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“It’s Hard to Know What to Expect”: Parents of Children with Disabilities in Retirement

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The research reported herein was performed pursuant to a grant from the U.S. Social Security Administration (SSA) funded as part of the Retirement and Disability Consortium. The opinions and conclusions expressed are solely those of the author(s) and do not represent the opinions or policy of SSA or any agency of the Federal Government. Neither the United States Government nor any agency thereof, nor any of their employees, makes any warranty, express or implied, or assumes any legal liability or responsibility for the accuracy, completeness, or usefulness of the contents of this report. Reference herein to any specific commercial product, process or service by trade name, trademark, manufacturer, or otherwise does not necessarily constitute or imply endorsement, recommendation or favoring by the United States Government or any agency thereof. The authors thank Liza Garrido and Charles Dasko for their assistance with data visualization.

Abstract

Income from the Social Security Administration (SSA)—through retirement, disability, and family benefits from the Old Age, Survivors, and Disability Insurance (OASDI) program and payments from the Supplemental Security Income (SSI) program—have the potential to provide substantial economic support for families with a retired householder caring for a child with a disability. Using a mixed-methods approach, this study aims to understand how households with retired adults and children with disabilities are faring economically, and how families perceive the adequacy of SSA benefits and supports for meeting family needs. We find that families with retired adults caring for children with disabilities are disproportionately likely to experience economic hardships, such as food insecurity, and that their overall economic well-being is often precarious. We further find that income from SSA is “vital” for many of these families, particularly for single-parent families; yet, for some families, SSA income does not fully alleviate hardship. Further, children's future financial and caregiving needs are a substantial concern for parents across an array of financial circumstances. We discuss policy mechanisms that could potentially support the economic well-being of these families and address structural disadvantages in the labor market that may lead to inequities in retirement savings. These include the following: accounting for a child's disability in eligibility and benefit calculations for parents, for SSA benefits and other public programs; reconsidering asset limits for SSA recipients; and examining opportunities to reduce benefits cliffs. Findings also indicate potential opportunities to support family access to economic supports through enhanced information-sharing and case management as well as through connecting families to community supports.

Keywords: Social Security, retirement, disability, caregiving

JEL: JEL: H5, I3, J26

1. Introduction

An increasing number of retirement-age adults have caregiving responsibilities for their children with disabilities. Social Security Administration (SSA) benefits for both parents (retirement and disability benefits) and their children (disability benefits) may be an important support for these families. Over half of households with older adults rely on SSA benefits for at least half of their household income (Dushi, Iams, and Trenkamp 2017), and, by some estimates, SSA benefits reduce poverty rates for older adults by 30–40 percent (Bee and Mitchell 2017; Romig 2022). SSA benefits may be even more salient for households with children with disabilities. These households tend to fare worse across measures of economic well-being (Sonik et al. 2016; Stabile and Allin 2012), and estimates suggest Supplemental Security Income (SSI) payments reduce poverty in households with children by 66 percent (Stegman Bailey and Hemmeter 2015). Despite the potentially crucial role of SSA benefits, the experiences of retired parents of children with disabilities generally and their experiences related to economic well-being specifically have largely been excluded from the research literature. There is little evidence about how families with retirement-age adults caring for a child with a disability are faring financially, and little is known about the extent to which they rely on SSA benefits relative to other income or about their perceptions of benefit adequacy. Additionally, there is some indication that overall economic well-being may differ by social characteristics, such as race, geography, and family structure. In this study, we aim to address this gap by focusing on the following research questions:

- (1) How are households with retired caregivers for children with disabilities faring economically? Are there differences based on social characteristics (e.g., race, ethnicity, or educational attainment) or where families live (e.g., in rural or urban areas)?
- (2) How do families perceive the adequacy of SSA benefits and available information for meeting family needs? Are there measurable differences in the role of SSA benefits in reducing hardship, and does this vary by family characteristics?

We aim to provide evidence about the economic well-being of a population of families likely to rely heavily on SSA benefits for household income, to center parent experiences, and to provide insight into families' perceptions of benefit adequacy. The study will approach all data collection and analysis with a lens towards disparities associated with sociodemographic characteristics. Understanding how economic well-being may be further compounded by structural

factors can provide the SSA with further insight into the well-being of these families. We take a mixed-methods approach to addressing our study's research questions; we use both quantitative (survey-derived) data and qualitative (interview-based) data, and we weave together learnings from these analyses throughout the findings and discussion sections of this report. By taking this approach, we aim both to provide insight into the experiences of retired parents of children with disabilities broadly and also to deepen our understanding of family experiences while hearing from parents in their own words.

2. Background and Literature Review

Retired adults with children with disabilities are likely an especially economically vulnerable group. Both retired adults and parents with a child with a disability are groups that are individually at increased risk for economic hardships and financial insecurity; as such, concerns about economic well-being are likely particularly salient for households with a retired adult caring for a child with a disability because they experience the risk factors and challenges of both groups. Additional demographic factors such as race and ethnicity, family structure, gender, or other factors could further exacerbate economic outcomes. SSA benefits, which target either or both retired adults and households with disabilities, offer one avenue to mitigate financial insecurity. Despite the high risk of economic insecurity for households with retired parents of individuals with disabilities, there is little research about their economic well-being, their unique challenges and decisions, or the role and adequacy of SSA benefits.

2.1. Economic Well-Being in Retirement

Retired adults are at elevated risk for economic insecurity, resulting from changes to their income streams and expenses after leaving the workforce. The risk of economic insecurity (Brown, Dynan, and Figinski 2020; Meschede, Sullivan, and Shapiro 2011) and wealth inequality (Sabelhaus and Volz 2022) for retirees is on the rise compared to earlier cohorts, particularly for those in the lower half of the income distribution. Prior research supports a model of cumulative advantage or disadvantage predicting well-being in retirement; inequalities that impact pre-retirement well-being are often compounded over time (Crystal and Shea 1990). Factors such as education, employment stability, earnings, benefit access, homeownership, and health are often interconnected and magnify each other, widening initial gaps in economic well-being.

Retirement security is often described as a “three-legged stool,” where SSA benefits, employer-sponsored pensions, and personal savings and investments make up retirement income (Engen, Gale, and Uccello 2005; Stanford and Usita 2002). Lower earnings throughout an individual’s working years decrease the likelihood that they will have adequate savings for retirement (Engen, Gale, and Uccello 2005). This means factors linked with lower income during working years are also linked with lower retirement security (Western et al. 2012), and these factors are often split along racial and gendered lines. For example, caregiving responsibilities disproportionately fall to women and are associated with reduced hours, pay, and earnings for women as well as the reduced likelihood of women working at all (Brandon 2007; Butrica and Karamcheva 2018; Carmichael and Charles 2003; Cohen et al. 2019; Dow and Meyer 2010; R. W. Johnson and Lo Sasso 2006; Lee and Tang 2015; Pavalko and Artis 1997; Wakabayashi and Donato 2005; Weller and Tolson 2018). There are also racial and ethnic differences in retirement contributions: Hispanic and Black workers have lower access, take-up, and contribution rates, differences largely explained by structural inequalities in educational attainment and labor market opportunities (Tamborini and Kim 2020).

Another factor in increasing retirement inequity and insecurity is increasing costs in retirement, which are impacted by an individual’s health, housing situation, family structure, and types of debt (Meschede, Sullivan, and Shapiro 2011). The factors associated with lower retirement income and those associated with higher retirement expenditures often overlap. Certain socioeconomic groups are at a cumulative disadvantage throughout their lives. People of color are often constrained in their employment opportunities and subsequent earnings and retirement savings because of lower education, increased health issues and disability, and discrimination in the workforce (Stanford and Usita 2002; Sullivan and Meschede 2016; Tamborini and Kim 2020). Additionally, there are cultural, language, and financial literacy barriers for racial and ethnic minorities that impact their understanding of and planning for retirement (Stanford and Usita 2002). Gender roles, such as disproportionate caregiving responsibilities, often limit women’s employment opportunities or create gaps in employment that decrease women’s ability to contribute to their retirement plans (Morris 2007). Those with cumulative disadvantages are also often at increased risk for increased expenses in retirement, as lower income is associated with being less likely to own a home (Meschede, Sullivan, and Shapiro 2011), worse health outcomes

(Kahn and Pearlin 2006; Smith and Kington 1997), and increased debt (Butrica and Mudrazija 2020).

2.2. Economic Well-Being for Families with Children with Disabilities

Economic well-being and childhood disability are intricately linked. Experiences of poverty or economic hardship may increase the likelihood of childhood disability, and having a child with a disability is associated with overall increases in the likelihood of poverty and economic hardship (Delobel-Ayoub et al. 2015; Palloni et al. 2009; Stabile and Allin 2012). These families disproportionately experience higher rates of poverty, food insecurity, housing instability, barriers to health care access, increased financial burden due to health care costs, and increased phone disconnection (Kuhlthau et al. 2005; Meyers, Lukemeyer, and Smeeding 1998; Parish et al. 2008; Rothwell et al. 2019). Family structure also impacts relative deprivation of families with children with disabilities, as single-mother and cohabitating-partner families experience more hardship than married-couple families (Sonik et al. 2016). Notably, families across income levels face increased hardship (Parish et al. 2008), indicating the high expenses of raising children with disabilities.

The increased risk of hardship may stem from increased costs to families. Families of children with disabilities face higher direct costs, both immediate and long-term, such as medical and specialized care, food, and transportation costs (Meyers, Lukemeyer, and Smeeding 1998). These families also face higher indirect costs, as they often have caregiving responsibilities that can impact labor market participation and that, in turn, may limit public benefit receipt for benefits dependent on paid work (Lukemeyer, Meyers, and Smeeding 2000). For wealthier parents, hiring a professional caregiver may be an option, but for the majority of low-income parents, caregiving is performed by family members. The amount of caregiving a family provides is strongly associated with the severity of the child's disability as well as with parental education, living arrangements, the presence of young siblings, parental disabilities, and the availability of other caregivers, such as grandparents (Rupp and Ressler 2009). Mothers often take on increased caregiving responsibilities for a child with disabilities (Rowbotham, Carroll, and Cuskelly 2011) and so disproportionately incur higher indirect costs (Lee and Tang 2015). Having a child with a disability decreases a mother's likelihood of entering the labor market once their child reaches school age and decreases the number of hours worked compared to mothers of non-disabled children of the same age (Porterfield 2002; Powers 2001). The economic impacts of raising a child with disabilities can continue throughout parents' lives; the likelihood of asset poverty and low

liquid assets is highest for younger cohorts of parents raising kids with disabilities but remains high even for older cohorts (Parish, Rose, and Swaine 2010). Even at midlife, when income is typically highest, parents of children with disabilities have lower savings and earnings than those of non-disabled children (Parish et al. 2004).

2.3. The Unique Situation of Retired Parents of Children with Disabilities

Prior research on aging parental caregivers of children with disabilities primarily focuses on outcomes related to mental and emotional well-being and coping as a caregiver in old age (for examples, see Band-Winterstein and Avieli 2017; Greenberg, Seltzer, and Greenley 1993; Kelly and Kropf 1995; Marsack-Topolewski and Church 2019; Minnes and Woodford 2004). The research also highlights the significant concerns of older parents about how their disabled child will fare in the future after their own death and who will take care of and provide for the disabled individual (Costanzo et al. 2022; Marsack-Topolewski and Graves 2020; Sivakumar et al. 2022).

Prior research also examines the impact of caregiving, typically for an aging parent, on retirement security and decisions. Providing informal care, which disproportionately falls to women, decreases labor participation, which decreases access to and the ability to contribute to retirement savings and benefits plans (Lee and Tang 2015) and which could reduce eligibility for public benefits (Lukemeyer, Meyers, and Smeeding 2000). Over time, caregivers have a lower asset growth and are more likely to fall below the poverty line (Butrica and Karamcheva 2018; Orel, Landry-Meyer, and Spence 2007; Wakabayashi and Donato 2006). The ability of parents of children with disabilities to participate in the labor force depends on the severity of the child's disability and on parental education attainment (Rupp and Ressler 2009). For retirees who provide care for a family member, caregiving can impact retirement plans and can bring additional costs (Dow and Meyer 2010). Needing to provide care also increases the likelihood of retirement for both men and women relative to peers retiring at the same age with no caregiving responsibilities (Meng 2012). Providing care can also impact the timing of retirement. Some mothers of children with disabilities are forced to retire early so that they can provide care for their children, while others have to continue working full- or part-time so they can afford the increased expenses related to their children's disabilities (Costanzo et al. 2022). This variation may be explained by intensity of care needs (Meng 2012). Research has found that most caregivers were unaware of the impact that providing care would have on their own retirement security (Orel, Ford, and Brock 2004).

The financial well-being of retired parents of children with a disability is understudied (Costanzo et al. 2022). Caring for a child with a disability has significant direct and indirect costs throughout the parents' and child's lives. These costs may result in cumulative disadvantages, increasing economic insecurity in retirement. Race and ethnicity, gender, family structure, and education are key risk factors of economic well-being for both retired adults and parents with children with disabilities; these factors are likely, therefore, to play a compounding role in the well-being of retired parents of children with disabilities, as are factors related to the child's health status and specific needs.

2.4. Policy Context

2.4.1. SSA benefits.

The unique context of retired parents caring for a child with a disability puts these families in a precarious state of economic well-being. Yet, current policy, primarily in the form of benefits from SSA, can potentially support these families through both benefits for retired parents and disability benefits or payments for disabled household members. We describe SSA benefits from the Old-Age, Survivors, and Disability Insurance (OASDI) program as well as payments provided through the Supplemental Security Income (SSI) program below.¹

Adults over 62 years old or adults with a qualifying disability that renders them unable to work for at least one year may be eligible to receive OASDI benefits depending on work history (e.g., at least ten years for retirement benefits) (Social Security Administration 2022b; 2023b). The monthly benefit amount is based on a worker's lifetime earnings up to a maximum and, for retirement benefits, the age at which benefits are claimed (Social Security Administration 2022b; 2023b). Certain family members of the retired or disabled worker, including the spouse, ex-spouse, widower, or child, may also be eligible to receive a certain percentage of the worker's benefit amount (e.g., up to 50 percent for retirement or disability benefits) (Social Security Administration 2022b; 2023b). Children of the worker are eligible to receive a child's benefit if they are under 18 years old or under 20 but still in secondary school (Social Security Administration 2022b; 2023b). Another benefit type that may be especially salient for households with retirees caring for a child with a disability are Disabled Adult Child benefits. Adult children with disabilities that began before age 22 may receive benefits from their parent's record once the parent begins receiving

¹ To the extent possible, we distinguish between OASDI benefits and SSI payments throughout, though we occasionally use the term "SSA benefits" to refer to both OASDI benefits and SSI payments.

disability or retirement benefits or is deceased (Social Security Administration 2022a). The total amount received by all eligible family members cannot exceed 150–180 percent of the qualifying worker’s benefits (Social Security Administration 2022b; 2023b).

