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# All in the Family: Parents of Children with Disabilities and Retirement

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## Abstract

Mothers of children with disabilities face unique tradeoffs in retirement decisions. They may be more constrained in their ability to save for retirement, and may require greater economic resources to support their families in retirement while also balancing caregiving responsibilities. Benefits from the Social Security Administration (SSA) have the potential to enhance economic stability for these families. We use a mixed-methods approach, leveraging data from the National Longitudinal Survey of Youth 1979 and data from interviews with twelve mothers, to examine differences in retirement outcomes for mothers of children with disabilities compared with other mothers and to understand how mothers of children with disabilities think about retirement options, and the role of SSA benefits in their retirement planning. Quantitative analyses largely find no differences in retirement timing or planning for mothers of children with disabilities, but find that mothers of children with disabilities have lower labor market participation than other mothers; interviews identify caregiving responsibilities as key considerations for mothers' decisions about when, where, and how much to work. Qualitative data reveal that even among our relatively advantaged sample, caregiving, career trajectories, and expected financial needs of children affected retirement plans. SSA benefits were not a primary retirement consideration for our qualitative sample, though quantitative analyses suggest mothers with significant caregiving responsibilities are more likely to receive retirement benefits at an early age. Our findings suggest a role for outreach to families about available benefits and emphasize the importance of additional research on this topic with more diverse families.

Keywords: retirement, caregiving, disability

JEL: H5, I3, J26

## 1. Introduction

Parents of children with disabilities face a unique set of constraints and tradeoffs in retirement decisions. Mothers of children with disabilities—the focus of this study—are particularly likely to face challenges in preparing for retirement as they disproportionately bear the responsibility of caregiving. While other mothers may begin saving towards retirement during their prime labor market years, mothers of children with disabilities (i.e., health conditions that may limit the child's ability to attend school or work) are more constrained in their ability to work and save due to steeper caregiving responsibilities as well as well as increased expenses.

Compounding these challenges, a child's disability may require both financial support and caregiving well into the child's adult years. Though all families face tradeoffs between higher retirement income or increased time spent in retirement when considering retirement timing, these families--and mothers in particular--must factor in increased and continued caregiving responsibilities and the resulting need for economic stability for themselves and their child in their consideration. Specifically, while retiring may provide more time for caregiving, it could come at the cost of accumulating a greater amount of retirement savings; conversely, continuing to work and ensuring higher income in retirement may come at the cost of caregiving time.

Benefits from the Social Security Administration (SSA), including retirement and childhood disability benefits, have the potential to alleviate these concerns and provide economic stability for these families. For mothers of children with disabilities, especially, SSA retirement benefits may comprise a large portion of their planned income into retirement as they have been constrained from saving for retirement. Furthermore, eligibility for some disability benefits for their children may be influenced by parental claiming and entitlement of benefits, which may influence mothers' retirement decisions and timing.

The decisions families make regarding retirement have important implications for their well-being. Additionally, understanding these choices has important implications for the role of SSA benefits in supporting the families' economic wellbeing and caregiving abilities. While there is a small body of literature on spousal and parental caregiving and retirement, little is known about the retirement behavior of mothers raising children with disabilities and the role of current policy. We aim to address this important gap by answering two questions:

- (1) Are there differences in retirement savings and timing for mothers of children with disabilities compared with other mothers?
- (2) How do mothers of children with disabilities think about retirement options, and what is the role of SSA benefits in their retirement planning?

To examine these questions, we conduct an explanatory, sequential, mixed-methods study that leverage multiple data sources. First, we use survey data derived from a large and nationally representative sample to understand patterns, trends, and statistical associations between a child's disability status and various retirement outcomes of the mother. Then, we use data gathered from interviewing mothers who provide care for children with a disability to provide a richer and more nuanced understanding of quantitative findings and to answer questions that cannot be addressed through survey data alone.

We anticipate that the context of retirement decisions for mothers of children with disabilities is unique from that of other mothers, which may result in differences in retirement timing, savings, and other planning behaviors. Findings can be used to understand the unique needs of this population and the retirement decisions they face and to determine if and how the current SSA benefit structure influences retirement decisions.

## **2. Literature Review**

The decision to retire, and the nuance of what retirement means, is driven by a variety of individual, family, and structural factors. Previous work examining the role of informal caregiving on retirement timing—almost exclusively focused on spousal or parental caregiving rather than caregiving for a child with a disability—contrasts the frameworks of role strain, which points to hastened retirement, with economic needs, which suggests retirement may be delayed (Dentinger and Clarkberg, 2002; Gonzales et al., 2017). Though we know of no study examining the retirement decisions and timing of mothers of children with disabilities, in what follows, we review the existing literature in related areas to guide expectations. We first examine the gendered nature of caregiving overall, with attention to its impacts on well-being into retirement. We then review what is known about mothers of children with disabilities and examine previous work focused on parental well-being in later life when caregiving for children with disabilities. Lastly, we include how SSA policy may play a role in mothers' economic stability in retirement.

## 2.1 Gendered Caregiving and Economic Implications

Providing care for family members, such as parents, spouses, and adult children with disabilities is a responsibility that disproportionately falls on women. Women are more likely to take on caregiving responsibilities earlier, to work while providing care, to spend more time on caregiving, and to have more intensive caregiving responsibilities (Brandon, 2007; Butricia and Karamcheva, 2018; Carmichael & Charles, 2003; Cohen et al., 2013; Dow and Meyer, 2010;).

Previous studies find that caregiving responsibilities reduce the number of hours that women work (Johnson and Lo Sasso, 2006; Lee & Tang, 2013; Pavalko and Artis, 1997; Wakabayashi and Donato, 2005) while men who provide care experience an increase or no change in the number of hours worked (Butrica and Karamcheva, 2018; Lundberg and Rose, 2000; Sanchez and Thomson, 1997). In addition to a reduction in hours, caregiving also increases the likelihood of working in a part-time position, which often means a position with limited benefits such as health insurance and retirement savings matching, and decreases the likelihood that women work at all (Butricia and Karamcheva, 2018; Dow and Meyer, 2010). In addition to labor supply, caregiving impacts women's earnings. Women who have caregiving responsibilities often work in jobs with lower pay and have lower earnings overall (Butricia and Karamcheva, 2018; Weller and Tolson, 2018). Furthermore, the earnings decline from providing parental caregiving is often bigger for women than for men (Van Houtven, et al., 2013).

The negative effect of caregiving on labor market outcomes has significant implications for retirement as retirement savings and eligibility for programs such as SSA retirement benefits are often tied to employment. For example, many jobs offer defined contribution plans, such as a 401(k), that workers can contribute a percentage of their paycheck to and the employer matches the employees' contribution percentage. Working less hours, working in jobs with lower pay, working in a part-time position that does not offer such a retirement savings vehicle, or not working at all means that by retirement age, women who are caregivers have had less access to and participation in retirement savings plans than those who did not provide care. For example, 79.7 percent of older women who provide spousal care participated in a retirement savings plan through their employer compared to 84.8 percent of those who did not provide spousal care (Weller and Tolson, 2020).

In addition, less access to retirement plans and lower take-up rates means that women who have caregiving responsibilities have less retirement savings overall by retirement age than those

who did not provide care. For example, one study estimated the retirement savings gap between caregivers and non-caregivers for older married women is approximately \$9,000 (\$43,000 compared to \$51,950, respectively) (Weller and Tolson, 2018). Differences in retirement savings may increase the likelihood that women who provide caregiving delay retirement until a later age or end up living below the poverty line during their retirement due to lower retirement income.

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

There is evidence that caregiving, and the resulting implications for economic well-being in retirement, may be particularly salient for mothers raising a child with a disability. Previous work suggests that families of children with disabilities are more likely to be economically disadvantaged across a number of measures. In addition to increased likelihood of income poverty (e.g., Parish and Cloud, 2006; Stabile and Allin, 2012), these families are more likely to experience material hardship (Ghosh and Parish, 2015; Stoddard-Dare et al., 2015) and food insecurity (Sonik et al., 2016), and are less likely to have substantial assets or savings (Porterfield et al., 2006). Given the heightened risk of economic insecurity across the child's life, establishing sufficient enough savings to ensure an economically stable retirement may be of particular concern for these mothers.

Further, there is evidence to suggest that mothers are particularly impacted by caregiving for a child with a disability (DeRigne and Porterfield, 2017; Eriksen et al., 2021). Mothers of children of disabilities have lower labor market participation, lower wages, and often are more likely to work part-time than mothers of typically developing children (Costanzo and Magnuson, 2019; Earle and Heymann, 2012; Powers, 2001; Rupp and Ressler, 2009; Scott, 2018). To further compound these economic disparities, mothers of children with disabilities also have caregiving needs that last longer, often continuing past midlife and into the mothers' retirement years (Glidden et al., 2021; Knox and Bigby, 2007; Smith et al., 2012). This results in differences in resources available to these two groups of mothers as they enter retirement age. Using the Wisconsin Longitudinal Survey (WLS), Parish and colleagues (2004) found that the earnings and savings of parents of children with developmental disabilities were substantially lower as parents drew near to retirement age (age 53) compared to parents of typically-developing children, though both groups had comparable savings at age 18. These differences may also influence the context of the retirement decision itself. A key aspect of retirement decisions is what "retirement" means to mothers; retirement might mean different things to different people, ranging from not working at all to working in new ways. For mothers who have not been able to work consistently throughout

their child's life, retirement may have a different meaning than for mothers with a consistent and more traditional labor market history, perhaps because their experiences with work have been different or due to a lack of certainty around available resources.

The impact of caregiving for a child with a disability also varies greatly by the needs of the child and additional resources available to parents and families. A review by Grossman and Webb (2016) detailed the range and intensity of caregiving that older adults may provide for children with disabilities. The caregiver may provide assistance with Activities of Daily Living (ADLs), including bathing, dressing, feeding, and other hygiene-related activities, and Instrumental Activities of Daily Living (IADLs), including shopping, help with transportation, and other tasks. Depending on the nature of the child's disability, a mother's caregiving responsibilities may range from providing support for ADLs multiple times each day or to providing care around the clock (Grossman and Webb, 2016).

The caregiving needs for the child may also determine whether a child is likely to co-reside with parental caregivers. Co-residence is often associated with higher caregiver burden and an increased number of caregiving hours per week (Grossman and Webb, 2016). These, in turn, are associated with negative outcomes for parents, including higher likelihood of employment interruptions (Smith et al., 2010), greater likelihood of depression (Piazza et al., 2014; Magaña and Smith, 2006), overall poorer mental health and well-being (Seltzer et al., 2011; Smith et al., 2010) and poorer physical health (Smith et al., 2010; Yamaki et al., 2009). Selection may also be driving some of these outcomes; families with more resources may be more likely to have alternative acceptable living situations for their children.

Family structure, specifically whether the family includes two parents or a single mother, is crucial for many measures of parental well-being as they care for their child with a disability in later life and is also relevant for economic well-being and retirement. There is some evidence that children with disabilities are more likely to live in single-parent homes, particularly single-mother homes (Reichmann et al., 2004). Unsurprisingly, the choice sets for single mothers raising a child with a disability are much more constrained compared to mothers with a partner (Brandon, 2000; Porterfield, 2002; Parish et al., 2006). Single mothers are more likely to have earnings throughout their child's life and they also have increased caregiving responsibilities (Scott, 2018). These constraints offer a different context for retirement planning and savings than those faced by

mothers in two-parent households, who may follow a more traditional household production model that include a specialized earner and a specialized caregiver (e.g., Becker, 1981).

In summary, though there are no previous studies examining retirement for mothers of children with disabilities, the relevant literature suggest that mothers' retirement decisions and timing are likely to be impacted given their disproportionate role in caregiving. Further, mothers of children with disabilities are likely to be constrained in their savings and earning for much of their child's life, creating a unique retirement context compared to other mothers. Caregiving into retirement age may significantly change how an individual is able to retire or view retirement and contextual factors such as family structure, co-residence, and the nature and intensity of caregiving are likely to play a role. Finally, the literature also highlights the importance of understanding the retirement context for these families to better understand their economic well-being.

