subgroups of the population. Data editing are preferred over statistical imputations and were used whenever a missing item could be logically inferred from other data that was provided (U.S. Census Bureau 2005).

The survey uses a four month recall period with about the same number of interviews conducted in each of the four month periods for each wave. My analysis is based on the SIPP 2001 panel, which initially consisted of 36,700 households that were to be interviewed nine times over the course of three years. Budget constraints caused the U.S. Census Bureau to reduce the number of households interviewed by 15 percent by Wave 2, leaving 31,195 households eligible for interviews. All household members at least 15 years old are interviewed by self-response.

### **Selection of Sample for Analysis**

SIPP is a survey of households and includes data on primary families, related and unrelated subfamilies, and primary and secondary individuals. The current analysis is limited to primary families with at least one residential child at entry into the study and excludes multi-generational households and single-parent households. The choice to exclude single parents was made after considering the different economic and caregiving challenges that married and single mothers are likely to face when raising a child with disabilities (see Lee et al. 2004). Coleman (1988) suggests that two-parent families and single parent families experience different structural disadvantages because of occupational demands and long hours in the paid labor force. Further, Tichenor (2005) found that the traditional marital contract serves as an ideology that reinforces gender expectations within families and may affect mothers' choice to work. In this study, family composition is held constant with only married mothers in the sample. The work-family balance of single mothers raising children with disabilities warrants separate study and is beyond the scope of the current research.

Mothers' responses are used for children less than 15 while those at least 15 years old are interviewed by self-response. The sample includes 6,165 married mothers with at least one residential child during the survey period. Nineteen percent (1,180) of the mothers in the sample have at least one residential child who meets the criteria of disability used in this analysis, which is consistent with national averages (for a discussion on the percentage of families raising children with disabilities see Wang [2005] and Malsch, Rosenzweig, and Brennan [2008]). This sample can be considered an accelerated longitudinal design because it consists of multiple birth cohorts (Raudenbush and Chan 1993). The advantage of using multiple birth cohorts is that it illustrates the effects that children have on maternal employment from birth to adulthood.

### **Dependent Variable**

A series of multilevel growth models are estimated to determine changes in maternal employment over time. Respondents (i.e., married mothers) are asked "How many hours per week did ... usually work at all activities at this job?" If participants had two jobs, their usual hours worked per week for both jobs were combined. Answers are reported using a continuous measure of usual hours worked each week. Table 2.1 shows that the average hours worked per week for married mothers with children with disabilities are fairly stable across waves with an average high of 21.73 hours per week at Wave 2 and an average low of 20.47 hours at Wave 8. Married mothers of typical children fluctuate more in their average hours worked per week with an average high of 24.25 hours per week at Waves 1 and 2 and a low of 22.94 hours by Wave 5.

## **Independent Variables**

*Measures of Disability.* The SIPP Topical Module on Functional Limitations and Disability from Waves 5 and 8 is used to identify children with disabilities. The American with Disabilities Act (ADA) (1990, 2008) defines disability as “a physical or mental impairment that substantially limits one or more major life activities of such individual.” My operational definition of disability is slightly more encompassing than the ADA (1990, 2008) definition and is based on both self-perceptions and clinical diagnoses of disabilities. I follow the same criteria of disability as identified by the World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health (ICF) and as used by the U.S. Census Bureau (see Wittenburg and Nelson 2006). I primarily rely on Erickson and Dumoulin-Smith’s (2009) Simplified Conceptual Model of Disability using ICF Concepts where children are considered disabled if they have either a physical, mental, or sensory impairment, participation restriction, and/or activity limitation. In this operational definition of disability, children with impairments are included even if the impairment does not significantly affect their daily living.

Physical impairment includes a long-lasting condition that limits the ability to move arms or legs (refers to children under three), limits the ability to walk, run, or play (refers to children between three and five), and limits the ability to walk, run or take part in sports and games (refers to children between six and fourteen). Children who are 15 years old answer questions about their difficulty lifting or carrying an object 10 pounds or heavier, pushing or pulling large objects, standing or sitting for an hour, stooping, crouching, or kneeling, reaching or grasping, walking three blocks or up a flight of stairs, or using a telephone.

Children less than six years old are considered mentally impaired if they have a serious mental condition or a developmental delay that limits ordinary activities. All other children (six and older) are considered mentally impaired if they have a learning disability (e.g., dyslexia), attention deficit hyperactivity disorder (ADHD), intellectual disability, developmental disability (e.g., autism or cerebral palsy), or any other developmental condition for which they have received therapy or diagnostic services. Children at least six years old with a sensory impairment have difficulty seeing words/letters, hearing even with an aid, or understanding speech.

To determine participation restrictions for children between the ages of 6 and 19, mothers indicate whether their children experience a physical, learning, or mental condition that limits the ability to do regular school work. Young adults 16 years and older are asked whether they have a long-lasting physical or mental condition that makes it difficult to remain employed or to find a job. Activities of daily living refer to children at least six years old and include needing help getting around inside the home, in and out of a chair, taking a bath or shower, putting on clothes, eating food, or using/getting to the toilet.

A dichotomous variable was created based on the operational definition of disability to indicate whether there was a child with disabilities in the family (1 = yes, 0 = no) at either Waves 5 or 8 using data from the Topical Module on Functional Limitations and Disability. This measure is used to divide the sample of mothers into two groups – those with a child with disabilities and those with typically developing children. Next, a disability index was created to measure the severity of the disability as a continuous time-varying variable. Scores are computed for each child with disabilities in the household with only the highest

disability index score from each family used as the measure of severity of disability. Scores range from 0-27 with higher scores indicating more severe disabilities. The sample primarily consists of children with non-severe disabilities with an average score of 1.908 across Waves 5 and 8 (see Table 2.2).

*Change over Time.* Mothers' actual ages are used to measure change over time. Averaging across all waves, married mothers of children with disabilities are 42.73 years old with a range of 18.8-86.9 years. In contrast, the average age of married mothers with typical children is 40.1 years old with a range of 17.75-86.6 years.

*Maternal Education.* To indicate maternal education, mothers responded to the following question: "What is the highest level of school...has completed or the highest degree...has received?" Responses were originally coded as a categorical variable ranging from completion to first grade to completion of an advance degree. A series of dichotomous variables was created from the original responses: no high school diploma (reference category), high school diploma, some college, bachelor's degree, and graduate/professional degree. Averaging across all waves, 14.8 percent of married mothers of children with disabilities did not have a high school diploma compared to 9 percent of married mothers with typical children. Slightly more married mothers of typical children earned a high school diploma (28 percent compared to 26 percent of married mothers of children with disabilities). Similar proportions (approximately 31 percent) in both categories completed some college. However, more married mothers with typical children went on to earn a bachelor's degree (21 percent compared to 17.8 percent of married mothers of children with disabilities) and

graduate/professional degree (10 percent compared to 9 percent of married mothers of children with disabilities) (see Table 2.2).

### **Control Variables**

*Time-Invariant Predictors.* In this study, race is measured as a series of dichotomous variables for white (88 percent of mothers of children with disabilities and 85 percent of mothers of typical children), African American (7 percent of mothers of children with disabilities and 8 percent of mothers of typical children), and other races (e.g., American Indians, Aleuts, Eskimos, Asians, Pacific Islanders, and those not previously specified) (5 percent of mothers of children with disabilities and 7 percent of mothers of typical children) (see Table 2.2). Maternal disability has shown to be a strong predictor of maternal employment (Parish and Cloud 2006) so I include a dichotomous variable to measure whether mothers had a disability (1 = yes, 0 = no) during the survey period using the disability index described in the *Independent Variables* section above. Thirty-three percent of married mothers of children with disabilities also have a disability themselves while only 16 percent of married mothers of typical children have a disability.

*Time-Varying Predictors.* I control for the number of residential children at each wave and the number of children with disabilities in a family. The number of residential children ranges from 1-8 with an average of 2.32 children across all waves in families of children with disabilities. Within these families, there is an average across all waves of 0.831 children with disabilities. Married mothers of typical children have an average of 1.92 children across all waves. Children's actual ages are used to create a series of variables for

the number of children in each age group (e.g., under three, preschool-age, adolescents, teenagers, and adult children) at each wave.

To determine whether caregiving affected maternal employment, I created a dichotomous variable using responses from the following three questions: 1) Respondents who had a job during the reference period and worked less than 35 hours some weeks answered the following question: “There are weeks when ... worked less than 35 hours. What was the main reason...worked less than 35 hours in those weeks?”; 2) Those who did not work during reference period answered: “Main reason ... did not have a job during the reference period.”; and 3) Respondents who worked during the reference period and were not contingent workers, but whose job ended during the reference period answered: “What is the main reason ... stopped working for...?” The original response categories are not mutually exclusive and varied somewhat for the three questions above; however, they all included options that pertained to raising children. Since I am primarily interested in whether mothers’ work was affected by caregiving, I coded this variable as dichotomous (1 = yes) if any of the following criteria were met: respondents could not work because of pregnancy/childbirth or taking care of children/other persons; respondents could not work full-time because of taking care of children/other persons; or respondents had to end work because of childcare problems. If at least one of these criteria were not met, then the “work affected by caregiving” variable was coded as 0 = no. An equal percentage (28 percent) of mothers of children with disabilities and typically developing children indicated that their employment was affected by caregiving demands.

Family income is a continuous measure of the average monthly family income for the reference period. The average monthly family income across all waves for married mothers of children with disabilities is \$5,868 and \$6,182 for married mothers of typical children. A variable for the receipt of public assistance was created from a series of questions about whether they or their children received Supplemental Security Income (SSI) or Social Security (e.g., “Did ... receive any Social Security payments on behalf of ...'s children during the reference period? Did ... receive any Supplemental Security Income (SSI) on behalf of ...'s children during the reference period? Did ... receive any Social Security payments for him/herself during the reference period? Did ... receive any income from Supplemental Security Income (SSI) for him/herself during the reference period?”). On average, 8.7 percent of married mothers of children with disabilities indicated that they received public assistance for themselves and 4 percent received it for their children. Only 2.9 percent of married mothers with typical children reported that they received public assistance for themselves with less than one percent receiving it for their children. See Table 2.2 for the descriptive statistics for all time-varying predictors.

### **Analysis**

The first two hypotheses are analyzed using multilevel growth models in SAS PROC MIXED.<sup>1</sup> Multilevel growth modeling is useful when researchers are interested in how an outcome changes over time and how to predict differences in these changes (Singer and Willett 2003). This technique allows researchers to distinguish between intraindividual and

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<sup>1</sup> I estimated several multilevel models in HLM6 with sampling weights and without, and the weights did not change the inferences drawn from the sample. Thus, the multilevel models in this analysis use an unweighted sample.

interindividual changes. For example, multilevel growth models are comprised of a within-person or level 1 model that characterizes individual patterns of change and a between-person or level 2 model that describes the associations between individual growth parameters and the predictors of change (Singer and Willett 2003). The level 1 model is used to depict the shape of each person's individual growth trajectory over time. The level 1 model can be written as:

$$Y_{ij} = \pi_{0i} + \pi_{1i} (AGE_{ij} \text{ Centered}) + \varepsilon_{ij} \quad (1)$$

where  $Y_{ij}$  is mother  $i$ 's hours of employment on occasion  $j$ ,  $\pi_{0i}$  is the intercept of the true change trajectory,  $\pi_{1i}$  is the slope of the true change trajectory centered on a specific temporal predictor  $AGE_{ij}$  to facilitate meaningful interpretation of the intercept<sup>2</sup>, and  $\varepsilon_{ij}$  is the measurement error across all occasions for individual  $i$ .

The level 2 model is used to “detect the heterogeneity in change across individuals and to determine the relationship between predictors and the shape of each person's individual growth trajectory” (Singer and Willett 2003:8). The level 2 model considers the effects of time-invariant predictors on the intercept and the slope. For example, a demographic variable such as race (dichotomized as African American and not African American) can be included as a predictor. The level 2 equation can be written as:

$$\pi_{0i} = \gamma_{00} + \gamma_{01}AFRICAN\ AMERICAN + \zeta_{0i} \quad (2)$$

and

$$\pi_{1i} = \gamma_{10} + \gamma_{11}AFRICAN\ AMERICAN + \zeta_{1i} \quad (3)$$

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<sup>2</sup> Age is centered on 17.749 years which is the youngest age of all mothers in the sample at Wave 1. For simplicity, I will begin to refer to the slope as Age instead of Age centered.

where  $\pi_{0i}$  (intercept) and  $\pi_{1i}$  (slope) are treated as level 2 outcomes. Considered fixed effects,  $\gamma_{00}$  and  $\gamma_{10}$  are level 2 intercepts with  $\gamma_{01}$  and  $\gamma_{11}$  as level 2 slopes. Each component has its own residual,  $\zeta_{0i}$  and  $\zeta_{1i}$ , which allows the level 1 parameters of one person to differ from those of others (Singer and Willett 2003). Time-varying predictors can be added to the model as a predictor of the growth curve. For example, in this research maternal education and family income are conceptualized as time-varying.

The last hypothesis is tested using Ordinary Least Squares (OLS) multivariate regression in SAS PROC REG. OLS multivariate regression is used to evaluate whether the severity of the child's disability decreases maternal employment for white mothers and increases it for African American mothers. The questions used to measure the severity of the child's disability were only asked at Waves 5 and 8, making multilevel growth modeling inappropriate. The regression equation is:

$$y = \alpha + \beta x + \varepsilon \quad (4)$$

where  $\alpha$  is the intercept,  $\beta$  is the slope (indicating whether the relationship is positive or negative), and  $\varepsilon$  is the error term or the difference between the predicted level of  $y$  and the actual observation (McClendon 2002).

## **RESULTS**

Multilevel growth modeling is used to track changes in maternal employment over time while specifically examining the effect that having a child with disabilities has on this change. Since having a child with a disability is hypothesized to directly affect maternal employment, separate models are estimated for mothers of typically developing children and mothers of children with disabilities. This will allow for a clearer interpretation of the data.

### Mothers of Typically Developing Children

First, an unconditional linear growth model (i.e., containing no level 2 predictors) of maternal employment is fitted for married mothers of typical children (see Table 2.3). The estimated average number of hours worked per week (22.498) at the baseline of 17.75 years old differs significantly from zero and contains significant variability, implying the need for the introduction of level 2 covariates in subsequent conditional models. The average rate of change (0.065) for mothers of typical children is significantly different from 0, indicating that there is an increase over time in the average hours worked per week as mothers get older. The variance components associated with the intercept and slope are statistically significant, suggesting that there are still amounts of variation associated with initial rates and change over time that could potentially be predicted with the addition of level 2 covariates.

Model 2 introduces the effects of race, a level 2 covariate, on the average hours worked per week for mothers of typical children (see Table 2.3). The inclusion of race suggests that African American mothers initially work an average of 13.606 ( $p < .001$ ) more hours per week than white mothers. The slope estimate is significant for white and African American mothers, indicating that their number of paid work hours changes over time. However, the model estimates a steeper slope for African American mothers ( $-0.299, p < .01$ ). Controlling for race significantly improves the fit of the data compared to the unconditional linear growth model, but there is still significant variability around the intercept and slope for mothers of typical children.

The number of residential children and the number of children in each age group are added to Model 3. The number of residential children does not have a statistically significant

effect on the intercept; however, it does have a statistically significant negative effect on the slope. More specifically, mothers with more residential children decrease their hours of work over time ( $-0.132, p < .01$ ) at a faster rate than mothers with fewer residential children, net of the effects of the other control variables. The findings also suggest that as the number of children under three, preschool-aged, and adolescents increase, the initial average number of hours worked per week decreases for married mothers with typical children. While the rate of change was negative, there was a positive effect on the slope for the number of preschool-aged children, adolescents, and teenagers, indicating that mothers who had more children in these groups decrease their average hours worked per week over time at a lower rate than mothers with fewer children in these age categories. Racial differences remain between white and African American mothers in their initial average hours worked per week, even after controlling for the number of residential children and their ages. African American mothers still show a decrease in average hours worked per week ( $-0.293, p < .01$ ) over time, while all the other mothers of typical children show little variability in their average hours worked per week over time. Although there is still unexplained variability around the intercept and slope, controlling for the number of residential children and their ages significantly improves the fit of the data.

Model 4 includes time-varying covariates for maternal education, controlling for other relevant variables. For mothers of typical children, education increases the initial average number of hours worked per week for those with a high school diploma and a graduate/professional degree (no high school diploma as the reference category) but does not have a significant effect on the slope, net of the effects of the other controls. The number of

children under three, the number of preschool-age children, and the number of adolescents continues to have significant negative effects on the initial average number of hours worked per week but does not affect the slope. Racial differences remain in the initial average number of hours worked per week between African American and white mothers of typical children, but the differences dissipate over time. For mothers with typical children, Model 4 provides the best fit for the data with some variability still remaining around the intercept.

### **Mothers of Children with Disabilities**

Turning to mothers of children with disabilities, the unconditional linear growth model illustrates that the intercept differs significantly from zero with a rate of 23.362 at the baseline of 17.75 years old, which is only less than a one hour difference per week than mothers with typical children (see Table 2.4 and Figure 2.1). The average rate of change for mothers of children with disabilities (-0.066) does not differ significantly from 0, indicating a constant common slope. The variance components associated with initial rates and rates of change are statistically significant, suggesting the need for level 2 covariates in subsequent conditional models.

Model 2 introduces the effects of race on the average numbers of hours worked per week. The model suggests that African American mothers of children with disabilities work on average 13.432 ( $p < .05$ ) more hours a week compared to white mothers of children with disabilities (22.348,  $p < .001$ ) and decrease their hours at a steeper rate over time compared to white mothers of children with disabilities (see Table 2.4). In addition, both white and African American mothers of children with disabilities work slightly more initial hours a week compared to mothers in the same racial category with typical children. Model 2 still has

statistically significant variability around the intercept and slope for mothers of children with disabilities and significantly improves the fit of the data compared to Model 1.

The coefficient estimates for African American mothers of children with disabilities remain nearly the same after controlling for the number of residential children and the number of children in each age group (see Model 3, Table 2.4), indicating that they work more hours than white mothers of children with disabilities. However, their rate of decrease in hours worked over time is not quite as steep as that of white mothers, net of the effects of the other controls. The intercept increases for white mothers of children with disabilities from 22.348 in Model 2 to 33.051 in Model 3 after controlling for the number of residential children and number of children in each age group. African American mothers of children with disabilities work an average of 5.751 more initial hours than African American mothers of typical children, and white mothers of children with disabilities work an average of 5.746 more hours a week than white mothers with typical children. The number of residential children is not statistically significant and the age of the children has a greater effect for mothers of children with disabilities than for mothers of typical children. Mothers with more preschool aged-children, more adolescents, and more teenagers work fewer initial hours and decrease their average hours worked per week over time at a lower rate than mothers with fewer children in these age groups, which is consistent with mothers of typical children. Model 3 improves the overall fit of the data and accounts for the variability around the slope. However, some variability remains around the intercept.

Racial differences remain with African American mothers of children with disabilities working significantly more initial hours per week than white mothers of children with

disabilities (36.722 and 26.641, respectively), net of the effects of education and other control variables (see Table 2.4). Education reduces the initial average hours worked per week for white mothers of children with disabilities by 6.41 and by 3.114 hours for African American mothers of children with disabilities compared to the coefficient estimates in Model 3. Controlling for education, mothers of “other races” that have children with disabilities work the fewest initial hours followed by mothers of “other races” with typical children. White mothers of children with disabilities work slightly less than white mothers of typical children, and African American mothers of children with disabilities work 1.563 more hours a week than African American mothers of typical children (see Figures 2.2 and 2.3). The slope estimate is no longer significant, indicating that mothers of children with disabilities have a flat or constant slope. For mothers of children with disabilities, education increases the initial average number of hours worked per week, but has little effect on hours worked over time, net of the effects of the other controls. The addition of maternal education and other relevant control variables in Model 4 improves the fit of the data and accounts for the variability around the slope; however, variability still remains around the intercept.

### **Cross-Sectional Analysis**

Separate models were estimated for mothers of children with disabilities by race at Waves 5 and 8. The *F* value was significant in each model, indicating that the model is a good fit for estimating the average hours worked per week for mothers of children with disabilities (see Table 2.5). Thus, the models predict the data better than chance alone. The models account for 34.5 percent of the variation in white mothers’ average hours worked per week at Wave 5 and 39.4 percent at Wave 8. For African American mothers, 42 percent of

the variation at Wave 5 and 33 percent at Wave 8 are explained by the models presented.<sup>3</sup>

The severity of the child's disability is not a significant predictor for white or African American mothers. While more education is predicted to increase initial hours of employment in the multilevel growth models, the cross-sectional analysis reveals that this occurs primarily for white mothers and is not a significant predictor for African American mothers.

## **DISCUSSION**

Maternal carework is embedded within the larger social structures of family, gender, race, and the economy. Carework is a shared experience of most women and is crucial to a sociological analysis of family, gender, and race. However, less research has focused on maternal carework for children with disabilities and the effect this has on employment. The primary goal of this chapter was to demonstrate how certain contexts of women's unpaid carework alter their employment trajectories while also conveying the importance of racial differences among women. Central to this analysis is the notion that disruptions or postponement in employment for mothers of children with disabilities results from atypical caregiving requirements, the increased time needed to take care of a child with disabilities, and lack of appropriate childcare. As a framework for this analysis, a gender/race economic model focuses on the production of gender within families, the underlying gendered expectations about the allocation of time in paid and unpaid work, and the power relations and material inequalities that constitute oppression at the macro-level. Instead of seeing maternal carework as "natural", a gender/race economic model frames carework as a

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<sup>3</sup> Mothers of other races are excluded in the OLS regression estimates due to small sample size.

complicated process that involves the unequal distribution of physical, mental, and emotional work (England 2005; Harrington 1999; Lukemeyer et al. 2000).

### **Differences in Maternal Employment**

My findings support previous research (e.g., Porterfield 2002; Powers 2003) and show that mothers of children with disabilities have lower rates of employment over time than mothers of typically developing children. After controlling for education and income, African American mothers of children with disabilities work the most initial hours while mothers of “other races” with children with disabilities work the fewest initial hours, (see Figures 2.2 and Figure 2.3). The higher initial hours of paid employment for African American mothers of children with disabilities may be due to economic necessity and the economic opportunities available to their spouses, while the lower rates of initial employment for mothers of “other races” may be attributed to more traditional gender ideologies. While only minimally significant, African American mothers of children with disabilities decrease their employment at a steeper rate over time than any other mothers in the sample. As children with disabilities become adolescents and teens, there are fewer childcare options outside of formal education. Black mothers, in particular, may decrease their paid employment at a steeper rate over time in order to provide more “protective carework” as a way to shield their children from peer pressure and victimization (Elliott and Aseltine 2012).

The children’s ages reduce maternal employment for all mothers with a greater effect for mothers of children with disabilities. While the greater number of children in each age group is predicted to decrease hours worked over time in the multilevel growth models, the

cross-sectional analysis reveals that this is primarily for white mothers. Consistent with Porterfield (2002), having older children (e.g., teenagers) reduces the hours worked per week for mothers of children with disabilities, but does not have the same effect for mothers of typical children. Mothers of older children with disabilities may work fewer hours compared to mothers with older typical children because of their time spent out of the labor force and the continued caregiving demands of their children (Porterfield 2002). This difference in employment trajectories for mothers of children with disabilities and mothers of typical children is consistent with the notion of caring for children with disabilities becoming a “career” for female caregivers (see Lefley 1997; Seltzer and Heller 1997) where unpaid carework replaces paid employment over time.