Unlike OASDI benefits, payments through the SSI program are not dependent on work history. SSI is a means-tested monthly payment for low-income individuals with limited resources who have a qualifying disability or are over 65 (Social Security Administration 2023a). Children under 18 years old who have a qualifying disability and live in a household with limited income and resources are also eligible for a monthly SSI benefit (Social Security Administration 2023a). Children who receive SSI as a child must re-qualify as an adult under the adult definition of disability (Social Security Administration 2023a). Additionally, many children with disabilities who may not have qualified in childhood due to their family’s income and assets may qualify for SSI payments at age 18.

As of the end of 2021, over 65.2 million individuals were receiving OASDI benefits. Retired workers or their dependents (spouses and children) constituted the majority of beneficiaries at 77 percent. Disabled workers and their dependents made up 14 percent, and the remaining 9 percent of beneficiaries were survivors of deceased workers. About 3.9 million beneficiaries were children of retired, disabled, or deceased workers, including 1.1 million disabled adult children. The average monthly benefit for all child beneficiaries (across eligibility type and age) was \$768.63; for disabled adult children, the average monthly benefit was slightly higher at \$904.36 (Office of Research Evaluation and Statistics 2022).

OASDI Dependent Child Beneficiaries (2021):

- 3.9 million
 - \$769/month
- Disabled Adult Children: 1.1 million
 - \$904/month

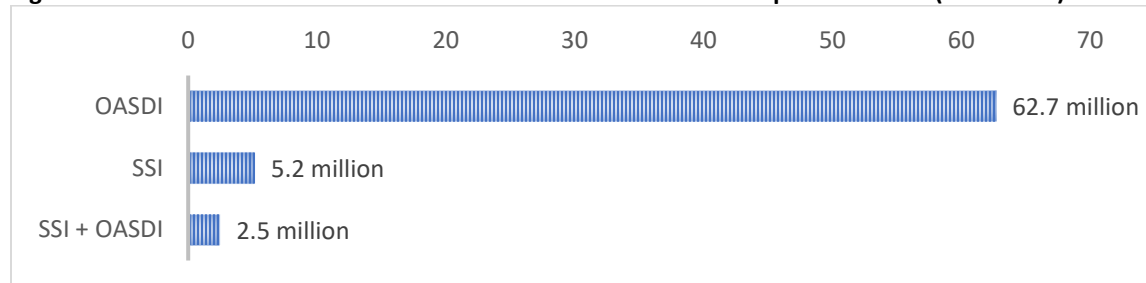
About 7.7 million individuals receive SSI benefits as of December 2021; about 1 million of these recipients were under 18 years old, and 2.3 million were aged 65 years or older (Office of Research Evaluation and Statistics 2022). In

SSI Recipients (2021):

- 7.7 million
 - 65 or over: 30%
 - Under 18: 14%
 - \$914/month

2023, the federal benefit rate, that is, the maximum monthly payment received by an individual SSI recipient, is \$914. This amount is the same for adults and children and is typically adjusted each year. About 2.5 million individuals receive both SSI and OASDI benefits (see Figure 1); this occurs when an OASDI benefit payment is less than the federal benefit rate (Office of Research Evaluation and Statistics 2022).

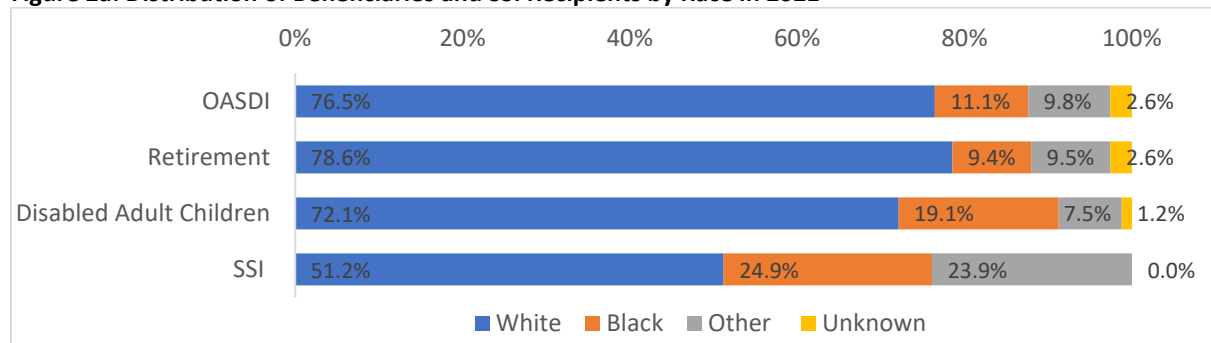
Figure 1: Number of OASDI and Concurrent Beneficiaries and SSI Recipients in 2021 (in millions)



Source: Office of Research, Evaluation, and Statistics, Social Security Administration.

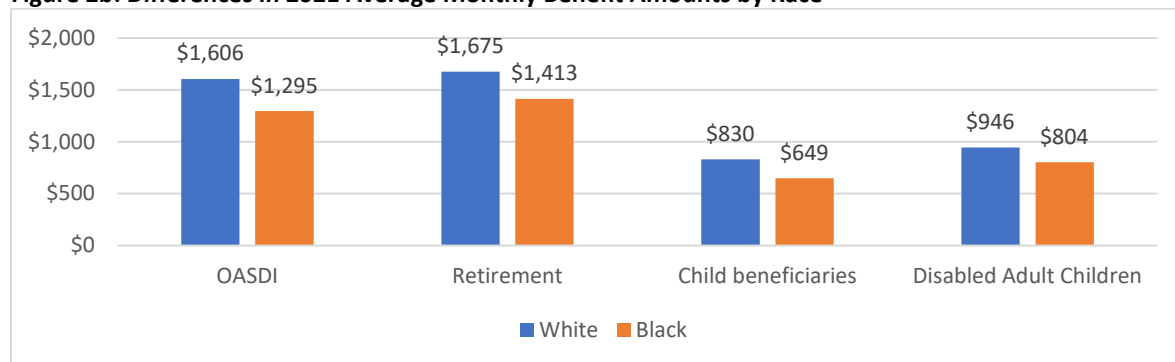
There are important differences in receipt of OASDI and SSI by race and ethnicity. African Americans are less likely to receive OASDI benefits and more likely to receive SSI benefits and, on average, reported receiving less in OASDI benefits and SSI payments annually than did all other OASDI beneficiaries and SSI recipients, respectively (Martin and Murphy 2014). Figures 2a and 2b graphically depict some of these disparities.

Figure 2a: Distribution of Beneficiaries and SSI Recipients by Race in 2021



Source: OASDI statistics from 2022 Annual Statistical Supplement. SSI racial distribution drawn from Geifer 2021.

Figure 2b: Differences in 2021 Average Monthly Benefit Amounts by Race



Source: OASDI statistics from 2022 Annual Statistical Supplement. SSI racial distribution drawn from Geifer 2021.

Eligibility for SSA retirement benefits is relatively straightforward and common throughout the United States, but differences in knowledge of the program and benefits can impact when individuals claim and thus how much they receive (Alattar et al. 2019; Peterson, Smith, and

Guan 2019; Rabinovich, Peterson, and Smith 2017). Conversely, Social Security Disability Insurance (SSDI) beneficiaries or SSI recipients must meet SSA's disability definition and, for SSI, must also prove income and asset eligibility. The increased complexity for eligibility may increase information barriers and transaction costs for application, meaning more individuals who are eligible may not be receiving benefits. Increases in application costs and potential administrative burdens, such as the closing of SSA field offices, decrease the number of disability applicants and, to a larger extent, recipients, especially among those with lower education and lower earnings (Deshpande and Li 2017). SSI participation rates may be diminished due to informational barriers. A recent study suggested that only half of American adults were aware of the SSI program generally, and knowledge of SSI and SSDI benefits were lower for Americans of color compared to non-Hispanic White Americans (Messel, Oluwole, and Rogofsky 2022). In addition to informational barriers to applying (and receiving) benefits (e.g., lack of awareness about eligibility, benefit amounts, or the application process), individuals with alternative resources may forego applying for benefits if they perceive that the modest benefits may not be worth the burden of the complex application process (Hemmeter et al. 2020; McGarry 1996).

2.4.2. Adequacy of benefits.

The high- and increasing-income inequality in retirement means SSA benefits—especially with their progressive calculation formula—play an increasingly important role for retirees with cumulative disadvantages. For about half of the population aged 65 and older, SSA benefits make up over 50 percent of their family's income. SSA benefits played a more significant role in the family income for individuals who were female, Black, Hispanic, less educated, or older (Dushi, Iams, and Trenkamp 2017). However, the relative impact of SSA benefits differs depending on the data source used (Bee and Mitchell 2017). SSA benefits also decrease poverty rates for adults 65 and older by about 3 percent (Romig 2022). OASDI benefits significantly increase total retirement wealth relative to pre-retirement income, particularly for lower-income households, which helps prevent shocks to living standards after retirement (Devlin-Foltz, Henriques, and Sabelhaus 2016). OASDI benefits are moderately successful in redistributing income among retirees; individuals who paid the bottom half of lifetime social security taxes in their cohort receive a little over 60 percent of the SSA benefits (Biggs, Sarney, and Tamborini 2009).

Child OASDI benefits in particular are a major source of income (23.4 percent on average) for recipient families, supporting children with a parent who is retired, disabled, or deceased. Child

beneficiaries were more likely to be Black, have unmarried parents, and have families with lower economic status and a higher rate of SSI and Supplemental Nutrition Assistance Program (SNAP) receipt than children not receiving OASDI benefits (Tamborini, Cupito, and Shoffner 2011). Without child SSA benefits, poverty among beneficiaries' families would increase by over 12 percent (Tamborini and Cupito 2012).

SSI payments are also critically important for families who receive them. Because it is a means-tested program, SSI recipients by definition have a very low income. Though SSI payments are relatively modest—\$914 per month per individual, or just under \$11,000 annually—SSI constitutes nearly 40 percent of household income for recipients under 18 and almost half for those between the ages of 18–64 (Messel and Trenkamp 2022). In 2013, SSI income moved 41 percent of child recipients and 36 percent of adult recipients from below the poverty threshold to above it (Stegman Bailey and Hemmeter 2015).

Despite its importance for families who receive SSI, the level of payments and the eligibility requirements limit its reach. For example, families of children with disabilities who had income at 100 to 199 percent of the poverty line had similar levels of material hardship to those with income below poverty. Because SSI is a means-tested benefit (i.e., SSI eligibility is based on having a very low income and limited assets), many of those families experiencing economic hardship are not eligible for SSI payments because their income is above the threshold for qualification (Parish et al. 2008). Additionally, there is significant variation in receipt across geographical areas, even when controlling for deprivation; these differences are correlated with race, share of population with a disability, urbanicity, and social capital (Levere, Wittenburg, and Hemmeter 2022).

2.4.3. Current study.

Given the significant concerns about the economic well-being of retirees caring for a child with a disability and the potential for SSA benefits to improve financial security, the current study seeks to understand the role of SSA benefits for this population of retirees and their children. We build on literature focused on the economic well-being of retirees and on parents of children with disabilities by examining the experiences of economic well-being for this understudied population. The current study addresses the aforementioned research questions:

- (1) How are households with retired caregivers for children with disabilities faring economically? Are there differences based on social factors (e.g., race, ethnicity, or educational attainment) or where families live (e.g., in rural or urban areas)?
- (2) How do families perceive the adequacy of SSA benefits and available information for meeting family needs? Are there measurable differences in the role of SSA benefits in reducing hardship, and does this vary by family characteristics?

3. Data and Methods

3.1. Overarching Design

This study uses an explanatory sequential mixed-methods design (Creswell and Plano Clark 2017; Teddlie and Tashakkori 2009) to explore the aforementioned research questions. 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” (R. B. Johnson, Onwuegbuzie, and Turner 2007, 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 they facilitate triangulation across data sources (Creswell and Plano Clark 2017; R. B. Johnson, Onwuegbuzie, and Turner 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 3) (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 the economic well-being of retired parents of children with disabilities 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 these parents through the qualitative analysis (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, Curry, and Creswell 2013, 2142).

Figure 3. Explanatory Sequential Mixed-Methods Design



Source: Adapted from Creswell & Plano Clark (2017).

Notes: “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 3 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

In the quantitative analysis phase, our aim was to descriptively examine the economic well-being of retired households with a child with a disability and how this compared to that of other households with retired adults and children in the household. To gain a broad understanding of the economic well-being of households with a retired adult caring for a child with a disability, we turned to available nationally representative data. In addition to guiding the qualitative sampling strategy and data collection, our quantitative analysis aimed to answer our first research question (i.e., whether retired households with children with disabilities face higher rates of economic insecurity than other retired households with children) and pieces of our second research question (i.e., whether there are measurable differences in the role of SSA benefits in reducing hardship and variation by social characteristics). In addition, we use our quantitative analysis to further understand the extent to which the experiences of families in our qualitative sample related to adequacy are borne out in a nationally representative sample.

3.2.1. Data and sample.

We use data from the 2018–2020 Survey of Income and Program Participation (SIPP) panels, which collect data each month on household income sources, assets, and a variety of other economic well-being measures. This includes detailed information about Social Security Administration (SSA) benefits and income as well as other retirement income sources. Additionally, the SIPP includes measures related to household composition and household measures. We use data from the first wave of a household’s SIPP participation. We limit our

sample to households with at least one ever-retired adult with their own child, of any age, in the household. Retired adults are identified through a question asking whether household members have ever retired from a job or business; therefore, some of the adults in our sample may currently be in the labor force. We are able to identify whether the ever-retired adult has a child in the household through SIPP relationship codes, regardless of the age of the child; we do not impose any age limits on the child. This results in a study sample of 2,876 households.