### **2.3 SSA Policy**

As mothers of children with disabilities consider retirement, SSA benefits have the potential to be a major factor in their future economic stability. Given that mothers of children with disabilities often have lower levels of earnings and labor market participation in their prime labor market years, they may have less retirement savings or access to retirement benefits through an employer, which boosts the importance of SSA retirement benefits. Further, SSA benefits are designed in part to offset some the wage disadvantages inherent in gendered caregiving, both in the benefits formula itself and through the provision of spousal benefits. Specifically, spousal benefits allow women who may have been the primary caregiver for their child with disability to collect retirement benefits based on the earnings records of her spouse (Rutledge et al., 2017).

In addition to retirement benefits, individuals with disabilities may qualify for SSA disability insurance benefits (SSDI) or Supplemental Security Income (SSI) payments. Before age 18, a child may qualify for SSI payments if their disability meets the SSA diagnosis criteria and their families have income and assets below a certain threshold.<sup>1</sup> These benefits may continue—or begin—after the child turns 18 as well. Another important program is the Disabled Adult

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<sup>1</sup> For minor children, SSA calculates the amount of parental income available to the child through a process called deeming. In 2022, in a two-parent household with one child, gross monthly income for the household would need to be below \$4,329 (equivalent to ~ \$51,948 annually) for the child to be eligible for any portion of an SSI monthly benefit (SSA, 2022). For more information about deeming, see: <https://www.ssa.gov/ssi/spotlights/spot-deeming.htm>

Children (DAC) benefit. To be eligible, an individual must have a qualifying disability that began before age 22 and have a parent who has died or is collecting retirement or disability benefits (SSA, 2022).<sup>2</sup> In this way, a parent's retirement claiming may compound the impact on the overall family well-being by opening an additional avenue for benefits for their child.

### 3. Data and Methods

#### 3.1 Overarching Design

The overarching design for this study is an explanatory sequential mixed-methods design (Creswell and Plano Clark, 2017; Teddlie and Tashakkori, 2009). Mixed methods research “combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration” (Johnson et al., 2007, p.123). Mixed methods approaches are appropriate for research questions that aim to explore multiple facets of an issue as they can provide researchers with a more complete understanding than either method could alone and facilitate triangulation across data sources (Creswell and Plano Clark, 2017; Johnson et al., 2007; Teddlie and Tashakkori, 2009).

Our explanatory sequential mixed methods design allows us to leverage information from the first (quantitative) analysis to inform the data collection approach for the second (qualitative) phase (Figure 1) (Creswell and Plano Clark, 2017; Teddlie and Tashakkori, 2009). Quantitative findings were used to define the target population; to highlight areas in which more or different information was needed to address our overarching research aims; and to develop the qualitative interview guide. Combining these methods provides greater *breadth* of insights into retirement savings and timing behavior by examining trends and making comparisons across groups through the quantitative analysis while also yielding insights of greater *depth* related to the experiences, thoughts, beliefs, and decision-making processes of mothers of children with disabilities (Curry and Nunez-Smith, 2014; Teddlie and Tashakkori, 2009). We integrate qualitative and quantitative findings using a “weaving” approach: Results are organized by topic, and qualitative and quantitative findings related to each topic are discussed together within the topic's narrative (Fetters et al., 2013, p.2142).

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<sup>2</sup> For more information about SSA family benefits, including DAC and spousal benefits, see <https://www.ssa.gov/benefits/retirement/planner/applying7.html>

**Figure 1. Explanatory Sequential Mixed Methods Design**

**Notes:** Adapted from Creswell & Plano Clark (2017). QUAN denotes the study’s quantitative component and qual denotes the study’s qualitative component. Capitalization reflects the prioritization of these data elements in our design. Figure reflects that quantitative analyses occurred first and drove the qualitative component’s design and both are combined in our interpretation of the data.

### 3.2 Quantitative analysis

**Data and sample.** For our quantitative analysis, we turn to available data sources that include measures of child’s disability and mother’s retirement. We use the National Longitudinal Survey of Youth 1979 (NLSY79) and the related NLSY79 Child and Young Adult (NLSY79 CYA) sample. The NLSY79 is a longitudinal survey first administered in 1979 that was administered annually from 1979 to 1994 and biennially from 1994 to present day. The survey sample is a nationally representative sample of youth, who were between the ages of 14 to 22 in 1979. In 2018, there were 6,878 respondents in the total sample.

**Table 1: NLSY Sample Counts**

	N	% Mother/Child Dyads
Number of Women in NLSY79	6283	
Number of Women in NLSY79 with Children	4,941	
Number of Children in NLSY79	11,545	
Children with Disabilities		
Child/YA reports limiting condition, ever	4,289	37.2%
Child/YA reports condition limiting work or school 2 consecutive waves	911	7.9%
Child/YA reports limiting condition, chronic	763	6.6%
Has a work-limiting condition in adulthood	1,113	9.6%
Mother has caregiving responsibility and child with limiting condition	773	6.7%

**Source:** Authors’ calculations from NLSY79 and CYA Sample.

The NLSY79 CYA surveys the biological children of the female NLSY79 respondents, who were born between 1970 and 2014. The survey was first administered in 1986 and biennially administered from 1986 to 2018. In 2018, there were 11,545 children included in the sample. These data provide rich information about children’s health and disability status as well as detailed

measures of the mothers' retirement savings and timing. The data also offer an adequate sample of children with reported disabilities.

To form our main sample of analysis, we start by linking the children from the Children and Young Adult (NLSY79 CYA) sample to their mothers in the NLSY79. Table 1 contains the size of the starting sample. Of 6,283 women in the NLSY79, 4,941 women, or 78.6 percent, had biological children who were included in the NLSY79 CYA sample. Note that there are 11,545 children to 4,941 mothers as 3,763 mothers, or 76.2 percent of mothers, had more than one child. Our main unit of analysis is mother-child dyads; we also include some models in which the mother is the unit of analysis.

### **Defining disability.**

The basis of our disability measures are questions from the NLSY79 CYA that ask whether the child at the time of the interview has some condition that limits their ability to do certain activities, such as attend school, complete schoolwork, do physical activity, or if they are an adult, work for pay. The survey also asks if the child at the time of the interview has a condition that requires medical attention, medication, or special equipment. Children are also asked about their specific conditions; diagnoses cover a wide range of medical conditions, in terms of type, duration, and severity.

Disability as a measure incorporates a variety of health conditions which may impact family life in different ways; some health conditions may require daily maintenance with little impact on day-to-day activities while others may require around-the-clock care. Therefore, how disability is measured in any given study has important implications for understanding results. To underscore the range of disability measures, the broadest possible measure of disability, which indicates whether the child ever answers in the affirmative for any of the relevant questions across all survey waves, yields 4,289 children, or 37.2 percent, of mother-child dyads. On the other hand, a measure that is restricted to children or young adults who continue to report a health condition in each subsequent wave that a child is interviewed following the first report of a disability, perhaps representing more chronic conditions, results in 6.6 percent of mother-child dyads.

In an effort to capture different dimensions of disability, we focus on three primary definitions. First, we use a measure of whether the child reports the condition in at least two consecutive interview waves; we find that 911, or 7.9 percent, of mother-child dyads report disability status under this definition. We use this measure as one of our key disability measures

for several reasons, First, because we are interested in understanding how a child's disability may influence retirement, we consider ongoing conditions to be particularly crucial in understanding the relationship between the child's health and the mother's retirement. Additionally, given that eligibility for SSA disability benefits requires a condition to last at least 12 months (or to result in death), we think this definition more closely matches qualifications for benefits.

Next, to approximate conditions and children who may qualify for DAC benefits from SSA, we consider a disability measure that places greater weight on conditions that occur in adulthood. For this measure, we consider the child to be disabled if the child has a condition that limits his or her ability to work for pay as an adult and if this condition began before the child turned 22. Table 1 shows that 1,113, or 9.6 percent, of mother-child dyads report disability status under this definition.

Finally, in order to better capture the role of caregiving, our last disability measure is intended to capture conditions that require more intensive caregiving. For this measure, a child is considered to be disabled if the child ever reports having a condition that limits his or her activity or requires medical attention, medication, or special equipment across all survey waves *and* the mother reports regularly spending time helping or taking care of a disabled or chronically ill household member.

### Sample Demographics.

**Table 2: Sample Demographics, Quantitative Sample**

	Full Sample of Mother/Child Dyads	Limiting Condition, Consecutive waves	Work Limiting Condition, < 22	Caregiving > 10 hours/week
Race/Ethnicity				
Non-Black, Non-Hispanic	76.2%	80.9% ***	82.2% ***	78.2%
Black	16.1%	13.0% ***	12.4% ***	14.6%
Hispanic	7.8%	6.1% ***	5.5% ***	7.2%
Marital Status				
Never Married	5.0%	4.6%	4.3%	3.6%
Married	60.2%	58.0%	61.0%	75.3% ***
Separated/Divorced	28.7%	30.9%	29.8%	18.9% ***
Widowed	6.1%	6.6%	5.0%	2.3% ***
Number of Children	2.84	2.89	2.77 *	2.80
Age at first birth	23.59	24.67 ***	24.22 ***	23.07 *
Highest Level of Education				

<HS	8.9%	7.4%	7.8%	12.3% *
HS	42.4%	35.2% ***	37.9% **	41.0%
Some College	24.7%	25.3%	25.4%	28.9% *
BA +	24.0%	30.6% ***	28.9% ***	17.9% ***
HH Income (2010\$)	\$ 77,336.00	\$ 79,444.00	\$ 78,597.00	\$ 63,761.00 ***
Mother's Self-rated health is Fair or Poor	12.5%	18.9% ***	16.9% ***	21.3% ***
Urban	76.1%	82.7% *	79.6%	80.0%

*Source: Authors' calculations using NLSY79 and CYA. Estimates based on NLSY sample weights. Measures taken from the final survey wave available, unless otherwise noted.*

The disability measures defined above allow us to subgroup the NLSY79 mother-child dyads into those whose children have a disability vs. those who do not. Table 2 contains the demographic breakdown when we subgroup using the disability measures. First, examining differences by mother's race, we find that mothers with children with disabilities as defined as a condition that limits school attendance or working for pay for two consecutive survey waves or a work-limiting condition for a child over age 22, are statistically significantly more likely to be non-Black and non-Hispanic than the general population of mothers. When disability is defined as the mother regularly spending time helping or taking care of a disabled or chronically ill household member and also having a child who has ever reported having a limiting condition, there is no statistically significant difference in racial make-up.

Next, looking at differences in the marital status of mothers, we find no statistically significant difference between the two subgroups and the full sample. However, mothers with significant caregiving responsibilities and a child with a disability are more likely to be married than the full sample, less likely to be separated and divorced, and much less likely to be widowed. We find very few notable differences in mother's number of children.

Age at the birth of the first child is statistically significant across subgroups. When disability is defined as the child having a limiting condition across two consecutive survey waves and the adult child having a condition that limits their ability to work for pay, the average age of the mother at her first birth is older (24.7 and 24.2, respectively compared to 23.6 for the full sample). Mothers with caregiving responsibilities, however, had their first birth at a younger age, on average (23.1).

The subsample of mother-child dyads who have a disabled child have different levels of maternal education than the full sample. When disability is defined as the child having a limiting

condition across two consecutive survey waves and the adult child having a condition that limits their ability to work for pay, mothers are statistically significantly more likely to have attained a bachelor's degree or higher than mothers in the full sample and are less likely to say that a high school diploma is their highest level of education. On the other hand, when disability is measured by the mother having caregiving responsibilities, mothers are statistically significantly less likely to have a bachelor's degree or higher as their highest level of education. Instead, they are more likely to have less than a high school diploma *or* have attained some years of college.