I hypothesized that the severity of the child’s disability would further reduce maternal employment for white mothers but increase it for African American mothers. Previous research (e.g., Leiter et al. 2004; Parish and Cloud 2006) suggests that children with more severe disabilities often need more specialized services that are not always covered by Medicaid or private insurance. This increases the financial costs for families as they provide care for their children with disabilities. Since African Americans have experienced racial discrimination in the workplace which often results in depressed wages, they may need to increase their hours of employment to pay for the extra costs associated with caring for a child with severe disabilities. However, my findings do not support this hypothesis. The severity of the child’s disability did not significantly affect hours of employment for white or African American mothers which contradicts Leiter et al. (2004) who found that mothers with children who have more severe disabilities are more likely to reduce their paid

employment to provide more carework. The lack of significant findings may also be due to the low levels of severely disabled children in the sample.

### **Education and Maternal Employment**

Human capital is an individual investment that includes education, job training, and work experience. Human capital is created by changes in a person's skill level and capabilities that make them able to act in new ways (Coleman 1988). Economic models of the family assume that mothers are the natural choice for unpaid care work because they have less human capital, earn less, and experience more discrimination in the workforce (Becker 1981). Mothers who have invested considerable time and resources on their own education, however, may not be the "natural" choice for unpaid care work and may have additional leverage when it comes to allocating household tasks.

I hypothesized that as education increases so do the number of hours worked per week, regardless of child's disability status. However, my results do not support this hypothesis and suggest that education does not have the same effect for all mothers in the sample. In general, mothers of children with disabilities see a better payoff for their investment in education. That is, mothers of children with disabilities work more initial hours as their education increases compared to mothers of typical children who only see a substantial increase in hours when they receive a graduate/professional degree. However, education is not significant over time, suggesting that mothers with more education have similar work patterns over time as mothers with less education. It may be that when mothers have a higher education and more human capital, fathers provide more childcare or these families have the ability to purchase childcare to substitute for maternal care. Over time,

these arrangements may be difficult to sustain with mothers reducing their employment to assist with long-term care, which results in a wage penalty for motherhood (Budwig and England 2001).

### **Conclusion**

The findings in this chapter show that mothers of children with disabilities have lower rates of employment over time than mothers of typical children, and that white mothers of children with disabilities work fewer hours than African American mothers of children with disabilities after including relevant control variables. These findings are consistent with previous research on mothers of children with disabilities (e.g., Lefley 1997; Porterfield 2002; Powers 2003; Seltzer and Heller 1997) and draw attention to racial differences among this group of mothers. The racial differences in employment outcomes between whites and African American mothers of children with disabilities may be due to several factors that are not included in the present analysis. First, I am unable to control for the type of childcare used because these questions were only asked in one wave of data. Next, I do not account for the extent of social networks. It may be that white and African American families of children with disabilities have different types of networks in place to help with caregiving, which may account for the differences in maternal employment.

Most importantly, the analysis does not take into account the paid work or carework contributions of fathers. Previous research suggests that fathers are more likely to be involved in the financial aspects rather than “hands on” direct care of children, and that the direct care of children with disabilities is characterized as optional or “helping” (Dowling and Dolan 2001; Hooyman and Gonyea 1995; Traustadottir 1991). Fathers’ involvement in

their children's lives has traditionally been viewed as secondary to their role as economic provider (Bernard 1991). African American fathers do not have the same economic opportunities as white fathers. Consequently, African American mothers may have to assume both breadwinner and caregiver roles. One could speculate then that African American fathers of children with disabilities are doing more carework than other fathers, which would account for the differences in employment for white and African American mothers of children with disabilities. However, this doesn't necessarily explain the steep rate of decrease in hours worked over time for African American mothers. As previously mentioned, African American mothers may provide more "protective carework" as their children get older especially if there are not any supervised activities available for their children, thus explaining their decrease in hours over time. I will explore this in more detail in Chapter 3.

This chapter attests to the importance of examining how a child's disability affects maternal employment. However, the analysis in this chapter is based on the assumption that the employment trajectories of mothers and fathers are independent. It would be beneficial to examine the couple (or parental) dyad to get a better idea of how race, class, and gender intersect with carework. In the next chapter, I extend my current findings by pursuing a dyadic analysis of parental employment. This type of analysis controls for the interdependency of employment trajectories within families and allows me to see whether a child's disability affects mothers and fathers differently across racial groups.

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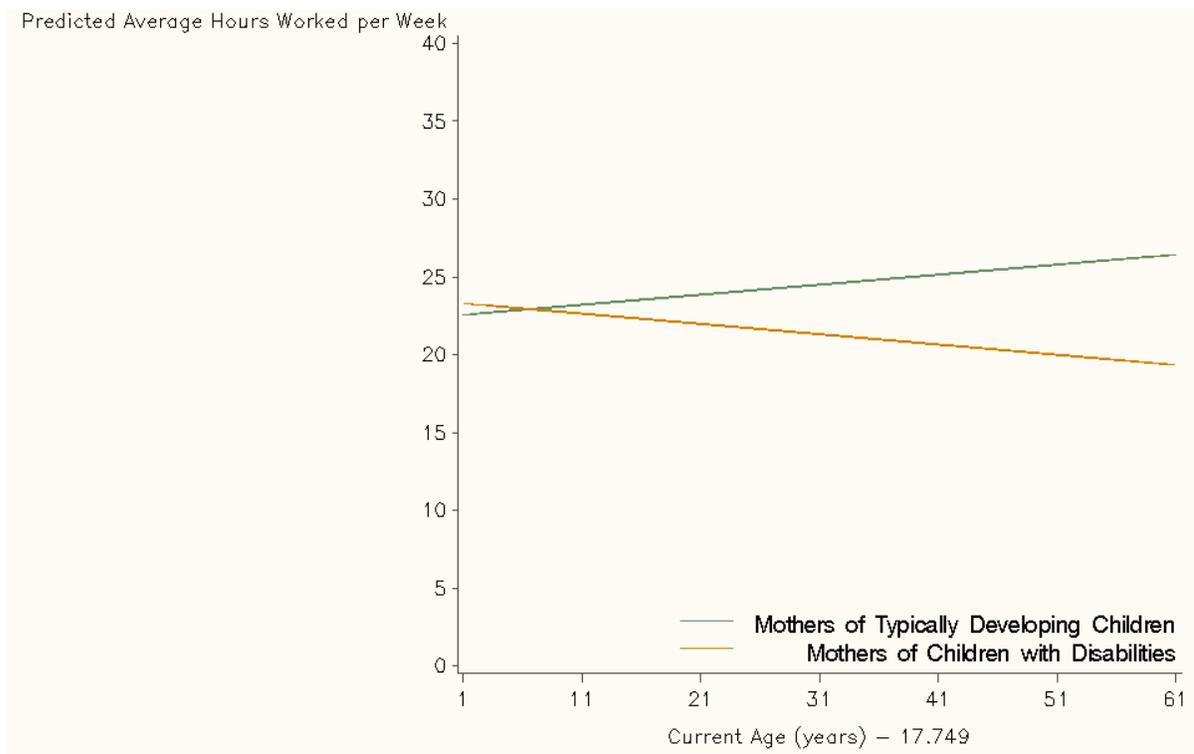
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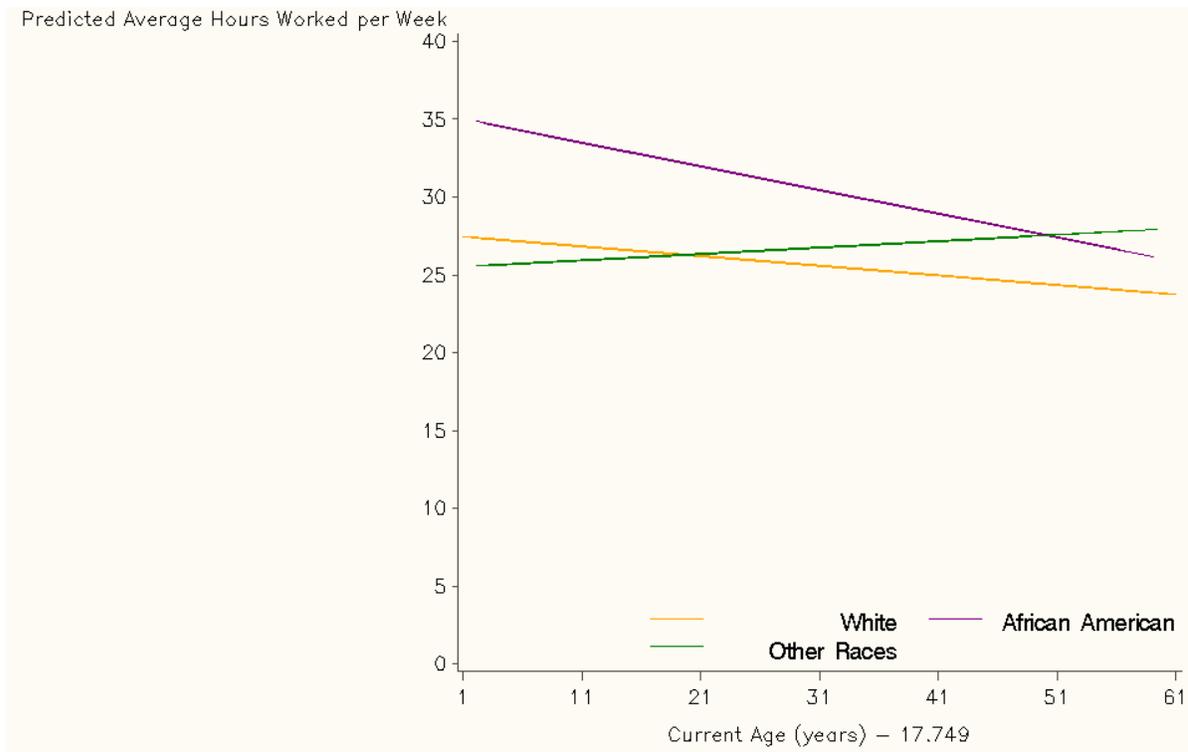
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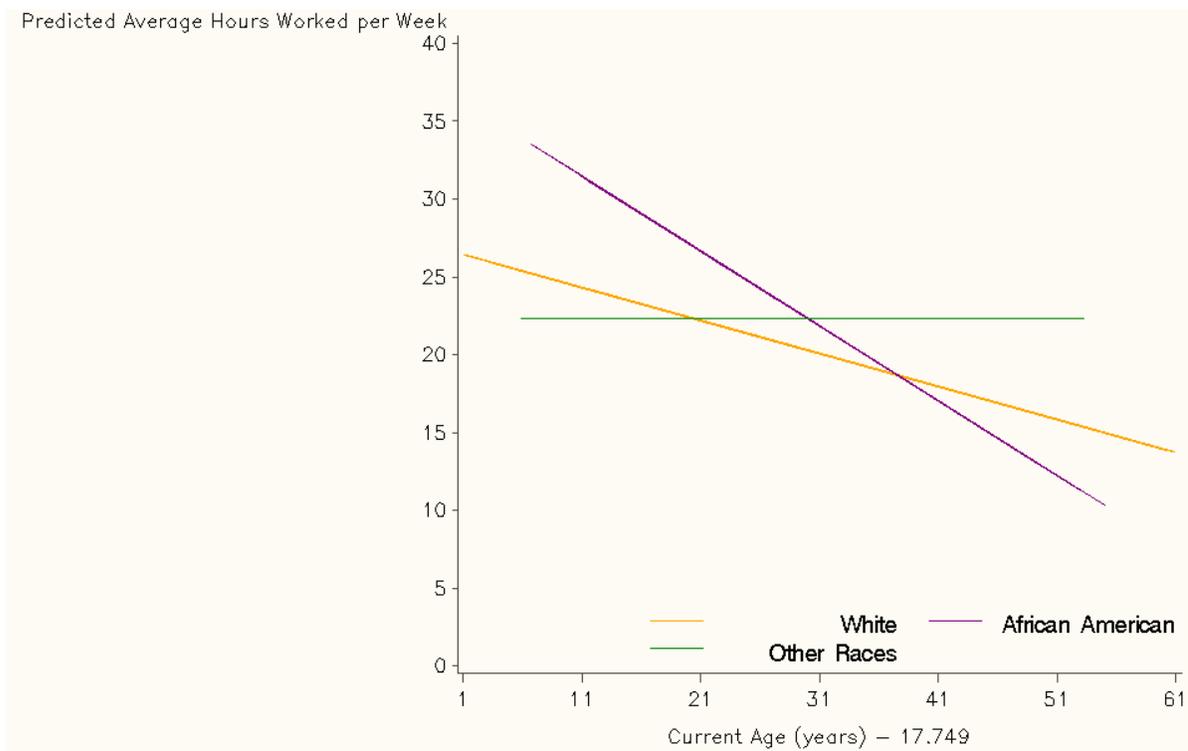
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**Figure 2.1. Unconditional Linear Growth Model Predicting Average Hours Worked per Week for Mothers by Child Disability Status**



**Figure 2.2. Full Linear Growth Model Predicting Average Hours Worked per Week by Race for Mothers with Typically Developing Children**



**Figure 2.3. Full Linear Growth Model Predicting Average Hours Worked per Week by Race for Mothers of Children with Disabilities**

**Table 2.1. Average Hours Worked per Week across Waves for Mothers in Two-Parent Households**

	Wave 1	Wave 2	Wave 3	Wave 4	Wave 5	Wave 6	Wave 7	Wave 8	Wave 9
<i>Mothers of Children with Disabilities</i>									
	21.64	21.73	20.55	20.73	20.64	20.52	20.96	20.47	20.83
	<i>21.39</i>	<i>21.02</i>	<i>21.23</i>	<i>20.83</i>	<i>20.84</i>	<i>20.46</i>	<i>21.03</i>	<i>20.55</i>	<i>20.58</i>
	[0-90]	[0-90]	[0-99]	[0-94]	[0-90]	[0-96]	[0-85]	[0-85]	[0-84]
<i>N =</i>	1067	1065	1066	1086	1134	1113	1100	1130	1052
<i>Mothers of Typical Children</i>									
	24.25	24.25	23.53	23.04	22.94	23.32	23.15	23.05	23.18
	<i>20.38</i>	<i>20.54</i>	<i>20.56</i>	<i>20.32</i>	<i>20.27</i>	<i>20.40</i>	<i>20.11</i>	<i>20.25</i>	<i>20.27</i>
	[0-99]	[0-99]	[0-99]	[0-95]	[0-95]	[0-96]	[0-92]	[0-90]	[0-95]
<i>N =</i>	4422	4430	4521	4657	4880	4738	4732	4840	4521

*Notes:* Table values are unweighted results. Standard deviations are in italics and ranges are in []. Source: Survey of Income and Program Participation 2001-2003.

**Table 2.2. Descriptive Statistics for Variables Used to Estimate the Average Hours Worked per Week for Mothers in Two-Parent Households**

	All Mothers <i>N</i> = 6,165	Mothers of Children with Disabilities <i>N</i> = 1,180	Mothers of Typical Children <i>N</i> = 4,985
<i>Time-Invariant Predictors</i>			
White (Ref Category)	86% <i>0.347</i>	88% <i>0.319</i>	85% <i>0.353</i>
African American	8% <i>0.267</i>	7% <i>0.253</i>	8% <i>0.271</i>
Other Races	6% <i>0.243</i>	5% <i>0.211</i>	7% <i>0.250</i>
Mother's Disability Status	19.61% <i>0.397</i>	33.18% <i>0.471</i>	16.42% <i>0.370</i>
<i>Time-Varying Predictors</i>			
Mother's Age	40.6 <i>9.692</i> [17.75-86.9]	42.73 <i>10.276</i> [18.83-86.9]	40.10 <i>9.481</i> [17.75-86.58]
Number of Children Under 3	0.250 <i>0.495</i> [0-4]	0.155 <i>0.411</i> [0-0]	0.273 <i>0.510</i> [0-4]
Number of Preschool-Aged Children	0.294 <i>0.523</i> [0-3]	0.241 <i>0.496</i> [0-3]	0.306 <i>0.529</i> [0-3]
Number of Adolescent Children	0.684 <i>0.834</i> [0-5]	0.849 <i>0.906</i> [0-5]	0.646 <i>0.812</i> [0-5]
Number of Teenagers	0.553 <i>0.792</i> [0-5]	0.814 <i>0.938</i> [0-5]	0.492 <i>0.740</i> [0-5]
Number of Adult Children	0.215 <i>0.493</i> [0-4]	0.263 <i>0.555</i> [0-4]	0.203 <i>0.477</i> [0-4]
Number of Residential Children	1.996 <i>0.963</i> [1-8]	2.32 <i>1.09</i> [1-8]	1.919 <i>0.914</i> [1-8]
Number of Children with Disabilities	N/A	0.831 <i>0.663</i> [0-5]	N/A
Severity of Child Disability	N/A	1.908 <i>3.609</i> [0-27]	N/A
No HS Diploma (Ref Category)	10.2% <i>0.302</i>	14.84% <i>0.355</i>	9.11% <i>0.288</i>
HS Diploma	27.75% <i>0.448</i>	26.59% <i>0.442</i>	28.02% <i>0.449</i>
Some College	31.48% <i>0.464</i>	31.75% <i>0.466</i>	31.42% <i>0.464</i>

**Table 2.2 continued.**

Bachelor's Degree	20.73% <i>0.405</i>	17.83% <i>0.383</i>	21.41% <i>0.410</i>
Graduate or Professional Degree	9.83% <i>0.298</i>	8.99% <i>0.286</i>	10.03% <i>0.300</i>
Average Monthly Family Income	6,122 <i>5,109</i> [0-107,873]	5,868 <i>4,993</i> [0-69,821]	6,182 <i>5,134</i> [0-107,873]
Work Affected by Caregiving	28.09% <i>0.449</i>	28.04% <i>0.449</i>	28.1% <i>0.449</i>
Public Assistance for Self	3.97% <i>0.195</i>	8.68% <i>0.282</i>	2.87% <i>0.167</i>
Public Assistance for Child	1.36% <i>0.116</i>	4.05% <i>0.197</i>	0.73% <i>0.085</i>

*Notes:* Values for the category of "All Mothers" are grand means or percentages. Table values for the categories of "Mothers of Children with Disabilities" and "Mothers of Typical Children" are group means or percentages. Standard deviations are in *italics* and ranges are in [].  
*Source:* Survey of Income and Program Participation 2001-2003.

**Table 2.3. Multilevel Growth Models Predicting Average Hours Worked per Week for Mothers in Two-Parent Households with Typically Developing Children (N=4,985)**

	<u>Model 1</u>		<u>Model 2</u>		<u>Model 3</u>		<u>Model 4</u>	
	Unconditional Linear		Race		Children		Maternal Education	
<i>Fixed Effects (on the intercept)</i>								
Intercept (Initial status)	22.498 ***	(0.710)	21.181 ***	(0.766)	27.305 ***	(1.125)	27.508 ***	(1.495)
African American			13.606 ***	(2.484)	13.19 ***	(2.429)	7.651 ***	(1.703)
Other Races			1.661	(2.959)	0.536	(2.898)	-2.028	(2.084)
Number of Residential Children					2.626	(1.517)	1.797	(1.364)
Children Under Three					-5.033 ***	(1.556)	-2.727 *	(1.394)
Preschool-Aged Children					-5.375 ***	(1.540)	-2.743 *	(1.383)
Adolescent					-5.249 ***	(1.499)	-2.942 *	(1.349)
Teenagers					-2.628	(1.455)	-0.940	(1.323)
High School Diploma							3.764 **	(1.356)
Some College							2.091	(1.434)
Bachelor's Degree							2.093	(1.672)
Graduate/Professional Degree							6.721 **	(2.170)
Monthly Family Income							0.001 ***	(0.000)
Work Affected by Caregiving							-18.698 ***	(0.425)
Aid Self							-6.086 **	(2.058)
Aid Child							-2.700	2.763
Mother's Disability							4.344 **	(1.394)
<i>Fixed Effects (on the slope)</i>								
Age (Rate of change)	0.065 *	(0.031)	0.096 **	(0.034)	-0.003	(0.051)	-0.062	(0.068)
African American			-0.299 **	(0.108)	-0.293 **	(0.106)	-0.090	(0.076)
Other races			-0.034	(0.125)	0.009	(0.123)	0.103	(0.089)
Number of Residential Children					-0.132 **	(0.051)	-0.094 *	(0.046)
Children Under Three					0.055	(0.059)	-0.024	(0.053)
Preschool-Aged Children					0.117 *	(0.056)	0.013	(0.050)
Adolescent					0.170 ***	(0.050)	0.066	(0.045)
Teenagers					0.096 *	(0.047)	0.025	(0.043)
High School Diploma							-0.074	(0.061)
Some College							0.049	(0.066)
Bachelor's Degree							0.078	(0.075)
Graduate/Professional Degree							-0.010	(0.094)
Monthly Family Income							0.000 ***	(0.000)
Work Affected by Caregiving							0.264 ***	(0.019)
Aid Self							0.030	(0.059)
Aid Child							0.115	(0.110)
Mother's Disability							-0.350 ***	(0.057)
Level 1: Within-person	99.962 ***	(0.780)	99.964 ***	(0.780)	99.961 ***	(0.779)	91.125 ***	(0.692)
Level 2: Intercept	753.99 ***	(54.796)	743.45 ***	(54.144)	695.56 ***	(52.050)	184.58 ***	(23.024)
In rate of change	1.107 ***	(0.115)	1.11 ***	(0.114)	1.048 ***	(0.112)	0.207 **	(0.057)
-2 Log Likelihood	327806		327743.3		327523		321379.1	

Notes: REML, SAS Proc Mixed. The results are unweighted. Numbers in Parentheses are standard errors. \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ . Source: Survey of Income and Program Participation 2001-2003.

**Table 2.4. Multilevel Growth Models Predicting Average Hours Worked per Week for Mothers in Two-Parent Households with Children with Disabilities (N=1,180)**

	<u>Model 1</u>		<u>Model 2</u>		<u>Model 3</u>		<u>Model 4</u>	
	Unconditional Linear		Race		Children		Maternal Education	
<i>Fixed Effects (on the intercept)</i>								
Intercept (Initial status)	23.362 ***	(1.487)	22.348 ***	(1.577)	33.051 ***	(2.475)	26.641 ***	(3.407)
African American			13.432 *	(5.286)	13.195 **	(4.417)	10.081 **	(3.817)
Other Races			-2.364	(7.669)	-4.265	(6.777)	-4.293	(5.738)
Number of Residential Children					3.011	(2.352)	-0.153	(2.217)
Children Under Three					-7.940 ***	(2.464)	-0.980	(2.365)
Preschool-Aged Children					-9.889 ***	(2.351)	-4.245 †	(2.267)
Adolescent					-5.935 **	(2.177)	-0.734	(2.114)
Teenagers					-8.405 ***	(2.121)	-3.555 †	(2.042)
High School Diploma							8.396 **	(2.805)
Some College							6.916 *	(2.963)
Bachelor's Degree							10.698 **	(3.812)
Graduate/Professional Degree							15.708 **	(4.984)
Monthly Family Income							0.000 **	(0.000)
Work Affected by Caregiving							-18.052 ***	(0.955)
Aid Self							-5.371 *	(2.264)
Aid Child							2.386	(2.176)
Mother's Disability							1.307	(2.447)
<i>Fixed Effects (on the slope)</i>								
Age (Rate of change)	-0.066	(0.075)	-0.036	(0.061)	-0.385 ***	(0.090)	-0.212	(0.128)
African American			-0.400 *	(0.205)	-0.354 *	(0.151)	-0.268 †	(0.141)
Other races			0.085	(0.283)	0.159	(0.235)	0.211	(0.207)
Number of Residential Children					-0.099	(0.079)	0.003	(0.074)
Children Under Three					0.177	(0.103)	-0.075	(0.097)
Preschool-Aged Children					0.338 ***	(0.092)	0.138	(0.088)
Adolescent					0.177 *	(0.075)	-0.009	(0.072)
Teenagers					0.304 ***	(0.069)	0.135 *	(0.067)
High School Diploma							-0.187 †	(0.102)
Some College							-0.078	(0.113)
Bachelor's Degree							-0.133	(0.141)
Graduate/Professional Degree							-0.162	(0.171)
Monthly Family Income							0.000	(0.000)
Work Affected by Caregiving							0.234 ***	(0.040)
Aid Self							0.013	(0.068)
Aid Child							-0.105	(0.094)
Mother's Disability							-0.167 †	(0.090)
Level 1: Within-person	108.07 ***	(1.734)	108.14 ***	(1.736)	109.27 ***	(1.665)	97.443 ***	(1.490)
Level 2: Intercept	588.12 ***	(1.735)	565.70 ***	(120.52)	354.32 ***	(42.518)	188.30 ***	(28.858)
In rate of change	0.491 *	(1.736)	0.461 *	(0.223)	0		0	
-2 Log Likelihood	77709.2		77696.6		77638.9		76237.5	

Notes: REML, SAS Proc Mixed. Results are unweighted. Numbers in Parentheses are standard errors. † $p < .10$ ; \* $p < .05$ ;

\*\* $p < .01$ ; \*\*\* $p < .001$ . Source: Survey of Income and Program Participation 2001-2003.