3.2.2. Measures.

Our main independent measure is a binary indicator of whether a child in the household, of any age, has a disability, as defined by answering “yes” to any one of the SIPP disability items. The SIPP disability items include three child-specific disability questions (whether a child who is under five has any conditions that limit ordinary activity, whether a child between five and 14 has any conditions that limit ability to play with other children, and whether a child between five and 14 has any conditions that limit the ability to do schoolwork), six general disability questions (whether household members over five have difficulty walking or climbing stairs, difficulty with cognition tasks, difficulty doing errands alone, difficulty hearing, or difficulty seeing), and two work-specific disability questions (whether the household member has a condition that makes it difficult to find or keep work, and whether the household member is able to work at all). Using this definition, 830 households in our sample, or 28 percent of the full sample, have at least one child who identifies as disabled. For descriptive purposes, we compare characteristics from one focal child from each household, which is either the child with a disability or a randomly selected child in households of typically developing children or multiple children with disabilities.

The SIPP contains detailed measures of income from earnings, retirement sources, public programs, and SSA programs specifically. To examine overall household resources and sources of income, we include a recoded measure of the total household income from all sources, income from wages or earnings (i.e., earned income from the labor market), income from all retirement sources including employer-sponsored and private thrift savings accounts and defined benefit plans, the value of retirement savings accounts (both private and employer-sponsored), whether anyone in the household has a pension or defined benefit plan (even if they are not currently receiving income from the plan), and whether the household receives Supplemental Nutrition Assistance Program (SNAP) or Temporary Assistance for Needy Families (TANF) benefits.

We also include detailed measures of income from SSA sources. We examine whether the household received any SSA benefits through the Old-Age, Survivors, and Disability Insurance (OASDI) program and then further disaggregate these into retirement benefits, disability benefits, widow/widower benefits, spousal benefits, or other benefits. We also examine child benefits for survivors or workers with a disability. Finally, we examine whether the household received SSI payments. We sum the amount of all benefits from SSA sources (i.e., both OASDI benefits and SSI payments), and we also compute the proportion of household income that comes from SSA sources.

Finally, we have measures of economic hardship, including the household's income-to-poverty ratio (based on the U.S. Census Bureau threshold), indicators of whether the ratio is below 100 percent or 200 percent of the federal poverty line, and three measures of specific hardships. We include the following: a measure of food insecurity, which is based on the six-item scale from the US Department of Agriculture (USDA) included in the SIPP; an indicator for utility hardship, which indicates whether a household missed at least one utility payment in the previous 12 months; and an indicator for rent/mortgage hardship, which indicates whether the household missed at least one rent or mortgage payment in the last 12 months.

We also include a variety of household demographic measures that are associated with economic well-being and disability diagnosis, including the total number of adults in the household (which could include children who are over 18), total number of retired adults in the household, number of children (including children over 18) in the household, number of children under 18 in the household, age of the oldest parent in the household, whether anyone besides the focal child has a disability in the household, the age of the focal child, the marital status of the adult head, the sex of the focal child, the race and ethnicity of the retired adult, the highest education level of any adult in the household, whether the household is a multigenerational household, whether the household is in a metro or non-metro area, and the census region of the household.

As indicated in Table 1, we find differences in household characteristics for households with a child with a disability and households with only typically developing children. The oldest parent and the focal child are, on average, slightly older in households with a child with a disability compared to households with typically developing children. Households with a child with a disability have a higher mean number of retired adults. Differences in the ages may reflect the likelihood of children with disabilities to continue to live with parents for a longer and extended

period of time compared to typically developing children. The majority of all households in our sample have another individual with disability in the household, though the proportion is statistically significantly higher for households with a child with a disability. Some of the SIPP disability questions are likely related to aging, such as difficulty using stairs or difficulty hearing; given that our sample selects on retirement, this, combined with the genetic component of some disabilities, may explain the overall prevalence of households with other members with a disability. Households with a child with a disability are slightly more likely to be multigenerational households, including either the child's children or the parent's parent. In keeping with overall disability diagnosis demographics, households with a child with a disability are more likely to have a White head of household and less likely to have an Asian head of household, and children with disabilities are more likely to be male. Households with children with disabilities are disproportionately more likely to have one parent, with higher proportions of both divorced and widowed parents, and less likely to have married adults. Households with children with disabilities have lower education levels and, following the literature, are more likely to live in non-metro areas, and there are differences by U.S. Census Bureau geographic region as well.

Table 1. Quantitative Sample Descriptive Statistics: Households with Retired Adults Co-residing with Children the SIPP

	Households with children with disabilities		Households with other children		Stat. sig.
	N	Mean/Percent	N	Mean/Percent	
Number of adults in household	830	2.0	2038	2.1	
Number of retired adults in household	830	1.3	2038	1.3	+
Number of children in household	830	1.4	2038	1.4	
Number of children under 18 in household	830	0.5	2038	0.6	
Age of oldest caregiver in household	830	72.4	2038	69.0	***
Other person with a disability in household	830	68.3%	2038	51.5%	***
Age of focal child	830	39.0	2038	37.6	***
Proportion with children under 18	830	15.9%	2038	14.3%	
Marital status of head of household					
Never married	13	1.6%	30	1.4	
Married	436	52.5%	1361	66.8	***
Separated	12	1.4%	28	1.4	
Divorced	105	12.7%	210	10.3	+
Widowed	264	31.8%	409	20.0	***
Focal child sex (male)		55.4%		50.7%	**
Adult race					
White	657	79.2%	1465	71.9%	***
Black	107	12.9%	289	14.2%	
Asian	30	3.6%	191	9.4%	***
Other	36	4.3%	93	4.6%	
Adult Hispanic/Latino		13.6%	306	13.5%	
Adult highest education level					
HS diploma/GED or less	251	30.2%	413	20.3%	***
Some college/2-Year degree	264	31.8%	611	30.0%	
Bachelors/4-year degree	167	20.1%	550	27.0%	***
Graduate or professional degree	148	17.8%	464	22.8%	**
Urbanicity					
Metro area	644	77.6%	1662	81.6%	*
Non-metro area	186	22.4%	376	18.4%	*
Region					
Northeast	103	12.4%	328	16.1%	*
Midwest	156	18.8%	325	16.0%	+
South	365	43.9%	818	40.2%	+
West	206	24.8%	566	27.8%	
Multigenerational households	223	26.9%	478	23.5%	+

Source: Authors' calculations from the 2018–2020 SIPP data.

Notes: ***p<.001 **p<. 01 *p<.05 +p<.10

3.2.3. Analysis.

Our analysis is focused on descriptively understanding the overall economic well-being of households with a retired adult and a child with a disability, the role of SSA benefits, and the extent to which social characteristics matter for these outcomes. To address the first question, how the overall economic well-being of households in our population of interest differs from that of other

households with retired adults and children, we first conduct simple differences in means tests, comparing households with a child with a disability to those with typically developing children. We further examine the association using regression analyses, which allow us to account for some potential confounding factors using demographic covariates (as seen in Table 1). We use ordinary least squares (OLS) models for both our continuous and bivariate outcomes for ease of interpretation but note that results are robust to use of logistic regression models for binary outcomes. To assess how social characteristics may impact economic well-being, we use subgroup analyses. We consider the association between having a child with a disability and economic well-being outcomes separately for White households and for households of color (i.e., the parent or the child in the household identifies as a race or ethnicity other than White, non-Hispanic), metro and non-metro households, single-parent households and two-parent households, and households with at least a college degree and those with a high school degree or less.

In the next phase of our analysis, we aim to further unpack the extent to which income from SSA sources, including OASDI benefits and SSI payments, may be supporting families' economic well-being. To do this, we use interaction models to assess how SSA benefit receipt may moderate the association between having a child with a disability in the household and our various measures of economic hardship. We use separate models interacting child's disability status with receipt of any OASDI benefits (i.e., retirement, disability, spousal, or other family benefits), receipt of retirement benefits only, and receipt of SSI payments. We again run models separately by subgroups of interest to understand whether there are differences by social characteristics, allowing us to assess any measurable differences in the role of benefits for each subgroup. For more information about our analyses, see Appendix A.

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 our study's quantitative findings. To augment quantitative findings from our first research question (whether households with retired adult caregivers for children with disabilities face higher rates of economic insecurity than other households), we explore themes from the qualitative interviews related to how caregiving affects work, retirement savings, and

economic well-being. We highlight emergent themes related to differences in family experiences by social characteristics of families. Next, we explore our second research question (how families perceive the role and adequacy of SSA benefits in family economic well-being), drawing primarily on data from the interviews.

3.3.1. Recruitment.

We recruited 12 parents who considered themselves partly or fully retired, with at least one child (of any age) with a disability for whom they provide care or support. To be considered eligible, at least one person in the participant's household needed to be the current recipient of any type of SSA benefit; alternatively, participants were considered eligible if they had a child with a disability living outside of the home who receives SSI, even if no one in the participant's household received other SSA benefits. Because the quantitative analysis identified race and marital status as related to economic well-being, we used recruitment quotas to ensure participation across groups. We aimed for a minimum of two participants in each of the following groups: White, currently married; White, not currently married; non-White, currently married; and non-White, not currently married. We also aimed to recruit, across these groups, at least two participants who were receiving SSI income or who had a spouse or child with a disability who was an SSI recipient. Because findings from the quantitative analysis suggested a broad definition of disability was likely both to maximize sample size and to promote greater diversity in sociodemographic characteristics, we employed a broad definition of disability in our recruitment materials.

To achieve recruitment targets, the study team shared a study flyer via email with 49 agencies, located across 28 southern and southeastern Wisconsin counties, that provide services or resources to people with disabilities or retired individuals. These included service providers such as local Aging and Disability Resource Centers (ADRCs), local National Alliance on Mental Health (NAMI) branches, statewide and local advocacy groups for individuals with disabilities, and local support programs for families of disabled individuals, as well as several providers that serve people of racial and ethnic minority backgrounds (such as local Urban League chapters). We asked agencies to post study information in their buildings; share the flyer through social media accounts; or distribute the flyer to any relevant listservs. The study flyer included information about the study's purpose and eligibility criteria as well as a QR code or a direct link to a Qualtrics survey to express interest in participation.

The Qualtrics survey screened potential participants using the aforementioned study criteria. Potential participants were also asked to provide demographic information (e.g., race and ethnicity, gender, highest level of education completed, and marital status), 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 39 apparently legitimate and eligible inquiries received during the recruitment phase, 12 interviews were scheduled and conducted.

Our qualitative interview sample included parents from an array of backgrounds (Table 2). Most (58 percent) were fully retired, though a substantial share (42 percent) considered themselves partly retired. The interview sample included men (17 percent) as well as women (83 percent). Over half (58 percent) of parents in our sample identified as White. Most (67 percent) participants were currently married, and one-third were never married, divorced, or widowed. Our interview sample had higher levels of educational attainment than did parents of children with disabilities in our quantitative sample, with half of sample members having completed a bachelor's degree or more. Additionally, while most parents in our qualitative sample had at least one adult child with a disability, 42 percent had at least one minor child with a disability—nearly three times as many as in our quantitative sample. Participants had an average of 2.8 children in total and averaged 1.3 children with a disability. All interview participants provided care for a child with a disability, and on average, participants estimated providing 280 hours of care per month for their child or children with a disability. Nearly all participants lived with at least one child with a disability; one-third lived alone with their child, and 58 percent of sample members lived with a spouse as well as a child with a disability.

Table 2. Qualitative Sample Participant Characteristics

	Count	Percent/Mean	Min – Max
Total	12		
Retirement status			
Fully retired	7	58.3%	
Partly retired	5	41.7%	
Gender			
Male	2	16.7%	
Female	10	83.3%	
Race/Ethnicity			
Black or African American	1	8.3%	
Hispanic or Latino	3	25.0%	
White	7	58.3%	
Other	1	8.3%	
Highest Level of Education			
High school diploma/GED or less	2	16.7%	
Some college/Associate's degree	4	33.3%	
Bachelor's degree	3	25.0%	
Graduate or professional degree	3	25.0%	
Marital Status			
Not married (never married, divorced, or widowed)	4	33.3%	
Currently married	8	67.7%	
Number of Children		2.8	1 – 5
Number of Children with a Disability		1.3	1 – 4
Has One or More Children with a Disability < 18	5	41.7%	
Hours of Care per Month		280	60 – 720
Participant Co-Resides with:			
Spouse only	1	8.3%	
Child(ren) with disability only	4	33.3%	
Spouse and child(ren) with disability	7	58.3%	
Main Source of Household Income			
SSA benefits alone	6	50.0%	
SSA benefits + other retirement income	2	16.7%	
Current wages; or current wages + other retirement	3	25.0%	
Other	1	8.3%	
SSA Benefits Coming into Household Include: (not mutually exclusive)			
Retirement	5	41.7%	
SSDI	6	50.0%	
Child benefit	4	33.3%	
Spousal benefit	1	8.3%	
SSI	8	66.7%	

Source: Authors' calculations from qualitative sample.

Notes: SSI benefits (bottom two rows) may also include some households where the parent or additional household member also receives SSI; as such, the bottom SSI proportions don't sum to the overall SSI proportion.

3.3.2. Data collection.

Data was gathered during individual interviews using a semi-structured interview guide. Interview questions were developed to address the study's research aims and to take into account key findings from the quantitative analysis. We therefore structured the interview to gather detailed contextual information about participants' households, families, and caregiving activities; to explore participants' work experiences and retirement circumstances; to identify income and benefits coming into the household in retirement and participants' perceptions of the adequacy of those resources for making ends meet; and qualitatively to explore participants' perceptions of, feelings about, and decision-making processes around caregiving, retirement, and work. All 12 participants completed the interview by phone or video chat. Interviews took 45 to 90 minutes, and participants who completed the interview received a 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.

3.3.3. Data analysis.

Interviews were analyzed thematically; 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. 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. The study used a hybrid inductive-deductive approach to coding and theme identification (Fereday and Muir-Cochrane 2006); the team developed the initial codebook using structural codes derived from the research questions and interview guides and then added emergent codes after initial transcript review. The team performed an initial round of coding using this scheme and added new codes (as separate codes or subcodes) as needed and developed and refined themes (Braun and Clarke 2006; Fereday and Muir-Cochrane 2006). Themes were explored both within and across cases (Ayres, Kavanaugh, and Knafl 2003). Early transcripts were double-coded, and the research team engaged in writing memos and peer debriefing throughout the coding, analysis, and writing process (Franklin and Ballan 2001; Nowell et al. 2017).

4. Results

4.1. How Are Households with Retired Caregivers for Children with Disabilities Faring Economically? Are There Differences Based on Social or Geographical Characteristics?