The only subgroup that shows statistically significant differences in household income is when disability is measured by the mother having caregiving responsibilities and having a child with a limiting condition. In addition to lower education levels, mothers with significant caregiving responsibilities have, on average, a lower household income in 2018 dollars; these mothers have an average household income of \$74,004 compared to \$81,354 of the full sample, or around nine percent less.

For all measures of disability, mothers who have a disabled child are statistically significantly more likely to have ever self-reported their physical health as being "fair" or "poor." Lastly, when disability is defined as the child having a limiting condition across two consecutive survey waves, these mothers are statistically significantly more likely to reside in an urban area than mothers in the full sample, but still the percentage of mothers who reside in an urban area remain high, ranging from 76.1 to 82.7 percent.

Overall, examining the sample composition suggests some important context. First, as expected, we find differences in the sample of mothers with children with disabilities, however defined, from the overall sample of mothers, highlighting the importance of accounting for selection into parenting a child with a disability in our analysis. Second, while mothers with children with disabilities under the first two definitions are similar in many of their characteristics, mothers with significant responsibilities are a distinct population of mothers and vary from the overall population of mothers as well as the population of mothers of children with disabilities who do not report caregiving responsibilities. This indicates the importance of measuring caregiving, and, perhaps, selection into caregiving. These mothers have lower levels of education and are more likely to have a partner, perhaps indicating the likelihood of living in a household with the characteristics of Becker's earner/career model (1981). Finally, mothers with children with disabilities, defined without caregiving responsibility, appear to be more advantaged across

a number of measures than other mothers in our sample. This is likely to impact our understanding of their retirement context.

### **Outcome Measures.**

For our quantitative analysis, the outcomes of interest are retirement-related measures of the mother. The final wave of NLSY79 survey data available is from 2018, which is when the respondents were between the ages of 53 and 61 and the survey began asking more retirement-related questions. When possible and appropriate, we use measures drawn from the latest wave of the survey; otherwise, we use the most recent measure available. We also examine trajectories of employment and retirement savings across multiple survey waves. Specifically, we look at the mother's overall employment history, including whether she has ever worked part-time; we use specific child ages (age-6 and age-18) to compare employment patterns. We also examine whether the mother has any retirement savings and the total retirement savings amount. The NLSY79 tracks the retirement savings amount across multiple survey years, specifically between 1994 to 2018; to account for differences in timing, we limit our analysis to retirement savings from 25-50, mothers' prime labor market years.

Many of our outcomes are related to timing of retirement. In 2012, some respondents were asked to provide the age at which they predicted they would retire. Though this is a limited sample, we include this measure. We also include measures from 2018 (if available) for whether the mother expects to be working after age 65, the age she expects to receive SSA retirement benefits (or started to receive them), and whether she has ever had any early withdrawals from her retirement account. Finally, we examine the age at which the mother reports that she is retired or plans to retire. In addition to timing measures, we also examine outcomes related to retirement planning activities and retirement definition and receipt of a variety of SSA benefits.

### **Method.**

We take a descriptive approach to our quantitative analysis, intending to understand patterns of retirement behavior and outcomes in a large sample. That is, we do not estimate precise or causal models but focus on broad associations between disability and relevant maternal retirement and labor market outcomes. Given the differences observed by disability status in our sample, to better isolate the role of child's disability on mother's retirement outcomes, we use inverse probability of treatment weighting (IPTW). IPTW is intended to create a synthetic sample balanced on baseline characteristics regardless of treatment status—in this case child's disability

status (e.g., Austin and Stuart, 2015). Appendix Figure 1 indicates the differences in our pre- and post-weighted sample.<sup>3</sup>

To estimate these associations, we use traditional OLS and bivariate models on our IPT weighted sample. We first use bivariate analysis to examine differences in labor force participation and retirement savings. We then use OLS and event history models to estimate an association between the child's disability and the mother's time to retirement. Given the age of our sample, we have significant right-censoring in our data; event history models are well-suited for accounting for bias from this truncation (Allison, 1984).

### **3.3 Qualitative Analysis**

The second phase of our study is a qualitative analysis that builds on the initial (quantitative) findings. We used findings from the quantitative analysis to define our target population for the qualitative interviews, to determine areas of focus and additional exploration during the interviews, and to refine our interview guide. Our goals for the qualitative analysis were two-fold. First, we aimed to provide context for the quantitative findings, which were related to our first research question (if there are differences in retirement savings and timing for mothers of children with disabilities compared to other mothers), by exploring themes related to how mothers of children with disabilities save for and time their retirement. Next, we aimed to explore our second research question (how mothers who provide care for a child with a disability think about retirement options and plan for retirement, and whether SSA benefits factor into those plans), which is intended to shed insight into the processes and conceptualizations underlying retirement behavior and planning.

We recruited twelve mothers who were at least 45 years of age, have at least one child (of any age) with a disability of any kind, and who provide at least 10 hours of care or support to their child each month. Because findings from the quantitative analysis suggested a broad definition of disability was likely to both maximize sample size and promote greater diversity in sociodemographic characteristics, we employed a broad definition of disability in our recruitment materials. To achieve this target, the study team shared a study flyer via email with twelve agencies

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<sup>3</sup> We use The Toolkit for Weighting and Analysis of Nonequivalent Groups (twang) package to generate weights (Ridgeway et al., 2021). Our weighting model includes exogenous variables measured at the time of or prior to the child's birth, including mother's race, mother's education, mother's self-rated health, mother's household income as a young adult, mother's family status, mother's marital status at the time of her first birth, mother's age at first birth, mother's self-assessed health status prior to first birth, and child's birth order.

in Dane County who provide services or resources to people with disabilities (e.g., local ADRC, Medicare waiver program providers, disability benefit specialists, day programs, etc.) (see Appendix A). Agencies were asked to post study information in their buildings, share the study flyer on their social media accounts, and distribute the flyer to any relevant mailings being sent to their participants. The study flyer included study information and eligibility as well as a QR code or a direct link to a Qualtrics survey. This survey screened potential participants using the aforementioned study criteria (i.e., mothers who were age 45 or older; provided care to at least one child with a disability for at least 10 hours per week; and resided within Dane County). Eligible mothers were asked to supply contact information and preferred method of contact. Potential participants were then contacted by members of the study team and scheduled for an interview. Of the sixteen inquiries that were received during the recruitment phase, twelve interviews were scheduled and conducted.

Data was gathered during individual interviews using a semi-structured interview guide (Appendix B). Interview questions were developed to address the study's research aims and took into account key findings from the quantitative analysis, with an emphasis on how caregiving responsibilities shape decision-making about retirement and retirement timing and how interview participants conceptualize retirement. Insights from the quantitative analysis suggested that a richer and more nuanced understanding of the contexts and constraints that shape mothers' experiences and how these experiences evolve would lead to a deeper understanding of mothers' experiences related to caregiving, work and retirement. We therefore structured the interview to gather detailed contextual information about mothers' families and caregiving activities; comprehensively examine mothers' work and caring experiences across adulthood; and qualitatively explore mothers' perceptions, feelings, and decision-making processes about caregiving, retirement, and work. Questions asked participants to walk through their employment history, current and past caregiving history, retirement planning, and basic demographic information.

Participants were invited to do interviews in person, via video chat, or via telephone. All twelve participants chose to do their interview by phone or video chat. Interviews took 30 to 90 minutes and participants who completed the interview were offered an electronic gift card for \$75 via email or mail as a thank you. Each respondent provided consent to take part in the research and

permission to audio-record their interview. All recruitment and data collection efforts were approved and overseen by the University of Wisconsin's Institutional Review Board.

With participant consent, interviews were recorded and transcribed using a professional transcription service. The study team then read each transcript individually to facilitate immersion in the data. Transcripts were each open coded thematically, organized into initial categories, axially coded into refined categories and subcategories, and recoded as subsequent themes emerged (Liamputtong, 2009). Themes were explored both within and across cases (Ayres et al., 2003). Thematic analysis entails the researcher closely examining the data to identify patterns in meaning that recur throughout the interviews to derive themes (Nowell et al., 2017). Researchers have found this to be an appropriate method to understand the experiences of participants in qualitative research.

As indicated in Table 3, the sample we recruited for our interviews was, on average, a highly advantaged sample across many domains. None of our mothers identified as African American or Hispanic American, three-quarters were married, three-quarters had a college degree or higher, and the mean household income was over \$125,000. This also differs from our quantitative sample, particularly in terms of education levels. Mothers in our sample were most likely to report that their child had a diagnosis of some developmental disability, usually autism or Down Syndrome.

**Table 3: Characteristics of Qualitative Sample (Interview Participants)**

Characteristic	Proportion/N
Race/Ethnicity	
Non-Black, Non-Hispanic	100%
Black	-
Hispanic	-
Marital Status	
Married	75%
Not Married	25%
Mean Number of Children	2.8
Highest Level of Education	
<HS	-
HS	-
Some College	25%
BA +	75%
Mean yearly household income	\$126,700

Child with a disability lives in the home	83%
Mothers who identified as retired at the time of the interview	25%
Age of Child with a disability	
Under 18	N = 5
18+	N = 7
Disability Diagnosis	
Down Syndrome	N = 5
Autism	N = 5
Other	N = 2

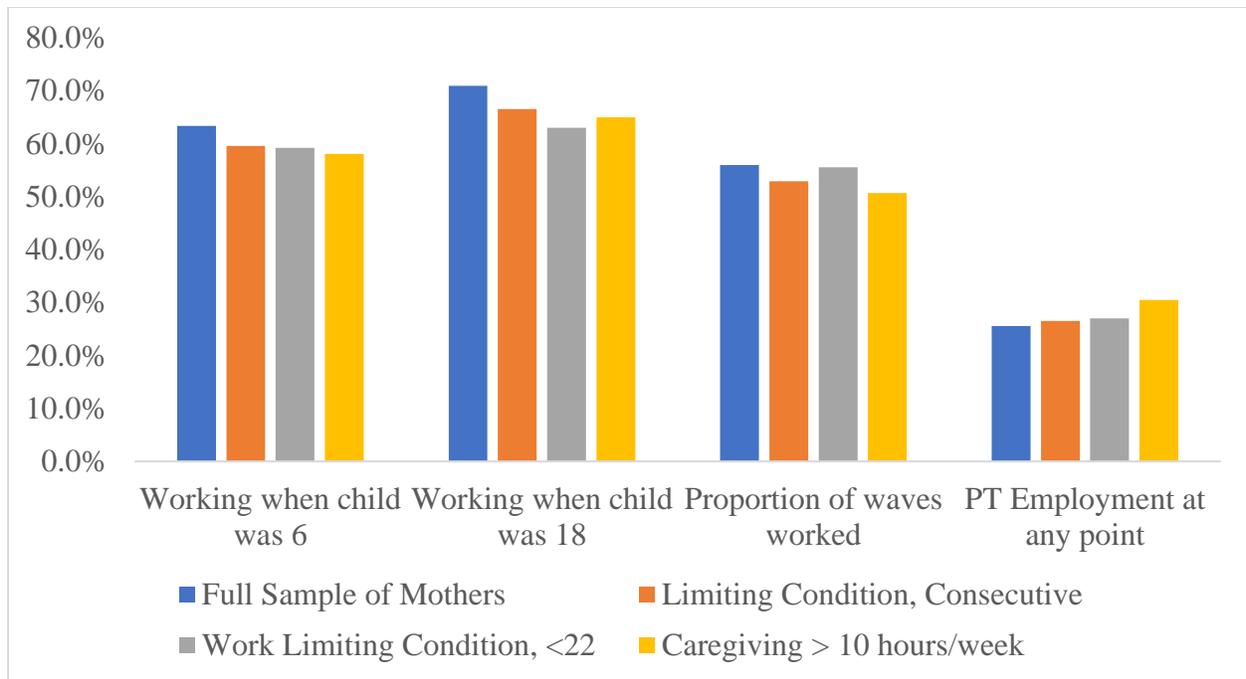
*Source: Authors' calculations from qualitative sample.*

## 4. Results

### 4.1 Are there differences in retirement savings and timing for mothers of children with disabilities compared with other mothers?