**Table 2.5. OLS Regression Results Predicting Average Hours Worked per Week for Mothers in Two-Parent Households with Children with Disabilities by Race (N=1,180)**

	White Mothers				African American Mothers			
	Wave 5		Wave 8		Wave 5		Wave 8	
Adjusted Model R2	0.3484		0.3816		0.4207		0.3304	
Model F	34.52	***	39.38	***	4.45	***	3.44	***
Intercept	26.607	*** (2.226)	23.419	*** (2.158)	28.367	*** (6.989)	31.695	*** (7.592)
N	1004		996		77		80	
Number of Residential Children	-0.321	(1.194)	-1.660	(1.055)	-5.526	(3.769)	-1.600	(3.829)
Number of Disabled Children	-0.421	(0.875)	1.262	(0.832)	-2.050	(2.993)	-2.188	(3.507)
High Child Disability Score	-0.107	(0.159)	-0.204	(0.156)	0.182	(0.648)	-0.452	(0.925)
Children Under Three	-1.877	(1.661)	-0.129	(1.624)	9.658	(6.213)	-1.307	(10.263)
Preschool-Aged Children	-0.817	(1.489)	1.733	(1.398)	4.999	(5.070)	3.052	(4.948)
Adolescents	-0.118	(1.124)	0.658	(0.996)	1.431	(3.582)	1.606	(3.659)
Teenagers	0.930	(1.155)	2.830	** (1.041)	4.000	(3.914)	1.351	(3.838)
High School Diploma	2.060	(1.784)	2.182	(1.728)	9.760	(6.768)	-2.120	(7.386)
Some College	3.797	* (1.779)	4.08	* (1.729)	0.941	(6.214)	3.390	(6.268)
Bachelor's Degree	3.290	(2.025)	3.761	† (1.973)	5.417	(7.300)	9.033	(7.542)
Graduate/Professional Degree	6.611	** (2.368)	5.690	* (2.315)	0.664	(12.136)	17.013	(13.492)
Monthly Family Income	0.000	(0.000)	0.000	*** (0.000)	0.002	* (0.000)	0.000	(0.001)
Work Affected by Caregiving	-22.889	*** (1.279)	-22.463	*** (1.211)	-20.402	*** (5.352)	-17.261	** (6.250)
Aid Self	-19.354	*** (2.177)	-16.501	*** (2.061)	-13.729	* (6.080)	-18.311	* (7.008)
Aid Child	2.991	(2.730)	-3.154	(2.734)	13.477	(8.436)	-8.998	(10.987)
Mother's Disability Status	-2.298	† (1.215)	-3.428	** (1.159)	-6.463	(4.698)	-12.241	* (4.966)

Notes: The results are unweighted. Table entries are unstandardized (metric) regression coefficients. Numbers in Parentheses are standard errors. † $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ . Source: Survey of Income and Program Participation 2001-2003.

### **CHAPTER 3 (STUDY 2): EMPLOYMENT TRAJECTORIES FOR PARENTS OF CHILDREN WITH DISABILITIES**

Decisions about paid and unpaid work in two-parent families are part of a dynamic process that often changes over time in relation to the caregiving needs of children. These decisions are further complicated when a child has a disability. My findings from the previous chapter are consistent with the research on employment trajectories for mothers of children with disabilities (e.g., Lefley 1997; Porterfield 2002; Powers 2003; Seltzer and Heller 1997) suggesting that they work fewer hours over time than mothers with typical children. The previous chapter demonstrates the importance of examining how a child's disability affects maternal employment. However, it was based on the assumption that the employment trajectories of mothers and fathers are independent, when decisions within families are often interdependent. If this is the case, then how do two-parent families balance employment and caregiving when they have children with disabilities, and how do they differ from families with typical children?

The purpose of this chapter is two-fold. First, I offer a family life course development perspective (see White and Klein 2002) to illustrate how individual life courses are embedded within different family contexts. Following this premise, decisions about paid and unpaid work within a particular family context are also shaped by larger gender, race, and class structures (Ferree 2010; Collins 2000). Second, I provide a dyadic examination of the variability within the family experience using multilevel growth modeling to demonstrate how parents' employment trajectories are interdependent over time.

## **LITERATURE REVIEW**

The two-parent family is a normative model that shapes decisions about paid and unpaid work. Smith (1993) refers to this as the “Standard North American Family” (SNAF) and suggests that it rests on the idea of a breadwinner/homemaker dichotomy where men are in paid employment. Women may work for pay, but their primary responsibility is to take care of their husband, children, and the home. However, the SNAF model has not been the reality for most families (see Stack 1974; Nelson 2006) and the economic conditions on which it is based are fading. For example, both parents in working-class and minority families have historically worked for pay (Thistle 2006), and more recently, the middle-class ideal is out of reach even for the middle class (Descartes and Rudd 2008). Paid employment for mothers of young children, especially married mothers, was once part of a deviancy discourse where mothers were expected to follow normative standards of intensive mothering (Ardenall 2000; Smith 1993). However, Cohany and Sok (2007) suggest that the reality of the lives we live certainly does not support such conceptions with the majority – 68 percent – of married mothers of children under 18 in some type of paid employment.

### **Labor Force Participation and Caregiving in Two-Parent Families**

Researchers (e.g., Kreps and Clark 1975; Masnick and Bane 1980; Spitze and Waite 1981) have long hypothesized that in terms of full-time permanent attachments women’s paid work patterns would increasingly take on the appearance of men’s. This can be seen in periods of economic uncertainty where the need for two incomes within families increases. Further, ideological shifts in the last 40 years (e.g., the erosion of the breadwinner/homemaker model) in normative gender expectations and the changing

economic structures affect the gender division of labor within families and create more fluidity between the boundaries of work and home (Padavic and Reskin 2002). Nonetheless, women's work patterns are still thought to be tenuous and unattached to the labor market due to their family responsibilities, resulting in more complex interactions in the labor market over their life course. A majority of women often have to modify work roles to accommodate family obligations; as a result, their family responsibilities may require movement into and out of the labor market over a series of years. This resonates in income loss and a wage gap between men and women, which Budwig and England (2001) suggest are wage penalties for motherhood, and Crittenden (2001) refers to as the "mommy tax".

Even as married women share the breadwinner role, men are still reluctant to share equally in domestic responsibilities (Gerson 2010). Gershuny, Bittman, and Brice (2005) suggest that women decrease their domestic labor upon entering full-time paid work while men show a lagged pattern of increase over time in domestic labor. However, it does not appear that it is domestic labor in general, but childrearing that has increased among fathers (Bianchi 2000; Craig 2006), which may reflect men's desire to devote more time and energy to fatherhood than their own fathers did (Coltrane 2000; Gerson 1993; Townsend 2002). Brandth and Kvande (1998) and Nock (1998) suggest that fathers use caregiving to demonstrate adult masculinity and benefit from caregiving (e.g., higher earnings and community status) in ways that are unavailable to mothers. Other research suggests that fathers' overall involvement is still minor compared to mothers' and that fathers rarely provide all of the childcare (Averett, Gennetian, and Peters 2005; Winslow 2005).

## **Balancing Work and Family**

Much of the contemporary family research on the division of household labor suggests that gender rather than rational allocation affects how married couples balance work and family (for a recent discussion see England 2011; Ferree 2010; Risman 2011; Sullivan 2011). This is particularly relevant for families with children with disabilities. Powers (2003) suggests that mothers of children with disabilities are less likely than other parents to work for pay. Several studies (e.g., Brandon 2000; Cuskelly, Pulman and Hayes 1998; Jinnah and Stoneman 2008; Kagan, Lewis and Heaton 1998; Shearn and Todd 2000) cite the lack of appropriate childcare and inflexibility of employers that make it more difficult for both parents of children with disabilities to sustain employment. Families with children with disabilities may face extra constraints compared to families with typical children when balancing paid work and unpaid carework. Similar to other families, decisions about working and caring are a complex combination of economic and ideological factors that are viewed through a gender lens (Lewis, Kagan, and Heaton 2000). What is different, though, is that the experience of carework for children with disabilities often extends across the life course for female caregivers (Lefley 1997; Seltzer and Heller 1997).

Lewis et al. (2000) found that two-parent families with children with disabilities develop strategies to manage paid work and unpaid carework by adapting to their child's specific needs. These strategies are similar to two-parent families with typical children (see Jacobs and Gerson 2004) except that families with children with disabilities have to consider the atypical caregiving needs of their children and the increased cost of taking care of a child with disabilities (Parish and Cloud 2006). Two of the patterns identified by Lewis et al.

(2000) resemble traditional divisions of labor where fathers work full-time and mothers either do not work for pay or work less than part-time (e.g., the modified-single-earner and a one-and-a-half earner model). Fathers are primarily involved in the financial aspects rather than “hands on” direct care of children with disabilities (Hooyman and Gonyea 1995), and their participation in the direct care of children with disabilities is constructed as optional and characterized as “helping” (Coltrane 2000; Craig 2006; Dowling and Dolan 2001; Traustadottir 1991). Families use this as a deliberate strategy to ensure childcare, and mothers frame their decisions not to work on a permanent basis within a “discourse of choice” (Dowling and Dolan 2001; Lewis et al. 2000; Stone 2007). These strategies emphasize the continuing pervasiveness of gender distinctions in family life and the saliency of gendered caregiving (Ardenall 2000; England 2005; Singley and Hynes 2005).

Lewis et al. (2000) identified two patterns among dual earners families (e.g., full-time dual-earners and flexible or part-time dual-earners) where parents use nonstandard work schedules, flextime, and family leave policies to balance paid work and caregiving (Presser 2003; Singley and Hynes 2005). Similar to the flexible dual-earners, Cowdry and Knudson-Martin (2005) found that more equal couples with typical children consciously collaborated to create gender-neutral solutions to work-family conflict. The strategies of dual-earner families in general reflect the shift towards a new “culture of fatherhood” (Larossa 1988; Marsiglio 1995) where fathers see themselves as more than just economic providers. Glauber (2008) found that African American married men do not experience the same wage premiums or increase in wages associated with fatherhood as white men and Latinos, nor do they increase their annual time at work. Thus, fulfilling a father role may indicate a

successful transition to adulthood and be particularly important for African American men given their constrained economic opportunities (Roy 2006; Smith et al. 2005). In general, the dual-earner strategies used by respondents in Lewis et al. (2000) study are considered an economic necessity for the family, and white mothers, in particular, are more likely to experience greater fluctuations in their work schedules to accommodate caregiving (Singley and Hynes 2005).

### **Conceptual Framework**

The family life course development framework focuses on the systematic and patterned changes experienced by families as they move through stages and events of their family life course (White and Klein 2002). The assumptions of this framework are based on two theoretical orientations - the family development theory and the life course perspective - both of which add to our understanding of the family as a group of individuals organized by social norms and who change over time in relation to these norms. This perspective assumes that developmental processes are inevitable and important in understanding families; the family group is affected by all levels of analysis; the family is a semi-closed group; and time is multi-dimensional (White and Klein 2002). Of particular importance for this analysis is the notion of the family as a social group (i.e., linked lives) and how families are affected by the larger social context (i.e., interactional and institutional levels of analysis).

*Importance of Linked Lives.* The embeddedness of individuals within family relationships, or “linked lives” (Elder 1994), is evident in the notion of caregiving as a dynamic process in two-parent families where “couples (rather than individuals) make *strategic selections*” about balancing work and family (Chesley and Moen 2006:1251). Lives

are linked through marriage, creating interdependency between spouses' life courses (Macmillan and Copher 2005). For example, marriage and children affect the distribution of paid and unpaid work within couples. Having children increases fathers' hours of paid work (Gerson 2010) with mothers still more likely to modify their paid work hours to accommodate carework (Maume 2001; Singley and Hynes 2005). Labor force participation reduces mothers' time spent on household labor, which in turn gradually increases husbands' household labor. These examples illustrate how decisions about paid work and carework are interdependent and often contingent upon the women in men's lives (Gerstel and Gallagher 2001).

*Larger Social Context.* While family life course development framework does acknowledge the development of family roles (e.g., mother and father), it does not offer any explicit analysis of how larger gender structures affect families. However, research on gender (e.g., Ferree 1990, 2010; Risman 1998, 2011) suggests that gender expectations within families are influenced by a gender ideology that operates at the individual, interactional, and institutional levels (Ferree 1990, 2010; Risman 1998, 2011). Individual gender ideologies are constructed in interaction with others. Parents "do gender" (West and Zimmerman 1987) and "do family" (Nelson 2006) through paid and unpaid labor, which involves the routine accomplishment of normative gender expectations that are embedded in everyday interactions. Parents constantly recreate gender differences and (re)produce gender inequality as they perform these tasks. At the institutional level, hierarchical gender segregation exists in the workplace where men are able to renegotiate and redefine their masculinity through workplace practices (Acker 1990; Aldous and Mulligan 2002; Hartmann 1976, 1981).

By assuming the “breadwinner role”, men reinforce their dominant position within the household, while women’s subordination in the labor market reflects their subordination in the domestic realm. As a result, families and workplaces define and reaffirm differences between men and women. For example, parental employment trajectories may reflect dominant gender ideologies and shift to more equal divisions of labor as normative gender expectations change over time. Furstenberg (2003) suggests that with the rise of dual-earner families, the life courses of men and women are converging across gender in regards to employment. Yet, women’s lower economic standing persists and may be widening among certain groups of women, which points to the intersection of race and class in women’s life course trajectories (Ferree 2010; McCall 2011).

*Variations in the Life Course.* The assumptions of the family life course development framework are based on universal or invariant notions of developmental processes or stages and do not take into account how the family life course differs by race. Differences in employment trajectories between families by race may result from historical and structural oppression. The prevailing definition of “normal” families has been based on the notion of family as a nuclear, heterosexual couple headed by wage-earning men (Smith 1993), which Collins (2000) finds particularly problematic for African American couples. African American women tend to have different experiences with the public and private spheres and in many cases have better employment opportunities than African American men (Gerson 2010; Thistle 2006). Vespa (2009) suggests that experiences with family structure, parenthood, and work create different gender ideologies with African American couples having more egalitarian gender ideologies. As such, any sociological analysis of family life

course patterns must take into account how the intersection of gender, race, and class (Furstenberg 2003) affect decisions about work and parental employment trajectories.

### **Research Question and Hypotheses**

The family life course development framework highlights the importance of family relationships and is well-suited to address the interdependency of parental employment trajectories. In this chapter, I am concerned with how two-parent families balance employment and caregiving when they have children with disabilities, and whether they differ from families with typically developing children. Further, I suspect that the larger social context (e.g., gender, race, and class structures) influences parental employment trajectories. I provide broad hypotheses to examine the differences in employment outcomes between parents of children with disabilities and parents with typical children and within parental dyads by gender.

Arber and Ginn (1995) and Powers (2003) both suggest that mothers caring for children with disabilities are less likely to work full-time compared to fathers of children with disabilities and parents of typical children. My findings from the previous chapter support this for white mothers, but not for African American mothers of children with disabilities. Specifically, I found that African American mothers of children with disabilities work more initial hours than the other mothers in the sample, but have a sharper rate of decline in hours over time. In this chapter, I include fathers in the analysis and examine the gap in hours worked over time between parents. I expect:

*Hypothesis 1: The difference in market work hours between mothers and fathers of children with disabilities is higher compared to mothers and fathers with typical children, and this effect varies by race.*

The gap in hours worked between parents with children with disabilities is even greater with an increase in the severity of the child's disability (Bristol, Gallagher, and Schopler 1988; Leiter et al. 2004; Leonard, Brust, and Sapienza 1992). Children with more severe disabilities need more specialized therapies, home modifications, and adaptive equipment that often carry out-of-pocket expenses even with public health care coverage (Parish and Cloud 2006). Thus I expect to find:

*Hypothesis 2: The severity of the child's disability increases the difference in market work hours for parents of children with disabilities.*

In families where two incomes are needed, parents may adopt the strategies (e.g., full-time dual earner or flexible dual-earners) identified by Lewis et al. (2000). Despite the seemingly gender-neutral appearance of these two strategies, women are more likely to alter their work schedule to accommodate for carework (Arber and Ginn 1995; Maume 2001; Singley and Hynes 2005; Webber and Williams 2008). Parents may further experience a redistribution of care within families based on the available labor market opportunities (Gerstel and Gallagher 2001; McCall 2010). Thus, I expect to find that:

*Hypothesis 3: Mothers of children with disabilities are more likely to reduce their hours of paid employment over time because of caregiving demands than are fathers of children with disabilities and parents of typical children.*

To summarize, I am comparing the employment trajectories of parents of children with disabilities and parents with typically developing children. Based on these comparisons, I expect to find that the child's disability status and the severity of the child's disability affect the difference in hours worked between parents. Further, I expect racial differences in this effect with the gap in hours being less for African American couples and more for white

couples due to the available economic opportunities. Lastly, mothers of children with disabilities are more likely to reduce their hours of paid employment because of specific caregiving demands than fathers of children with disabilities and parents of typical children.

## **DATA AND METHODS**

Researchers concerned with the context of family relationships are increasingly using multilevel modeling to investigate marital dyads (Lyons and Sayer 2005). This allows for the examination of individual level outcomes such as employment within the dyadic relationship and also controls for the interdependency of spouses' employment and caregiving decisions. My analysis in this chapter will improve on the existing literature on caregiving by using a multilevel dyadic approach to examining employment trajectories for parents of children with disabilities and parents of typical children. This chapter provides a unique opportunity to examine the relational characteristics of the dyad unit and the interdependency of change over time (Thompson and Walker 1982).

The Survey of Income and Program Participation (SIPP) is a continuous series of national panels designed to measure the effectiveness of existing programs and estimates future costs and coverage of government programs (U.S. Census Bureau 2005). SIPP content is built around "core" questions on income, labor force participation, program participation and eligibility, and general demographics. "Topical modules" are asked throughout the panels to provide additional information for analyses. SIPP utilizes a multi-stage stratified sample of the U.S. civilian non-institutionalized population. Imputation procedures are employed to reduce the bias of survey estimates and are based on the assumption that data are missing at random within subgroups of the population. Data editing are preferred over

statistical imputations and were used whenever a missing item could be logically inferred from other data that was provided (U.S. Census Bureau 2005).

The survey uses a four month recall period with about the same number of interviews conducted in each of the four month periods for each wave. My analysis is based on the SIPP 2001 panel, which initially consisted of 36,700 households that were to be interviewed nine times over the course of three years. Budget constraints caused the U.S. Census Bureau to reduce the number of households interviewed by 15 percent by Wave 2, leaving 31,195 households eligible for interviews. All household members at least 15 years old are interviewed by self-response.

### **Selection of Sample for Analysis**

SIPP is a survey of households and includes data on primary families, related and unrelated subfamilies, and primary and secondary individuals. The current analysis is limited to the same primary families used in the previous chapter and excludes multi-generational households and single-parent households. The choice to exclude single parents was made after considering the different economic and caregiving challenges that they are likely to face when raising a child with disabilities compared to two-parent families (see Lee et al. 2004). Coleman (1988) suggests that two-parent families and single parent families experience different structural disadvantages because of occupational demands and long hours in the paid labor force. In this study, family composition is held constant with only married couples in the sample. The work-family balance of single parents raising children with disabilities warrants separate study and is beyond the scope of the current research.

Parental responses are used for children less than 15 while those at least 15 years old are interviewed by self-response. The sample includes 6,168 marital dyads with at least one residential child during the survey period. Nineteen percent (1,180) of the couples in the sample have at least one residential child who meets the criteria of disability used in this analysis, which is somewhat higher than national averages (for a discussion on the percentage of families raising children with disabilities see Wang [2005] and Malsch, Rosenzweig, and Brennan [2008]). This sample can be considered an accelerated longitudinal design because it consists of multiple birth cohorts (Raudenbush and Chan 1993). The advantage of using multiple birth cohorts is that it illustrates the effects that children have on maternal employment from birth to adulthood.

### **Dependent Variable**

A series of multilevel growth models are estimated to determine whether parental employment is interdependent over time and how it varies across dyads. Respondents are asked “How many hours per week did ... usually work at all activities at this job?” If participants had two jobs, then their usual hours worked per week for both jobs were combined. Answers are reported using a continuous measure of usual hours worked each week. Fathers, on average, work more hours at each wave than mothers (see Table 3.1). The average hours worked per week for mothers of children with disabilities are fairly stable across waves (average high of 21.73 hours per week at Wave 2 and average low of 20.47 hours at Wave 8) with less stable hours for fathers of children with disabilities (average high of 35.03 at Wave 1 and average low of 33.32 at Wave 7). Mothers with typical children have slight fluctuations in their hours worked with an average high of 24.25 hours per week at

Waves 1 and 2 and a low of 22.94 hours by Wave 5. Fathers with typical children have the highest average hours worked per week at 36.68 (Wave 1) and show slight but steady declines in average hours worked over time with a low of 34.72 by Wave 8.

### **Independent Variables**

*Measures of Disability.* The SIPP Topical Module on Functional Limitations and disability from Waves 5 and 8 is used to identify children with disabilities. The American with Disabilities Act (ADA) (1990, 2008) defines disability as “a physical or mental impairment that substantially limits one or more major life activities of such individual.” My operational definition of disability is slightly more encompassing than the ADA (1990, 2008) definition and is based on both self-perceptions and clinical diagnoses of disabilities. I follow the same criteria of disability as identified by the World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health (ICF) and as used by the U.S. Census Bureau (see Wittenburg and Nelson 2006). I primarily rely on Erickson and Dumoulin-Smith’s (2009) Simplified Conceptual Model of Disability using ICF Concepts where children are considered disabled if they have either a physical, mental, or sensory impairment, participation restriction, and/or activity limitation. In this operational definition of disability, children with impairments are included even if the impairment does not significantly affect their daily living.

Physical impairment includes a long-lasting condition that limits the ability to move arms or legs (refers to children under three), limits the ability to walk, run, or play (refers to children between three and five), and limits the ability to walk, run or take part in sports and games (refers to children between six and fourteen). Children who are 15 years old answer

questions about their difficulty lifting or carrying an object 10 pounds or heavier, pushing or pulling large objects, standing or sitting for an hour, stooping, crouching, or kneeling, reaching or grasping, walking three blocks or up a flight of stairs, or using a telephone. Children less than six years old are considered mentally impaired if they have a serious mental condition or a developmental delay that limits ordinary activities. All other children (six and older) are considered mentally impaired if they have a learning disability (e.g., dyslexia), attention deficit hyperactivity disorder (ADHD), intellectual disability, developmental disability (e.g., autism or cerebral palsy), or any other developmental condition for which they have received therapy or diagnostic services. Children at least six years old with a sensory impairment have difficulty seeing words/letters, hearing even with an aid, or understanding speech.