We address our first research question primarily with our quantitative data. In our initial bivariate analysis (Table 3), we find retired households with a child with a disability are more economically disadvantaged across a variety of measures compared to retired households with typically-developing children. Looking at overall household income, a measure that combines both earnings and unearned income, households with a child with a disability have incomes nearly 25 percent lower (\$86, 552 compared to \$115, 367) on average; however, median household incomes between the two do not differ statistically. These households also have, on average, a lower income-to-poverty ratio (3.92 versus 5.74), including a statistically significantly higher proportion with household income below 200 percent of the federal poverty line (30 percent compared to 18 percent). Households with a child with a disability are also more likely to experience other hardships, including twice the level of food insecurity (13.4 percent compared to 6.6 percent), nearly twice the level of missed utility payments (10.1 percent compared to 5.4 percent), and higher levels of missed rent or mortgage payments (6.0 percent compared to 4.0 percent). Households with a child with a disability also report receiving Supplemental Nutrition Assistance Program (SNAP) or Temporary Assistance for Needy Families (TANF) benefits, both means-tested safety net programs, at higher rates than other households in our sample.

Table 3. Economic Well-Being Measures and Income Sources in Retirement

	Retired households with child with disability	Retired households with other children	Stat. sig.
	Mean/Percent	Mean/Percent	
Economic Well-Being Measures			
Total household income	\$ 86,522	\$ 115,367	***
Total household income (Median)	\$ 60,984	\$ 86,500	
Income to poverty ratio	3.92	5.74	***
<100% Poverty	7.4%	5.9%	
< 200% Poverty	30.1%	17.9%	***
Food insecurity scale (scored using USDA measure)	0.58	0.28	***
Food insecure (USDA measure) [Food hardship]	13.4%	6.6%	***
Missed rent or mortgage payment [Mortgage/rent hardship]	6.0%	4.0%	*
Missed utility bills [Utility hardship]	10.1%	5.4%	***
Receive SNAP	27.8%	14.0%	***
Receive TANF	1.4%	0.7%	+
Wages, Retirement Income, SSA Benefit Receipt			
Any income from current wages/earning	64.2%	87.3%	***
Income from current wages/earnings	\$ 46,891	\$ 80,170	***
Any income from retirement sources	40.9%	40.2%	
Has 401K/403b/TSP account	38.3%	51.1%	***
401K/403b/TSP account value	\$ 67,891	\$ 99,263	*
Value of all retirement accounts	\$ 145,220	\$ 195,236	*
Has pension or defined benefit plan	11.9%	19.2%	***
Pension income amount	\$ 8,021	\$ 8,593	
Any SSA benefits from OASDI	82.1%	65.9%	***
Retirement	70.8%	57.4%	***
Disability	29.6%	11.0%	***
Widowed	8.3%	5.6%	**
Spouse	2.6%	2.1%	
Other	3.4%	2.1%	**
Adult SSA income amount	\$ 20,438	\$ 14,663	***
Any child (<18) in HH receives SSA benefits	5.3%	3.8%	+
Any child in HH (<18) — SSA benefit amount	\$ 426	\$ 328	
Receive any SSI payments in household	22.0%	8.3%	***
Household SSI payment amount	\$ 1,624	\$ 513	***
Total SSA payments amount	\$ 22,063	\$ 15,176	***
SSA as percent of income	42.2%	22.7%	***
<i>N</i> =	830	2038	

Source: Authors' calculations using the 2018–2020 SIPP.

Notes: ****p*<.001 ***p*<.01 **p*<.05 +*p*<.10. Food insecurity measure derived from the USDA food insecurity scale. Measures of missed payments or benefit receipt account for the last 12 months.

There are also important differences in the sources of retirement income coming into households (Table 3, second panel). While the majority of all sample households with children report some wages from labor market earnings, 87 percent of households with typically developing children report wage income compared to 64 percent of households with a child with a disability. While a similar proportion of households report income from any private retirement source—

including a pension or monthly payment from a 401K or similar retirement savings account—there are differences in the availability of these retirement sources. Households with a child with a disability report lower rates of having a pension or defined benefit plan (11.9 percent compared to 19.2 percent); these households also have lower rates of having a 401K/403b or a TSP (Thrift Savings Plan) account, and, when they do have these accounts, they have on average lower levels of savings.

When considering benefits and payments from the Social Security Administration (SSA)—a major focus of our analysis—there are significant differences in terms of the amount of income from SSA and the likelihood of receipt by child’s disability status (Table 3). Eighty-two percent of households with a child with a disability receive some benefit from the Old-Age, Survivors, and Disability Insurance (OASDI) program compared to two-thirds of other households with children; this includes differences across all OASDI benefit types, including retirement (70.8 percent compared to 54.5 percent), disability (29.6 percent compared to 11 percent), widow/widower benefits (8.3 percent compared to 5.6 percent), other family OASDI benefits, and child benefits, including survivor and disability (5.3 percent compared to 3.8 percent). This results in a higher, on average, amount of income from SSA benefits for households with a child with a disability by almost 40 percent (\$20,438 compared to \$14,663). Unsurprisingly, households with a child with a disability are more than twice as likely to receive Supplemental Security Income (SSI) payments, and, on average, they receive more of their income from SSI than do other households. Taking both SSI payments and OASDI benefit income into account, households with a child with a disability receive, on average, over 40 percent of their household income from SSA, compared to over 20 percent for other households.

The overall association between having a child with a disability and our economic hardship measures diminishes some but generally holds when we employ our multivariate models to control for other factors that may be associated with economic hardship and child’s disability status (see Table 4 and Figure 4). Estimates from our ordinary least squares (OLS) models indicate that, while controlling for other factors, having a child with a disability in the household increases the likelihood of having income below 200 percent of the poverty threshold by approximately 9 percent. Our coefficient estimate indicates that having a child with a disability decreases income-to-poverty ratio by .858, equivalent to 85.8 percentage points. We also continue to find statistically significant associations with our general economic hardship measures, including that these

households are 5.6 percent more likely to experience food insecurity, 4.3 percent more likely to report missing a utility payment, and 2.0 percent more likely to report missing a mortgage or rent payment. Households with a child with a disability also, on average, report a higher proportion of household income from all SSA sources (14 percent higher).

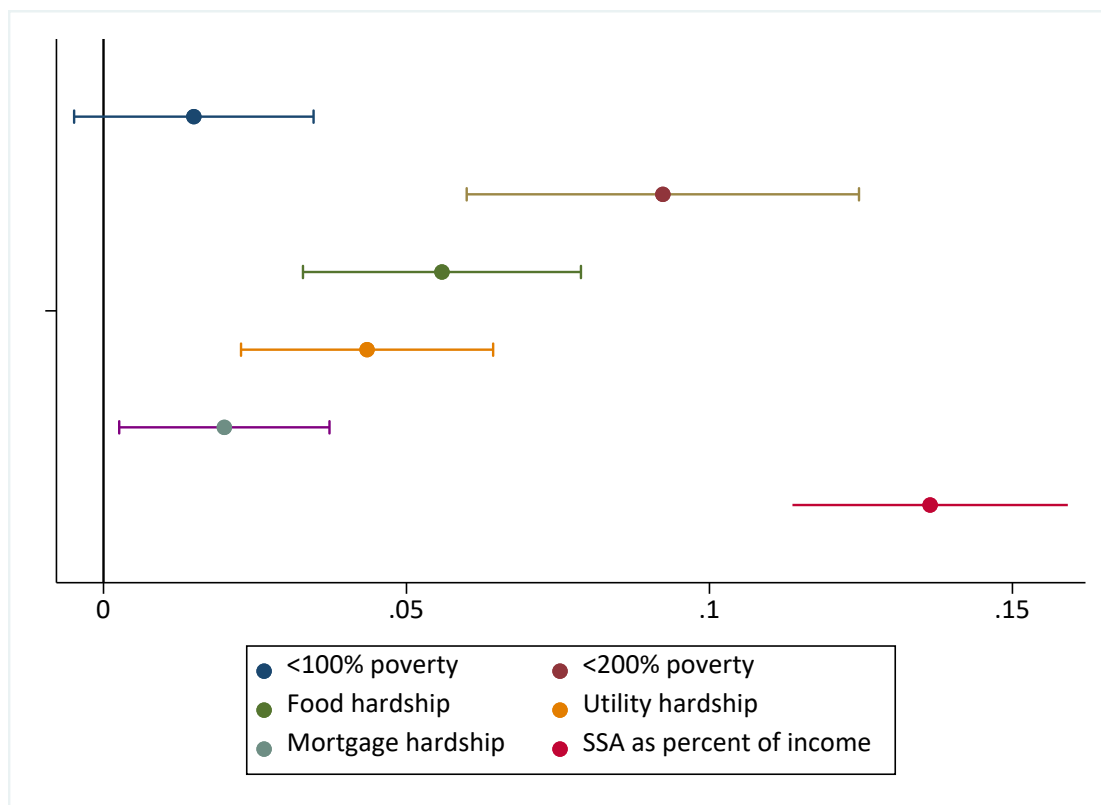
Table 4. Ordinary Least Squares (OLS) Estimates of Economic Well-Being Measures by Child Disability Status

	<100 % Poverty	<200% Poverty	Income to poverty ratio	Food hardship	Utility hardship	Mortgage/ rent hardship	SSA as Percent of Income
Child with Disability (CWD)	0.015 (0.010)	0.092*** (0.017)	-0.858*** (0.179)	0.056*** (0.012)	0.043*** (0.011)	0.020* (0.009)	0.136** (0.013)

Source: Authors' calculations using the 2018–2020 SIPP.

Notes: Standard errors in parentheses. ***p<.001 **p<.01 *p<.05 +p<.10. Models include the following covariates: number of retired adults in household, number of children under 18 in household, race/ethnicity of householder, highest level of education, sex of focal child, U.S. Census Bureau region of household, marital status of householder, indicator for additional household members with a disability, and household urbanicity.

Figure 4. Estimates of Association of Having a Child with a Disability with Economic Well-Being Measures for Retired Households



Source: Authors' calculations using 2018–2020 SIPP.

Figures 5a–5g. Heterogeneity in Association between Having a Child with a Disability and Economic Well-Being Measures for Retired Households by Social and Geographic Characteristics

Figure 5a: 100% Poverty

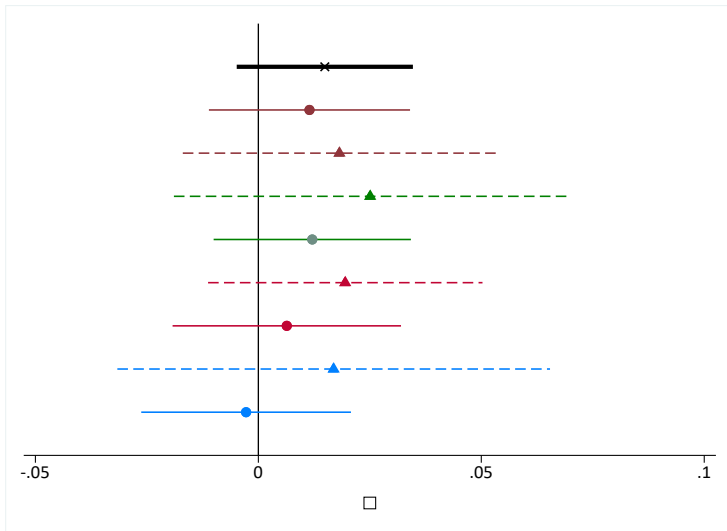


Figure 5b: 200% Poverty

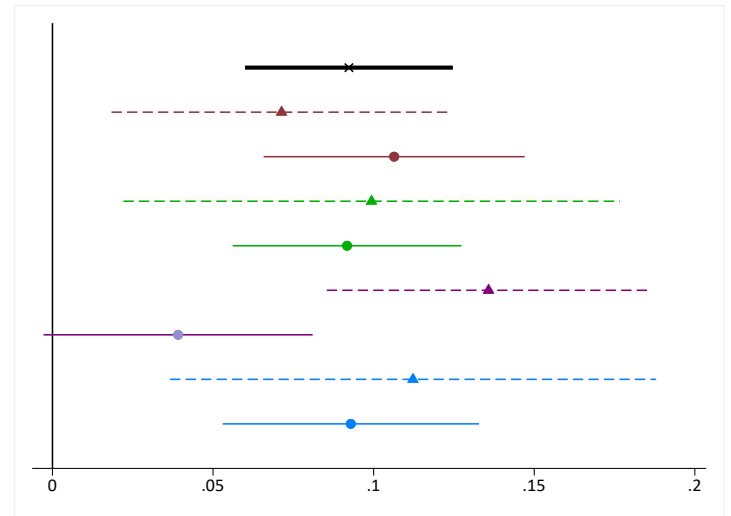


Figure 5c: Mortgage/rent Hardship

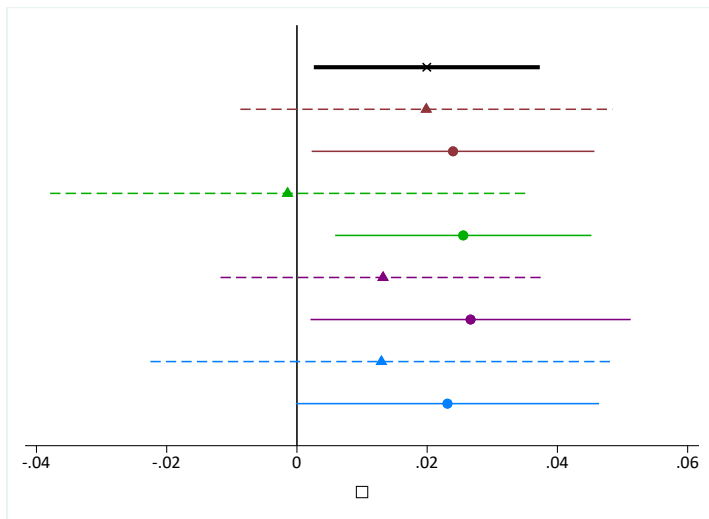


Figure 5d: Utility Hardship

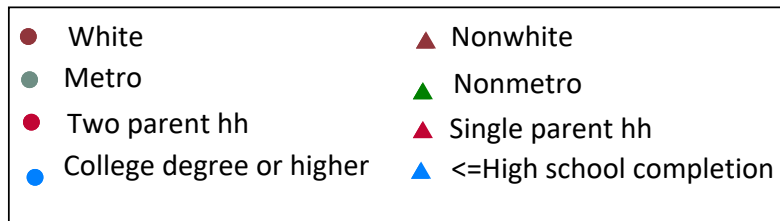
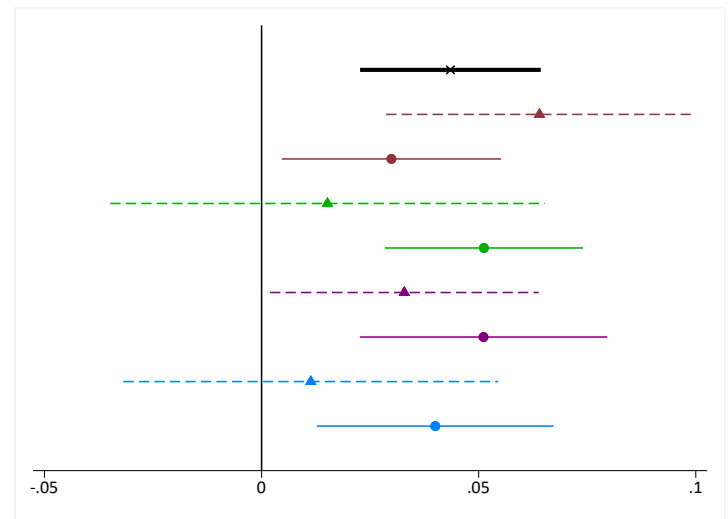