To address our first research question—whether mothers with a child with a disability have different patterns of retirement savings and timing—we primarily rely on quantitative analyses bolstered by contextual insights yielded from our qualitative interviews. We begin by examining the labor market history of mothers as crucial context for retirement. If mothers' labor market participation is limited due to caregiving responsibilities as suggested in prior literature, the context for retirement decisions and resources may differ markedly. From our quantitative analysis, we find that mothers of children with disabilities, across all measures of disability, have lower labor market participation than other mothers, which is noted in Table 4 and accompanying Figure 2. This gap widens as their child ages. Though not shown, the estimates of differences in employment at the child's 18<sup>th</sup> birthday hold in a multivariate regression context as well. If mothers are less likely to work, this impacts the resources available as they reach retirement.

**Figure 2: Mothers' Employment Trajectories**



**Table 4: Mothers' Employment Trajectories and Retirement Savings in Midlife by Child's Disability Status**

	Full Sample of Mothers	Limiting Condition, Consecutive Waves	Work Limiting Condition, <22	Caregiving > 10 hours/week
Working when child was 6	63.4%	59.6%	59.2%	58.1%*
Working when child was 18	70.9%	66.5%	63.0%*	65.0%*
Proportion of waves worked	56.0%	52.9%	55.5%	50.7%*
PT Employment at any point	25.6%	26.5%	27.0%	30.5%*
Any Employer-Sponsored Retirement Savings	21.3%	20.7%	21.0%	16.4%*
Amt in Employer-Sponsored Retirement Savings (conditional on any savings)	\$46,703	\$41,921	\$41,602	\$32,948*

**Source** Figure 2 and Table 4: Authors' calculations using IPTW sample of NLSY79 and CYA. Retirement savings measures drawn from ages 40 to 55. Notes: Figure 2 graphically depicts the first four rows of Table 4 with a bar graph displaying the proportions of mothers working when their child was ages 6 and 18, the proportion of waves worked, and proportion with part-time employment at any point.

\* indicates statistically significantly different from full sample of mothers at  $p < .05$

We also examine bivariate differences in retirement savings from age 40 through age 55. We do not find statistically significant differences in personal, pre-tax retirement savings during these years of mothers' lives, using any of the measures of child disability (not shown). We do find, following from the differences in likelihood of employment, differences in the likelihood of having any retirement savings through an employer-sponsored account for mothers of children with significant care giving responsibilities. When we examine the amount of savings, conditional on whether mothers have any savings, we again find that mothers with significant caregiving responsibilities report fewer savings on average. We note that these measures are relatively noisy; that is, there is a wide variation in savings generally, which may make it difficult to detect differences. Additionally, a majority of mothers have no retirement savings, so, mothers with any savings reported are likely to represent a particularly advantaged group. Next, we estimate OLS models predicting the age a mother plans to retire, whether she expects she will be working full-time after age 65, the age at which she expects to collect SSA retirement benefits, and whether she has taken any early withdrawals from her retirement savings. Overall, our estimates are rather imprecise and suggest no clear relationship between our measures of child disability and mothers' retirement timing or planning. We also estimate a Cox Proportional Hazard model to understand how having a child with a disability may impact the risk of retirement.<sup>4</sup> These models suggest a statistically significant decreased hazard of retirement across all three measures of disability; this statistical significance holds for mothers with significant caregiving responsibility when employing the inverse probability of treatment weighting as well. This suggests that mothers with caregiving responsibilities may be less likely to report retiring than other mothers, contingent upon having worked during the child's lifetime. We also estimated models separately for married mothers and single mothers, but find no differences in our estimates by mother's marital status.

**Table 5: Retirement Timing and Other Outcomes by Child's Disability Status**

	Age Plans to Retire	Expects to be Working After Age 65	Age R Expects to Collect SSA retirement	Any Early Withdrawals	Hazard of Retirement
Limiting Condition, Consecutive waves	0.928 (1.53)	0.011 (0.027)	0.026 (0.204)	0.043 (0.029)	0.88 (0.111)
Work Limiting Condition < 22	0.508	0.003	-0.178	0.339	0.866

<sup>4</sup> Because our sample suffers from right-censoring bias, we expect the Cox models to provide more unbiased estimates of the relationship between retirement and child's disability.

	(1.69)	(0.030)	(0.236)	(0.033)	(0.130)
Caregiving	-1.65	0.005	-0.231	-0.017	0.753+
	(1.93)	(0.043)	(0.353)	(0.044)	(0.111)

**Source:** Authors' calculations using sample of NLSY79 and CYA. Robust standard errors in parentheses. Covariates include: mother's race, sex, education, marital status, age at first birth, number of adults in the household, number of children in household, age at last interview, year of interview, poverty status of mother's household in 1979, mother's health status, child's age. Hazard of retirement is estimated using a Cox Proportional Hazard Model and displayed as hazard ratios. All other estimates are OLS coefficient estimates.

\*\*\* $p < .001$  \*\* $p < .01$  \* $p < .05$  + $p < .10$

We next turn to our qualitative analysis to provide additional context on the quantitative findings. All of the mothers we interviewed had spent time in paid employment while providing care for a child with a disability at some point in their life. These mothers discussed several factors that affected the extent of their labor market participation, as well as the types of jobs they held. Many mothers emphasized the critical need to have a flexible workplace, which looked different depending on the needs of her family. It may have been a workplace with daycare on site or an opportunity to work from home. Many mothers we interviewed worked only during school hours while their children were in school. The most common adaptation was a flexible weekly schedule that could be adjusted with short notice. Described one mother:

*It was worth taking a pay cut to be in a place where, you know, I could go in on a Saturday instead of being a nine-to-fiver Monday through Friday. I mean, more flex and flow. And when you have that, you can meet your obligations, whether it's doctor's appointments or, you know, whatever else is going on or an early release day (at school) or whatever. If that exists, you can meet it.*

When the mothers we interviewed found a workplace that could accommodate their needs, they tended to stay in these positions for many years, despite the impact staying in a job might have on career advancement. One mother noted the resistance to pursue career advancement or higher pay for fear of losing the flexibility in her current job:

*I mean, I have, you know, it's hard to walk away from something that is so flexible and allows me to be there to care for him. But then, you know, I can't do, I'm not always available to do trainings and, or look for a better paying job or anything like that so that's hard.*

Mothers also described how caregiving requirements affected the amount that they were able to work. Many talked about needing to cut back on their hours, either temporarily or

permanently, to meet the caregiving needs of their children at different points in their life. Others talked about taking contract or seasonal work to accommodate their need for a flexible schedule. Some mothers talked about this as a conscious choice they made to spend more time with their children. However, most mothers talked about these changes as unavoidable, since alternative care was not available for their child. Almost all families talked about the school system being the only consistent care their child had, outside of the family.

*Since my (child) graduated from high school. Or I should say -- how about this -- not graduated from high school. Since my (child) transitioned from 40 hour a week stable educational access point to the 18 to 21 program, I have not been able to maintain full-time employment because I cannot maintain full-time care.*

While some mothers were able to return to full-time or adjust to reduced hours, this was not possible for all. Some mothers, typically those who had children with more significant caregiving needs or complex health conditions, tried to work reduced hours but eventually needed to leave their paid employment completely. Described one mother:

*...At one point he had over twenty different doctors. So juggling appointments all the time, juggling surgery, complications, routine tests all the time, so there would just be no way; I can't work. There's just too much that needs to be taken care of with him.*

A key factor affecting mothers' decisions about work was whether or not they had other sources of income flowing into the household. Mothers who were single parents talked about the importance of formal or informal child support payments from the other parent and public benefits, which allowed them to either stay home or work reduced hours while their child was in school. However, caregiving needs and financial strain lasted long after their child reached adulthood. For some mothers, their child reaching adulthood was a concern, specifically for those who relied on care from the school system and child support from the other parent that would stop or reduce greatly when their child was 18.

Mothers in two-parent, dual-earner households discussed a different set of considerations and trade-offs. Multiple mothers who were in two-parent households noted that they relied on one parent to work while the other stayed home or had a significantly reduced work schedule. Typically, reflecting traditional gender roles, it was the mother who stayed home. Only one family talked about a specific point in time where they made a decision about which parent would stay

home based on who was the higher earner. The rest of the mothers could not identify such a decision point. For most mothers, this did not feel like a choice. Rather, they felt it was necessary to meet the needs of their family. Upon reflection, mothers had a range of feelings about their experiences. Some noted that this was their preference as they wanted to leave their career to be home, providing care for their child. However, others talked about the conflict of wanting to provide care but also wishing there were other options. One mother talked about her experience staying home.

*I don't want to say stuck, because it is still choices along the way, but it just—my husband got to go do it and do his thing and I was here doing—I was a traditional mom, taking care of everything in the house and I would have liked to maybe not do all that, you know?*

Other mothers in two-parent households noted that they took positions with weekend or evening hours that were opposite of their partner who had a more “typical” schedule so there would always be someone at home who could provide care for their children. In these families, the partner played a larger caregiving role than the more traditional care models of the families described above. One mother who worked in a job with primarily evening hours noted the reality of their schedule:

*My husband was very cooperative. If I walked in – most of the times he walked in the door, and I walked out the door.*

Taken together, our quantitative estimates and qualitative findings suggest different patterns of employment across a child’s life course and potentially, different patterns of retirement risk for mothers with significant caregiving responsibilities. Though quantitative analyses suggest little evidence of differences in the timing of retirement, the qualitative data suggest that a child’s disability and mother’s caregiving responsibilities do indeed play a role. To better understand the mechanisms and nuances of these patterns, we turn to our second research question.

#### **4.2 How do parents of children with disabilities think about retirement options, and what is the role of SSA benefits in their retirement planning?**

We approach our second research question—how parents think about retirement options and the role of SSA benefits—with an emphasis on data collected via interviews with mothers and present those findings first. We used initial and helpful—though limited—insights gained through the quantitative analysis as a starting point for developing questions about the nuanced facets of how

mothers conceptualize and plan for retirement. Here, we explore what retirement means to mothers, mothers' expectations and hopes for retirement, how mothers make decisions about retirement, and how SSA benefits factor into retirement planning.

### **Meaning of Retirement.**

Most of the mothers we interviewed had difficulty defining retirement, and, once they were able to settle on a definition, these definitions varied. Of the mothers we spoke with who considered themselves retired at the time of the interview, most viewed leaving their career as the threshold that defined their retirement. However, this became more complex due to the reality of parenting a child with a disability. For some, their retirement happened much earlier than planned as they needed to leave the labor force to provide care for their child. A small portion of the mothers who were working in a paid position at the time of their interview noted that they did not see themselves ever retiring, as they did not plan to stop working entirely. Even if they planned to retire from their current job, these mothers noted the importance of having something to do and continuing to contribute to their community. They wanted to continue to work in some capacity, but retirement meant they could choose something of interest or work reduced hours.