To determine participation restrictions for children between the ages of 6 and 19, mothers indicate whether their children experience a physical, learning, or mental condition that limits the ability to do regular school work. Young adults 16 years and older are asked whether they have a long-lasting physical or mental condition that makes it difficult to remain employed or to find a job. Activities of daily living refer to children at least six years old and include needing help getting around inside the home, in and out of a chair, taking a bath or shower, putting on clothes, eating food, or using/getting to the toilet.

A dichotomous variable was created based on the operational definition of disability to indicate whether there was a child with disabilities in the family (1 = yes, 0 = no) at either Waves 5 or 8 using data from the Topical Module on Functional Limitations and Disability. This measure is used to divide the sample of families into two groups – those with

a child with disabilities (19 percent) and those with a typically developing child. Next, a disability index was created to measure the severity of the disability as a continuous time-varying variable. Scores were computed for each child with disabilities in the household with only the highest disability index score from each family used as the measure of severity of disability. Scores range from 0-27 with higher scores indicating more severe disabilities. The sample primarily consists of children with non-severe disabilities with an average score of 1.912 across Waves 5 and 8.

*Gender.* Two separate measures to account for gender differences are included in the analysis. Most of the multilevel models use a two intercept approach with separate estimates for males and females. In these models, male is measured as 1 = yes and 0 = no and female is measured as 1 = yes and 0 = no. In the models that allow for one intercept, gender is included using effect coding -1 = female and 1 = male.

*Race.* Race is measured as a series of dichotomous variables for white (86 percent of all parents with slightly more parents of children with disabilities), African American (8 percent of all parents with slightly more parents of typical children), and other races (e.g., American Indians, Aleuts, Eskimos, Asians, Pacific Islanders, and those not previously specified) (6 percent of all parents with slightly more parents of typical children).

*Caregiving Demands.* To determine whether caregiving affects maternal employment, I created a dichotomous variable using responses from the following three questions: 1) Respondents who had a job during the reference period and worked less than 35 hours some weeks answered the following question: “There are weeks when ... worked less than 35 hours. What was the main reason...worked less than 35 hours in those weeks?”; 2) Those

who did not work during reference period answered: “Main reason ... did not have a job during the reference period.”; and 3) Respondents who worked during the reference period and were not contingent workers but whose job ended during the reference period answered: “What is the main reason ... stopped working for...?” The original response categories are not mutually exclusive and varied somewhat for the three questions above; however, they all included options that pertained to raising children. Since I am primarily interested in whether respondents’ work was affected by caregiving, I coded this variable as dichotomous (1 = yes) if any of the following criteria were met: respondents could not work because of pregnancy/childbirth or taking care of children/other persons; respondents could not work full-time because of taking care of children/other persons; or respondents had to end work because of childcare problems. If at least one of these criteria were not met, then the “work affected by caregiving” variable was coded as 0 = no. An equal percentage of mothers (28 percent) and fathers (1 percent) indicated that their employment was affected by caregiving demands.

### **Control Variables**

*Time-Invariant Predictor.* Personal disability has shown to be a strong predictor of employment (see Bureau of Labor Statistics 2011; Parish and Cloud 2006) so I include a dichotomous variable to measure whether parents have a disability (1 = yes, 0 = no) during the survey period using the disability index described in the Independent Variables section above. Thirty-three percent of mothers and 26 percent of fathers of children with disabilities have a disability, while only 16 percent of mothers and 14 percent of fathers with typical children have a disability.

*Time-Varying Predictor.* Farley (1995) and Furstenburg (2003) suggest that social class is the most important predictor of life course patterns and crosscuts any distinctions in gender and race/ethnicity while McCall (2011) points to the intersection of race and class in the continued racial gap in earnings. Family income was a significant predictor of maternal employment in the previous chapter. Since this chapter is based on a dyadic analysis, I control for average monthly personal income. Parents of children with disabilities have lower average personal incomes across all waves compared to parents with typical children. Mothers of children with disabilities have an average monthly personal income of \$1,624 and fathers average \$3,827 a month. In contrast, mothers of typical children earn on average \$1,738 a month with fathers averaging \$4,042 a month. See Table 3.2 for the descriptive statistics of all predictors.

### **Analysis**

Three different types of multilevel models are used in this analysis.<sup>4</sup> First, individual multilevel growth models are estimated using SAS PROC MIXED to determine if there are significant differences in employment hours by family type (i.e., having a child with disabilities and having a typical child). This is a useful approach for evaluating whether an outcome changes over time and how to predict differences in the changes (Singer and Willett 2003). In individual multilevel growth models, the level 1 model is used to depict the shape of each person's individual growth trajectory over time, while the level 2 model tests the

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<sup>4</sup> The analysis in this chapter is based on an unweighted sample. All continuous predictor variables are grand mean centered for the analysis.

relationship between predictors, and the individual growth trajectory and evaluates differences across individuals. The level 1 model can be written as:

$$Y_{ij} = b_{0i} + b_{1i} (TIME_{ij}) + e_{ij} \quad (1)$$

where  $Y_{ij}$  is individual  $i$ 's hours of employment on occasion  $j$ ,  $b_{0i}$  is the intercept of the true change trajectory,  $b_{1i}$  is the slope of the true change trajectory based on a specific temporal predictor  $TIME_{ij}$  measured as the actual wave in this analysis, and  $e_{ij}$  is the measurement error across all occasions for individual  $i$ . The level 2 equation can be written as:

$$b_{0i} = \gamma_{00} + \gamma_{01} CHILD\ WITH\ DISABILITIES + u_{0i} \quad (2)$$

and

$$b_{1i} = \gamma_{10} + \gamma_{11} CHILD\ WITH\ DISABILITIES + u_{1i} \quad (3)$$

where  $b_{0i}$  (intercept) and  $b_{1i}$  (slope) are treated as level 2 outcomes. Considered fixed effects,  $\gamma_{00}$  and  $\gamma_{10}$  are level 2 intercepts with  $\gamma_{01}$  and  $\gamma_{11}$  as level 2 slopes. Each component has its own residual,  $u_{0i}$  and  $u_{1i}$ , which allows the level 1 parameters of one person to differ from those of others (Singer and Willett 2003).

Secondly, dyadic multilevel growth models are estimated using SPSS19 Mixed. Extending the basic premises of individual multilevel growth models, dyadic multilevel growth models are useful in addressing whether a variable changes in a systematic way as a function of time; whether other factors (e.g., individual differences or contextual variables) moderate the degree of change over time; and whether the change over time is coordinated across the two related individuals. It is still a two-level model where level 1 refers to time or observation and level 2 is the dyad. Basically, each person is nested within a dyad and time is crossed with the person, not nested. Both members of the dyad have their own intercepts and

slopes which are often correlated across dyad members. The level 1 equation can be written as:

$$Y_{ijt} = b_{01j}M + b_{02j}F + b_{11j}M(TIME_t) + b_{11j}F(TIME_t) + Me_{1jt} + Fe_{1jt}. \quad (4)$$

The use of one equation allows for the modeling of non-independence due to dyad membership. The parts of equation 4 that represent the growth curves for mothers and fathers, respectively, are:

$$Y_{ijt} = b_{01j}M + b_{11j}M(TIME_t) + Me_{1jt} \quad (5)$$

and

$$Y_{ijt} = b_{01j}F + b_{11j}F(TIME_t) + Fe_{1jt} \quad (6)$$

where  $Y_{ijt}$  is each dyad members' (M = male and F = female) hours of employment on occasion  $t$ ,  $b_{01}$  is the intercept,  $TIME$  is measured as the actual wave of data collection, and  $b_{11}$  is the slope. Both slopes and intercepts may be random variables and may have variances and covariances (Kenny, Kashy and Cook 2006).

Lastly, the Actor-Partner Interdependence Model (APIM) for distinguishable dyads is used to test whether the severity of the child's disability affects parental employment (Hypothesis 2). APIM is used when one is interested in seeing whether both partners' value on an independent variable predicts a particular outcome. Individuals are nested within dyads in this multilevel model and the variability between and within dyads are considered. I use the two intercept approach (see Kenny, Kashy, and Cook 2006) where the equation for the lower level model is:

$$Y_{ij} = b_{1j}M + b_{2j}F \quad (7)$$

and the full lower model is:

$$Y_{ij} = b_{1j}M + b_{2j}F + b_{3j}M * ACaregive + b_{4j}F * ACaregive + b_{5j}M * PCaregive + b_{6j}F * PCaregive + e_{1j} + e_{2j}. \quad (8)$$

In this equation,  $Y_{ij}$  is each dyad members' (M = male and F = female) employment outcomes, and  $b_{1j}M$  and  $b_{2j}F$  are the intercepts for males and females, respectively. The slopes are denoted as  $b_{3j}M$  and  $b_{4j}F$  with ACaregive indicating whether the actor (or the individuals) employment was affected by caregiving while PCaregive indicates the effect of whether the partners' employment was affected by caregiving. For example,  $b_{5j}M * PCaregive$  is the partner effect for caregiving demands affecting maternal employment on the average hours per week worked by fathers while  $b_{6j}F * PCaregive$  is the partner effect for caregiving demands affecting paternal employment on mothers' hours worked per week. The residual variances, or unexplained variance, are denoted as  $e_{1j}$  for fathers and  $e_{2j}$  for mothers.

## RESULTS

### Individual Multilevel Growth Models

Three individual multilevel growth models are estimated to determine if there are differences between family types (i.e., have a child with disabilities and have a typically developing child) (see Table 3.3 and Figure 3.1). Model 1 includes the effect of a level 2 covariate (having a child with disabilities) on the average hours worked per week for all parents. The findings suggest that parents of children with disabilities work significantly less ( $p < .001$ ) average hours per week at entry into the study than parents of typical children. The slope estimate is significant for parents of typical children indicating that their predicted number of hours worked per week decreases over time ( $-0.194, p < .001$ ) while parents of children with disabilities have a more constant slope.

Model 2 examines differences between mothers similar to the analysis in Chapter 2. Mothers of typical children work 23.8 hours at entry into the study and have a significant rate of decrease ( $-0.113, p < .001$ ) while mothers of children with disabilities are work 2.44 ( $p < .001$ ) fewer hours a week than mothers of typical children; however, their slope estimate is insignificant. Model 3 predicts hours worked per week for fathers. Fathers of typical children are predicted to work an average of 36.576 hours a week with fathers of children with disabilities working 1.785 ( $p < .01$ ) hours less a week. The slope estimate is significant for fathers of typical children, indicating that their number of hours worked per week changes over time ( $-0.275, p < .001$ ) while fathers of children with disabilities have a more constant employment trajectory over time.

### **Dyadic Multilevel Growth Models**

Two different dyadic multilevel growth models are estimated separately for parents by their child's disability status to predict gender differences in average hours worked per week. Model 1 (Table 3.4) uses a two intercept approach and estimates fixed effect parameters for both mothers and fathers. The estimates are similar to the individual growth curve estimates in Models 2 and 3 in Table 3.3 and show that the intercepts for mothers and fathers in both groups are significantly different than zero and that the slope is significantly different from zero for all parents with the exception of mothers of children with disabilities (see Figures 2 and 3). Model 2 (Table 3.4) specifically tests whether the gender differences in the fixed effects are statistically significant. The findings indicate that fathers of children with disabilities ( $6.728, p < .001$ ) and fathers of typical children ( $6.392, p < .001$ ) have significantly higher rates of employment at entry into the study than mothers. The slope

estimates predict a significant negative trajectory over time, which is moderated by gender for parents of typical children, but not for parents of children with disabilities. Thus, gender does not account for the change over time in employment for parents of children with disabilities. The correlation between residuals (CSH rho) is non-significant and the random effects for Models 1 and 2 (Table 3.4) are all significant suggesting that there are amounts of variation associated with initial rates and change over time across and within dyads that could potentially be predicted with the addition of other predictors.

Table 3.5 illustrates that the inclusion of race is non-significant or only minimally significant in most instances (see Figures 3.4 and 3.5). The initial status and rate of change for white parents is significantly different from zero, and including fathers in the analysis shows no statistically significant differences by race between white and African American couples in their average hours worked per week. Tables 3.6 and 3.7 show the effects of caregiving on the average hours worked per week. The coefficient estimates for caregiving are significantly different than zero at entry into the study for all parents. The models in Table 3.6 predict that mothers of children with disabilities have a greater reduction in hours (-11.580,  $p < .001$ ) because of caregiving than fathers of children with disabilities (-9.174,  $p < .001$ ). The opposite is true for parents of typical children with fathers' hours reduced more (-15.569,  $p < .001$ ) than mothers' (-12.648,  $p < .001$ ). These patterns remain after removing race from the analysis and controlling for personal income and personal disability. In Tables 3.6 and 3.7, partners' caregiving increases the hours worked for each parent. Further, caregiving does not mediate the effect of gender on hours worked over time for parents of children with disabilities or fathers of typical children. However, it is minimally significant

for mothers of typical children. The addition of caregiving and the control variables in Table 3.7 improves the overall fit of the data. However, the correlation between residuals (CSH rho) is non-significant and the random effects are significant for both family types, suggesting that there are amounts of variation associated with initial rates and change over time across and within dyads that could potentially be predicted with the addition of other predictors.

### **Actor-Partner Interdependence Models**

An Actor-Partner Interdependence Model is used to evaluate whether the severity of the child's disability increases the difference in paid work hours for parents of children with disabilities. The questions used to measure the severity of the child's disability were only asked at Waves 5 and 8, making multilevel modeling over time inappropriate. However, multilevel models can still be used to estimate the effects at each wave (see Table 3.8). There are no significant racial differences in main effects at Wave 5. At Wave 8, mothers of "other races" work 13.159 ( $p < .05$ ) more hours than white mothers and fathers of "other races" work 10.196 ( $p < .05$ ) fewer hours than white fathers. No statistically significant differences were found between white and African American parents in their hours worked per week. The severity of the child's disability is not a significant predictor for mothers, but it is for white fathers ( $-0.704$ ,  $p < .001$ ) at both waves, indicating that they reduce their hours of employed as the severity of the disability increases. The correlation of the residuals (CSH rho) is statistically significant, indicating that there is still considerable similarity in hours worked at each wave for parents of children with disabilities.

## **DISCUSSION**

Chapter 2 focused specifically on mothers and demonstrated that mothers of children with disabilities have lower rates of employment over time than mothers with typical children, and that this effect varies by race. I speculated that the findings may be a result of the paid work or carework contributions of fathers. In this chapter, I extend these findings to include fathers' employment and control for the interdependency of employment trajectories within families. My analysis is based on a family life course development perspective to illustrate the interconnectedness of individual lives within families (Elder 1994; White and Klein 2002).

### **Differences in Hours Worked by Gender and Race**

I hypothesized that the difference in paid works hours between mothers and fathers of children with disabilities is higher compared to mothers and fathers with typical children, and that this varies by race. The descriptive statistics presented in Table 3.1 demonstrate that there are differences in the hours worked by mothers and fathers. The findings from Tables 3.3 and 3.4 support the notion that families of children with disabilities have different employment trajectories than families with typical children, as well as there being gender differences across and within family types. Mothers of children with disabilities have the lowest rates of employment of all parents in the sample, which is consistent with Chapter 2 and previous research on mothers of children with disabilities (e.g., Lefley 1997; Porterfield 2002; Powers 2003; Seltzer and Heller 1997). Further, comparing coefficient estimates shows that the gap in paid hours between mothers and fathers of children with disabilities is larger than the differences for mothers and fathers of typical children. Upon closer

examination, this gap in employment between parents of children with disabilities is primarily referring to white parents who have a difference of 14.5 hours of employment, whereas African American parents have a difference of 9.5 hours. While gender is a significant predictor of employment at entry into the study for all parents, it does not predict employment over time for parents of children with disabilities. It may be that fathers reduce their paid employment over time as a way to alleviate maternal stress associated with caregiving especially if the child has a more severe disability.

The findings in Chapter 2 show that African American mothers of children with disabilities work more initial hours than other mothers in the sample while mothers of other race with children with disabilities work the fewest initial hours. While there is variation in employment trajectories by race for parents of children with disabilities, the findings from the dyadic multilevel growth models do not provide much support for statistically significant gender differences by race within or across family types (see Figures 3.4 and 3.5). This is likely due to the inclusion of partner effects and a different measure of time used in this analysis. In Chapter 2, a centered age variable was used as the measure of time which places the respondents on a common initial age-based status as their entry point into the study. In this chapter, the baseline is based on the time (or wave) of data collection and does not consider the age of respondents. Using a centered variable versus a non-centered variable does change the estimates on the intercept, but does not affect the rate of change over time.

I hypothesized that the severity of the child's disability increases the difference in paid work hours for parents of children with disabilities. It is costly to care for children with severe disabilities who may need specialized medical equipment and services (Leiter et al.

2004; Parish and Cloud 2006). This not only places a financial burden on families, but takes an enormous amount of time to coordinate care and services. My findings in this chapter for mothers is consistent with my findings in Chapter 2, suggesting that the severity of the disability does not significantly affect maternal work hours since women are more likely to work fewer hours than their spouses. However, it does significantly reduce hours for white fathers at Wave 5 and 8. As previously mentioned, the gap in paid work hours is the largest among white couples with white fathers reducing their employment when the nature of the disability requires more caregiving.

### **Caregiving and Paid Employment**

I hypothesized that mothers of children with disabilities are more likely to reduce their hours of paid employment because of caregiving demands than fathers of children with disabilities and parents of typical children. After including caregiving in the models, mothers of children with disabilities still work fewer hours than other parents and their work hours are affected more than the fathers of children with disabilities. For families of children with disabilities, caregiving is still constructed in relation to a dominant ideology of intensive mothering and is likely due to exceptional caregiving needs (Leiter et al. 2004; Traustadottir 1991) while men's contributions are still primarily economic (Lewis et al. 2000).

The findings in Tables 3.6 and 3.7 suggest that fathers of typical children are the ones who see the largest reduction in hours when their work is affected by caregiving followed by mothers of typical children. Brandth and Kvande (1998) contend that fatherhood is a new way for men to demonstrate their masculinity by integrating childcare into their work identities. This may be indicative of what Shows and Gerstel (2009) refer to as "private

fatherhood” or the actual daily care of children. On the other hand, it is important to note that fathers of typical children also work the most hours each week. Even with a reduction in their hours, they are still working more than most of the other parents in the sample. The question remains as to how much caregiving actually affected their paid work.

### **Conclusion**

The overall findings in this chapter are consistent with Lewis et al.’s (2000) qualitative research that suggests families adapt to the caregiving needs of their children. However, maternal employment is still more likely to be affected by caregiving with dominant ideologies about intensive mothering lingering on even after considering paternal contributions. The analysis in this chapter does not consider other relevant factors that may influence the decision-making process and subsequent strategies that parents use to balance caregiving and paid employment. For example, a closer examination of the type of employment and job quality would benefit this analysis since it is intrinsically linked to caregiving strategies (Lewis et al. 2000). Acker (1990) suggests that organizations and workplaces are gendered, which contributes to the conception of the universal male worker. Women are often perceived as having less organizational commitment because of family obligations (Marsden, Kalleberg, and Cook 1993). Webber and Williams (2008) found that women use part-time work as a temporary solution to childcare responsibilities. Parents of children with disabilities, in particular, need employment that allows for flexibility in scheduling, the ability to take time off for doctors’ appointments or emergency situations, and extended family leave policies. However, workers do not always make use of these available work arrangements due to the larger organizational culture and workers’ fear of

informal sanctions (Malsch et al. 2008). This is may be particularly heightened for mothers who want to avoid the “mommy track” and the wage penalty for motherhood (Budwig and England 2001; Crittenden 2001).

Secondly, I am unable to control for the type of childcare used because these questions were only asked in one wave of data. Nor do I account for the extent of social networks or community supports available to parents. Even with the passing of the Individuals with Disabilities Education Act, center-based childcare and appropriate educational settings are often difficult to find for children with physical, mental, sensory, or developmental challenges. This leaves private care workers, family-based care by either a parent or another family member, or nonstandard work schedules by both parents (Lewis et al. 2000). To maintain employment, parents often have to rely on their social networks to weave together an array of formal and informal childcare arrangements and community-based services. Conversely, these supports also help families deal with the stress of having children with exceptional caregiving needs.

In the next chapter, I consider whether employment mediates the relationship between caring for children with disabilities and poor mental health outcomes. Previous research (e.g., Romans-Clarkson et al. 1986; Thyen, Kuhlthau, and Perrin 1999) found that employment was a significant predictor of mental health especially for mothers of children with disabilities. In their qualitative research, Lewis et al. (2000) found that mothers often spoke of the psychological benefits associated with work while fathers did not. As such, I draw on Pearlin et al.’s(1990) stress process model to examine how the effects may be different for

mothers and fathers and compare across family types (e.g., having a child with disabilities versus having a typically developing child).