Figure 5e: Food Hardship

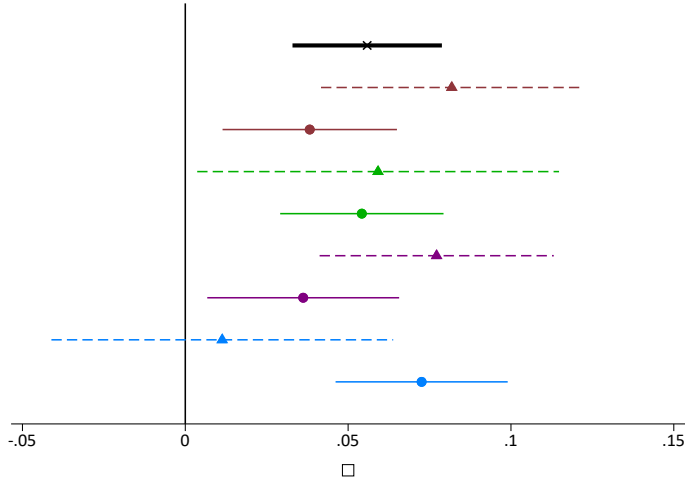


Figure 5f: SSA as Percent of Income

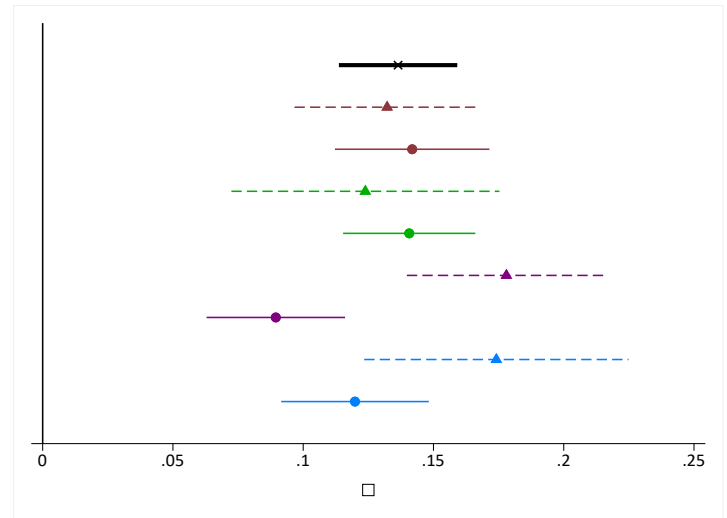
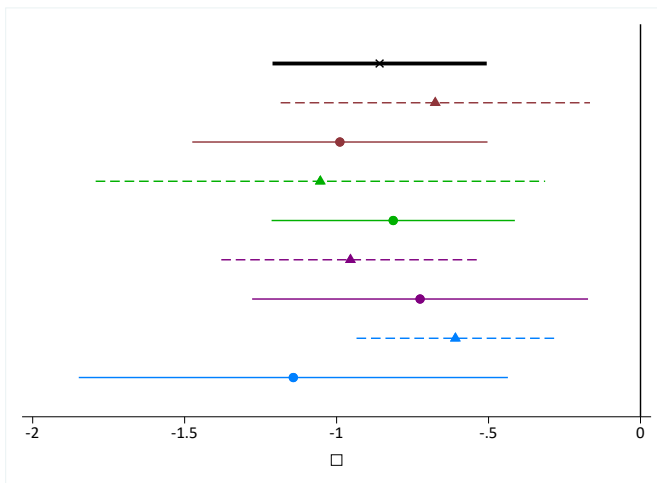


Figure 5g: Income-to-Poverty Ratio



Source: Authors' calculations using the 2018–2020 SIPP.

Notes: Estimates are presented as coefficient plots from OLS models estimating the associations between having a child with a disability in a household and various outcomes. All models are run separately by subgroup and include the following covariates: number of retired adults in household, number of children under 18 in household, race/ethnicity of householder (excluded from race/ethnicity subgroup models), highest level of education (excluded from education subgroup models), sex of focal child, U.S. Census Bureau region of household, marital status of householder (excluded from family structure subgroup models), indicator for additional household members with a disability, and household urbanicity (excluded from metro subgroup models). For more information, see Appendix A.

To better understand differences in economic well-being by social characteristics, we also conducted subgroup analyses in our quantitative data (Appendix Table B1, Figures 5a–5g). We focused on historically marginalized subgroups, with a specific interest in comparing the experiences of families of color with those of White families. Given differences in available resources by geographic region and differences in rates of disability diagnosis, we also examined families in metro and non-metro areas separately. Finally, we considered differences for single-parent and two-parent families, and we also examined the role of parental education in potential disparities.

Though there are few statistical differences when considering households of color separately from White households, in several instances the magnitude of the estimates for the impact of having a child with a disability on economic hardship is larger for households of color. The association with income below 200 percent of the poverty line is nearly seven times greater for households of color than for White households, and, for food insecurity and utility hardships, notably, the estimate is twice as great. Having a child with a disability is statistically associated with rent or mortgage hardship for White households but not for households of color, who may generally be more likely to experience missing a rent payment whether or not they have a child with a disability. When we examine differences for households in metro and non-metro areas, we find that households with a child with a disability in metro areas are significantly likely to experience both rent and utility hardships, while households in rural areas are not. This difference could be due to the differences in cost of living between rural and metro areas. Additionally, given the literature on differences in family structure and outcomes, we examined outcomes for households with two parents compared to those for households with a single parent. One large difference we find here is that single-parent households rely on SSA benefits for a much greater portion of their income than do households with two parents, by a margin of two to one (17.8 percent of household income on average compared to 8.9 percent). Another noteworthy difference in magnitude is that in the estimates for food insecurity, which again is nearly twice the size for single-parent households. Perhaps reflecting single-parent families' likelihood of having lower income-to-poverty ratios generally, having a child with a disability is not associated with a decreased likelihood of having income below 200 percent of poverty for single-parent families, the only subgroup we examined for which this is the case. Finally, we examined the role that parental education may have in outcomes. Here we find that while having a child with a disability

is associated with increased likelihood of several hardship experiences for parents with at least a college degree, there is no statistical association for parents with a high school degree or less.

4.1.1. Caregiving, employment, and earnings.

Our study's qualitative component provides insight into factors that can affect the economic resources available to families of children with disabilities, some of which may drive the differences in subgroups indicated above. Key among these factors was the relationship between caregiving, work, and opportunities to save for retirement. All of the parents in our sample had spent time in the paid labor force while simultaneously providing care and support for a child with a disability, and some continued to work part-time in retirement. Most had, at some point in their working years, made an employment transition affected by their child's care needs—either transitioning from full-time pay to part-time pay, to lower-wage work, or to work without benefits. These transitions often had consequences for income and retirement savings. Many participants also had the experience of providing varying levels of care for other people in their lives, including parents, spouses with disabilities or serious health conditions, or grandchildren, in addition to a child with a disability.

Parents identified several ways in which caregiving affected their employment, including the extent of their labor market participation and the kinds of jobs they held. A key consideration for parents was workplace flexibility; nearly all parents we spoke with emphasized the need for at least one parent in the household to have a flexible work environment in order to balance work and caregiving responsibilities. For many parents, flexibility in work schedules was crucial. Parents emphasized the importance of being able to adapt schedules to align with their children's work, school, or activities as well as being able to take time off or adjust work hours to accommodate doctors' appointments or health issues. As one mother described:

I can work between 8:00 or 7:30 and 3:00. After 3:00, she's home. She cannot stay by herself because there's—I don't trust her in the house. She's made mac and cheese and started a fire before. You know, she just really can't be home.

Parents also described needing to take paid or unpaid time away from work in order to address children's health issues or medical procedures. Due to the ongoing nature of their children's health needs, some parents experienced multiple periods of time away from work. Many parents described complex medical interventions or surgeries related to their child's disability that caused

them to take time away from work, sometimes over a period of multiple months or years. Described one mother:

I had to take a lot of paid and non-paid days because I had used them for surgeries that she had. She has had multiple surgeries in the last couple of years.... I had to take family leave to care for her inside the hospital and out. My company was very gracious and allowed me to do that. We had like a shared sick leave pool that I was able to draw from. But once my approved hours were done, you know, I couldn't do that for follow-up appointments if I had to leave early or, you know, take time off to care for either one of them. So, it did affect my work.

In addition to workplace flexibility affecting employment decisions, some parents also sought employment in physical locations that aligned with their child's care needs, such as jobs that allowed them to work remotely, or onsite at their child's school or childcare facility, or in a specific state or country that facilitated improved access to care and support for their child's disability. These constraints meant that parents sometimes needed to be flexible in the kinds of employment they pursued. One mother, a single parent, described leaving an in-office job with a meeting-heavy schedule in order to be home with her child. She explained:

When [my child] was sick, his symptoms would always show up in the morning. It would be like, "Can he go to school or not?" I've got appointments, [people] scheduled to see me from 9 am to 4 pm. And it was just like, "I can't do that in-person stuff." So, then I took a job where I was able to do more remote work. ... Caring for [my child], I can't just let him sit there all day on his own, right? I mean, we have to have some interaction and do things.

A father described that in his family, their daughter's care needs shaped the decisions he made about where to work, whereas his spouse exited the labor force to provide care. He stated:

Early on, after [our daughter's] birth, her situation has affected both her mom and I. Her mom decided not to go seek employment, and to stay home to take care of her. And also, that may have influenced my decision to stay in the U.S. [for work].

Parents described that their need for flexibility—in work hours, leave time, or work location—was particularly crucial given that many experienced challenges obtaining regular, adequate care or access to supported activities outside of the home, challenges that some families found were exacerbated by the COVID-19 pandemic. These challenges included turnover among care providers, concerns about quality of care, service costs, and limited availability of in-home and out-of-home service providers and programs. One mother described the role that limited service availability played in her career transition to a more flexible job:

At the time that he was born, and he was a young child, we did not have daycare options for a child with special needs. There wasn't daycare options—there barely were preschool options. You know, preschool options were very limited. So, we've always juggled work schedules and I was, you know, I, being the mom, I stepped back from my career. I went into a different career that gave me flexibility, but definitely I cannot commit to a full-time career.

Supportive service availability was a concern particularly emphasized by parents residing in more rural areas, where health and care providers were sometimes located a considerable distance from the family and where programmatic and in-home care options were more limited than other areas. These parents described greater difficulty obtaining in-home care, fewer community resources and places children could go for supported care time outside of their households, and longer travel times in order to visit doctors' offices and other care providers for children. Described a parent from a more rural area, "There's a lot of travel with medical ... every trip is over an hour one way for us." These constraints placed greater caregiving responsibilities on these parents and restricted their out-of-home employment options.

Finally, parents highlighted that caregiving responsibilities affected their tenure in the paid labor force. For some parents, this meant that they exited the labor force early or unexpectedly in order to facilitate caregiving at home; for these parents, this abrupt exit from the workforce meant that they were often unable to engage in retirement planning prior to leaving work. A mother who shared her experience of balancing her child's care needs with paid and unpaid time off found that she ultimately needed to leave employment unexpectedly in order to meet her family's care needs. She highlighted the challenge of knowing that leaving her job without notice could affect her career prospects yet needing to prioritize her child's care. She stated:

Towards the end, I ended up having to leave abruptly and quitting. I couldn't give a two week notice and had to be, like, "I'm done tomorrow and I'm sorry, but my family is much more important to me." And you know, "This is a more serious matter." And you know, I could probably never return to that position or that company.

For several parents who were providing both care for a child with a disability and frequent, intensive care for another person, balancing employment and caregiving became untenable. Described a mother providing care for multiple children with disabilities requiring significant care as well as a spouse with disabilities who had experienced recent additional medical issues:

I pretty much have to take care of everyone in the house. ... I want to go out and work, like provide more for the household. But I feel my priority right now is my family, their health and their well-being. ... Everything fell in the same year. COVID hit. My husband lost his

job because of his illness. I took care of three kids. So, it was just up to me. And when COVID started, that's when everything came crashing down. I had to make a right-then-and-there decision to care for the whole family.

Other parents found that having a child with a disability led them to stay in the paid labor force longer than they otherwise might have because they were unable to afford to retire, they needed the health insurance for their child or to maximize retirement earnings, or they needed to provide for children's care in addition to their own needs.

4.1.2. Children's needs and economic hardship.

In addition to the income constraints faced by families with caregiving responsibilities, parents described several additional ways in which the financial needs of their children also affected their household's available financial resources in retirement. Most of the parents we interviewed co-resided with one or more of their children with disabilities and provided significant economic support for their children. The children of many parents we spoke with did not work in any paid employment, and for those that did, parents described the benefits of this work primarily as social or skill-building for the children; children's jobs were typically very limited in hours and pay, sometimes irregular in hours, and nowhere near adequate for covering their living, health, and care costs. The children of nearly all parents we spoke with received SSA benefits (often SSI income), and some of the parents we interviewed had taken steps to augment their children's benefits with other forms of public assistance (such as FoodShare).