*I guess I would never want to just be completely retired. I would have to do something. So I'm hoping that maybe, you know, if I retire from my company maybe I can help or assist in where (my child) goes.*

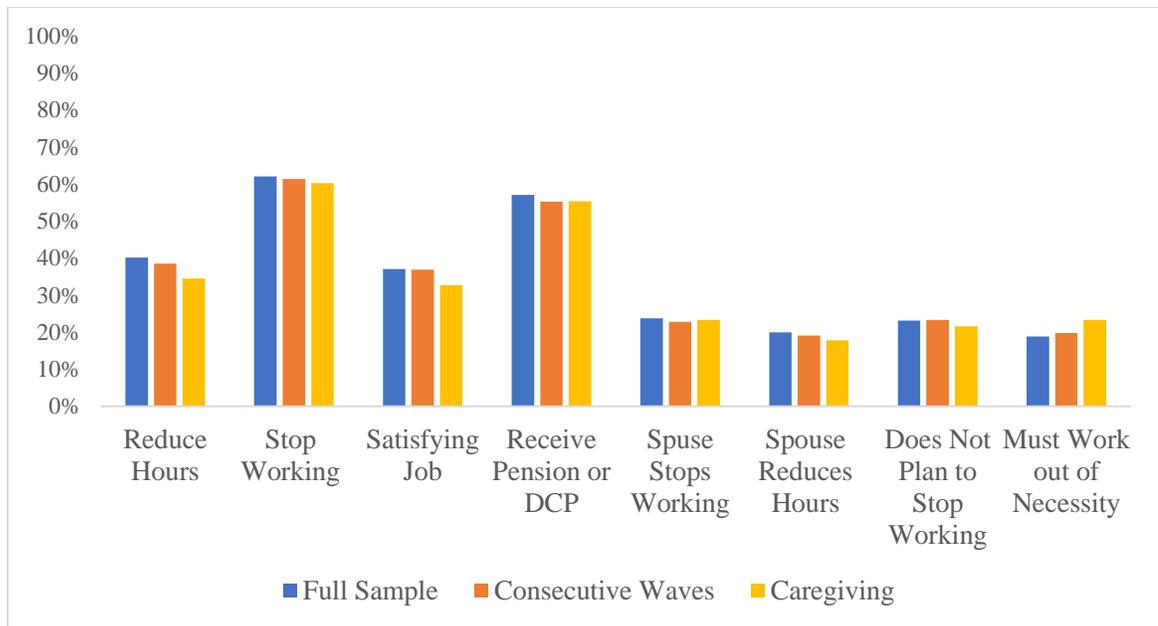
While not directly related to the topic of when or how to decide whether to retire, it is noteworthy that these mothers also discussed that constructs such as "working" and "retirement" as traditionally defined meant something different for them, given that their caregiving responsibilities for their child would continue beyond paid labor market participation. Many noted that retirement would mark the end of their employment in a formal job, but unlike their peers, would not represent a significant change in lifestyle as they expected to continue providing full-time or nearly full-time care for a child with a disability. Described one mother, "Yes, technically, (I'm retired) from the workforce but I work all the time. I mean, literally, I am always working." Another mother explicated how caregiving will mean her work will continue beyond a more traditional conceptualization of retirement, this way:

*I don't know if I will ever have retirement per se. I mean, if my husband and I try to go away once a year, where our parents can stay with the kids, that will be considered like my week of retirement or something, but I don't think it will*

*ever be (retired), you know, (my son is) here, all my jobs are right here within the household and stuff.*

We also explored whether mothers in the quantitative sample were more or less likely to define retirement differently based on their child’s disability status. Mothers were asked about a variety of ways they may define retirement, such as reducing the number of hours worked, stopping work entirely, working for fun at a satisfying job, or receiving retirement income via pension or defined contribution plans. Here, we show the proportion of the IPT weighted sample responding affirmatively to each definition. As with our qualitative data, we see some differences in how mothers with children with disabilities, and, in particular, mothers with considerable caregiving responsibilities, define retirement. These mothers are less likely to define retirement as a reduction in hours worked than other mothers and marginally more likely to say that they must continue to work out of necessity.

**Figure 3: Definitions of Retirement**



**Table 6: Definitions of Retirement by Mothers in IPT-Weighted Sample**

	Reduce Hours	Stop Working	Satisfying Job	Receive Pension or DCP	Spouse Stops Working	Spouse Reduces Hours	Does Not Plan to Stop Working	Must Work out of Necessity
Full Sample	0.402	0.621	0.371	0.571	0.238	0.2	0.232	0.189
Limiting Condition, Consecutive waves	0.385	0.614	0.369	0.553	0.228	0.191	0.233	0.198
Caregiving	0.345*	0.603	0.327	0.554	0.233	0.178	0.216	0.233+

**Source** Figure 3 and Table 6: Authors' calculations using IPTW sample of NLSY79 and CYA. Bivariate proportions shown. Mothers may select more than one definition.

\*\*\* $p < .001$  \*\*  $p < .01$  \*  $p < .05$  +  $p < .10$

### Plans and hopes for retirement.

Most mothers talked about how their previous view of retirement had changed since having a child with a disability. Many noted that they would need to increase the amount of savings needed to retire since they would also be saving for their child's future. For most families, this meant working longer than planned. Described one mother:

*You know, I'm projecting myself to be at a transitional point at 72, because I think I need to be earning up until that point in order to make sure that I have more set aside for my daughter. And I don't consider my needs to be primary. I consider hers to be primary in terms of resources. So I, you know, have always kind of thought everything I'm putting in the pot is, you know, 50% mine, 50% hers. But as I start to see the way the economy is shifting, now we're going 40-60 And I'm putting 60% for her and 40% for myself because, you know, I know that I have to be the engine that powers us.*

Many mothers who had yet to retire at the time of their interview had a hard time visualizing their retirement as they were still learning how independent their child could become. Many noted that they were working toward more independence for their child but were ultimately unsure how much support their child would require as they age. This uncertainty made it difficult for them to plan when and how they would retire. For those closer to being ready to retire, this uncertainty seemed to cause more distress. Described a mother:

*And of course, I worry, you know, is my son going to be living with us? Is he going to be able to go off on his own? Yes, he's independent, but I don't know if that – I don't know what that's going to look like.*

Another mother echoed these feelings of uncertainty and a desire to balance being present to provide protection and support for their child with facilitating their child's independence. She stated:

*I feel like it's a lot – there's a lot more unknown to retirement because we want (our child) to be as independent as possible. But we are also like very protective of (our child) so there's just, a lot of unknowns about retirement now. It doesn't feel as wide open.*

### **Constraints and trade-offs in retirement timing.**

Financial ability to stop working was the primary factor that motivated the timing of retirement for almost all of the mothers we interviewed. Caregiving requirements for their child with a disability were also heavily considered. While many mothers had other caregiving responsibilities beyond that of their child with a disability (grandchildren, parents, neighbors, etc.), mothers did not feel that these additional caregiving responsibilities factored into the timing of their retirement. A few mothers also talked about their retirement occurring when their own medical needs meant they were not able to continue working.

In addition to these primary reasons, mothers had other factors to consider when planning the timing of their retirement. For some, once their partner retired, they were highly motivated to retire themselves, particularly if they had the financial means to do so. A few mothers talked about career ambitions and retiring once they felt that they were finished with their career. Only one mother mentioned the availability of health insurance as a prime consideration for the timing of her retirement. One mother captured the complexity of figuring out the timing of retirement when she talked about some of her considerations:

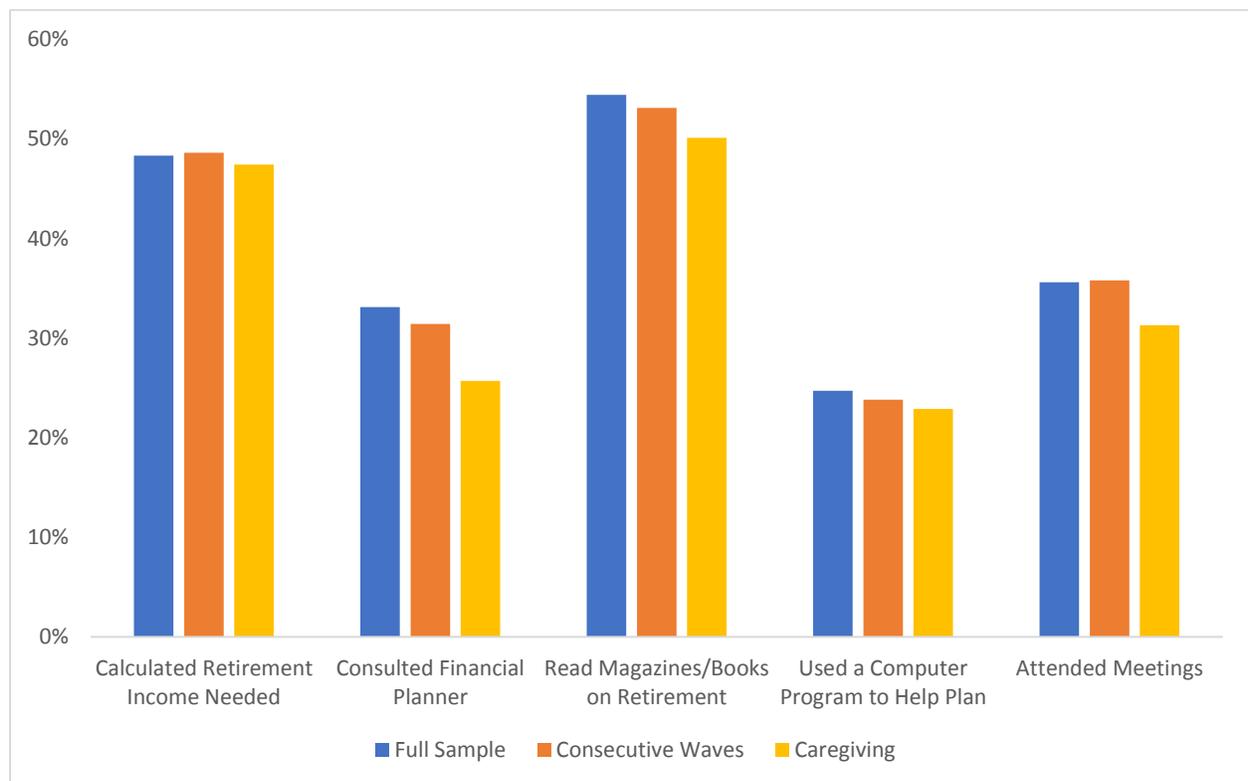
*Obviously, what's paid off. Let's see. Probably do I feel like I have more to offer to my career? Can I truly afford it? You know where will (my child) be at that point? Is he going to be with us or is he going to be living somewhere else? A lot of questions on that to determine.*

### **Planning for Retirement.**

All of the mothers we talked to had done some kind of preparation for retirement. For some, they did their own calculations and planning. However, most had sought outside expertise. The most common resources were those available through employers such as human resources departments or benefits specialists. Several families had also met with a combination of financial planners, benefit specialists, and/or lawyers to ensure they had what they needed in place for themselves and their child with a disability. These mothers noted the difficulty of and importance in finding a professional with the knowledge of disability benefits and retirement more broadly.

Findings from quantitative analyses suggest similar retirement planning for all mothers, regardless of child’s disability status. Using a multivariate model and our IPT weighting, we find no differences in likelihood of any retirement planning by child’s disability status (not shown). We find one statistically significant difference in specific retirement behaviors when examining the bivariate relationships between planning and child’s disability in our IPT-weighted sample: Fewer mothers with significant caregiving responsibility report consulting with a financial planner than other mothers (26% compared to 33% of all mothers).

**Figure 4: Retirement Planning Behaviors**



**Table 7: Retirement Planning Behavior in IPT-Weighted Sample**

	Calculated Retirement Income Needed	Consulted Financial Planner	Read Magazines/ Books on Retirement	Used a Computer Program to Help Plan	Attended Meetings
Full Sample	0.483	0.331	0.544	0.247	0.356
Limiting Condition, Consecutive Waves	0.486	0.314	0.531	0.238	0.358
Caregiving	0.474	0.257**	0.501	0.229	0.313

**Source** Figure 4 and Table 8: Authors' calculations using IPTW sample of NLSY79 and CYA. Bivariate proportions shown here.