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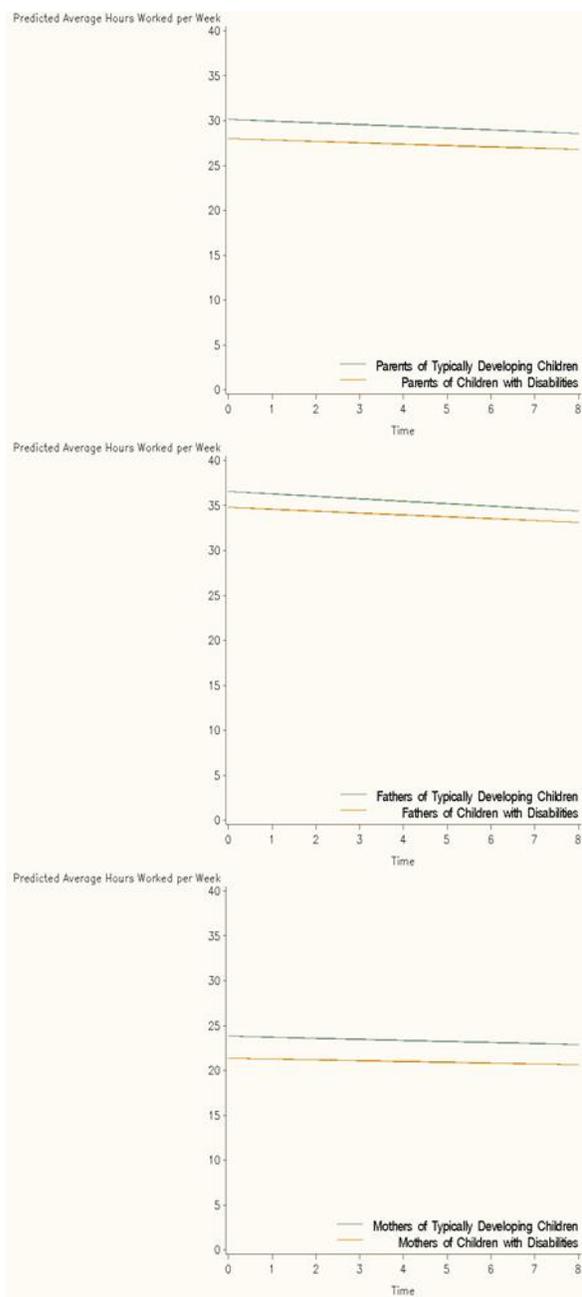
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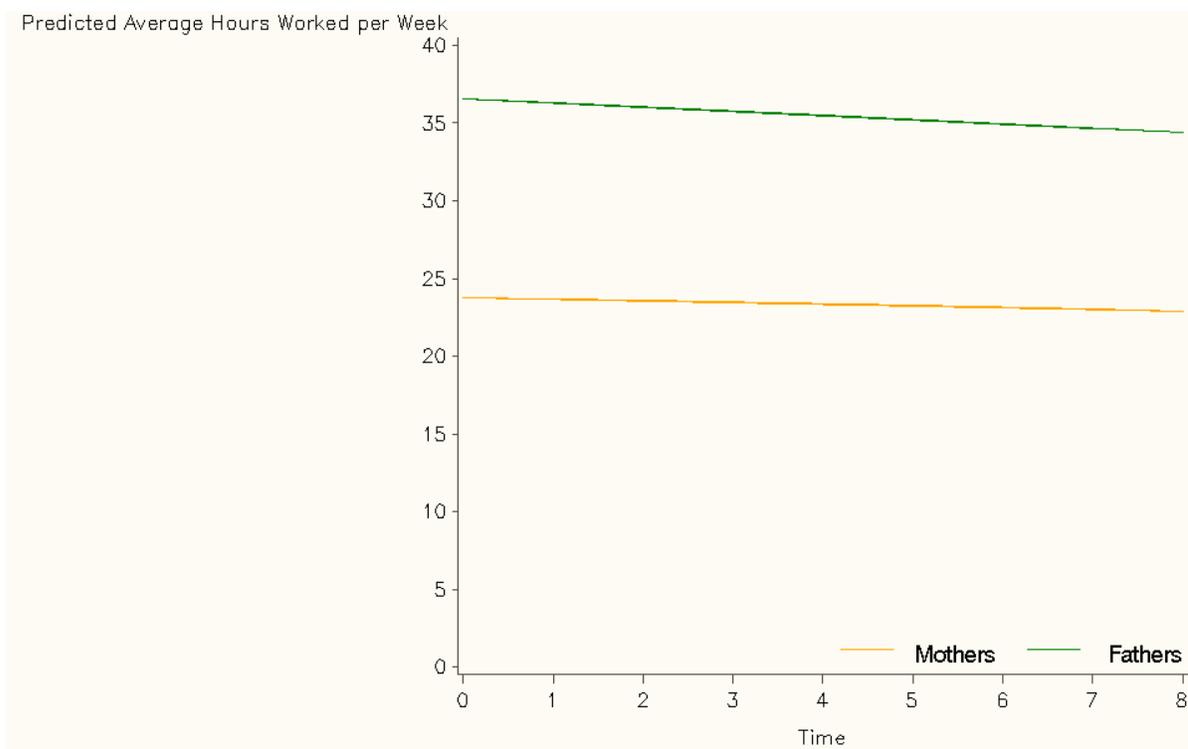
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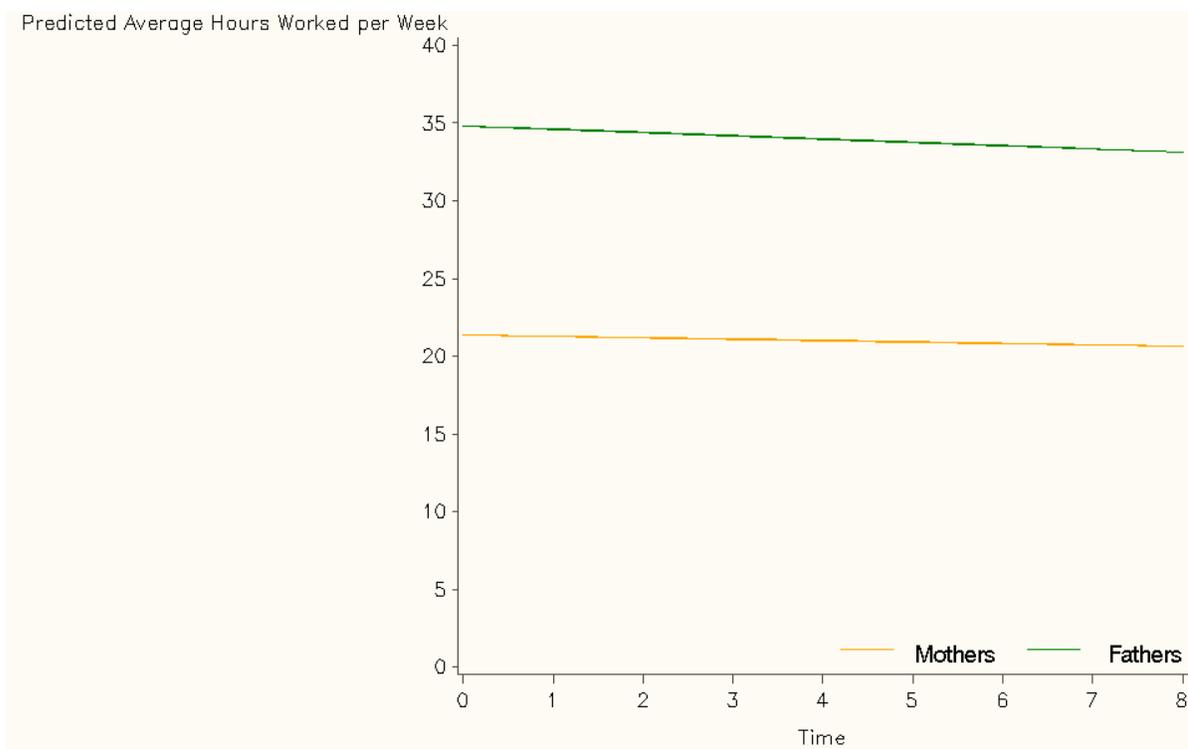
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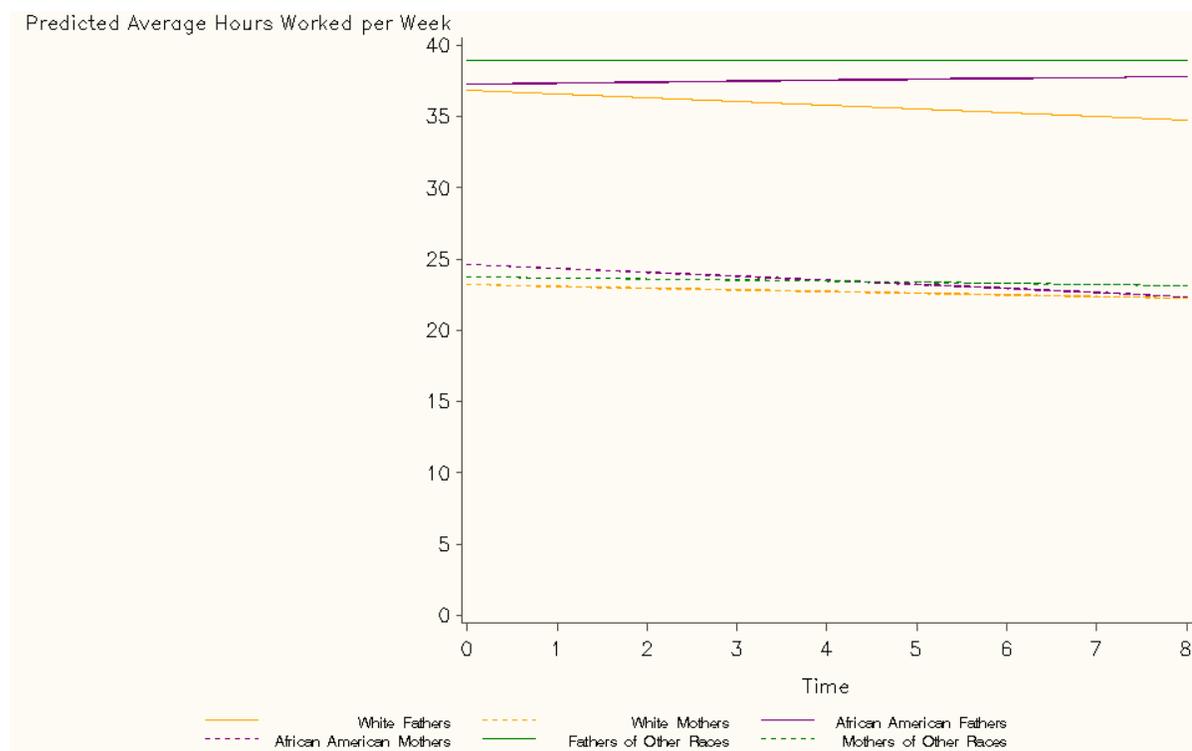
**Figure 3.1 Individual Linear Growth Models Predicting Average Hours Worked per Week for Parents**



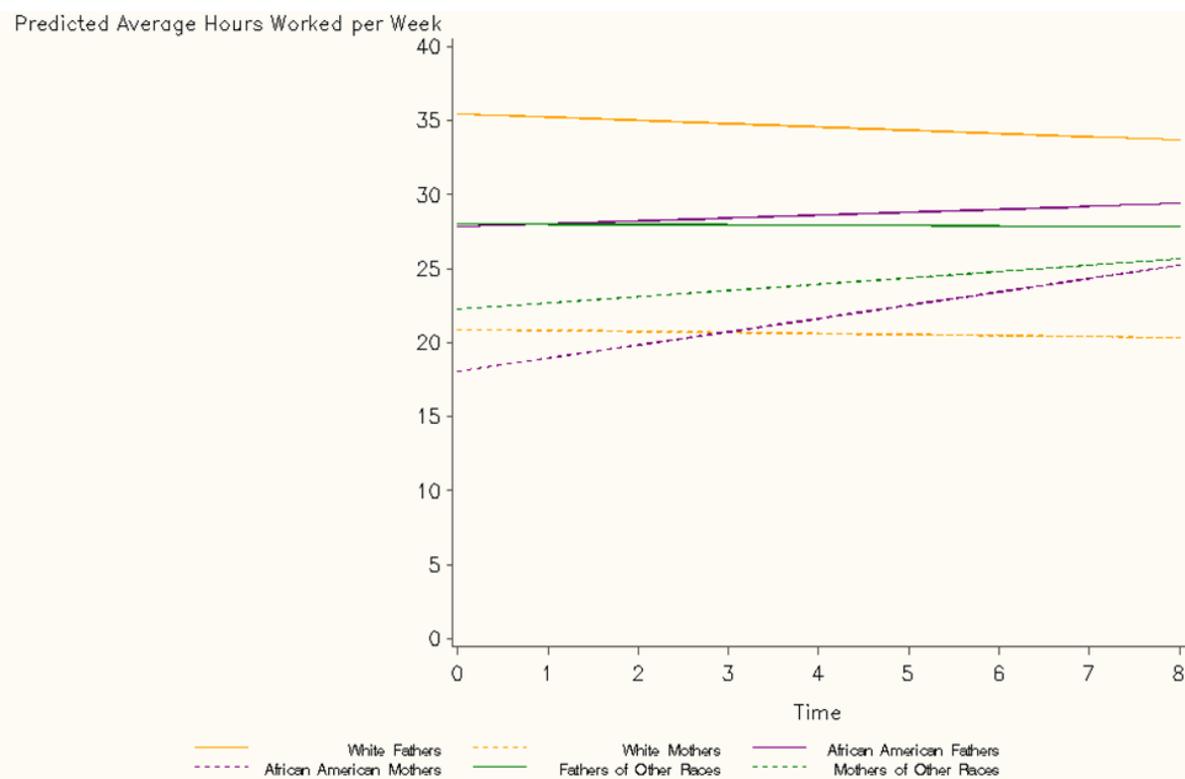
**Figure 3.2 Dyadic Linear Growth Model Predicting Gender Differences in Average Hours Worked per Week for Parents with Typically Developing Children**



**Figure 3.3 Dyadic Linear Growth Model Predicting Gender Differences in Average Hours Worked per Week for Parents of Children with Disabilities**



**Figure 3.4 Dyadic Multilevel Growth Model Predicting Average Hours Worked per Week by Race for Parents with Typically Developing Children, Controlling for Partners' Work Hours**



**Figure 3.5 Dyadic Multilevel Growth Model Predicting Average Hours Worked per Week by Race for Parents of Children with Disabilities, Controlling for Partners' Work Hours**

**Table 3.1. Average Hours Worked per Week across Waves for Mothers and Fathers in Two-Parent Households**

	Parents of Children with Disabilities		Parents of Typical Children	
	Mothers	Fathers	Mothers	Fathers
Wave 1	21.64 <i>21.39</i> [0-90] <i>N=1,067</i>	35.03 <i>22.45</i> [0-99] <i>N=1,035</i>	24.25 <i>20.38</i> [0-99] <i>N=4,422</i>	36.68 <i>21.15</i> [0-99] <i>N=4,357</i>
Wave 2	21.73 <i>21.02</i> [0-90] <i>N=1,065</i>	34.86 <i>21.96</i> [0-96] <i>N=1,025</i>	24.25 <i>20.54</i> [0-99] <i>N=4,430</i>	36.86 <i>21.05</i> [0-99] <i>N=4,335</i>
Wave 3	20.55 <i>21.23</i> [0-99] <i>N=1,066</i>	34.54 <i>22.69</i> [0-99] <i>N=1,027</i>	23.53 <i>20.56</i> [0-99] <i>N=4,521</i>	35.59 <i>21.01</i> [0-99] <i>N=4,442</i>
Wave 4	20.73 <i>20.83</i> [0-94] <i>N=1,086</i>	33.84 <i>22.16</i> [0-99] <i>N=1,058</i>	23.04 <i>20.32</i> [0-95] <i>N=4,657</i>	35.38 <i>20.92</i> [0-99] <i>N=4,593</i>
Wave 5	20.64 <i>20.84</i> [0-90] <i>N=1,134</i>	33.48 <i>22.10</i> [0-99] <i>N=1,111</i>	22.94 <i>20.27</i> [0-95] <i>N=4,880</i>	35.31 <i>21.30</i> [0-99] <i>N=4,089</i>
Wave 6	20.52 <i>20.46</i> [0-96] <i>N=1,113</i>	33.84 <i>22.23</i> [0-99] <i>N=1,091</i>	23.32 <i>20.40</i> [0-96] <i>N=4,738</i>	35.46 <i>21.13</i> [0-99] <i>N=4,682</i>
Wave 7	20.96 <i>21.03</i> [0-85] <i>N=1,100</i>	33.32 <i>22.12</i> [0-92] <i>N=1,074</i>	23.15 <i>20.11</i> [0-92] <i>N=4,732</i>	34.85 <i>20.96</i> [0-99] <i>N=4,667</i>
Wave 8	20.47 <i>20.55</i> [0-85] <i>N=1,130</i>	33.69 <i>22.52</i> [0-99] <i>N=1,105</i>	23.05 <i>20.25</i> [0-90] <i>N=4,840</i>	34.72 <i>21.12</i> [0-99] <i>N=4,773</i>
Wave 9	20.83 <i>20.58</i> [0-84] <i>N=1,052</i>	33.68 <i>22.59</i> [0-99] <i>N=1,032</i>	23.18 <i>20.27</i> [0-95] <i>N=4,521</i>	34.84 <i>21.28</i> [0-99] <i>N=4,442</i>

*Notes* : Standard deviations are in *italics* and ranges are in []. *Source* : Survey of Income and Program Participation 2001-2003.

**Table 3.2. Descriptive Statistics for Variables Used to Estimate the Average Hours Worked per Week in Two-Parent Households (N=6,168 Dyads)**

	All Parents	Parents of Children with Disabilities			Parents of Typical Children		
	(N=12,208)	Both (N=2,321)	Mothers (N=1,180)	Fathers (N=1,141)	Both (N=9,887)	Mothers (N=4,985)	Fathers (N=4,902)
<i>Time-Invariant Predictors</i>							
White (Ref Category)	86.04% <i>0.347</i>	88.51% <i>0.319</i>	88.47% <i>0.319</i>	88.55% <i>0.318</i>	85.46% <i>0.352</i>	85.37% <i>0.353</i>	85.56% <i>0.351</i>
African American	7.89% <i>0.270</i>	6.90% <i>0.253</i>	6.88% <i>0.253</i>	6.92% <i>0.254</i>	8.12% <i>0.273</i>	7.96% <i>0.271</i>	8.28% <i>0.276</i>
Other Races	6.07% <i>0.239</i>	4.59% <i>0.209</i>	4.65% <i>0.211</i>	4.53% <i>0.208</i>	6.42% <i>0.245</i>	6.67% <i>0.250</i>	6.16% <i>0.240</i>
Parental Disability Status	17.81% <i>0.383</i>	29.53% <i>0.456</i>	33.18% <i>0.471</i>	25.79% <i>0.438</i>	15.06% <i>0.358</i>	16.42% <i>0.370</i>	13.69% <i>0.344</i>
<i>Time-Varying Predictors</i>							
Monthly Income	2,849.10 <i>3,564.08</i> [0-64,728]	2,711.45 <i>3,493.02</i> [0-63,158]	1,624.79 <i>2,220.28</i> [0-30,226]	3,827.10 <i>4,148.58</i> [0-63,158]	2,881.28 <i>3,579.75</i> [0-64,728]	1,738.28 <i>2,322.55</i> [0-64,728]	4,042.11 <i>3,062.00</i> [0-58,114]
Caregiving	14.74% <i>0.355</i>	14.87% <i>0.356</i>	28.04% <i>0.449</i>	1.34% <i>0.115</i>	14.71% <i>0.354</i>	28.10% <i>0.449</i>	1.11% <i>0.105</i>
Severity of Child Disability	N/A	1.912 <i>3.622</i> [0-27]	1.908 <i>3.609</i> [0-27]	1.916 <i>3.636</i> [0-27]	N/A	N/A	N/A

*Notes* : Table values for the category of “All Parents” are grand means or percentages. Table values for the categories under “Parents of Children with Disabilities” and “Parents of Typical Children” are group means or percentages. Standard deviations are in *italics* and ranges are in []. *Source* : Survey of Income and Program Participation 2001-2003.

**Table 3.3. Individual Multilevel Growth Models Predicting Differences in Average Hours Worked per Week in Two-Parent Households (N=12,208)**

	<u>Model 1</u>	<u>Model 2</u>	<u>Model 3</u>
	Both Parents	Mothers Only	Fathers Only
<i>Fixed Effects (on the intercept)</i>			
Intercept (Initial status)	30.145 *** (0.212)	23.804 *** (0.281)	36.576 *** (0.290)
Have Disabled Child	-2.157 *** (0.487)	-2.440 *** (0.644)	-1.785 ** (0.667)
<i>Fixed Effects (on the slope)</i>			
Wave (Rate of change)	-0.194 *** (0.024)	-0.113 *** (0.033)	-0.275 *** (0.034)
Have Disabled Child	0.042 (0.054)	0.023 (0.075)	0.066 (0.078)
Level 1: Within-person	89.704 *** (0.456)	79.896 *** (0.572)	99.671 *** (0.719)
Level 2: Intercept	407.62 *** (5.692)	360.58 *** (7.109)	371.36 *** (7.493)
In rate of change	3.536 *** (0.072)	3.595 *** (0.099)	3.455 *** (0.105)
-2 Log Likelihood	806011.7	400983.8	403228.5

Notes: REML, SAS Proc Mixed. The results are unweighted. Numbers in parentheses are standard errors. \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ . Source: Survey of Income and Program Participation

**Table 3.4. Dyadic Multilevel Growth Models Predicting Gender Differences in Average Hours Worked per Week in Two-Parent Households (N=6,168 Dyads)**

	Parents of Children with Disabilities		Parents of Typical Children	
	Model 1	Model 2	Model 1	Model 2
<i>Fixed Effects (on the intercept)</i>				
Intercept (Initial Status)		28.097 *** (0.458)		30.192 *** (0.204)
Gender		6.728 *** (0.416)		6.392 *** (0.195)
Mothers	21.369 *** (0.560)		23.800 *** (0.278)	
Fathers	34.826 *** (0.636)		36.584 *** (0.285)	
<i>Fixed Effects (on the slope)</i>				
Time (Rate of Change)		-0.151 ** (0.048)		-0.193 *** (0.023)
Gender		-0.061 (0.050)		-0.082 *** (0.023)
Mothers	-0.090 (0.069)		-0.111 *** (0.033)	
Fathers	-0.212 ** (0.070)		-0.276 *** (0.034)	
-2 Log Likelihood	152974.476	152977.248	651630.406	651633.178
<i>Random Effects</i>				
For Mothers:				
Variance of Intercepts	386.504 *** (17.494)		354.565 *** (7.763)	
Variance of Slopes	3.677 *** (0.237)		3.583 *** (0.109)	
Variance of Residuals	85.102 *** (1.399)		78.647 *** (0.625)	
For Fathers:				
Variance of Intercepts	422.844 *** (19.357)		358.901 *** (8.071)	
Variance of Slopes	3.568 *** (0.250)		3.441 *** (0.115)	
Variance of Residuals	97.446 *** (1.626)		100.269 *** (0.805)	
CSH rho	0.013 (0.012)		0.001 (0.006)	

Notes: REML, SPSS19 Mixed. The results are unweighted. Numbers in parentheses are standard errors. \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ . Source: Survey of Income and Program Participation 2001-2003.

**Table 3.5. Dyadic Multilevel Growth Models Predicting Gender and Race Differences in Average Hours Worked per Week in Two-Parent Households (N=6,168 Dyads)**

	Parents of Children with Disabilities				Parents of Typical Children			
	Mothers		Fathers		Mothers		Fathers	
<i>Fixed Effects (on the intercept)</i>								
Intercept (Initial Status)	20.905 ***	(0.653)	35.461 ***	(0.679)	23.205 ***	(0.305)	36.808 ***	(0.310)
Black (Self)	-2.874	(5.544)	-7.637	(5.731)	1.453	(2.653)	0.470	(2.640)
Black (Partner)	7.563	(5.513)	2.998	(5.759)	4.873 †	(2.598)	-0.313	(2.692)
Other Races (Self)	1.322	(4.401)	-7.478	(4.691)	0.574	(2.119)	2.121	(2.250)
Other Races (Partner)	-2.060	(4.502)	0.331	(4.587)	0.407	(2.214)	-5.506 *	(2.156)
<i>Fixed Effects (on the slope)</i>								
Wave (Rate of Change)	-0.072	(0.074)	-0.221 **	(0.075)	-0.119 ***	(0.035)	-0.257 ***	(0.037)
Black (Self)	0.970	(0.619)	0.417	(0.623)	-0.166	(0.315)	0.326	(0.321)
Black (Partner)	-1.181 †	(0.616)	-0.400	(0.626)	0.206	(0.309)	-0.585 †	(0.328)
Other Races (Self)	0.500	(0.504)	0.207	(0.524)	0.040	(0.247)	0.254	(0.267)
Other Races (Partner)	-0.539	(0.513)	-0.020	(0.514)	-0.025	(0.257)	-0.230	(0.256)
-2 Log Likelihood	150917.347				646221.06			
<i>Random Effects</i>								
Variance of Intercepts	388.742 ***	(17.906)	420.691 ***	(19.300)	352.049 ***	(7.776)	358.226 ***	(8.060)
Variance of Slopes	3.695 ***	(0.241)	3.583 ***	(0.251)	3.539 ***	(0.108)	3.438 ***	(0.115)
Variance of Residuals	84.865 ***	(1.414)	97.446 ***	(1.626)	78.061 ***	(0.625)	100.265 ***	(0.802)
CSH rho	0.015		(0.012)		0.001		(0.006)	

Notes: REML, SPSS19 Mixed. The results are unweighted. Numbers in parentheses are standard errors. † $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ . Source: Survey of Income and Program Participation 2001-2003.