However, nearly all of the parents we spoke with described that the needs of their children could not be fully met through their SSA benefits and other income sources; therefore, parents found that they needed to fill the gaps, while often living on a fixed income themselves. Described a mother reflecting the income received by her child, "[My child] receives help from us. You know, he couldn't live without the support we get. I mean, the support that Social Security gives for people with a disability is under \$1,000 a month." This meant spending some of their own SSA or other retirement resources on the needs of their children, which was a particular challenge for those with fixed and limited incomes.

Beyond additional expenses, some parents described that even before they had retired, they needed to draw on or cash out retirement account balances to meet the costs of children's care and to cover basic household expenses—leaving them with fewer financial resources available in retirement beyond SSA benefits. One mother described that her family had cashed out her

husband's account to pay for treatments for their child not covered by insurance. She explained their decision had "... wiped out his 401k. Gone. But it's okay. I'd do it again; I really would. Because I think it helped.... We would have spent all the money we had." Another mother described having a retirement plan through a previous employer, but after leaving employment abruptly to meet her child's care needs, she "obviously had to tap into that and help make ends meet."

Balancing children's needs and available household financial resources presented challenges across many families, but interviews highlighted particular challenges for making ends meet in single-parent families. The parents we spoke with in two-parent families often described that one or both parents reduced hours or took a job with greater flexibility and that mothers generally made substantial adjustments to meet children's caregiving needs. Those in single-parent families, however, often experienced compounding difficulties. As their child's sole caregiver and income-earner during their working years, the single parents we spoke with often needed to make tradeoffs between work and caregiving that limited their income potential and retirement savings. In retirement, parents in single-parent households had only one benefits stream to draw on to meet both their own and their children's needs.

Given these challenges for earning and savings faced by some interview participants, and consistent with findings from the quantitative analysis, many families in the qualitative interview sample experienced varying degrees of financial hardship. Some families in our sample—particularly those that had multiple earners during working years and multiple sources of income to draw from—described generally being able to make ends meet, though they often also reported monitoring expenses closely given limited income in retirement. Described a parent, "I have written down our expenses from the 1st to the 15th. And on the 15th through the 30th. And we do not deviate. If we go out to dinner, it's a special thing, you know?" One participant described that while their family's current financial situation was sufficient for making ends meet, doing so when their children were younger—particularly given the costs associated with meeting the needs of their child with a disability—was a challenge. She stated:

We've had years where it's been really pressing, and that's when we were trying—we were putting [our child with a disability]'s brother through college. There's certain points in your life, you know, like when you're young and you have a child with disability and you struggle. It's hard, it's really hard. And as you get older you pay—you know, insurance has changed over the years. The insurance pays for more therapy now than it did when he

was a kid ... we paid for therapy, behavioral therapy, we had to pay for counseling sessions out of pocket because insurance didn't cover those things.

For other families, however, covering the costs of even basic expenses and household member needs—including rent, utilities, and the cost of medication—was a struggle. For some parents, this meant owing substantial amounts of money to utility companies, or considering cutting back on medication or food, or deciding between bills to pay. Described one parent:

Sometimes you have to make decisions. Like for example, like toiletries, or laundry soap, or things that are less important. They're necessary, but less important. Because like I said, we don't get food stamps and we have to put the food as priority, the bills as priority. ... I add up what we have coming in and then prioritize the more important things. We need the light and we need the gas, that's the heat for the children.

A parent who had lost her spouse and who resided with her adult child with a disability highlighted the economic hardship that comes with losing a spouse's SSA income. She stated:

I'm lucky because I have the house. But for people who don't, I don't know how they survive ... when my husband was alive, the expenses were all the same. The only thing that differs is maybe a little less food, maybe not, and a couple extra bills. But you're still in your house. Your electric bill is going to always be the same. Your expenses are the same, really, except for his medical expenses. So, it must be hard on a lot of people, especially if they still have to pay a mortgage or rent. I wonder if I could pay rent now.

Families experiencing these hardships included families that received state benefits, such as energy or food assistance, as well as families who lived just beyond the threshold to be considered eligible for public benefits. Described one mother whose family lacked sufficient income to meet household needs, causing the family to cut back on essentials:

Oh, my goodness, gas and electric and water. That's pretty high. We have some debt that we need to take care of. We have our rent, we pay rent. For those that I—those are the main ones, the rent, the vehicle, and I would say the regular bills. Now, I always make sure that we have the staples we need for nutrition and food and things like that... But according to the state we make too much money to be able to be given any kind of extra assistance.

A single mother who co-resided with two adult children with disabilities and lived on a fixed income said that the effect of an unexpected expense would be devastating; she stated, “That would be—that could shut us down. That would—that would put us out.” Even families that reported being able to make ends meet, however, often described fear or anxiety about the financial implications of an unexpected expense that might arise. Described another mother in a married-couple relationship, “We do put away for like a rainy day too, but, you know, if we had a huge car

bill or any type of medical bill unplanned, that's really hard." Other parents had already had the experience of encountering unexpected expenses and not being able to cover them with savings; in response, some went without a vehicle for extended periods of time or took loans to cover these expenses. Described one mother:

I had to ask my mother to pay for it because I—actually my car completely died.... I'm paying her back for it because there's no way I can afford it. And I did have to take out loans from the—they're pay-based loans where you get them based on when you get paid. Sort of like payday loans. I took out three of them. One of them, I paid off two. I still have one that's over \$3,000. I'll never be able to pay it off.

4.2. How Do Families Perceive the Adequacy of SSA Benefits and Available Information? Are There Measurable Differences in the Role of SSA Benefits in Reducing Hardship?

A key goal of our study's qualitative component was to understand how parents of children with disabilities perceive the adequacy of SSA benefits for meeting their household's financial needs. SSA benefits—of varying types and amounts and targeted at different household members—served as an income source for all of the sample members in our study's qualitative component.

4.2.1. The role of SSA benefits in current family economic situations.

In the course of discussions with parents, the *role* that SSA benefits play in a family's overall economic situation provides important context for considering the *adequacy* of benefits. Interviews with parents highlighted that SSA benefits matter differently for families in different circumstances. Half of our interview sample described SSA benefits as their household's main source of income in retirement, while the other half described sources other than SSA benefits (such as current wages or retirement accounts) as their household's main source of income or relatively equal shares of SSA benefits and other income sources flowing into the home.

In families that had access to multiple sources of income in retirement—such as pensions, personal retirement savings, or income from earnings or assets—and particularly for families in which both parents had been earning income and saving for retirement during their working years, SSA benefits played a role in family economic well-being in retirement but were typically not the household's main source of income. In families that lacked these other income sources in retirement—because parents either did not work in jobs with retirement benefits or did not have or had already cashed out any retirement savings—and particularly in households with only one

earner, SSA benefits were often the main or only source of income flowing into the household. In these situations, parents described SSA benefits as crucial to family survival. When parents without ample additional retirement benefits were asked what it would mean for their family to be without SSA benefits in retirement, their responses included, “I’d probably be out on the street. Yeah. That’s my income,” “We would be destitute,” and “We’d be homeless” without SSA benefits. Another mother, for whom her own and her child’s SSA benefits were the main source of income for her household, expressed fear of potentially losing SSA benefits during her child’s redetermination process and worry about the potentially devastating financial impact this loss could have on her household. She described:

She's still going to be in high school during when she's 18. So, there's just so many things that change, and like so many things that changed in our financial situation. Like, are we going to be homeless because I'm not going to have any money? You know, like can I even survive that last year? And it's only a year away from now so it's scary. Like, am I going to be able to afford to live and to buy us food when I'm already, at the moment, going to food pantries?... She's not going to move out. She doesn't want to move out. She doesn't want to go into her own living place. So, it's like, you know, the two of us need a two-bedroom apartment. Am I going to be able to afford it because [my SSA benefit], I think, is like only \$400 more than rent? And that doesn't leave enough after bills to pay for anything.

In families for which SSA benefits were the main or sole sources of income in retirement, while these benefits were critical for family survival, for some families, they were also insufficient for fully meeting family economic needs. These families described living month-to-month, often with difficulty meeting everyday expenses. The mother quoted above, whose household relied on her own and her child’s SSA benefits for income, described, “But it's still not like a lot when you combine the two; it's not a lot to live on. We're living on basically nothing.” A single mother co-residing with two adult children with disabilities, for whom her children’s SSI was the household’s only source of income, described that living together was the only way that her family was able to afford rent. And yet, SSA benefits remained insufficient for covering the family’s needs. She stated:

The money—I mean, it's just not enough, obviously. You know, I don't know what these boys would do without me. Their Social Security money is not enough. You figure that three of us live together now so, you know, we divide stuff by three, but those boys come up short every month. I mean, can you imagine if they were separate and paying, you know, an apartment for \$850, \$875? Like, I can't imagine.

In addition to the important role SSA benefits played in family financial circumstances, families also emphasized that SSA benefits played a key role in their ability to meet the care needs of their children; these benefits made it possible for one or more parents to be retired and to provide care for children with disabilities in their retirement. Some parents found that without these benefits, they would need to return to work or increase work hours in order to make sufficient income to cover their households' expenses, limiting their capacity for providing care to children. One parent explained that without SSI income for her child, she or her husband, whom she co-resides with and who provides substantial care for their child, would need to return to the workforce part-time. Another described that without SSA benefits, she and her disabled husband would both need to return to the workforce—a physical impossibility for her spouse. Described one parent, who co-resided with her adult child with a disability and served as his primary caregiver, without SSA benefits, “It would be a big impact. I would definitely mean that we would be working more. I mean, quite a bit more, quite a bit more. I would be filling up my schedule with another contract or something, just to fill the gap.”

Our quantitative analysis suggests the experiences we heard from families are not outside the norm. Using interaction models, we consider the extent to which receipt of any benefit modifies hardship for families with a child with a disability experience (Figures 5a–5c; Appendix Table B2). The main effects of having a child with a disability in our interaction models broadly follows the overall pattern noted in Table 4 (that is, we see an increase in economic hardship across all measures). The main effects of receiving OASDI benefits or retirement benefits (see Appendix Table B2) specifically indicate a decreased likelihood of having household income below either 100 percent or 200 percent of the federal poverty level but do not indicate statistically significant impacts on other outcomes. In contrast, reflecting its status as a means-tested benefit, receipt of SSI is associated with an increased likelihood of having income below poverty and a lower income-to-poverty level.

Our focus, however, is on our interaction estimates, which measure the effect of receipt of SSA benefits for families with a child with a disability on economic hardship measures (i.e., how SSA benefits moderate the association between economic hardship and having a child with a disability in the household [as demonstrated in Tables 3 and 4]). These estimates suggest that receipt of OASDI benefits is associated with a 5.8-percent decrease in the likelihood of household income falling below the poverty threshold, and retirement benefits are associated with a 4.1-

percent decrease for families with children with disabilities compared to families of typically developing children. OASDI benefits are marginally associated with a 7-percent increase in the likelihood of having income below 200 percent of the federal poverty line, an association we do not see with just retirement benefits. This may be suggestive of differences in economic well-being for families who receive retirement benefits and those who receive disability or survivor benefits and may indicate that retirement benefits offer slightly more security than do the other OASDI benefits. We also find that retirement benefits are marginally statistically significantly associated with a 4.5-percent decrease in the likelihood of households experiencing food insecurity and a 4.3-percent decrease in households missing a utility payment. OASDI benefits are similarly associated with a decrease in missing utility payments but not with a decrease in food insecurity. Receipt of SSI is associated with a statistically significant decrease in income below 100 percent poverty of about 6 percent and, remarkably, a 16.8-percent decrease in the likelihood of having income below 200 percent of the federal poverty line. SSI does not moderate the association between a child's disability status and food insecurity, utility hardships, or rent hardships. Taken together, these estimates indicate that SSA retirement benefits, specifically, and SSI payments do play a role in supporting the economic well-being of retired households with a child with a disability and may be modestly adequate in providing support for families.

Figures 6a-6c: Interaction Estimates: The Role of SSA Benefits and SSI Payments in Moderating Measures of Hardship