\*\*\* $p < .001$  \*\*  $p < .01$  \*  $p < .05$  +  $p < .10$

Notably, the available quantitative data and our estimates limit our understanding about the retirement planning process, emphasizing the importance of enhancing these data with our qualitative data from mothers' themselves.

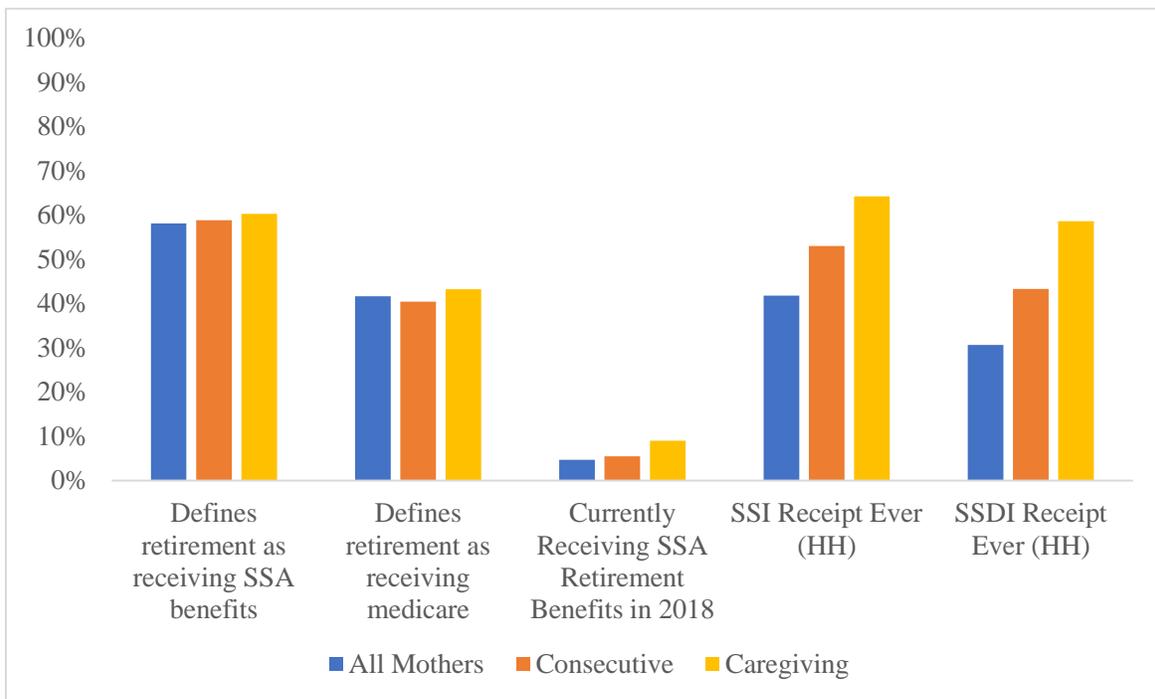
### **SSA Benefits.**

Finally, understanding how mothers think about SSA benefits as they approach retirement is of particular interest to the policy community and SSA. In our interviews, mothers noted that they figured SSA benefits into their retirement planning, but no mothers noted it as a primary source of income. Stated one mother, "They're part of the picture but not THE picture. We are not relying on those benefits."

Rather, most mothers we spoke with reported that employer-sponsored retirement accounts or personal investments would be the primary source of their retirement income. A small minority also anticipated an inheritance from other family members but clarified that it would be used to support their child once they were retired. It is important to note many mothers in our sample did not provide and seemed to not to know specific household financial information related to retirement income and potential SSA benefits. Most had an overall sense of the big picture of retirement finances and indicated their partner or a financial professional was more involved in the specific financial management for their household.

Our quantitative analyses yielded some additional information about SSA benefits for this population of families. In keeping with our qualitative findings, these households were no more or less likely to define retirement in terms of SSA benefit receipt. And, unsurprisingly, households with a child with a disability were significantly more likely to have ever received SSI payments or SSDI benefits. However, these households were also more likely to be receiving retirement income from SSA at the time of the 2018 interview (9% of the sample compared to 5% of all mothers), and this association holds in a multivariate context for mothers with significant caregiving responsibilities. These mothers were 6 percentage points more likely to be receiving SSA retirement benefits, even when controlling for other relevant factors.

**Figure 5: SSA Benefits**



**Table 8: SSA Benefits and Retirement**

	Defines Retirement as Receiving SSA Benefits	Defines Retirement as Receiving Medicare	Currently Receiving SSA Retirement Benefits in 2018	SSI Receipt Ever (HH)	SSDI Receipt Ever (HH)
All Mothers	0.5805	0.416	0.047	0.418	0.306
Limiting Condition, Consecutive Waves	0.588	0.404	0.055**	0.53**	0.433***
Caregiving	0.602	0.432	0.09***	0.642***	0.586***
	Defines Retirement as Receiving SSA Benefits	Currently Receiving SSA Retirement Benefits in 2018			
Limiting Condition, Consecutive Waves	0.019 (.027)	0.019 (0.012)			
Work Limiting condition, <22	-0.027 (0.030)	0.021 (0.015)			
Caregiving	0.023 (0.041)	.056** (0.021)			

**Source** Figure 5 and Table 9: Authors' calculations using IPTW sample of NLSY79 and CYA. Top panel shows raw bivariate proportions. Bottom panel shows robust standard errors in parentheses. Covariates include mother's race, sex, education, marital status, age at first birth, number of adults in the household, number of children in household, age at last interview, year of interview, poverty status of mother's household in 1979, mother's health status, child's age

\*\*\* $p < .001$  \*\*  $p < .01$  \*  $p < .05$  +  $p < .10$

## 5. Discussion/Policy Implications

The first aim of our study was to examine patterns in retirement savings and timing for mothers of children with disabilities and to understand how they compare with other mothers. Looking to the quantitative data, we find very similar patterns for mothers of children with disabilities compared to other mothers, with some exceptions. Notably, for mothers who are responsible for significant caregiving, we find fewer reporting retirement by the time of their last NLSY interview wave compared to other mothers. We also find lower household income among mothers with significant caregiving responsibilities, which has potential implications for family economic well-being as

well as savings available as mothers reach retirement age. These findings are in keeping with our qualitative interviews, in which mothers shared a broad array of ways that caregiving affected their earning potential and retirement plans. Some mothers told us that they needed to work longer than they planned to prior to becoming a parent of a child with a disability due to the amount of savings they anticipated needing for their child's care, in addition to their own retirement. Other mothers noted that they never planned to retire fully. Most of the mothers we spoke with described prioritizing flexibility in a workplace over pay and cutting hours or leaving the paid labor force to accommodate caregiving obligations, and many took these steps out of necessity rather than as a choice. Even among our sample of relatively advantaged interviewees, caregiving responsibilities, career trajectories, and the expected financial needs of children affected retirement plans.

Our second aim was to understand how parents of children with disabilities think about retirement options, and the extent that SSA benefits may factor into retirement planning. As with our findings related to retirement timing, our quantitative results suggest that mothers with extensive caregiving requirements are less likely to define retirement in terms of reduced working hours and more likely to say that they will need to continue to work out of financial necessity. These mothers are also more likely to be receiving SSA benefits in 2018, perhaps suggesting that they rely both on income from employment and retirement benefits for economic support. In interviews, we heard from mothers that they factored SSA benefits into their planning for retirement, but did not expect to rely on these benefits. It is noteworthy, however, that the single mothers we spoke with described greater economic precarity and reliance on child support payments and public benefits to help offset income losses due to providing care instead of working in the formal economy. Additional outreach to single parents, in particular, about how SSA benefits can help improve economic stability in retirement is worthy of consideration.

Our quantitative analysis underscores the importance of defining disability in large data sets and attending to the amount and intensity of caregiving in parenting a child with a disability. We find different associations across a variety of retirement outcomes using our caregiving measure, compared to measures focused solely on a child's health condition. In fact, we generally find no association between our outcomes and a child's health condition when not accounting for caregiving. We also find that caregiving matters across a number of dimensions; we find differences for mothers with significant caregiving responsibilities in work history, retirement timing, retirement planning, and benefit receipt.

The qualitative data offers a story consistent with our quantitative results and provides crucial insight into the context and mechanisms that further explain the relationship we are seeing between caregiving and retirement behavior. Specifically, we heard that the intensity of a child's caregiving needs, financial circumstances of the household as a whole, and the work arrangements available to mothers (including the flexibility of those arrangements and compatibility with caregiving as well as, potentially, the employment circumstances of a partner in the household) factor into a mother's decision-making. We also learned that in many cases, "decisions" did not feel like choices to mothers at all; rather, mothers often felt that they were taking the only possible route to meet their family's needs due to family schedules, household financial circumstances, or lack of other caregiving options for their children. More broadly, whether conceptualizing what retirement means or thinking through retirement options, the mothers we spoke with highly prioritized their children's caregiving and financial needs when discussing retirement options; the needs of children rose to the top of mothers' planning considerations. This prioritization, however, made planning for retirement all the more challenging, as some aspects of their children's needs – in particular, the level of care and support needed and children's financial needs – were often uncertain.

Our mixed methods approach offers important insights that would be overlooked with either method individually. Using the quantitative data to understand trends at scale in a large, nationally representative sample of mothers, we can glean the importance of caregiving and the nuance in defining disability. This insight from the quantitative data is further bolstered by qualitative interviews which allow us to dig into the mechanisms, thought-processes, feelings, and perceptions of retirement to families. Building on the quantitative findings with qualitative data allows us to contextualize findings in a way that would not be possible with existing quantitative measures.

Moreover, the quantitative analysis leaves us with some questions. Though we have essentially null results for many of our estimates, is it really the case that there is no relationship between child's disability and mother's retirement? Or are our null findings reflective of measurement error or other data or methodological limitations? The qualitative data allow us to unpack this, and, seem to suggest it is the latter. In particular, we hear from families that a child's disability deeply impacts parental retirement decisions and planning. While our quantitative estimates indicate few impacts of child's disability on mother's retirement, if any, our qualitative

interviews argue strongly otherwise. Though there are multiple explanations of this mismatch in findings, one may be the limits of available quantitative data to accurately capture the different dimensions of disability.

## **5.1 Policy Implications**

Our findings have several important policy implications, particularly for SSA programs. First, we build on previous work demonstrating the gender imbalance in caregiving and its negative economic implications for women, particularly in retirement. This underscores the importance of policy design that attends to some of these imbalances, such as SSA's attention to benefit formulas and family benefits, and the need to continue to monitor trends and differential outcomes at retirement by gender. In addition, our study also points to the cost of caring for a child with a disability due to the lack of institutional supports for families. We heard from mothers that they are less able to work during the child's youth and may need to continue to work and provide intensive caregiving into their retirement years and their child's adulthood. Investments in social programs and policies that provide adequate economic support for all parents and people with disabilities and their families could facilitate a more equitable transition into retirement. For example, economic supports for parents through the expanded Child Tax Credit (CTC) and Earned Income Tax Credit (EITC) can have important financial impacts for families with children (National Academies of Sciences, 2019; Parolin et al., 2021); this is important for families with children with disabilities as well, and may point to the possibility of considering adjustments in eligibility or benefit formula for these families in particular. Additionally, given what we heard from mothers about the need for workplace flexibility and caregiving support, instituting broad paid family leave policies may be particularly important for labor market participation and economic security for families with a disabled child. Similarly, ensuring access to early care and education options may also benefit mothers in supporting employment.

Finally, SSA programs, particularly income support from the childhood Supplemental Security Income (SSI) program, may be particularly salient for these families. However, asset limits for SSI recipients, in particular, may impact how and whether these families can save for their own retirement, either in terms of retirement income or for providing for their child's future. Though there some types of savings not counted towards asset limits, including trusts and accounts for children's education, families may not be aware of specific programmatic rules.