**Table 3.6. Dyadic Multilevel Growth Models Predicting Gender and Race Differences in Average Hours Worked per Week Due to Caregiving Responsibilities in Two-Parent Households (N=6,168 Dyads)**

	Parents of Children with Disabilities				Parents of Typical Children			
	Mothers		Fathers		Mothers		Fathers	
<i>Fixed Effects (on the intercept)</i>								
Intercept (Initial Status)	24.392 ***	(0.608)	35.191 ***	(0.698)	27.072 ***	(0.269)	36.740 ***	(0.321)
Black (Self)	-3.224	(4.955)	-7.547	(5.688)	0.276	(2.244)	0.368	(2.618)
Black (Partner)	6.176	(4.927)	3.179	(5.716)	4.102 †	(2.197)	-0.226	(2.671)
Other Races (Self)	1.505	(3.933)	-7.609	(4.656)	0.288	(1.790)	2.345	(2.232)
Other Races (Partner)	-2.296	(4.023)	0.507	(4.552)	0.162	(1.870)	-5.581 **	(2.138)
Caregiving (Self)	-11.580 ***	(0.556)	-9.174 ***	(1.801)	-12.648 ***	(0.260)	-15.569 ***	(0.976)
Caregiving (Partner)	3.281 *	(1.638)	1.470 *	(0.604)	3.445 ***	(0.848)	0.932 **	(0.300)
<i>Fixed Effects (on the slope)</i>								
Wave (Rate of Change)	-0.109	(0.076)	-0.165 *	(0.083)	-0.211 ***	(0.036)	-0.271 ***	(0.041)
Black (Self)	0.871	(0.569)	0.411	(0.619)	-0.077	(0.287)	0.379	(0.319)
Black (Partner)	-1.029 †	(0.566)	-0.419	(0.620)	0.203	(0.281)	-0.621 †	(0.326)
Other Races (Self)	0.415	(0.464)	0.200	(0.519)	-0.002	(0.224)	0.234	(0.265)
Other Races (Partner)	-0.459	(0.472)	-0.019	(0.509)	0.076	(0.234)	-0.212	(0.254)
Caregiving (Self)	-0.035	(0.118)	0.150	(0.453)	0.171 **	(0.055)	0.242	(0.232)
Caregiving (Partner)	-0.301	(0.412)	-0.245 †	(0.131)	-0.546 **	(0.200)	0.012	(0.063)
-2 Log Likelihood	149816.090				641043.811			
<i>Random Effects</i>								
Variance of Intercepts	306.038 ***	(14.630)	413.938 ***	(19.046)	244.127 ***	(5.822)	352.366 ***	(7.938)
Variance of Slopes	2.996 ***	(0.203)	3.482 ***	(0.247)	2.748 ***	(0.090)	3.396 ***	(0.114)
Variance of Residuals	78.600 ***	(1.313)	97.167 ***	(1.622)	73.324 ***	(0.592)	98.806 ***	(0.791)
CSH rho	0.014		(0.012)		0.004		(0.006)	

Notes: REML, SPSS19 Mixed. The results are unweighted. Numbers in parentheses are standard errors. † $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ . Source: Survey of Income and Program Participation 2001-2003.

**Table 3.7. Dyadic Multilevel Growth Models Predicting Gender Differences in Average Hours Worked per Week in Two-Parent Households with Relevant Control Variables (N=6,168 Dyads)**

	Parents of Children with Disabilities				Parents of Typical Children			
	Mothers		Fathers		Mothers		Fathers	
<i>Fixed Effects (on the intercept)</i>								
Intercept (Initial Status)	28.580 ***	(0.679)	37.023 ***	(0.826)	30.359 ***	(0.266)	37.722 ***	(0.333)
Caregiving (Self)	-10.971 ***	(0.557)	-8.689 ***	(1.800)	-11.686 ***	(0.263)	-14.721 ***	(0.971)
Caregiving (Partner)	3.141 †	(1.609)	1.452 *	(0.617)	2.266 **	(0.834)	0.681 *	(0.309)
Monthly Income (Self)	0.002 ***	(0.000)	0.000 ***	(0.000)	0.002 ***	(0.000)	0.001 ***	(0.000)
Monthly Income (Partner)	-0.000 **	(0.000)	0.000	(0.000)	-0.000 ***	(0.000)	-0.000 **	(0.000)
Disabled (Self)	-4.896 ***	(1.099)	-8.883 ***	(1.448)	-3.397 ***	(0.604)	-11.084 ***	(0.819)
Disabled (Partner)	-0.474	(1.179)	-2.087	(1.348)	-1.278 *	(0.650)	-2.610 ***	(0.760)
<i>Fixed Effects (on the slope)</i>								
Wave (Rate of Change)	-0.034	(0.089)	-0.057	(0.100)	-0.220 ***	(0.037)	-0.269 ***	(0.044)
Caregiving (Self)	0.005	(0.119)	0.156	(0.451)	0.108 †	(0.056)	0.247	(0.230)
Caregiving (Partner)	-0.333	(0.405)	-0.261 †	(0.135)	-0.358 †	(0.197)	0.026	(0.066)
Monthly Income (Self)	0.000	(0.000)	0.000	(0.000)	-0.000 ***	(0.000)	-0.000	(0.000)
Monthly Income (Partner)	0.000 *	(0.000)	-0.000	(0.000)	0.000	(0.000)	0.000	(0.000)
Disabled (Self)	-0.147	(0.135)	-0.459 **	(0.163)	-0.481 ***	(0.079)	-0.309 **	(0.099)
Disabled (Partner)	-0.295 *	(0.145)	-0.015	(0.152)	0.166 †	(0.085)	0.061	(0.092)
-2 Log Likelihood	149197.048				637929.232			
<i>Random Effects</i>								
Variance of Intercepts	250.162 ***	(12.390)	389.182 ***	(17.983)	203.667 ***	(4.983)	331.692 ***	(7.501)
Variance of Slopes	2.650 ***	(0.186)	3.302 ***	(0.238)	2.450 ***	(0.082)	3.334 ***	(0.112)
Variance of Residuals	76.186 ***	(1.276)	96.236 ***	(1.608)	71.226 ***	(0.576)	97.107 ***	(0.778)
CSH rho	0.013		(0.012)		0.005		(0.006)	

Notes: REML, SPSS19 Mixed. The results are unweighted. Numbers in parentheses are standard errors. † $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ . Source: Survey of Income and Program Participation 2001-2003.

**Table 3.8. Actor-Partner Interdependence Model Predicting Gender Differences in the Effect of the Severity of a Child's Disability on Average Hours Worked per Week in Two-Parent Households**

	Wave 5 (N=1,111 Dyads)				Wave 8 (N=1,105 Dyads)			
	Mothers		Fathers		Mothers		Fathers	
<i>Actor Effects</i>								
Intercept	31.484 ***	(0.783)	35.037 ***	(0.995)	30.782 ***	(0.763)	35.622 ***	(0.993)
African American	0.988	(7.868)	-1.677	(5.728)	-1.688	(7.730)	0.945	(5.762)
Other Races	6.233	(6.287)	-3.501	(4.673)	13.159 *	(6.123)	-10.196 *	(4.652)
Severity of Child Disability	0.347	(0.215)	-0.704 ***	(0.186)	0.257	(0.222)	-0.593 **	(0.189)
Sev Child Dis*African American	-1.017	(2.204)	-2.706	(2.730)	0.587	(2.224)	4.504	(2.759)
Sev Child Dis*Other Races	-1.994	(1.627)	-4.116 †	(2.113)	-0.750	(1.325)	-0.718	(1.838)
Caregiving	-18.199 ***	(1.165)	-15.139 *	(6.155)	-17.043 ***	(1.200)	-14.929 *	(7.290)
Monthly Income	0.003 ***	(0.000)	0.001 ***	(0.000)	0.003 ***	(0.000)	0.001 ***	(0.000)
Disabled	-4.976 ***	(1.105)	-10.088 ***	(1.505)	-5.167 ***	(1.088)	-12.090 ***	(1.525)
<i>Partner Effects</i>								
African American	2.383	(7.875)	-0.675	(5.754)	3.764	(7.753)	-2.123	(5.840)
Other Races	-0.265	(6.262)	-5.012	(4.585)	-9.313	(6.103)	5.124	(4.590)
Sev Child Dis*African American	0.657	(2.149)	2.166	(2.799)	-0.899	(2.119)	-4.914 †	(2.894)
Sev Child Dis*Other Races	3.058 †	(1.663)	4.553 *	(2.067)	2.179	(1.412)	-0.075	(1.725)
Caregiving	2.023	(4.845)	3.632 *	(1.480)	9.373 †	(5.600)	2.153	(1.562)
Monthly Income	-0.000 **	(0.000)	-0.001 †	(0.000)	0.000	(0.000)	-0.000	(0.000)
Disabled	-1.024	(1.185)	-1.390	(1.404)	-2.463 *	(1.171)	-1.408	(1.417)
-2 Log Likelihood	19232.7				19081.879			
<i>Random Effects</i>								
Variance of Residuals	274.291 ***	(11.722)	442.567 ***	(18.914)	260.345 ***	(11.157)	441.173 ***	(18.906)
CSH rho	0.184 ***		(0.029)		0.138 ***		(0.030)	

Notes: REML, SPSS19 Mixed. The results are unweighted. Numbers in parentheses are standard errors. † $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ .

Source: Survey of Income and Program Participation 2001-2003.

## **CHAPTER 4 (STUDY 3): PSYCHOLOGICAL DISTRESS IN PARENTS OF CHILDREN WITH DISABILITIES**

Parents of children with disabilities often find intense personal satisfaction and show signs of positive adaptation to their caregiving roles (Kearney and Griffin 2001; Summers, Behr, and Turnbull 1989). Many parents even become disability activists (Blum 2007; Griffith et al. 2011; Litt 2004; Traustadottir 1991). However, some parents also report a “caregiver burden” or physical, psychological and social consequences of taking care of a child with disabilities (Paúl and Martin 2003). Specifically, research shows that the extraordinary caregiving needs of children with disabilities affects employment (Porterfield 2002; Powers 2003) and mental health (Dyson 1993, 1997; Friedrich and Friedrich 1981; Kazak and Marvin 1984; Keller and Hnog 2004; Sloper and Turner 1993). Studies have found that many parents of children with disabilities, and mothers in particular, report high levels of psychological distress associated with their caregiving roles (e.g., Breslau, Staruch, and Mortimer 1982; Erikson and Upshur 1989; Freidrich, Wilturner, and Cohen 1985; Johnson, O’Reilly, and Vostanis 2006; Leonard, Johnson, and Brust 1993; McKinney and Peterson 1985).

Why do some caregivers fare worse than others? The stress process model focuses “attention on the relationships among the many conditions leading to personal stress and the ways these relationships develop” (Pearlin et al. 1990). Caregiving for a child with disabilities can be considered as the primary stressor with employment as a possible secondary role strain for caregivers as well as a coping strategy. I extend my findings from previous chapters by examining whether parents of children with disabilities have higher

levels of psychological distress and whether this relationship is mediated by employment. Further, I add to the literature by examining gender and race differences in psychological distress between families of children with disabilities and families with typically developing children.

## **LITERATURE REVIEW**

Hill (1949, 1958) was one of the first scholars to develop a comprehensive theoretical model of family stress which focused on the stressor, resources to deal with the stress (or coping skills as the mediators), perceptions of the stressor, and the stress outcome. These basic tenets underlie more general stress and coping models (e.g., Folkman et al. 1987; Lazarus and Folkman 1984) and have been used in the caregiver literature for decades to explain caregiver stress (Haley et al. 1987; Pearlin et al. 1990). However, distinctive sociological theories of stress draw attention to stratification systems, the structural context of caregiving (Pearlin 1989), and cultural differences among caregivers (Knight et al. 2000). Pearlin's (1989) model, in particular, has direct applicability to the stress process associated with caregiving for children with disabilities (Raina et al. 2004).

### **Caregiving and Psychological Distress**

Many parents can recall both positive and negative experiences associated with the parenting role, with researchers (e.g., Deater-Deckard 2004) agreeing that parenting brings about a normal level of stress. However, there is a difference between normal and pathological parenting stress (Deater-Deckard 2004). Parenthood, in general, is associated with high levels of psychological distress (Deater-Deckard and Scarr 1996; Evenson and Simon 2005; Galambos and Krahn 2008; McLanahan and Adams 1987). The chronic strains

of caregiving (i.e., the caregiver burden) increase levels of psychological distress among families with children with disabilities (Bailey and Smith 2000; Kazak and Marvin 1984; Thoits 2011). Pearlin (1989) suggests that caregiving of impaired individuals often results in role overload or role strain and becomes the primary stressor. This is likely due to the stress associated with daily care, the diagnostic process, and the availability of resources/supports (Hogan 2012; Kelso, French, and Fernandez 2005; Knussen and Sloper 1992).

Primary stressors are intensified by secondary stressors. Caregivers who are employed might experience conflicting pressures from work and family, which is sometimes referred to as role conflict or the work-family divide (Jacobs and Gerson 2004; Roxburgh 1999). These pressures are associated with higher psychological distress (Nguyen 2009; Murphy et al. 2001; Pearlin et al. 1997). Conversely, the same situations that might cause role conflict for some caregivers might result in role enhancement for others. In caregiving research, role enhancement refers to the positive effect of occupying multiple roles. Specifically, research suggests that role enhancement decreases psychological distress by providing different areas for life satisfaction (Gove 1972; Gove and Geerken 1977; Rozario, Morrow-Howell, and Hinterlong 2004). This is also referred to as a positive work-family spillover where the beneficial effects of working spill over to caregiving and vice versa (Crouter 1984; Grzywacz, Almeida, and McDonald 2002; Hammer et al. 2005). Rather than a secondary stressor, employment may actually mediate the stress process by serving as a coping strategy that reduces psychological distress.

One of the strengths of Pearlin's (1989) theoretical model is the recognition of the structural contexts of the stress process. More specifically, Pearlin and colleagues (1990)

recognize that the unequal allocation of resources and differential statuses within stratification systems based on gender and race are embedded throughout the stress process. Pearlin's (1989) sociological approach to the stress process shifts attention to women in families who are the majority of caregivers (England 2005; Hooyman and Gonyea 1995), and demonstrates how the stress African Americans experience outside of the home (e.g., racial discrimination) combine with their caregiving responsibilities to produce stress outcomes (Lincoln and Chae 2010).

### **Gender, Caregiving, and Psychological Distress**

Tichenor (2005) suggests that marital relationships are still constructed around the ideology of separate spheres where women are the primary caregivers. The National Alliance for Caregiving and the AARP (2009) estimate that 66 percent of all caregivers are women. While this estimation includes all caregivers and not just caregivers of children with disabilities, it supports the notion of gendered caregiving. Male caregivers are increasing, though, as the number of care recipients steadily increases. Nonetheless, women are more likely to handle the daily tasks of bathing, dressing, and feeding care receivers and also report higher levels of stress associated with caregiving (National Alliance for Caregiving and the AARP 2009).

Many studies have documented gender differences in psychological distress among parents (e.g., Bird 1997; Kohler, Behrman, and Skytthe 2005; Nomaguchi and Milkie 2003). Yet, research on families with children with disabilities is somewhat mixed. For example, Dyson (1997) found differences in psychological distress between families of children with disabilities and families with typical children, but did not find any gender differences

between parents of children with disabilities. Similarly, Keller and Hnag (2004) reported that mothers and fathers of children with disabilities have similar levels of stress. There are situations unique to raising a child with disabilities that are equally as stressful for mothers and fathers (e.g., the diagnostic process); however, research suggests that the increased carework for children with disabilities results in higher levels of psychological distress in mothers since fathers are rarely the primary caregivers (Blum 2007; Griffith et al 2011; Knussen and Sloper 1992; Olsson and Hwang 2001; Traustadottir 1991).

Sen and Yurtsever (2007) reported that mothers experience deep sadness and feeling overwhelmed about their child's disability. Qualitative research (e.g., Blum 2007; Gray 2003; Scott 2010) describes how mothers respond to the stress emotionally, for example, by "Crying a lot. It's a big release" (Gray 2003:639). This emotional response is coupled with a sense of grieving (Sen and Yurtsever 2007) where one mothers says "I seem to feel everything, experience everything, really, really strongly. Lots of depth, but I am aware that I am going through constant grief all the time too, so I feel that I, if I'm not angry and frustrated, which is sort of eighty percent of the time, I'm grieving" (Gray 2003:636).

Many mothers blame themselves for their child's disability, which is often reinforced by the child's father, other mothers, and service providers (Blum 2007; Gray 2003; Johnson et al. 2006; Kearney and Griffin 2001; Litt 2004; Singh 2004). As one mother states, "I think he [my husband] always felt that it was my fault and I still think he does in a way" (Gray 2003:637). In response, mothers often develop a heightened view of intensive mothering for children with disabilities where one mother describes it as "a certain amount of always being conscious...It's a whole lot more than just being a parent" (Litt 2004:632). Some parents try

to counteract the blame by doing advocacy carework (Blum 2007; Griffith et al 2011; Litt 2004; Traustadottir 1991) while others socially isolate themselves (Blum 2007; Dowling and Dolan 2001; Johnson et al. 2006; Litt 2004).

While the caregiving needs of children with disabilities are attributed to psychological distress (Blum 2007; Griffith et al 2011; Olsson and Hwang 2001; Traustadottir 1991), research on employment as a secondary stressor is inconsistent. Women are more likely to experience disruptions in employment due to caregiving and a lack of appropriate childcare (e.g., role conflict) (Brandon 2000; Cuskelly, Pulman and Hayes 1998; Jinnah and Stoneman 2008; Shearn and Todd 2000), which may cause more psychological distress. As a mother of a son with autism describes, “Yes, I do work, but of course, again [my son] dominated that. I knew a long time ago that I was never going to be able to hold down another [full time] job with all our appointments and whatever (Gray 2003:637).” This is consistent with Litt (2004) who suggests that caregiving for a child with disabilities combined with characteristics of the labor market (e.g., inflexible, low-wage work environments) cause greater stress for mothers. In contrast, employment may be conducive to maternal mental health and parenting satisfaction and serve as a mediator in the stress process. Kessler and McRai (1982) and Thyen, Kuhlthau, and Perrin (1999) found that mothers of children with disabilities who were employed outside of the home (i.e., role enhancement) had better mental health compared to mothers who were not. Likewise, the mothers in Lewis, Kagan, and Heaton’s (1996) sample describe employment as giving them sanity. Knussen and Sloper (1992) found that employment was an important factor for

maternal adaptation to stress and employed mothers of children with disabilities exhibited less depression than unemployed mothers of children with disabilities.

### **Race and Psychological Distress**

Previous research (see Thoits 2010) has found that differential exposure to stressful life situations (e.g., racism and discrimination) accounts for racial differences in mental health. Racism is often reduced to personal attitudes or prejudices, and in so doing, the structural impacts are often overlooked (Bonilla-Silva 2001; Feagin 2000; Wellman 1993). Racism is systemic and embedded in major social institutions. For example, Bonilla-Silva (2001) and Feagin (2001) document persistent racial inequality through residential segregation, education, voting and representation, unfair police practices, employment, and in everyday interactions. The cumulative stress experienced by minorities manifests itself in physical and mental health disparities (Turner 2003; Williams and Collins 2007; Williams et al. 1997). However, studies comparing mental health outcomes of African Americans with those of whites are somewhat mixed with some findings suggesting that African Americans have higher rates of psychological distress due to socioeconomic status and discrimination (for a discussion see Vega and Rumbaut 1991; Williams et al. 1997) while others have found that African Americans and Hispanics have equal or lower levels of psychological distress than whites (see Thoits 2010), which is attributed to more extensive familial social networks.

Less research has focused explicitly on the relationship between race, caregiving, and psychological distress. Most of this research is based on older care receivers; however, the findings are still applicable to stress processes associated with caregiving for children with disabilities. Lincoln and Chae (2010) found that African Americans experience a negative

spillover where stress outside of the home affects family life and leads to high levels of psychological distress. This suggests that African American caregivers would have higher levels of psychological distress than whites. However, Knight et al. (2000) found similar levels of distress among caregivers of family members with dementia, regardless of race. Other studies (e.g., Guarnaccia and Parra 1996; Horwitz and Reinhardt 1995; McCabe et al. 2003; Stueve, Vine, and Struening 1997) have found that African American caregivers report lower levels of stress than other racial groups. Lower caregiver stress among African Americans is attributed to specific protective factors such as kinship support (Stueve et al. 1997), spirituality (Weinland 2009), and employment outside of the home (Rozario and DeRienzi 2008).

### **Research Question and Hypotheses**

The stress process model highlights the importance of the structural context of caregiving. It is a causal model where the primary stressor (e.g., child's disability) predicts the stress outcome (e.g., psychological distress). Secondary stressors intensify the stress outcome while other factors may mediate it. In this chapter, I am interested in whether parents of children with disabilities have higher levels of psychological distress and whether this relationship is mediated by employment. Based on the basic premises of Pearlin and colleagues' (1990) stress process model, I derive hypotheses that test the effects of the primary stressor (i.e., child's disability), a secondary stressor (i.e., severity of disability), and possible interaction effects with gender and race.

*Hypothesis 1a: Parents of children with disabilities have higher levels of psychological distress than parents of typical children.*

*Hypothesis 1b: The severity of the child's disability is positively related to levels of psychological distress.*

*Hypothesis 2: The difference in psychological distress between mothers and fathers of children with disabilities is greater compared to mothers and fathers of typical children, and this varies by race.*

Next, I evaluate whether employment mediates the stress process. As previously discussed, the literature on employment, caregiving, and psychological distress has been somewhat mixed. While some research supports the notion of employment as a secondary stressor (e.g., Litt 2004), others (e.g., Kessler and McRai 1982; Thyen, Kuhlthau, and Perrin 1999) suggest that employment enhances the caregiving role by serving as a coping resource (Knussen and Sloper 1992). I expect to find that:

*Hypothesis 3: Employment mediates the effects of a child's disability on psychological distress.*

To summarize, I am comparing reported levels of psychological distress between parents of children with disabilities and parents with typical children. I suspect that the child's disability acts as a primary stressor and that the severity of the disability acts as a secondary stressor. Both the primary and secondary stressors increase levels of psychological distress among parents of children with disabilities. I expect to find gender and racial differences in psychological distress, and test whether employment mediates the stress process.

## **DATA AND METHODS**

The Survey of Income and Program Participation (SIPP) is a continuous series of national panels designed to measure the effectiveness of existing programs and estimates future costs and coverage of government programs (U.S. Census Bureau 2005). SIPP content

is built around “core” questions on income, labor force participation, program participation and eligibility, and general demographics. “Topical modules” are asked throughout the panels to provide additional information for analyses. SIPP utilizes a multi-stage stratified sample of the U.S. civilian non-institutionalized population. Imputation procedures are employed to reduce the bias of survey estimates and are based on the assumption that data are missing at random within subgroups of the population. Data editing are preferred over statistical imputations and were used whenever a missing item could be logically inferred from other data that was provided (U.S. Census Bureau 2005).

The survey uses a four month recall period with about the same number of interviews conducted in each of the four month periods for each wave. My analysis is based on Wave 8 of the SIPP 2001 panel, which initially consisted of 36,700 households that were to be interviewed nine times over the course of three years. Budget constraints caused the U.S. Census Bureau to reduce the number of households interviewed by 15 percent by Wave 2, leaving 31,195 households eligible for interviews. All household members at least 15 years old are interviewed by self-response.

### **Selection of Sample for Analysis**

SIPP is a survey of households and includes data on primary families, related and unrelated subfamilies, and primary and secondary individuals. The current analysis is limited to the same primary families used in the previous chapters and excludes multi-generational households and single parent households. The choice to exclude single parents and grandparents was made after considering the unique challenges they face as caregivers and the higher levels of psychological stress that have been reported in previous research (e.g.,

Kelch-Oliver 2008; Thoits 2010; Weinland 2009). In this study, family composition is held constant with only married couples in the sample. The stress process of single parents and grandparents raising children with disabilities warrants separate study and is beyond the scope of the current research.

Parental responses are used for children less than 15 while those at least 15 years old are interviewed by self-response. The sample includes 5,969 marital dyads with at least one residential child at Wave 8 of the survey period. Approximately 13.2 percent (787) of the couples in the sample have at least one residential child who meets the criteria of disability used in this analysis, which is slightly higher than national averages (for a discussion on the percentage of families raising children with disabilities see Wang [2005] and Malsch, Rosenzweig, and Brennan [2008]).