Figure 6a: Interaction Estimates: OASDI Receipt

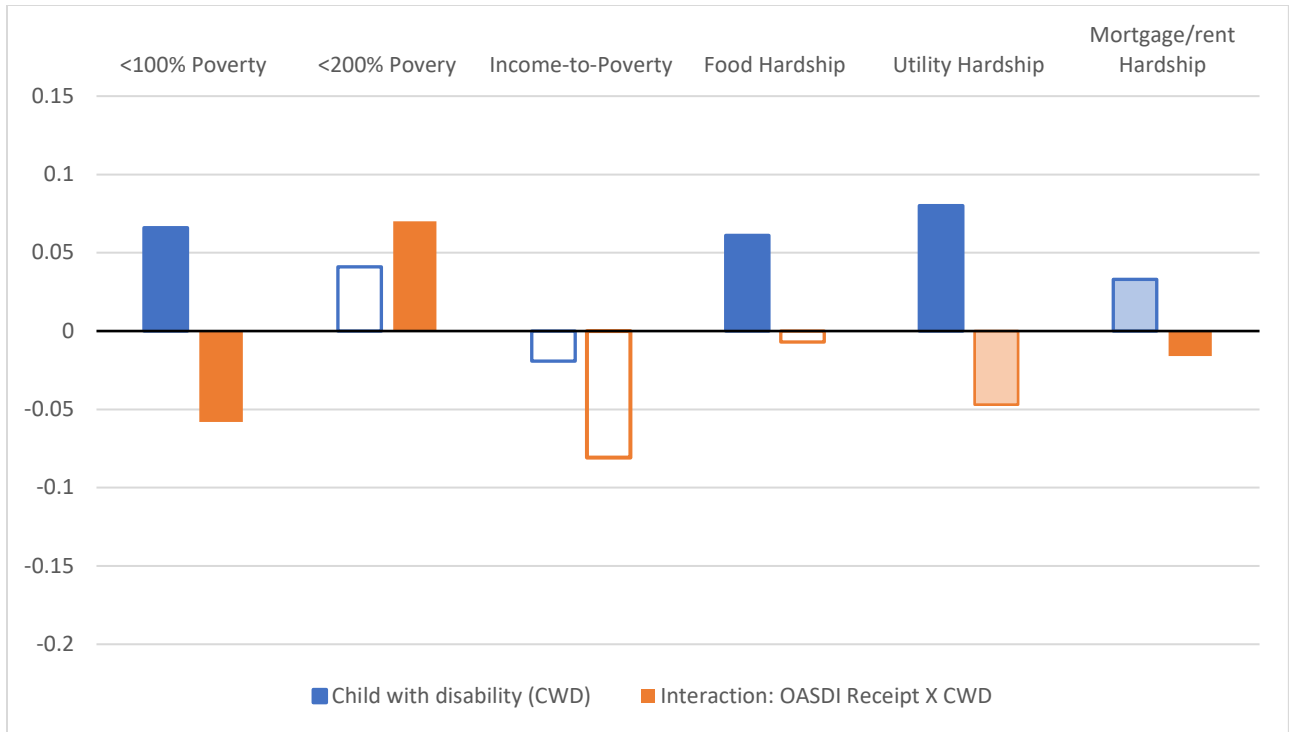


Figure 6b: Interaction Estimates: Retirement Benefits

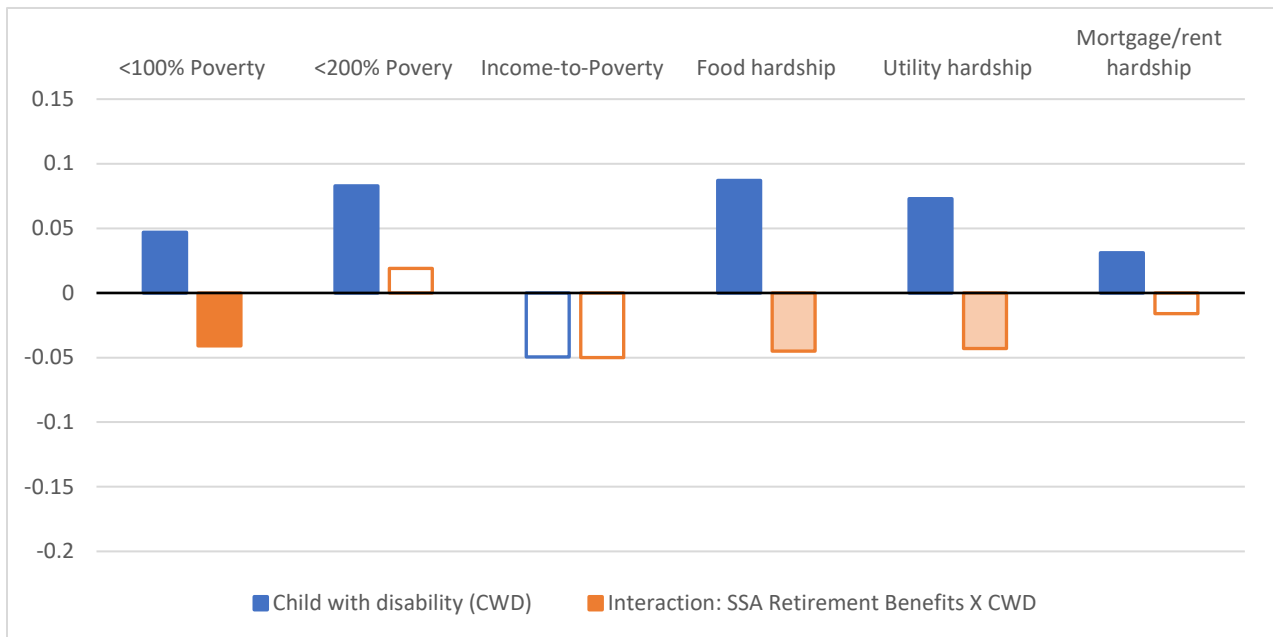
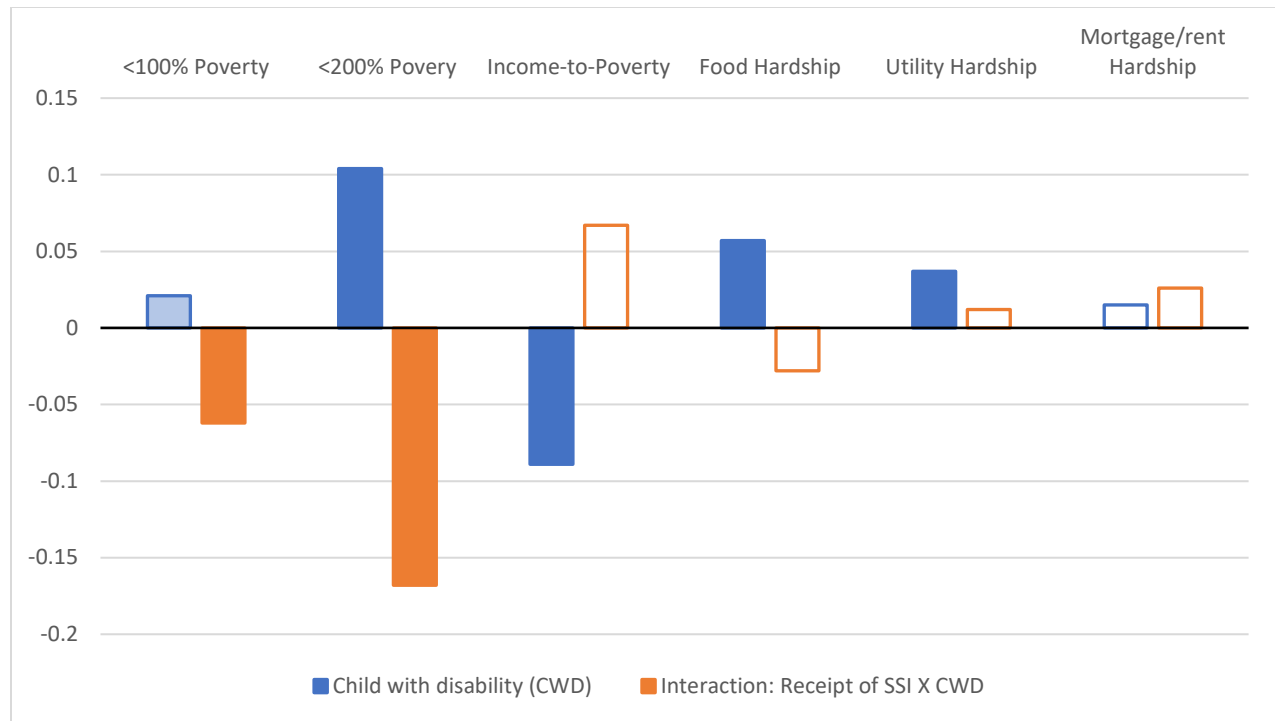


Figure 6c: Interaction Estimates: SSI Payments



Source: Authors’ calculations using the 2018–2020 SIPP.

Notes: Bold filled bars indicate statistical significance at $p < 0.05$ or above; faint filled bars indicate marginal statistical significance at $p < 0.10$. Bars without fill indicate estimate was not statistically significant. Estimates for income-to-poverty ratio are scaled down 10 percent to maintain overall scale. Estimates are derived from OLS interaction model estimating the interaction of having a child with a disability in the household and receipt of OASDI benefits, retirement benefits, or SSI payments respectively and various outcomes. All models include the following covariates: number of retired adults in household, number of children under 18 in household, race/ethnicity of householder (excluded from race/ethnicity subgroup models), highest level of education (excluded from education subgroup models), sex of focal child, U.S. Census Bureau region of household, marital status of householder (excluded from family structure subgroup models), indicator for additional household members with a disability, and household urbanicity (excluded from metro subgroup models). For more information about models, see Appendix A. For full results of models, see Appendix B.

However, these estimates are averaged across our full sample and may not reflect the experiences of all households (Figures 7a–7d). As we heard from families we interviewed, retired parents with children with disabilities are a heterogeneous group whose economic well-being is likely to be impacted differently based on their social characteristics. When we examine estimates from the interaction models for subgroups of interest, we find very few statistically significant estimates for differences for White families and non-White families. Receipt of all different types of payments moderate the association between having a child with a disability and the likelihood of having income below 100 percent of poverty for families of color, while there is no statistically significant effect for White families. Notably, receipt of OASDI benefits *increases* the likelihood of having income below 200 percent poverty for White families; this is likely reflective of the

comparison group, which may include families who have one or more household members still in the labor force. SSI receipt is marginally statistically significantly associated with a decrease in food insecurity for households of color, and receipt of OASDI similarly is marginally associated with a decreased likelihood of utility hardship for families of color with a child with a disability. When we consider differences by whether families live in a metro or non-metro area, we find that receipt of both OASDI benefits and SSI payments decreases the likelihood of experiencing food insecurity and utility hardships for households in non-metro areas but does not do so in metro areas. In metro areas, receipt of SSI payments decreases the likelihood of experiencing rent or mortgage hardship, though it does not do so in non-metro areas. There are also important differences by family context. We find that receipt of benefits (excluding SSI) is associated with a decreased likelihood of utility hardships for single-parent families but not for two-parent families. These findings suggest that family context plays an important role in both economic well-being and benefit adequacy. Finally, when we consider differences by parental education level, we find that retirement benefits moderate the likelihood of experiencing food and utility hardships for parents with higher-levels of education, but this is not the case for parents with lower-levels of education.

Figure 7a–7d: Heterogeneity in Interaction Estimates: The Role of SSA Benefits and SSI Payments in Moderating Measures of Hardship by Subgroups



Source: Authors' calculations using the 2018–2020 SIPP.

Notes: Bold filled bars indicate statistical significance at p<0.05 or above; faint filled bars indicate marginal statistical significance at p<0.10. Estimates for income-to-poverty ratio are scaled down 10 percent to maintain overall scale of other outcomes. Full results are available in Appendix Table B2.

4.2.2. Concerns about adequacy of benefits for children's futures.

For many of the parents we interviewed, the topic of SSA benefit adequacy was closely tied to their thoughts and worries about the future. Parents had given considerable thought to how children's economic and caregiving needs would be met after their own deaths. Described a mother:

You know, I think it's one of those intangibles, but it's never far from our minds, what happens when we die? I have one of the most loving families on the planet. But they are daunted by the potential responsibility of caring in the hands-on way that I do for my daughter. And not that Social Security can do anything about that. I don't know. You know, I don't know. That is something that I know all of us it's just part of—it's part of the journey and it never leaves our minds. You know, I mean, you worry about your typically developing kids after you die. Amp that up a hundred-fold, you know, it's so out of your control. And it doesn't mean we love our children any less because they have special needs—you find a whole new level of faith [brief laughter]. You have to.

For parents, concerns about where their children would live and who would provide care for them after parents were gone were closely related to fears for their children's long-term economic well-being.

Parents of all economic backgrounds—including those who were relatively well-off and had multiple income streams in retirement—expressed anxiety about their children's financial futures. Stated a mother:

No one's ready for this until it happens. If your child is on SSI, and a parent passes... with having a special needs child and being in the system on Social Security, I think you want to make sure that he's not going to fall through the crack somehow because of a loss.

Parents were providing significant financial support for their children with disabilities in life, and they worried about who or what entity would watch out for their children's financial futures after their deaths. Further, most parents we interviewed co-resided with children, addressing children's care needs but also meeting their housing needs. The future costs associated with stable, safe, and supportive housing; ongoing medical treatment; and adequate care—particularly for children who required round-the-clock or highly specialized care—loomed large for parents. Parents often described that they did not have a family member available to step into the role of providing full-time, live-in care for their child in the way that they had been doing; as one mother of two children with disabilities described: “I worry what'll happen to—will happen to these two when I'm done—I'm gone. I mean—you know, it's a devotion. No one's going to just give up their life to take care

of two boys.” At the same time, parents had concerns about the costs and quality of residential care and about the ability of such facilities to meet their children’s needs; as one mother described:

When somebody says, “Well, aren't you going to put your son into a group home?”, I'm like, “No, no, not going to do that.” That would be the last avenue that I would do, because of his complex medical.

Many were aware that even if such a facility were a viable option for the family, moving to an institution ran counter to their child’s wishes. Described a father:

[My daughter] doesn't, you know, she doesn't want to live in a group home. She hates the idea of moving out. We try hard to kind of prepare her to a time when we will not be here, so we—her mom and I—will take her to visit someone that is in a group home, somebody that she knows, to have her feel not be afraid or scared of situation like that. But she is hesitant, I guess, and we—that's a worrisome area for us. And her mom and I also don't want to burden her brother, that, you know, after we pass away, she would—we don't want her to be a burden on him.

Similar to our findings on perceptions of SSA benefit adequacy for meeting current household needs, parents often viewed SSA benefits as “vital” to their children’s future economic well-being. As one mother stated, “Oh, [SSA benefits are] vital. Just absolutely vital ... we hope she's able to do some meaningful employment, but it would never be enough to support her at all.”

Another mother explained:

If [my daughter's SSI benefits] hadn't been in place, there's no way we could have had another life. You know, then, I mean, between getting her these two jobs, and her Social Security, I knew that I could die. You know, we could die, and she was going to be—not flourishing, but she would survive.

And yet, they often feared that SSA benefits alone would not be adequate for fully covering children’s expenses. Some families had established other sources of income, such as trusts, for their children with disabilities or purchased life insurance in an effort to increase resources for children. A mother of four children with disabilities described her decision to prioritize purchasing life insurance for herself and her husband, even as her family struggled to cover basic household expenses each month:

The only thing I knew, we had to get life insurance because that's my biggest fear. That if I were to pass away tomorrow or the day after, God forbid, what—I don't want to leave the kids on the street.

Even having additional sources of future income for their children, however, while a source of some comfort, did not preclude these parents from worrying about their children's financial futures. Described a mother:

I'm already thinking about like things like, what happens after someday when I'm not around anymore? Who's going to be there when my mom's not there and my brother's not there? Like, are there cousins that are going to be there? Who's going to be there to help her? And then, it's just like you want everything in order so that there isn't much to do when it comes to money and stuff.

Parents lacking these other financial resources for children held very substantial concerns about the adequacy of SSA benefits for meeting their children's most basic needs—care, food, shelter, and medical expenses—after their deaths.

4.2.3. The role of uncertainty and support from SSA.

Among many parents we spoke with, feelings of considerable uncertainty across many domains affected their perceptions of adequacy and fears for their children's futures. Parents expressed uncertainty about their own lifespans and the longevity of their children; what care needs and costs would look like for both parents and children; and what financial resources—after addressing their own later-life needs—would remain for their children after their own deaths. Described a father:

We hope that we can secure some—secure financial setting for her for the future. And as we do that, we know what resources we have right now, and what we can devote to her, or what we can, you know, use ourselves right now as, you know, something that we could, you know, benefit from, instead of saving it for her if she doesn't need it. We don't know. So that's kind of—it impacts all of us.