We also find some differences in how mothers with significant caregiving responsibilities think about and define retirement, both in our quantitative and qualitative samples. Our study highlights the importance of understanding these differences, particularly as they relate to overall mother's employment and earnings trajectories. We heard from mothers in our interviews that they may continue to work through traditional retirement years. Our quantitative estimates, too, suggest that mothers with significant caregiving responsibilities may be more likely than other mothers to plan to continue to work indefinitely. We also find that these mothers are more likely to already be collecting SSA retirement benefits. Taken together, these findings indicate the importance for mothers in understanding SSA policy, particularly as it relates to earnings limits when collecting retirement benefits. Given the relatively young-age of our quantitative sample, this may also indicate that these mothers are more likely to claim retirement benefits prior to full-retirement age (FRA). Understanding claiming behavior, and continued earnings, for this sample of families may be of particular interest to SSA.

## 5. Conclusions

Our findings indicate the importance of further research for this population and the limitations of existing research, including our own. We use one of the few publicly available datasets with measures of child's disability and parental retirement behavior, and our exploratory analysis indicates that these data may not accurately capture the nuance of disability, limiting what we can learn from existing datasets. Future research should attend to how best to measure and operationalize disability, including engaging the disability community and families on measures and broadly incorporating more measures of disability in other relevant large datasets, specifically those focused on retirement. Funding for data collection focused specifically on this population of families or collaborating with other federal agencies to add relevant measures to existing data collection efforts, as has recently been done with the Survey of Income and Program Participation (SIPP), could help further research in this area. Additionally, SSA administrative data may be particularly poised to answer research questions related to retirement for parents of children with disabilities; it may be possible to link children who receive SSI (or those who applied) with their parents, allowing for measurement of retirement claiming of parents among other measures.

Our quantitative analysis primarily served to provide broad understanding of associations between childhood disability and mother's retirement. Though we use IPTW to better isolate the role of childhood disability, we are limited in what we can learn from the available data; therefore,

we are interested in descriptive, large-scale associations with nuances filled in by our qualitative data. With this important first step, we leave to future researchers more precise, and, eventually, causal models and estimations with more adequate data and measures.

Some of the limitations of existing quantitative data resources can be supplemented by our qualitative data. Indeed, the data we collected via interviews with mothers represent an important step forward given the relative lack of attention to this topic. However, our qualitative data, too, are not without limitations. We were limited in the number of interviews we could conduct, and we cast a wide net with few restrictions on eligibility criteria—within a limited and relatively advantaged geographic area—resulting in an economically well-off and racially homogenous sample; findings from this sample cannot be extrapolated more broadly. It is also noteworthy that participants who expressed interest in the study responded quickly and with a lot of interest in the topic; a harder-to-reach sample might have experienced different constraints (particularly due to work and childcare obligations) than the sample we spoke with. That we find significant financial concerns about retirement reported in our well-off, readily willing to participate sample is notable. This underscores the importance of future work focusing on more diverse samples, with built-in stratification techniques to target underrepresented groups, to better account for different experiences. We might also expect that less-advantaged samples may provide more insight into the need for SSA retirement and disability benefits.

Further, we recruited from only one Wisconsin county, a community resource-rich environment containing one of the state's largest urban areas. Mothers in communities with fewer community supports, particularly mothers living in rural areas, likely have different experiences and constraints than mothers within Dane County; future research could recruit from broader array of counties with different characteristics. Additionally, our recruitment strategy yielded a sample of mothers whose children had one of only several primary diagnoses; however, we note that the diagnoses encompassed within our analysis are among the most prevalent diagnosed disability types. Future studies could consider recruitment strategies that specifically aim for more variation in disability type, if salient for the study's goals.

This work is an important first step to begin to understand differences in retirement decisions for mothers of children with disabilities. Our findings indicate the importance of this topic for families as well as the importance for policymakers and researchers to continue to attend to this population. As the number of children with identified disabilities grows, we can anticipate

more families facing these questions in coming cohorts of parents, perhaps adding some urgency to research in this area. Though our work highlights the importance of this topic, there is still much to learn about economic well-being of families and the experiences of more diverse samples.

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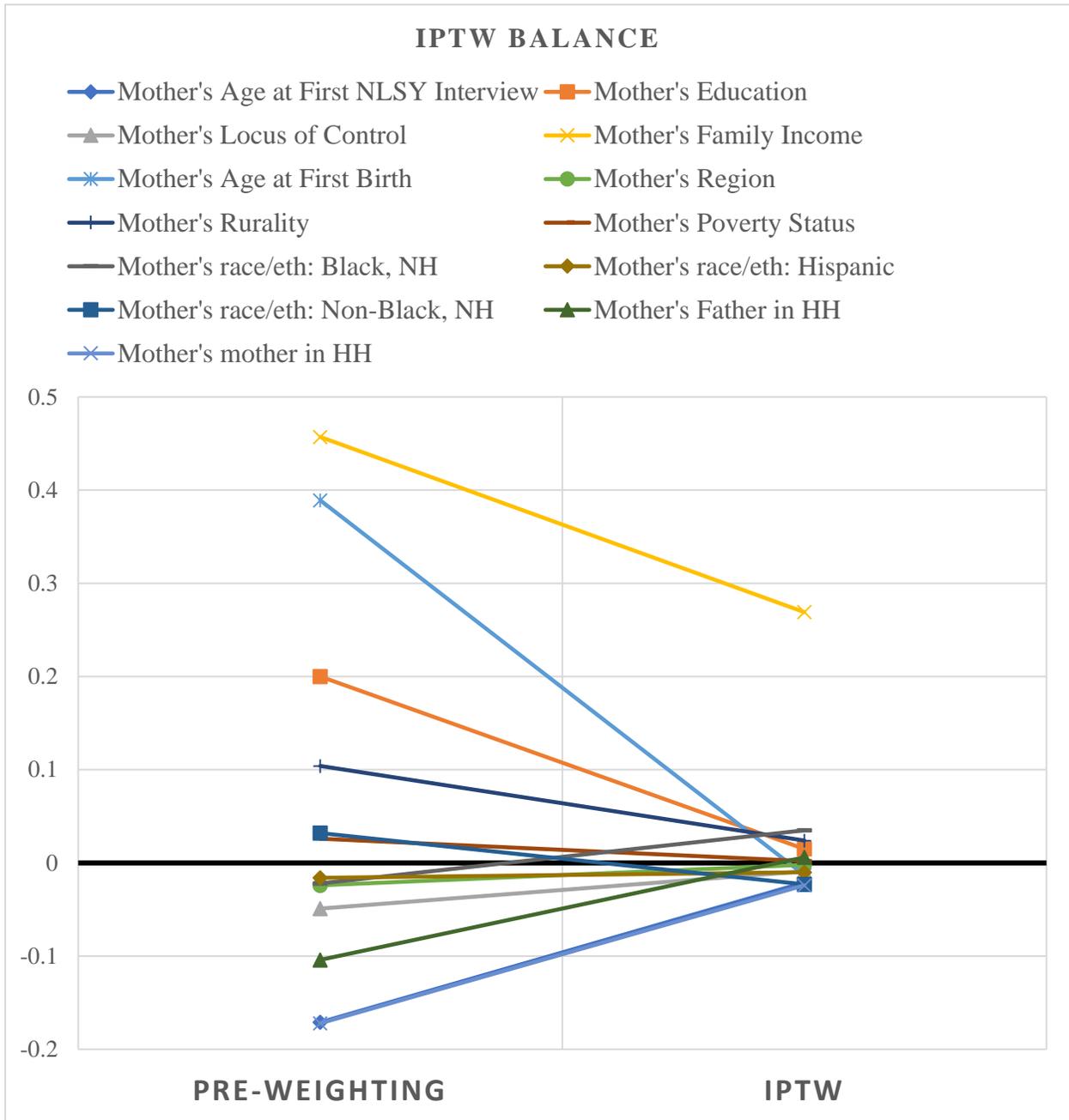
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## Appendix A

Figure A1: Effect Size Differences on Select Baseline Measures Pre- and Post- Inverse Probability of Treatment Weighting (IPTW)



Source: Author's calculations from NLSY79 and CYA Sample Data

## Appendix B



### Are you the mother of a child with a disability?

- Are you 45 years old or older?
- Do you provide care or support for your child?

**Participate in a 90 minute interview** to help us understand how parents of children with disabilities think about and plan for their own retirement. This information could help inform policy to better support the needs of parents whose children have disabilities.

#### Interested?

For more information, call 608-263-1612  
Visit [go.wisc.edu/qp191s](https://go.wisc.edu/qp191s) or scan the QR Code



**Participants will receive a \$75 gift card after completing an interview.**

## Appendix C

### **All in the Family: Qualitative Interview Protocol Household Overview and Family Composition**

To get started, we have a few questions about you and your family. First, I'll ask about your children.

1. How many children do you have? [IF NEEDED: *Please include adult children as well as children who aren't 18 yet.*]
2. Can you please tell me the first name, or initials, of each of your children? [FOR EACH]:
  - a. How old is [CHILD]?
  - b. Has [CHILD] been diagnosed with a disability? [PROBE FOR: Disability type; year of diagnosis]
  - c. [FOR CHILDREN 18 OR OLDER WITH A DISABILITY]: Have you been given any legal authority with as a decision maker such as guardianship, conservator, power of attorney? [PROBE FOR: Type of legal authority]
  - d. Does [CHILD] currently live with you? [IF CHILD HAS A DISABILITY AND DOES NOT LIVE WITH RESPONDENT: Where does [CHILD] currently live? PROBE FOR: alone or with others; in own home or with others; whether in a residential care setting.]
3. Are you currently in a romantic relationship?
  - a. IF YES: Can you please tell me the first name, or initials, of your partner?
  - b. IF YES: How would you describe your relationship status with [PARTNER/SPOUSE]?
  - c. IF NO: Have you been married at any time in the past? [IF YES: When did your marriage to [PARTNER/SPOUSE] end?
  - d. IF YES: Do you and [PARTNER/SPOUSE] live together in the same household?

#### **Respondent's Employment History**

4. Are you currently working in a paid job?
5. These next questions ask for a little more information about your employment.
  - a. [IF NOT CURRENTLY WORKING FROM Q3]: Earlier you mentioned that you are not currently working in a paid job. Have you ever worked in a paid job?
6. INTERVIEWER: **GO TO EMPLOYMENT ROSTER ON PAGE 2.** Walk through the employment roster with the respondent, capturing each job they worked in adulthood (from current/most recent working backwards).
7. [IF REPORTED A SPOUSE AT Q3: Is [SPOUSE] currently working?
  - a. IF YES: **GO TO EMPLOYMENT ROSTER ON PAGE 2.** Walk through the employment roster with the respondent, capturing information about the spouse's current job.

8. [IF REPORTED LIVING WITH OTHERS AT Q2/Q3: You mentioned that you and [FILL FROM Q2 and Q3] live in the same household.] Do any other adults or children currently live in your household? [IF YES: Collect number of household members, ages, relationship to respondent]
- a. *IF OTHER ADULTS IN HOUSEHOLD, ASK FOR ADULTS OTHER THAN SPOUSE: Are any of these adults currently working in a paid job? [IF YES: Probe for which adults; whether working full-time or part-time]*
  - b. Thinking about all of the adults in your household including you [and your spouse], about how much money did all of the adults in your household earn from wages in the last 12 months?
  - c. *Other than income from wages, do any of the adults or children in your household currently have income from any other sources? For example, income from a retirement plan, a pension, a government program, or anything else? [IF YES: Probe for source, government program type if applicable, who gets it, amount per month]*

**EMPLOYMENT ROSTER**

Job Title/Role:			
Approximate Start and End Dates (Years):	Started	Ended	
Status :	<input type="checkbox"/> Full time <input type="checkbox"/> Part- time <input type="checkbox"/> Seasonal/ Contract <input type="checkbox"/> Other		
Type:	<input type="checkbox"/> For Profit <input type="checkbox"/> Non-profit <input type="checkbox"/> Government <input type="checkbox"/> Self-Employed <input type="checkbox"/> Other		
Retirement Plan	Offered	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Participated	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Health Insurance	Offered	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	Participated	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Approximate Income	\$_____ Per _____		

**Caregiving**

I'd like to transition now to talking about your role in providing care and support for [FILL WITH CHILD/CHILDREN DIAGNOSED WITH A DISABILITY AT Q2].