### **Dependent Variable**

A series of multilevel models are estimated to evaluate the stress process of families by their child's disability status. Respondents are asked a series of questions about their psychological well-being from the Topical Module on Adult Well-Being in Wave 8. The questions include: 1) "Are you frequently depressed or anxious?"; 2) "Do you have trouble getting along with others and making-keeping relationships?"; 3) "Do you have a lot of trouble concentrating long enough to finish everyday tasks?"; and 4) "Do you have trouble coping with day-to-day stresses?" Responses are coded dichotomously (1 = yes, 0 = no) and scaled to create a single variable for psychological distress that ranges from 0-4 with 0 indicating no psychological distress and 4 indicating high levels of psychological distress. The Cronbach's alpha is used as a measure of internal consistency with researchers agreeing

that 0.7 is an acceptable reliability coefficient (see Santos [1999] for a discussion). The Cronbach's alpha for the measure of psychological distress used in this analysis is 0.76. On average, the parents in the sample report low levels of psychological distress. Fathers of typical children have an average of 0.07 with an average of 0.08 for mothers of typical children. Fathers of children with disabilities have an average of 0.17 while mothers of children with disabilities average 0.24.

### **Independent Variables**

*Gender.* Two separate measures to account for gender differences are included in the analysis. Most of the multilevel models use a two intercept approach with separate estimates for males and females. In these models, male is measured as 1 = yes and 0 = no and female is measured as 1 = yes and 0 = no. In the models that allow for one intercept, gender is included using effect coding -1 = female and 1 = male.

*Race.* Race is measured as a series of dichotomous variables for white (86 percent of all parents with a slightly more parents of children with disabilities), African American (8 percent of all parents with slightly more parents of typical children), and other races (e.g., American Indians, Aleuts, Eskimos, Asians, Pacific Islanders, and those not previously specified) (6 percent of all parents with slightly more parents of typical children).

*Disability.* Child disability is considered the primary stressor in this research with the severity of the disability conceptualized as a secondary stressor. The SIPP Topical Module on Functional Limitations and Disability from Wave 8 is used to identify children with disabilities. The American with Disabilities Act (ADA) (1990, 2008) defines disability as “a physical or mental impairment that substantially limits one or more major life activities of

such individual.” My operational definition of disability is slightly more encompassing than the ADA (1990, 2008) definition and is based on both self-perceptions and clinical diagnoses of disabilities. I follow the same criteria of disability as identified by the World Health Organization’s (WHO) International Classification of Functioning, Disability, and Health (ICF) and as used by the U.S. Census Bureau (see Wittenburg and Nelson 2006). I primarily rely on Erickson and Dumoulin-Smith’s (2009) Simplified Conceptual Model of Disability using ICF Concepts. Children are considered disabled if they have either a physical, mental, or sensory impairment, participation restriction, and/or activity limitation. In this operational definition of disability, children with impairments are included even if the impairment does not significantly affect their daily living.

Physical impairment includes a long-lasting condition that limits the ability to move arms or legs (refers to children under three), limits the ability to walk, run, or play (refers to children between three and five), and limits the ability to walk, run or take part in sports and games (refers to children between six and fourteen). Children who are 15 years old answer questions about their difficulty lifting or carrying an object 10 pounds or heavier, pushing or pulling large objects, standing or sitting for an hour, stooping, crouching, or kneeling, reaching or grasping, walking three blocks or up a flight of stairs, or using a telephone. Children less than six years old are considered mentally impaired if they have a serious mental condition or a developmental delay that limits ordinary activities. All other children (six and older) are considered mentally impaired if they have a learning disability (e.g., dyslexia), attention deficit hyperactivity disorder (ADHD), intellectual disability, developmental disability (e.g., autism or cerebral palsy), or any other developmental

condition for which they have received therapy or diagnostic services. Children at least six years old with a sensory impairment have difficulty seeing words/letters, hearing even with an aid, or understanding speech.

To determine participation restrictions for children between the ages of 6 and 19, mothers indicate whether their children experience a physical, learning, or mental condition that limits the ability to do regular school work. Young adults 16 years and older are asked whether they have a long-lasting physical or mental condition that makes it difficult to remain employed or to find a job. Activities of daily living refer to children at least six years old and include needing help getting around inside the home, in and out of a chair, taking a bath or shower, putting on clothes, eating food, or using/getting to the toilet.

A dichotomous variable was created based on the operational definition of disability to indicate whether there is a child with disabilities in the family (1 = yes, 0 = no) at Wave 8 using data from the Topical Module on Functional Limitations and Disability. This measure is used to divide the sample of families into two groups – those with a child with disabilities (13.2 percent) and those with a typically developing child. Next, a disability index is created to measure the severity of the disability as a continuous variable. Scores are computed for each child with disabilities in the household with only the highest disability index score from each family used as the measure of severity of disability. Scores range from 0-26 with higher scores indicating more severe disabilities. The sample primarily consists of children with non-severe disabilities with an average score of 2.75 at Wave 8.

*Employment.* Respondents are asked “How many hours per week did ... usually work at all activities at this job?” If participants have two jobs then their usual hours worked

per week for both jobs are combined. Answers are reported using a continuous measure of usual hours worked each week at Wave 8. Fathers, on average, work more hours than mothers. The average hours worked per week for mothers of children with disabilities is 20 hours and 33.4 hours for fathers of children with disabilities. Mothers with typical children work 23 hours per week with fathers of typical children working 34.7 hours per week.

### **Control Variables**

*Caregiving Demands (or role conflict).* To control for role conflict, I created a dichotomous variable using responses from the following three questions: 1) Respondents who had a job during the reference period and worked less than 35 hours some weeks answered the following question: “There are weeks when ... worked less than 35 hours. What was the main reason...worked less than 35 hours in those weeks?”; 2) Those who did not work during reference period answered: “Main reason ... did not have a job during the reference period.”; and 3) Respondents who worked during the reference period and were not contingent workers but whose job ended during the reference period answered: “What is the main reason ... stopped working for...?” The original response categories are not mutually exclusive and varied somewhat for the three questions above; however, they all include options that pertained to raising children. Since I am primarily interested in whether respondents’ work is affected by caregiving, I code this variable as dichotomous (1 = yes) if any of the following criteria are met: respondents could not work because of pregnancy/childbirth or taking care of children/other persons; respondents could not work full-time because of taking care of children/other persons; or respondents had to end work because of childcare problems. If at least one of these criteria is not met, then the

“caregiving” variable is coded as 0 = no. A nearly equal percentage of mothers (28 percent) and fathers (less than 1 percent) report that their employment is affected by caregiving demands.

*Human Capital.* Keller and Hnog (2004) and Thoits (2010) suggest that those with lower human capital (i.e., education and income) have the highest rates of psychological distress. Further, education may moderate the mediating factor of employment (Scott 2010). I control for both education (coded dichotomously as 1 = some college and 0 = no college) and personal income (coded as a continuous variable) at Wave 8. Fifty-eight percent of parents of children with disabilities and 62 percent of parents with typical children have completed some college. Parents of children with disabilities report lower average personal incomes compared to parents with typical children. Mothers of children with disabilities have an average monthly personal income of \$1,660 at Wave 8 and fathers average \$3,939 a month at Wave 8. In contrast, mothers of typical children earn on average \$1,778 a month at Wave 8 with fathers of averaging \$4,159 a month at Wave 8. Table 4.1 provides descriptive statistics for all variables used in the analysis.

### **Analysis**

I use SAS PROC REG to compute three bivariate regression models to predict differences in levels of psychological distress between parents of children with disabilities and parents with typically developing children.<sup>1</sup> The regression equation is:

$$y = \alpha + \beta x + \varepsilon \quad (1)$$

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<sup>1</sup> All analyses in this chapter are based on an unweighted sample. All continuous predictor variables are grand mean centered for the analysis.

where  $\alpha$  is the intercept,  $\beta$  is the slope (indicating whether the relationship is positive or negative), and  $\epsilon$  is the error term or the difference between the predicted level of  $y$  and the actual observation (McClendon 2002).

Next, I use SAS PROC MIXED to estimate a series of multilevel models. I use a combination of basic multilevel modeling to test actor effects and Actor-Partner Interdependence Models for distinguishable dyads to test whether both actor and partners' values on the independent and control variables predict psychological distress. In both types of models, individuals are nested within dyads and the variability between and within dyads are considered. I use a two intercept approach (see Kenny, Kashy, and Cook 2006) where the equation for the lower level model is:

$$Y_{ij} = b_{1j}M + b_{2j}F \quad (2)$$

and the full lower model without partner effects is:

$$Y_{ij} = b_{1j}M + b_{2j}F + b_{3j}M * AJobHours + b_{4j}F * AJobHours + e_{1j} + e_{2j} \quad (3)$$

and with actor and partner effects is:

$$Y_{ij} = b_{1j}M + b_{2j}F + b_{3j}M * AJobHours + b_{4j}F * AJobHours + b_{5j}M * PJobHours + b_{6j}F * PJobHours + e_{1j} + e_{2j}. \quad (4)$$

In the multilevel equations,  $Y_{ij}$  is each dyad members' (M = male and F = female) levels of psychological distress and  $b_{1j}M$  and  $b_{2j}F$  are the intercepts for males and females, respectively. The slopes are denoted as  $b_{3j}M$  and  $b_{4j}F$  with AJobHours indicating the actors' (or the individuals') own hours worked per week while PJobHours in Equation 4 indicates the effect of the partners' hours worked per week. For example,  $b_{5j}M * PJobHours$  is the partner effect for the mothers' hours worked per week on the fathers' psychological distress

while  $b_{6j}F * PJobHours$  is the partner effect for the fathers' hours worked per week on the mothers' psychological distress. The residual variances, or unexplained variance, are denoted as  $e_{1j}$  for fathers and  $e_{2j}$  for mothers.

## RESULTS

### Bivariate Regression

Three bivariate regressions models are estimated to predict differences in psychological distress between parents of children with disabilities and parents with typically developing children. The  $F$  value is significant in each model indicating that the models are a good fit for predicting differences in psychological distress between parents (see Table 4.2). Thus, the models predict the data better than chance alone. However, since there is only one predictor in each model the adjusted  $R^2$  accounts for 1 percent of the variation or less depending on the model. Nonetheless, Models 1-3 (see Table 4.2) illustrate that having a child with disabilities significantly increases predicted levels of psychological distress for both mothers and fathers ( $p < .001$ ).

### Multilevel Models

A series of multilevel models are used to estimate 1) whether there are differences in psychological distress between parents of children with disabilities and parents with typically developing children by gender and race, 2) whether the severity of the child's disability increases psychological distress among parents of children with disabilities, and 3) whether employment mediates psychological distress. Tables 4.3 – 4.6 include basic models with the primary variables of interest to show the isolated effects of the child's disability, parental

gender and race, and employment on psychological distress. Table 4.7 estimates the final model with relevant control variables.

Model 1 (see Table 4.3) uses a two intercept approach and estimates fixed effect parameters for both mothers and fathers. The estimates are similar to the bivariate regression results in Table 4.2 and show that the levels of psychological distress for mothers and fathers in both groups is significantly different than zero ( $p < .001$ ). Model 2 (see Table 4.3) specifically tests whether the gender differences in the fixed effects are statistically significant. The findings indicate that mothers, regardless of child's disability status, have significantly higher rates of psychological distress than fathers ( $p < .001$ ). The correlation between residuals (CSH rho) is significant indicating considerable similarity in psychological distress for parents even though the models predict a significant gender difference. The residuals for Models 1 and 2 (see Table 4.3) are all significant, suggesting that there are amounts of variation associated across and within dyads that could potentially be accounted for with the addition of other predictors.

Table 4.4 introduces actor and partner effects of race on levels of parental psychological distress. There are no significant racial differences in predicted levels of psychological distress. The correlation between residuals (CSH rho) is significant, indicating considerable similarity in psychological distress for parents despite their race. The addition of race improves the overall fit of the model even though there are still amounts of variation that could potentially be reduced with the addition of other predictors.

Table 4.5 includes multilevel and Actor-Partner Interdependence Models to test whether the severity of the child's disability increases psychological distress in parents of

children with disabilities. The severity of the child's disability is not significant in Model 1 (Table 4.5). However, the interaction effects with maternal race and severity of child disability are significant in Model 2 (Table 4.5). The models predict that for each one-unit increase in the severity of the child disability (from the mean), the levels of psychological distress increase by 0.202 ( $p < .05$ ) for African American mothers and 0.212 ( $p < .01$ ) for mothers of "other races." There are also significant partner effects indicating that psychological distress decreases by 0.220 ( $p < .05$ ) for mothers with African American husbands and 0.225 ( $p < .001$ ) for mothers with husbands of "other races" as the severity of the child's disability increases. There is only one significant partner effect for fathers: psychological distress increases for fathers with African American wives as the severity of the child's disability increases (0.232,  $p < .01$ ). The correlation of the residuals (CSH rho) is significant, indicating that there is still considerable similarity in psychological distress for parents of children with disabilities.

Two multilevel models are estimated to test the effects of employment on parental psychological distress. Table 4.6 shows a significant negative effect for mothers, indicating that as hours worked per week increase (from the mean) psychological distress decreases by 0.005 ( $p < .001$ ) for mothers of children with disabilities and 0.002 for mothers of typical children ( $p < .001$ ). Table 4.7 includes actor and partner effects with relevant control variables. Hours worked per week remain significant for mothers and are now significant for fathers, net of the effect of the other control variables. For both mothers and fathers, an increase in hours worked per week (from the mean) decreases psychological distress ( $p < .001$ ), with mothers of children with disabilities having the largest decrease in psychological distress

(-0.006). There are no significant partner effects for parents of children with disabilities, but there are for parents of typical children, where an increase in fathers' hours worked per week reduces maternal psychological distress and an increase in mothers' hours worked per week increases paternal psychological distress. Mothers whose work is affected by caregiving (e.g., have to reduce their hours worked per week or end employment) also have a significant decrease in psychological distress (-0.263,  $p < .001$  for mothers of children with disabilities and -0.055,  $p < .001$  for mothers of typical children). The correlation of the residuals (CSH rho) in Tables 4.6 and 4.7 are significant, indicating that there is still considerable similarity in psychological distress for parents even after including relevant control variables in Table 4.7. The residuals are also all significant, suggesting that there are amounts of variation associated across and within dyads that could potentially be accounted for with the addition of other predictors.

## **DISCUSSION**

In this chapter, I extend the previous analyses on employment trajectories conducted in Chapters 2 and 3 by considering whether employment mediates psychological distress. I draw on Pearlin's (1989) sociological theory of the stress process to examine how the effects may be different for mothers and fathers and compare across family types (e.g., having a child with disabilities and having a typically developing child). The findings in this chapter illustrate that parents of children with disabilities have higher levels of psychological distress, which is consistent with previous research (see Bailey and Smith 2000; Hogan 2012; Kazak and Marvin 1984; Kelso, French, and Fernandez 2005; Knussen and Sloper 1992; Pearlin 1989). Mothers of children with disabilities have the highest levels of psychological

distress followed by fathers of children with disabilities, mothers of typical children, and then fathers of typical children.

### **Differences in Psychological Distress by Gender and Race**

I hypothesized that parents of children with disabilities have higher rates of psychological distress than parents of typically developing children and that the difference in psychological distress between mothers and fathers of children with disabilities is greater compared to mothers and fathers with typical children. Further, I expected the rates of psychological distress to vary by race. The findings in Table 4.2 show that parents of children with disabilities have higher rates of psychological distress than parents of typical children, which is consistent with Hogan (2010), Kelso et al. (2005), and Knussen and Sloper (1992), all of whom cite the increase of stress associated with daily care, the diagnostic process, and availability of resources and supports.

Table 4.3 demonstrates that there are significant gender differences in psychological distress among parents of children with disabilities and parents of typical children. While many studies have documented gender differences in psychological distress among parents (e.g., Bird 1997; Kohler, Behrman, and Skytthe 2005; Nomaguchi and Milkie 2003), research on families with children with disabilities is somewhat mixed. My findings show that mothers have higher levels of psychological distress regardless of their child's disability status and that the gap between mothers' and fathers' psychological distress is greater among parents of children with disabilities. This gap in psychological distress between parents of children with disabilities is likely due to the increased caregiving responsibilities that are often done by mothers (Blum 2007; Griffith et al. 2011; Knussen and Sloper 1992), who may

respond through intensive mothering (Blum 2007; Gray 2003; Litt 2004; Sen and Yurtsever 2007; Scott 2010) or through social isolation (Blum 2007; Dowling and Dolan 2001; Litt 2004).

Interestingly, the multilevel models do not predict any significant gender differences by race. The general literature on stress (see Thoits 2010 for a review) suggests that minorities are often exposed to stressful life situations that increase their levels of psychological distress. However, previous research on race and caregiving yields inconsistent results with Lincoln and Chae (2010) finding higher levels of psychological distress in African American caregivers, Knight et al. (2000) finding similar levels of psychological distress among caregivers, and a host of other studies (e.g., Guarnaccia and Parra 1996; Horwitz and Reinhardt 1995; McCabe et al. 2003; Stueve, Vine, and Struening 1997) finding lower levels of psychological distress in African American caregivers. My findings suggest that, all things being equal, African American and white parents of children with disabilities have similar levels of psychological stress. However, we know that all things are not equal and we have to consider secondary stressors when evaluating psychological distress.

### **Severity of a Child's Disability as a Secondary Stressor**

I hypothesized that the severity of the child's disability is positively related to levels of psychological distress in parents of children with disabilities. Pearlin (1989) suggests that secondary stressors further intensify the stress process. In this analysis, severity of disability is conceptualized as a secondary stressor since the extra resources, and daily care that children with more severe disabilities need often leads to higher levels of parental stress (Keller and Hnag 2004; Parish and Cloud 2006). While there were no significant racial

differences in previous models, the findings in Model 2, Table 4.5 suggest significant racial differences in maternal psychological distress as the severity of the child's disability increases but not for paternal psychological distress. African American mothers and mothers of "other races" had higher levels of psychological distress than white mothers when controlling for the severity of the child's disability. Thus, the severity of the child's disability acts as a secondary stressor for nonwhite mothers. This may be due to the extra expenses associated with taking care of a child with more severe disabilities that nonwhite families, who have less household wealth and income than white families, struggle to meet (Conley 1999; Oliver and Shapiro 1995).

### **Employment and Psychological Distress**

I hypothesized that employment would mediate the effects of a child's disability on psychological distress. My findings in Table 4.6 support this for mothers with employment significantly decreasing psychological distress. A more nuanced picture of employment emerges in Table 4.7 after including relevant control variables. Employment remains significant, indicating that as hours worked per week increases levels of psychological distress decrease for *all* parents in the sample with mothers of children with disabilities having the highest reduction in psychological distress as their hours of employment increase followed by fathers of children with disabilities. These findings support the notion of role enhancement for working parents, especially parents of children with disabilities (Gove 1972; Gove and Geerken 1977; Rozario, Morrow-Howell, and Hinterlong 2004). However, it appears that caregiving demands (i.e., quitting a job or reducing hours due to caregiving) also lowers predicted levels of psychological distress in mothers with a greater reduction for

mothers of children with disabilities, which supports role strain or role conflict (Jacobs and Gerson 2004; Roxburgh 1999) for working parents. Mothers, in particular, may experience role conflict due to ideologies of intensive mothering and may have more of their identities invested in their carework. Thus, quitting a job for these mothers may reduce their psychological distress. The findings also suggest that being employed may not be the most important factor to consider, but rather job quality. Jobs with low flexibility may make it more difficult for mothers to balance work and family in the same way that professional jobs with high demands may cause mothers to leave employment when paid work is not conducive with carework (Stone 2007).

### **Conclusion**

The findings in this chapter demonstrate that a child's disability affects parental levels of psychological distress. Further, mothers of children with disabilities have the highest rates of psychological distress of all parents in the sample, which is consistent with previous research (e.g., Blum 2007; Griffith et al 2011; Knussen and Sloper 1992; Olsson and Hwang 2001; Traustadottir 1991). As expected, employment reduces psychological distress in all parents. Interestingly, mothers who quit a job or reduce their hours to provide carework also see a reduction in predicted levels of psychological distress. A major limitation of this research is the lack of a measure for job quality. Litt (2004) argues that mothers of children with disabilities experience higher levels of stress because of inflexible and low-wage employment that is often characteristic of nonstandard jobs. Thus, one could speculate that if mothers leave these types of jobs, their levels of psychological distress would decrease. Since mothers of children with disabilities are still the primary caregivers, they often need

employment with flexibility and benefits, which are characteristics of “good jobs” or professional jobs in the primary labor market (Hodson and Kaufman 1982; Kalleberg, Reskin, and Hudson 2000). However, Stone’s research (2007) suggests that some mothers in professional jobs with high demands also leave employment because of the imbalance between work and family. Thus, there may be a false dichotomy in characterizing jobs as “good” or “bad” with perceptions of job quality depending largely on the ability to effectively balance work and family. Future research should examine the type of employment and job quality to see whether this mediates the stress process for mothers of children with disabilities.

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**Table 4.1. Descriptive Statistics for Variables Used to Estimate Psychological Distress in Two-Parent Households (N=5,969 Dyads)**

	All Parents	Parents of Children with Disabilities			Parents of Typical Children		
	(N=11,825)	Both (N=1,548)	Mothers (N=786)	Fathers (N=762)	Both (N=10,277)	Mothers (N= 5,180)	Fathers (N=5,097)
<i>Outcome Variable</i>							
Psychological Distress	0.092 <i>0.440</i>	0.202 <i>0.647</i>	0.235 <i>0.686</i>	0.168 <i>0.603</i>	0.075 <i>0.397</i>	0.083 <i>0.406</i>	0.067 <i>0.387</i>
<i>Predictor Variables</i>							
White (Ref Category)	85.88% <i>0.348</i>	87.79% <i>0.327</i>	87.91% <i>0.326</i>	87.66% <i>0.329</i>	85.59% <i>0.351</i>	85.52% <i>0.352</i>	85.66% <i>0.351</i>
African American	8.02% <i>0.272</i>	7.36% <i>0.261</i>	7.25% <i>0.260</i>	7.48% <i>0.263</i>	8.12% <i>0.273</i>	7.95% <i>0.271</i>	8.30% <i>0.276</i>
Other Races	6.10% <i>0.239</i>	4.84% <i>0.215</i>	4.83% <i>0.215</i>	4.86% <i>0.215</i>	6.29% <i>0.245</i>	6.53% <i>0.247</i>	6.04% <i>0.238</i>
Hours Worked per Week	28.50 <i>21.71</i> [0-99]	26.55 <i>22.84</i> [0-99]	19.94 <i>20.73</i> [0-80]	33.37 <i>22.92</i> [0-99]	28.79 <i>21.51</i> [0-99]	25.95 <i>20.41</i> [0-90]	34.71 <i>21.15</i> [0-99]
College	61.74% <i>0.486</i>	58.07% <i>0.494</i>	58.65% <i>0.492</i>	57.48% <i>0.495</i>	62.29% <i>0.485</i>	62.74% <i>0.484</i>	61.84% <i>0.486</i>
Monthly Income	2,936.36 <i>3,696.98</i> [0-45,946.25]	2,782.40 <i>3,603.75</i> [0-31,460]	1,660.50 <i>2,258.50</i> [0-25,922]	3,939.63 <i>4,300.94</i> [0-31,460]	2,959.55 <i>3,710.44</i> [0-45,946.25]	1,778.42 <i>2,327.78</i> [0-31,922]	4,159.92 <i>4,404.05</i> [0-45,946.25]
Caregiving Demands	14.32% <i>0.350</i>	14.28% <i>0.350</i>	27.35% <i>0.446</i>	0.79% <i>0.088</i>	14.32% <i>0.350</i>	27.53% <i>0.447</i>	0.90% <i>0.095</i>
Severity of Child Disability	N/A	2.749 <i>3.986</i> [1-26]	2.732 <i>3.962</i> [1-26]	2.766 <i>4.013</i> [1-26]	N/A	N/A	N/A

*Notes* : Table values for the category of “All Parents” are grand means or percentages. Table values for the categories under “Parents of Children with Disabilities” and “Parents of Typical Children” are group means or percentages. Standard deviations are in *italics* and ranges are in []. *Source* : Survey of Income and Program Participation 2001-2003 Wave 8.