9. You mentioned earlier that [CHILD] has [DISABILITY] and this was diagnosed in [YEAR]. I'm going to go through a list of regular activities. For each one I'd like you to indicate if [CHILD] currently does this independently, if you support them with the task, or if they receive support from someone else- for example, from your spouse, other children, friends or relatives, or from an agency or program.

**INTERVIEWER: GO TO CAREGIVING ROSTER ON PAGE 3 AND COMPLETE FOR EACH CHILD.**

**CAREGIVING ROSTER**

<b>Activity</b>	<b>Independent</b>	<b>Mother Support</b>	<b>If Mother Support, Time Spent</b>	<b>Other Support</b>
<b>Eating</b>			<input type="checkbox"/> Per Week <input type="checkbox"/> Per Month	
<b>Toileting</b>			<input type="checkbox"/> Per Week <input type="checkbox"/> Per Month	
<b>Transferring</b>			<input type="checkbox"/> Per Week <input type="checkbox"/> Per Month	
<b>Dressing</b>			<input type="checkbox"/> Per Week <input type="checkbox"/> Per Month	
<b>Bathing</b>			<input type="checkbox"/> Per Week <input type="checkbox"/> Per Month	
<b>Using the telephone</b>			<input type="checkbox"/> Per Week <input type="checkbox"/> Per Month	
<b>Shopping</b> (Making a list, facilitating transactions)			<input type="checkbox"/> Per Week <input type="checkbox"/> Per Month	
<b>Preparing food</b>			<input type="checkbox"/> Per Week <input type="checkbox"/> Per Month	
<b>Cleaning the house</b>			<input type="checkbox"/> Per Week <input type="checkbox"/> Per Month	
<b>Laundry</b>			<input type="checkbox"/> Per Week <input type="checkbox"/> Per Month	

<p><b>Transportation</b> (scheduling rides, driving, using the bus)</p>			<p><input type="checkbox"/> Per Week <input type="checkbox"/> Per Month</p>	
<p><b>Medications</b> (taking correct dosage, calling for refills, etc.)</p>			<p><input type="checkbox"/> Per Week <input type="checkbox"/> Per Month</p>	
<p><b>Managing finances</b> (day to day transactions, paying bills, major purchases)</p>			<p><input type="checkbox"/> Per Week <input type="checkbox"/> Per Month</p>	

**INTERVIEWER: IF MULTIPLE CHILDREN WITH A DISABILITY, ASK Q10 THROUGH Q15 FOR EACH.**

10. Some programs pay family members who provide care or support to someone with a disability. Are you paid for all or part of the time you spend providing care? [PROBE IF YES: Where does that funding come from?]

11. How do you feel about the *time spent providing* care and support you provide to [CHILD], and the *type* of care and support you provide? {IF NEEDED: For example, would you prefer to provide more or less, or are you happy with the amount you provide now? Or, would you prefer to be providing care and support of some kind that you do not currently provide, or would you prefer not to be providing some kind of care or support that you provide now? [PROBE IF DIFFERENT: Can you tell me more about that? What do you wish was different, and why? What gets in the way of making that change?]

12. [IF R REPORTS CARE FROM OTHERS]: You mentioned that [CHILD] receives support from someone other than you. Can you tell me more about that? [PROBE FOR MULTIPLE CAREGIVERS AS NEEDED]

d. Who provides this care or support?

e. How many hours do they provide in a typical week or month currently?

f. How regular is this care or support? [PROBE: Is this care and support provided on a live in, come in, or infrequent basis?]

13. [IF R REPORTS NO SUPPORT FROM OTHERS]: Do you have additional support available if you were unable to provide care?

14. How has your role as a caregiver changed throughout [CHILD]'s life?

15. Other than the care you provide to [CHILD], do you provide care or support for anyone else in your life? For example, a parent, a spouse, or grandchildren?

a. What kinds of care or support do you provide?

- b. How much care and support do you provide in a typical week or typical month currently?
- c. How regular is this care or support? [PROBE: Is this care and support provided on a routine basis, or on an as needed or infrequent basis?]

**Caregiving and Employment Decisions**

16. Think back about the caregiving and support you've provided to [CHILD] throughout [his/her] life. Are there ways in which the care you have provided to [CHILD] has affected any aspect of your work throughout your life? [IF YES: Can you tell me more about that? In what way? When?]
- a. Has your caregiving for [CHILD] affected your ability to work, or how much you work?
  - b. Has your caregiving for [CHILD] affected the kinds of work you've done or decisions about particular jobs?
  - c. Has your caregiving for [CHILD] affected the decisions you've made about pursuing additional opportunities to further your career?
17. Are there ways in which the caregiving or support you've provided for people other than [CHILD] affected any aspect of your work throughout your life? [IF YES: Can you please tell me more about that? Caregiving for whom? What effect did this have, and when?]
- a. Has this caregiving affected your ability to work, or how much you work?
  - b. Has this caregiving affected the kinds of work you've done or decisions about particular jobs?
  - c. Has your caregiving for [CHILD] affected the decisions you've made about pursuing additional opportunities to further your career?

**Retirement and Planning**

Next we'll switch to talking about retirement.

18. Do you consider yourself to be retired now? [IF YES: Do you consider yourself to be partly retired, fully retired, or something else?]
19. What does "retirement" mean to you? [PROBES: When you [retire/retired], what [will/did] this look like?]
- a. Has the way you think about retirement changed over time?
  - b. [What do you imagine your life will be like/what is your life like] in retirement?
  - c. [What do you imagine your financial situation will be like/what is your financial situation like] in retirement?
  - d. [How do you feel about the idea of retirement/how do you feel about being retired]?
20. [IF CURRENTLY RETIRED]: Can you tell me about the circumstances that led to your retirement?
- a. What factors led to retire when you retired?
    - i. PROBE IF NEEDED: Did your caregiving responsibilities for [CHILD] affect your decisions about retirement? [IF YES: How did they affect your decision?]

- ii. Did your caregiving responsibilities for others affect your decisions about retirement? [IF YES: Caring for whom? How did they affect your decision?]
- iii. PROBE IF PARTNERED: Did your spouse or partner's work or retirement situation affect your decision? If so, how?]
- b. Did you do any sort of retirement planning prior to retiring? [IF YES: Can you tell me more about that? What sorts of planning did you do? When did you start planning?]
- c. *Did you ever meet with a retirement professional about planning for retirement? [IF YES: Can you tell me more about that? What sort of professional did you meet with? What sorts of advice did they give you, and how helpful was it?*
- d. Did you retire at the time you *intended or planned to*, or not? [IF NOT: Can you tell me more about that?]
- e. Did you retire at the time you *wanted* to retire, or not? [IF NOT: Can you tell me more about that?]
- f. To what extent did any benefits you receive, or expected to receive, from the Social Security Administration affect your decisions about retirement? [PROBES: What benefits affected your decision, and how?]
  - i. To what extent did any other benefits you receive or expected to receive, such as Medicare, retirement benefits, or any other benefits, affect your decisions about retirement? [PROBES: What benefits affected your decision, and how?]

21. [IF NOT CURRENTLY RETIRED]: Have you thought at all about retirement yet – for example, when you would like to retire or how to decide when it's the right time to retire? [IF YES: Can you please walk me through your thinking about that?]
- a. When you think about retiring in the future, what factors play into your decisions and thoughts?
    - i. PROBE IF NEEDED: Do your caregiving responsibilities for [CHILD] affect your thoughts about retirement? [IF YES: How did they affect your thoughts?]
    - ii. Do your caregiving responsibilities for others affect your thoughts about retirement? [IF YES: Caring for whom? How did they affect your thoughts?]
    - iii. PROBE IF PARTNERED: Did your spouse or partner's work or retirement situation affect your decision? If so, how?]
  - b. Have you done any sort of retirement planning prior to retiring? [IF YES: Can you tell me more about that? What sorts of planning have you done? When did you start planning?]
  - c. *Have you ever met with a retirement professional about planning for retirement? [IF YES: Can you tell me more about that? What sort of professional did you meet with? What sorts of advice did they give you, and how helpful was it?*
  - d. To what extent do any benefits you expect to receive from the Social Security Administration affect how you are thinking about retirement? [PROBES: What benefits have affected your thinking, and how?]

- i. To what extent do any other benefits you expect to receive, such as Medicare, retirement benefits, or any other benefits, affect your thinking about retirement? [PROBES: What benefits affect your thinking, and how?]

22. *If you have questions about [your retirement or retirement benefits /plans for retirement or retirement benefits], are there places you would look, or people you would ask, for help? [IF YES: What person or agency would you contact?]*  
 a. *Have you ever reached out to this person or agency before? [IF YES: To what extent were they able to help answer your questions?]*

23. Now, I am going to read you several possible sources of income in retirement. Please tell me if you expect each source to be a major source of income in your retirement, a minor source of income, or if you are not expecting to use this in retirement. [IF MARRIED, FOR EACH MAJOR OR MINOR SOURCE: PROBE FOR SELF, SPOUSE, OR BOTH].

<input type="checkbox"/> Self <input type="checkbox"/> Spouse	A traditional employer-provided <b>pension</b> that pays a set amount each month for life in retirement, or a <b>lump sum</b> distribution from a traditional pension	<input type="checkbox"/> Major <input type="checkbox"/> Minor <input type="checkbox"/> Not at all
<input type="checkbox"/> Self <input type="checkbox"/> Spouse	An employer-sponsored retirement savings plan, such as a <b>401(k)</b> or <b>403(b)</b> , or money from an individual retirement account, or <b>IRA</b>	<input type="checkbox"/> Major <input type="checkbox"/> Minor <input type="checkbox"/> Not at all
<input type="checkbox"/> Self <input type="checkbox"/> Spouse	Personal <b>investments</b> , such as CDs, mutual funds, bonds, stocks, stock options, or annuities, not investments in a work-related retirement plan or IRA	<input type="checkbox"/> Major <input type="checkbox"/> Minor <input type="checkbox"/> Not at all
<input type="checkbox"/> Self <input type="checkbox"/> Spouse	Personal <b>savings</b> , meaning money in a non-investment savings bank account	<input type="checkbox"/> Major <input type="checkbox"/> Minor <input type="checkbox"/> Not at all
<input type="checkbox"/> Self <input type="checkbox"/> Spouse	<b>Employment</b> during retirement	<input type="checkbox"/> Major <input type="checkbox"/> Minor <input type="checkbox"/> Not at all
<input type="checkbox"/> Self <input type="checkbox"/> Spouse	<b>Social Security</b>	<input type="checkbox"/> Major <input type="checkbox"/> Minor <input type="checkbox"/> Not at all
<input type="checkbox"/> Self <input type="checkbox"/> Spouse	<b>Other:</b>	<input type="checkbox"/> Major <input type="checkbox"/> Minor <input type="checkbox"/> Not at all

24. Overall, how prepared [did you feel/do you feel] for retirement? [PROBE: Can you tell me more about that? In what ways do you feel prepared or not prepared?]

**Wrap Up Questions**

I have just a few last questions before we wrap up.

25. I have a few questions about how you are doing.

- a. Overall, how would you describe your physical health – excellent, very good, good, fair, or poor?
- b. Overall, how would you describe your mental health - – excellent, very good, good, fair, or poor?

26. I have a few questions about your background.

- a. What is the highest level of education you have completed?
- b. What is your race or ethnicity?

27. Is there anything related to caregiving, work and retirement that we haven't talked about today, that you'd like to share with me before we wrap up our interview?



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