**Table 4.2. Bivariate Regression Results Predicting Differences in Psychological Distress in Two-Parent Households (N=11,825)**

	Model 1: Both Parents		Model 2: Mothers Only		Model 3: Fathers Only	
Adjusted Model R <sup>2</sup>	0.0094		0.0126		0.0063	
Model F	113.37 ***		77.33 ***		37.90 ***	
Intercept	0.075 ***	(0.004)	0.083 ***	(0.006)	0.067 ***	(0.006)
Have Disabled Child	0.127 ***	(0.012)	0.153 ***	(0.017)	0.101 ***	(0.016)

*Notes:* SAS PROC REG. The results are unweighted. Table entries are unstandardized (metric) regression coefficients. Numbers in Parentheses are standard errors. \*\*\*  $p < .001$ . *Source:* Survey of Income and Program Participation 2001-2003 Wave 8.

**Table 4.3. Multilevel Models Predicting Gender Differences in Psychological Distress in Two-Parent Households (N=5,969 Dyads)**

	Parents of Children with Disabilities		Parents of Typical Children	
	Model 1	Model 2	Model 1	Model 2
Intercept		0.202 *** (0.018)		0.075 *** (0.004)
Gender		-0.034 * (0.014)		-0.007 * (0.004)
Mothers	0.235 *** (0.024)		0.083 *** (0.006)	
Fathers	0.168 *** (0.022)		0.068 *** (0.005)	
-2 Log Likelihood	2987.029	2985.643	9999.466	9998.080
<i>Random Effects</i>				
Variance of Residuals (Mothers)	0.471 *** (0.024)		0.165 *** (0.003)	
Variance of Residuals (Fathers)	0.363 *** (0.019)		0.150 *** (0.003)	
CSH rho	0.259 *** (0.034)		0.185 *** (0.014)	

*Notes:* REML, SAS PROC MIXED. The results are unweighted. Numbers in parentheses are standard errors. \*  $p < .05$ ; \*\*\*  $p < .001$ . *Source:* Survey of Income and Program Participation 2001-2003 Wave 8.

**Table 4.4. Actor-Partner Interdependence Models Predicting Gender and Race Differences in Psychological Distress in Two-Parent Households (N=5,879 Dyads)**

	Parents of Children with Disabilities				Parents of Typical Children			
	Mothers		Fathers		Mothers		Fathers	
<i>Actor Effects</i>								
Intercept	0.232 ***	(0.027)	0.162 ***	(0.023)	0.083 ***	(0.006)	0.063 ***	(0.006)
African American	0.076	(0.208)	0.098	(0.304)	0.016	(0.053)	0.022	(0.079)
Other Races	0.249	(0.178)	-0.441 †	(0.260)	0.072 †	(0.042)	-0.058	(0.064)
<i>Partner Effects</i>								
African American	-0.083	(0.205)	0.035	(0.304)	-0.043	(0.052)	0.027	(0.079)
Other Races	-0.211	(0.180)	0.318	(0.261)	-0.070	(0.044)	0.091	(0.064)
-2 Log Likelihood	2953.144				9798.358			
<i>Random Effects</i>								
Variance of Residuals	0.471 ***	(0.024)	0.363 ***	(0.019)	0.160 ***	(0.003)	0.150 ***	(0.003)
CSH rho	0.259 ***		(0.034)		0.182 ***		(0.014)	

Notes: REML, SAS PROC MIXED. The results are unweighted. Numbers in parentheses are standard errors. † $p < .10$ ; \*\*\* $p < .001$ . Source: Survey of Income and Program Participation 2001-2003 Wave 8.

**Table 4.5. Multilevel and Actor-Partner Interdependence Models Predicting the Effect of the Severity of a Child's Disability on Psychological Distress in Two-Parent Households**

	Model 1 ( <i>N</i> =787 Dyads)				Model 2 ( <i>N</i> =767 Dyads)			
	Mothers		Fathers		Mothers		Fathers	
<i>Actor Effects</i>								
Intercept	0.235 ***	(0.024)	0.168 ***	(0.022)	0.229 ***	(0.027)	0.161 ***	(0.023)
Severity of Child Disability	0.004	(0.006)	-0.006	(0.007)	0.004	(0.007)	-0.009	(0.207)
African American					0.309	(0.227)	-0.296	(0.331)
Other Races					0.233	(0.183)	-0.464 †	(0.266)
Sev Child Dis*African American					0.202 *	(0.102)	-0.126	(0.085)
Sev Child Dis*Other Races					0.212 **	(0.065)	-0.090	(0.059)
<i>Partner Effects</i>								
African American					-0.315	(0.221)	0.486	(0.330)
Other Races					-0.250	(0.182)	0.378	(0.265)
Sev Child Dis*African American					-0.220 *	(0.096)	0.232 **	(0.089)
Sev Child Dis*Other Races					-0.225 ***	(0.068)	0.090	(0.057)
-2 Log Likelihood		3001.591				2978.266		
<i>Random Effects</i>								
Variance of Residuals	0.471 ***	(0.024)	0.364 ***	(0.019)	0.466 ***	(0.024)	0.358 ***	(0.018)
CSH rho		0.260 ***	(0.034)			0.259 ***	(0.034)	

Notes: REML, SAS PROC MIXED. The results are unweighted. Numbers in parentheses are standard errors. †*p* <.10; \**p* <.05; \*\**p* <.01; \*\*\**p* <.001. Source: Survey of Income and Program Participation 2001-2003 Wave 8.

**Table 4.6. Multilevel Models Predicting Effects of Employment on Psychological Distress in Two-Parent Households (N=5,879 Dyads)**

	Parents of Children with Disabilities				Parents of Typical Children			
	Mothers		Fathers		Mothers		Fathers	
Intercept	0.193 ***	(0.026)	0.191 ***	(0.022)	0.074 ***	(0.006)	0.081 ***	(0.006)
Hours Worked each Week	-0.005 ***	(0.001)	0.000	(0.001)	-0.002 ***	(0.000)	-0.000	(0.000)
-2 Log Likelihood	2965.520				9928.345			
<i>Random Effects</i>								
Variance of Residuals	0.459 ***	(0.023)	0.351 ***	(0.018)	0.164 ***	(0.003)	0.148 ***	(0.003)
CSH rho	0.248 ***		0.034		0.184 ***		(0.014)	

Notes: REML, SAS PROC MIXED. The results are unweighted. Numbers in parentheses are standard errors. \*\*\*  $p < .001$ . Source: Survey of Income and Program Participation 2001-2003 Wave 8.

**Table 4.7. Actor-Partner Interdependence Models Predicting Effects of Employment on Psychological Distress in Two-Parent Households with Relevant Control Variables (N=5,879 Dyads)**

	Parents of Children with Disabilities				Parents with Typical Children			
	Mothers		Fathers		Mothers		Fathers	
<i>Actor Effects</i>								
Intercept	0.360 ***	(0.049)	0.203 ***	(0.044)	0.110 ***	(0.016)	0.091 ***	(0.011)
African American	0.135	(0.202)	0.001	(0.300)	0.009	(0.053)	0.024	(0.078)
Other Races	0.182	(0.175)	-0.418	(0.255)	0.078 †	(0.042)	-0.061	(0.063)
Hours Worked per Week	-0.006 ***	(0.001)	-0.004 ***	(0.001)	-0.002 ***	(0.000)	-0.002 ***	(0.000)
Caregiving	-0.263 ***	(0.064)	-0.148	(0.251)	-0.055 ***	(0.016)	-0.107 †	(0.057)
Monthly Income	-0.000	(0.000)	-0.000 *	(0.000)	0.000 †	(0.000)	0.000 *	(0.000)
College Education	-0.162 **	(0.058)	-0.025	(0.050)	-0.027 *	(0.014)	-0.035 **	(0.013)
<i>Partner Effects</i>								
African American	-0.162	(0.199)	0.119	(0.296)	-0.037	(0.052)	0.013	(0.078)
Other Races	-0.219	(0.176)	0.302	(0.255)	-0.073 †	(0.043)	0.089	(0.064)
Hours Worked per Week	-0.001	(0.001)	-0.001	(0.001)	-0.001 *	(0.000)	0.001 *	(0.000)
Caregiving Demands	-0.011	(0.282)	-0.009	(0.057)	-0.027	(0.059)	0.003	(0.015)
Monthly Income	0.000	(0.000)	-0.000	(0.000)	0.000 **	(0.000)	0.000 *	(0.000)
College Education	-0.054	(0.056)	0.001	(0.051)	-0.003	(0.014)	0.016	(0.013)
-2 Log Likelihood	3024.247				9836.080			
<i>Random Effects</i>								
Variance of Residuals	0.441 ***	(0.023)	0.349 ***	(0.018)	0.158 ***	(0.003)	0.147 ***	(0.003)
CSH rho	0.246 ***		(0.246)		0.178 ***		(0.014)	

Notes: REML, SAS PROC MIXED. The results are unweighted. Numbers in parentheses are standard errors. † $p < .10$ ; \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ . Source: Survey of Income and Program Participation 2001-2003 Wave 8.

## **CHAPTER 5: CONCLUSION**

*“Care is a costly morality: costly in the personal and emotional resources it demands and in the time it consumes (time that cannot be devoted to investing in a career or advancing oneself materially). When care is not adequately supported, either the cost of care is borne by the caregiver alone or the charge [recipient] fails to receive adequate care – or both suffer” (Kittay 2002:272).*

How do the needs of children with disabilities affect parental employment and how does this effect vary by gender and race? Do parents of children with disabilities have higher rates of psychological distress, and does employment mediate this effect? In this chapter, I review the findings in the previous chapters and reiterate my contributions to the literature. I argue that research needs to take into account that family context matters and suggest that to effectively advocate for the cared-for we must advocate for the caregiver (Kittay 2002). I conclude with the major limitations of these data and suggest areas for future research in caregiving for children with disabilities.

### **SUMMARY OF FINDINGS**

In Chapter 2, I compare employment outcomes over time for mothers of children with disabilities and mothers of typically developing children. In Chapter 3, I extend the analysis to include fathers. The findings in both chapters suggest that parents of children with disabilities work fewer hours than parents of typical children. Further, having a child with disabilities reduces maternal employment, which is consistent with previous research (Porterfield 2002; Powers 2003). The results also point to significant racial differences in this effect. When using an age-based measure of time (i.e., comparing mothers at the same age),

African American mothers of children with disabilities worked more hours for pay than white (and other) moms when their children with disabilities were young, but reduced paid employment over time at a steeper rate than the other mothers in the sample, controlling for education and income. The higher initial hours of paid employment for African American mothers of children with disabilities may be due to economic necessity and the economic opportunities available to their spouses while the difference in employment over time by race may reflect “protective carework” often used by African American mothers as their children get older (Elliott and Aseltine 2012). Mothers might reduce their employment over time to provide direct supervision as a way to protect their children from victimization and exploitation when structured activities are not available for their children and to advocate for their children as they navigate racist institutional contexts (Elliott, Powell, and Brenton forthcoming). The results also suggest that education does not have the same effect for all mothers in the sample. Mothers of children with disabilities see an initial payoff for increased education, but this effect stagnates over time. For these mothers, working in more professional jobs that require advanced educations may not be conducive to the extraordinary caregiving needs of children with disabilities so they reduce or change their employment to assist with long-term care and end up experiencing a wage penalty for motherhood despite an increased education.

The findings in Chapter 3 suggest that parents of children with disabilities have lower rates of employment over time compared to parents of typical children, with mothers of children with disabilities having the lowest rates of employment. The gap in initial hours worked is larger for parents of children with disabilities, suggesting that gender moderates

initial levels of employment, but does not affect employment over time for parents of children with disabilities. This large gap in employment between parents of children with disabilities primarily refers to white couples, with African American couples having more similar levels of paid employment. Mothers of children with disabilities are also more likely to reduce their hours of paid employment because of caregiving demands than fathers of children with disabilities and parents of typical children. However, white fathers, who work more hours than African American fathers, reduce their employment when their children have more severe disabilities. These findings reinforce the notion that white parents have more traditional divisions of labor compared to African American parents and that parents of children with disabilities modify their division of labor in responses to the specific caregiving needs of their child.

The racial difference between mothers in the previous analysis was no longer significant in Chapter 3. I was unable to use an age-based measure of time in the dyadic analysis in Chapter 3 since the models were comparing partners at a particular point in time. The centered age variable used as the measure of time in Chapter 2 places the respondents on a common initial age-based status as their entry point into the study. In Chapter 3, the baseline is based on the time (or wave) of data collection and does not consider the age of respondents. Using a centered age variable versus a non-centered variable, such as wave, changes the estimates on the intercept, but does not affect the rate of change over time. The measure used for time as well as adding fathers into the analysis minimize the racial effects between mothers observed in Chapter 2.

I shift the focus somewhat in Chapter 4 to consider why some caregivers have higher rates of psychological distress than others. The findings suggest that caregiving for children with disabilities increases parental levels of psychological distress, with mothers of children with disabilities having the highest rates of psychological distress. This effect is even stronger for parents of children with more severe disabilities. I hypothesized that employment would reduce psychological distress in all parents. Mothers of children with disabilities have the highest reduction in psychological distress as their hours of employment increase followed by fathers of children with disabilities, suggesting that work may have more of a protective effect for these mothers. Parents of typical children see a similar reduction in psychological distress as their hours of employment increase. Interestingly, quitting a job or reducing hours due to caregiving demands also lowers predicted levels of psychological distress in mothers with a greater reduction for mothers of children with disabilities, suggesting that being employed may cause more stress for some mothers if job demands are too high or there is low job flexibility. The contrasting findings for employment suggest that it may be more beneficial to examine job quality rather than just being employed and to consider gender ideology which may affect how parents balance work and family.

### **UNFINISHED GENDER REVOLUTION**

Since the 1960s, there have been dramatic changes in women's work trajectories that affect the breadwinning dynamics in married couples (Graf and Schwartz 2011). The increases in female labor force participation indicate that women have entered traditionally male domains; yet, men have been less likely to reciprocate this in their household labor. England (2010) maintains that the changes in the gender system are uneven since "female"

activities (i.e., caregiving) are still devalued, resulting in little incentive for men to participate in these activities. While some research (e.g., Bianchi, Robinson, and Milkie 2006) suggests recent increases in men's household labor and childcare, others argue that fathers are more likely to play with their children rather than do routine household labor and rarely provide all of the childcare (Coltrane and Shih 2010). The overall argument in this dissertation is that caregiving is still primarily a mother's responsibility. The findings show lower levels of employment and higher levels of psychological distress for mothers compared to fathers, with mothers of children with disabilities having the lowest rates of employment and highest levels of psychological distress. For mothers of children with disabilities, it appears that the gender revolution has been even more stagnant.

Gerson (2010) and Graf and Schwartz (2011) argue that the gender revolution is embedded within social institutions that are resistant to change, thus creating conflicts in work and family. This is particularly relevant for families of children with disabilities who face outdated and inadequate institutional supports. Gerson's (2010) suggestion is to focus on family pathways rather than family types where breadwinning and caregiving are more flexible depending on the family situation. This requires a paradigm shift where families and their decisions about work and caregiving are seen as fluid rather than static. While it may appear that families have choices about balancing work and care, these choices are often constrained by structural factors. Stone (2007) refers to this as the double-bind where the rhetoric of choice collides with the reality of constraints. Thus, families experience public issues as personal troubles (Mills 1959).

Disability adds another layer of complexity as families reconcile the incapability of their public and personal lives. Families respond by compromising and forging new pathways. Lewis et al. (2000:1053) illustrate that challenging dominant gender expectations towards caregiving is difficult in a society with a “strong ideology of mothers as the carers for sick or disabled children.” Contrary to Lewis et al. (2000), Gerson (2010) suggests that gender ideologies are changing, but that economic structures do not support egalitarian relationships within families. This incompatibility derives from a view of care as a private good rather than a public good that benefits society as a whole (Folbre 2001, 2008).

Is it possible to create a new ethic of care? Folbre (2008) calls for reforming all carework, which Kittay (2002:257) suggests is possible if carework is not based on traditional gendered divisions of labor and “caring is just and justice is caring.” In individualistic societies, carework is dichotomized or seen as a binary – you are either dependent (in need of care) or independent. This binary view of carework does not consider the importance of our dependence and the reciprocal exchanges of care across the life course (Folbre 2008; Kittay 2011). To create a new ethic of care, we first have to recognize that we all receive care throughout our lives. Next, we have to address existing economic structures and the workplace practices that make it difficult for families to provide care. Below I propose policy changes that would do just that.

## **POLICY IMPLICATIONS**

The data in this analysis are not just numbers, but represent real people who experience adverse outcomes based on the unequal distribution of resources. The findings highlight the “burden of care” that disproportionately falls upon women and the need for

caregiver supports. As with most sociological research, my hope is that the findings in this dissertation influence social change so that we can begin to envision a society where care is valued and supported. Services and resources are part of the core of disability policy; however, policies have not changed in accordance with family needs. What do families of children with disabilities need?

To have equal opportunity, children with disabilities and their families need appropriate services and assistance with service coordination. Caregivers often need to understand the specialized language or “acronym soup” that service providers use (e.g., ADA, IEP, and IFSP). The process of applying and accessing social services is time consuming and complicated, and families often do not get support until a crisis occurs (Dowling and Dolan 2001). Families with children with disabilities often lack welfare benefits, access to information, appropriate childcare, public transportation, and appropriate housing as the child enters adulthood (Barnes, Mercer, and Shakespeare 1999; Kagan, Lewis, and Heaton 1998). Health care services are inflexible and schools provide limited job-training and post-secondary opportunities. Family caregivers lack informal support and experience work barriers (e.g., long hours, lack of flexibility, job insecurity) as evidenced in this dissertation.

Early identification and intervention are essential to assisting families of children with disabilities. Kilmer, Cook, and Munsell (2010) support the use of a system of care approach where the needs of the family as a whole are considered, including those who receive care and those who provide care. This type of service delivery supports the family unit and maximizes child outcomes by using an individualized family services plan.

Individualized family services plans do not assume that all families with children with disabilities are the same and are tailored to the family context. However, it is hard to translate these principles into practice. Changes are needed in the way social services are funded and delivered. Many services are provided through Medicaid and other needs-based funding through federal and state monies. These services and programs are also many of the first to receive less funding during times of federal and state budget cuts. Families cannot count on federal and state funded services and programs, and even with financial assistance, families often incur out-of-pocket expenses as they seek the appropriate care and services for their children. Several national nonprofit organizations such as The Arc and the Special Olympics provide families and persons with disabilities access to financial and caregiver support information, advocacy, employment training, and recreational opportunities. However, more support is needed for caregivers including appropriate childcare even as the child with disabilities grows older; better health, welfare, and educational services for children with disabilities; and expanded opportunities for children with disabilities to live at their fullest potential.

## **LIMITATIONS**

As with most research, there are limitations with the data. While these data are longitudinal, they only span a three year period, which hinders a full examination of both change and continuity over time. The structure of the data does address some of the shortcomings in past research by providing dyadic and household information. However, a series of questions about child well-being asked at one time point were primarily answered by mothers (and not by fathers) and thus had to be excluded from a dyadic analysis. The

questions addressed whether parents felt like their child was harder to care for than other children, if their child did things that really bothered them, if they found themselves giving up more of their life to meet their child's needs than expected, and whether they felt angry with their child. These questions would have made an important contribution to the analysis of psychological distress in Chapter 4.

As mentioned in Chapters 2 and 3, I do not control for childcare use since the questions were only asked in one wave of data, nor do I account for the extent of social networks. Appropriate childcare for children with disabilities is difficult to find and sustain. Parents often use a combination of private careworkers, family-based care, and nonstandard work schedules (Brandon 2000; Lewis, Kagan, and Heaton 2000; Malsch, Rosenzweig, and Brennan 2008; Presser 2003). Finding and arranging childcare can be a stressful process in and of itself. However, I would speculate that these supports (e.g., childcare and extended social networks) would allow mothers to have more gainful employment and also alleviate some of the psychological distress associated with caregiving (Shilling, Gilchrist, and Schinke 1984).

The addition of the type of employment and job quality data would have added to the overall analyses. Lewis et al. (2000) argue that caregiving strategies are inherently linked to job characteristics. For example, Webber and Williams (2008) found that women use part-time work as temporary solutions for their childcare difficulties while others (e.g., Lewis et al. 2000; Presser 2003) cite the use of nonstandard work schedules among parents. Litt's (2004) findings extend the connection between caregiving strategies and job characteristics by showing that mothers of children with disabilities experience higher levels of stress

because of job characteristics (e.g., inflexibility and low-wages) associated with nonstandard or “bad” jobs. The findings in Chapter 4 reveal that employment and quitting a job or reducing hours due to caregiving demands reduces psychological distress in mothers of children with disabilities. These findings suggest different pathways for mothers based on their employment. It may be that employment in “good” professional jobs reduces psychological distress for some mothers because of the working conditions while quitting “bad” service sector jobs with little flexibility reduces psychological distress in other mothers. It could also be that the same “good” professional jobs may increase psychological distress for some mothers because of the high job demands so mothers may leave these jobs to reduce their psychological distress. Without measures of employment type and job quality, one is left merely speculating about these processes.

### **FUTURE RESEARCH**

Single parents are purposely excluded from this dissertation because of the different economic and caregiving challenges that they face when raising a child with disabilities. Do single parents have the same employment outcomes as married parents? Cohen and Petrescu-Prahova (2006) found that children with disabilities were more likely to live with single parents, particularly their mothers. Some studies suggest similar employment outcomes for married and single-mothers based on the age of the child (e.g., Lee et al. 2004; Porterfield 2002) while others suggest a more consistent negative effect on single-mothers’ employment (e.g., Powers 2003). More research is needed in this area and should also consider whether employment mediates or intensifies psychological distress among single-parents.

A growing body of literature in family sociology suggests that women perceive the unequal division of household labor as fair based on comparisons to others (Greenstein 1996; Lennon and Rosenfeld 1994) and is contingent upon gender ideology (Greenstein 1996, 2009). Perceptions of fairness may be the link between the division of household labor and individual outcomes (Claffey and Manning 2010). For example, perceived fairness mediates the stress process with unfair divisions of labor increasing psychological distress (Claffey and Mickelson 2009; Lennon and Rosenfeld 1994). To my knowledge, perceptions of fairness have not been included in an analysis of caregiving for children with disabilities. Given my findings, future research would benefit from examining whether mothers perceive the effects that caregiving for a child with disabilities has on their employment as fair, whether they use a discourse of choice to explain these arrangements, and whether perceptions of fairness mediate the stress process.

Family sociology, in general, is encouraging more cross-national comparative research (Davis 2010). Researchers (e.g., Dowling and Dolan 2001; Leiter et al. 2004) have noted the importance of national policies in shaping the kind of care that families are able to provide for children with disabilities. This research connects macro- and micro-levels but rarely compares *across* national contexts. Does having a child with disabilities affect maternal employment in the same manner across countries? What role do national workplace policies (flex-time, parental leave, etc.), healthcare, public subsidies, and gender equity play? Is maternal employment lower in countries where fathers are encouraged to take family leave? Do mothers of children with disabilities exhibit the same levels of psychological distress across countries? Future research would benefit from cross-national comparisons.

As this dissertation demonstrates, there is a need for large-scale survey datasets to assess the extent of families who need services and to determine the effects that carework has on outcomes such as maternal employment. However, there is more to understanding the complexity of disability and carework than quantifiable data allow for. One avenue of inquiry is structured interviews with family caregivers as well as less structured family narratives that extend over a period of time to provide an account of the full range of interactions and activities in which families participate. It is also beneficial to look at situational complexities and cross-cultural comparisons to get a better idea of how race, class, and gender intersect with disability. One notable example, Schwartzberg (2005), relies on a multi-method approach that incorporates interviews, photographs, newspaper clippings, official documents, and personal mementos. This is a promising approach for sociologists who are concerned with communicating the lived experiences of marginalized groups and placing their accounts within a broader social and historical context.

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