Parents worried about the costs of care increasing and benefits not increasing to match these costs, and some also feared that potential policy changes resulting in the loss of SSA benefits could leave children with disabilities without essential resources. Described a single mother:

I'm a saver, I always have been. So, I've had that to, you know, help. But I knew Social Security would be a safety net for us—for me and for us, and that it would be guaranteed. And I hope it still is.

We asked parents, in interviews, to reflect on their experiences applying for and accessing SSA benefits. In the course of these reflections, many parents expressed uncertainty about the SSA benefits available to themselves and their children—currently and in the future—as well as uncertainty about how to get information and answers to questions. Parents called for information and support across several domains related to this current and future-facing uncertainty. First, parents wanted more information about the SSA benefits currently available for their children with

disabilities. Parents expressed uncertainty about how current parent and child SSA benefits affect each other. Described one mother whose daughter's benefits changed in response to her own benefits changing:

[SSA] just sort of did it. And then that's why I'm not sure if it's really the [correct] amount, because I swear she got more before but I'm not exactly positive. I don't know if I want to open the can of worms at all.

Parents were also uncertain about whether and how the timing of benefits claiming could help optimize benefits levels. Described a mother:

I want to go in and talk, and I want my papers in front of me, and I want to take notes, and I want to see somebody when I'm talking. And because there's a lot I don't know, you know. I don't know how all of this affects [my son]. And so, you know, what is he—what's his guarantee if something were to happen to me? Am I better off to take it now so that he would get a higher rate? You know, if something were to happen to me, how do they determine his rate, then, of benefits? I'm, I guess, embarrassed to say, I don't know that.

Additionally, some parents expressed uncertainty about how other income sources—such as income from earnings and investments—might affect SSA benefit levels, for themselves or their children. One father expressed uncertainty about how receipt of additional income would affect his own current benefits:

I have some investment funds with [my former employer] ... once I receive that money from these funds after I reach 72, how is that going to affect my taxes or Social Security? You know, that is something I don't know the answer to. It would be nice to kind of provide guidance. Not necessarily just the current moment, but also for a future time point when things will change.

Next, parents wanted information about whether and how benefit eligibility for their children would change after their own deaths. Described a father:

I would like to know what, you know, what would happen, let's say, after [my daughter's] mom and I passed away. Would she still be getting the retirement benefits or not? Would her support from Social Security change? You know, would it be higher, lower? So that's information on that to help us plan for the future. That's a big area that they could help with.

Another father expressed uncertainty about whether and how money left to his child upon his death would impact her SSA benefits, and he noted that this uncertainty makes future financial decision-making and decision-making about financial planning for a time after his death difficult.

I would like clarifications or information on [my daughter's] Social Security benefits. If they would be reduced if, like, after we die, and let's say, she inherited something from us. ... How is that going to affect her, and you know, does that reduce her Social Security?

And, you know, is there a way to know for sure what will happen under different circumstances if she has inheritance from us? Like a guideline of, you know, “If she gets X amount, then they will stop providing support for her,” or if it gets lowered, you know what would be the support that she gets? That would be valuable information for us to kind of try to plan for her.

These parents often worried about the potential for inadvertently impacting benefit amounts through other income sources. Described a mother:

[I want to] not be afraid to say something. I mean, that's really what I'm all—I'm like, okay, what am I going to say, or do—or like, “Oh my gosh, I didn't know I was supposed to be doing this,” and then jeopardize something. I mean, that's really—I know enough to be dangerous. Sometimes Social Security, I just go, “Oh God, no, here comes a letter. Now what did I do wrong?”

Finally, parents of minor children wanted information about the process of determining their child’s eligibility for employment upon turning 18 and its implications for SSA benefits.

Described a mother:

They have all these programs, like the going back to work program that they have, but for [my daughter], it's like it's going to work for the first time. So, it's like, you know, how do I know if she can go to work? Does she get Social Security until we figure out if she can go to work, you know? Just all those things. And there's nobody, to like, really ask. And if you ask the office, you get like a blank, like, “I don't know.”

4.2.4. Parent calls for increased support around SSA benefits.

Many parents expressed a desire for SSA to provide information and support that could help alleviate or address some of their uncertainty related to SSA benefits. Parents called for the following:

- **Information and guidance to help parents understand options and to plan for children’s futures**, including information about available benefits and eligibility, for themselves and their children, now and upon parents’ deaths; parent-child benefit interactions; thresholds related to and information about the impacts of other sources of income. Parents also called for information and support about caregiving resources and other benefits—beyond those administered by SSA—for which children with disabilities might be eligible.
- **Assigned case managers and parent advocates, with sufficient bandwidth to provide personalized care and support.** Parents often described being “bounced” across SSA staff rather than having an assigned caseworker or benefits navigator dedicated to their case. Parents felt that having a specific staff member familiar with their case would prevent them from

having to relay complex medical information many times to many people and would reduce the likelihood of being provided with conflicting direction or advice. Stated a mother, “I wish they assigned a person that would explain it to you, you know, more.... They don't explain to you the process, you know?”

Other parents called for individuals who could provide advocacy or peer support for parents navigating SSA processes; as one parent stated, “Nobody should go into Social Security without an advocate.” Parents wanted access to an individual with specific knowledge about rules and processes within their state or local area, who could point parents to resources and information beyond those directly related to SSA benefits and who had specific expertise in children with disabilities. Suggested a parent:

If they could have a dedicated team. Like, there's a team of five people, they're going to handle Wisconsin and all these people who have disabled kids.... Get two people who really know the law, disability laws and programs that are available to us, and that when we call there's a person—not a website.

Parents also underscored the importance of staff carrying caseloads that allowed them to spend enough time with parents to help them clarify misunderstandings, address questions, and build trust. Described a father, “It would have been better if they take more time to kind of explain things more and tell us all of our options ... it would have been nice if they take more time to explain things better.”

- **More direct avenues for reaching SSA staff and more proactive outreach from SSA staff.** Parents expressed a wish to be able to reach a specific individual directly (for example, by being provided a direct telephone extension or email address for their assigned case manager). In addition to being able to reach SSA staff with questions, parents expressed a desire for SSA staff to engage in direct and proactive outreach to parents to identify changes, address questions, or provide relevant information about upcoming deadlines or timing considerations.
- **SSA experts available at local sites**, such as schools or ADRCs, to help point parents to resources and to address parent questions. Given that a substantial share of our qualitative sample had children with disabilities under age 18, parents stressed the value of schools as a potential source of information about applying for and re-qualifying for SSI benefits at age 18 as well as for obtaining information about other SSA benefits potentially available to families. Explained a parent:

I actually think that the school system should have a resource person that is educated in the Social Security program for their students. Because I would have to say that would be the best resource for anybody to have because every child is in school, and every child with a cognitive disability is in from the age of 18 to 21.... I think it should be part of the IEP because that's the only way I think you can really get a parent's attention. You can't just have a meeting on a Tuesday night and [expect] Social Security to come in. They're not going to show up.

- **Simplified and transparent processes, paperwork, and procedures.** Many experienced the current process as burdensome, time-consuming, opaque, and fraught with opportunities to commit inadvertent errors that could cause benefits denials or significant delays to their case.

Described a mother:

I remember I came in there with all kinds of information, and then I had to have disability determination. I got an IEP, I got doctors' notes, I handed them all this stuff. And then there was, like, one piece of information missing. [I was] like, "But that wasn't on your checklist that you gave me!" She was like, "Oh, sorry." And so, then she had to setup another meeting, and even when you set up a meeting for a time and a place, that doesn't mean you get it that time and place.... Sometimes you get a person who is working with you who really does understand what's going on. I mean, you have to fill out the forms, and they tell you exactly what to bring or how to send it so that you don't have to come in again. But other times, they don't know what they're—they don't know.

5. Discussion

Economic well-being for retired parents with a child with a disability is precarious. Though financial security in retirement may be elusive for many Americans (R. W. Johnson and Favreault 2021), our findings emphasize the particular difficulty for these families. In interviews, we heard from parents that family needs took precedence over employment throughout parent labor market years, which may have constrained available resources in retirement. Some parents reported spending down retirement savings as needed for children's expenses prior to reaching retirement; some also described having to choose between which expenses to prioritize each month. Indeed, in our quantitative analysis, we find that in a recent nationally representative sample of households with a retired adult co-residing with a child, having a child with a disability is associated with an increased likelihood of experiencing a variety of hardships. Even when controlling for demographic and household factors, having a child with a disability in the household is associated with an overall decrease in income-to-poverty ratio and with increased risks of having income below 200 percent of the federal poverty threshold, of food insecurity, of missing a rent or mortgage payment, or of missing a utility payment.

Though this experience of increased economic precarity was salient for the majority of families, regardless of social characteristics or resources, financial security seemed especially tenuous for single-parent households. The strength of the relationship between food insecurity and having a child with a disability in the household (compared to a typically developing child) is notably larger for single-parent households compared to two-parent households. Interviews with parents provided insight into some of the unique challenges faced by single-parent families, given experiences of limited flexibility in caregiving and earning in earlier years and the difficulty of having a single parent's income or retirement stream to draw on for both parent and child.

In this context, one of our key findings is, in the words of one parent, how “vital” Social Security Administration (SSA) benefits are for many families, with many describing income from SSA as an economic lifeline. The quantitative data illustrate this clearly in many respects; a large majority of retired households with a child with a disability receive SSA benefits through the Old-Age, Survivors, and Disability Insurance (OASDI) program (82 percent) and nearly a quarter receive Supplemental Security Income (SSI) payments. In combination, OASDI benefits and SSI payments make up a substantial amount of families' total income, 42 percent on average. What these statistics represent to family experiences was abundantly clear in our interviews. Half of the families in our qualitative sample reported that either or both SSA benefits and SSI payments were their main source of income, and families described the centrality of benefits to household survival, with some indicating that SSA income was what allowed them to meet the family's basic needs, such as housing. Parents also explained that SSA benefits provided not only income but flexibility in meeting care needs. The role of SSA benefits was particularly salient for households with limited resources and particularly for single-parent families.

Still, we find that income from SSA programs is not always fully adequate in meeting family needs, particularly for families who receive SSI. Some families told us payments were crucial but still did not alleviate their financial hardships. Further, our quantitative analysis indicates that though SSI receipt was associated with a decrease in the likelihood of having income below 100 percent and 200 percent of the poverty level for households with a child with a disability, there was no statistically significant impact on the effects of having a child with a disability on other measures of hardship for the full sample. For households in non-metro areas, non-White households, and two-parent households, SSI did statistically decrease the likelihood of

hardships. It did not, however, do so for single-parent families, which is the subgroup that we find to be most disadvantaged financially in both our quantitative and qualitative samples.

Additionally, we find that parents of children with disabilities experience unique challenges when considering the adequacy of SSA benefits for economic well-being. For the parents we spoke with, the well-being of children was inextricably linked to the role of SSA benefits in the family economic landscape. Uncertainty about their own needs and costs now and later in retirement—as well as their children’s current needs and costs related to care, housing, and essential needs—loomed large for parents in considering the role of SSA benefits not only in their current realities but also for children’s long-term well-being. Some of parents’ uncertainties—such as how long they or their children would live and what future economic conditions would look like—were fundamental and unknowable. Yet, much uncertainty was related to issues for which additional information could help ameliorate parent concerns and could enable parents to adjust plans for the future. In particular, parents called for more information about benefit availability, access, and options for parents and children as well as how income and benefits for parents affect children’s benefits, and vice versa.

5.1. Policy Considerations

Our findings reinforce previous literature suggesting that a child’s disability has an impact on employment and, therefore, resources available in retirement for families. Without employment supports for families earlier in the life course, or mechanisms for savings, these families are left without private or employer-provided sources of retirement income. This emphasizes the outsized role of SSA benefits, of all kinds, in retirement packages for parents and household income generally. For households who face other structural disadvantages in labor market participation, including households of color and single-parent families, this may be particularly salient. Women, who disproportionately provide caregiving, are a population of particular concern. SSA family benefits and overall benefit formulas account for some of these considerations. Our findings indicate that accounting for a child’s disability in eligibility or benefit calculation for parents may be worth examining, particularly given concerns about equity in retirement for women and households of color.

Attending to the consequences of eligibility requirements for current policies, including those related to SSA benefits, on coverage gaps and payment cessations may also be warranted. Asset limits for SSI recipients were a particular concern for parents who wondered how potential

resources could jeopardize eligibility for SSI income for their children. Reconsidering the asset limit may provide additional security for all SSI recipients but for these families in particular. For many families, SSA family benefits, through Disabled Adult Child benefits or spousal benefits, were relevant, and many families in our qualitative sample had experienced or were fearful of experiencing benefit changes as a result of a parent's death. Providing information about how these changes could impact benefits as well as explicitly considering the impacts for families with a child with a disability and how to ease benefit cliffs could be of use.

Like all families with children, families with children with disabilities are eligible for a host of programs and supports throughout their child's lifetime. In some cases, given families' unique needs and contexts, these policies, which are designed to support families with typically developing children, are not sufficiently meeting family needs, which results in decreased economic well-being in retirement. For example, parents described in interviews being unable to access sufficient child care or early childhood education resources for their children, and parents also described increased costs as a result of their child's disability. Our quantitative estimates indicate that families are receiving Supplemental Nutrition Assistance Program (SNAP) at higher rates than other retired households with children. Family policies, broadly, could consider a child's disability in eligibility or benefit formulas to provide more adequate support. SNAP and Special Supplemental Nutrition for Women, Infants, and Children Program (WIC) benefits could account for the unique feeding needs of children. Expanding access to care supports for families could increase labor market participation, which would increase economic well-being for families in retirement.

Findings from our qualitative analysis suggest that parents of children with disabilities may benefit from enhanced information-sharing and case management for SSA-eligible families. Interviews with parents highlighted the complex challenges parents face in applying for and obtaining information about benefits levels and eligibility for themselves and their children.

Exploring opportunities to streamline processes, to simplify documents, and to make information broadly available through multiple formats and channels could help parents obtain information, understand options, and obtain access to benefits, as could providing parents with an assigned sole case manager, benefits navigators, or family advocate and cultivating. Finally, findings also highlight the potential benefit of fostering connections between SSA offices and other community supports. Parents of school-aged children highlighted the potential value of schools as

a source of information about SSA benefits, and interviews with parents underscored that many families lack information about or access to local resources that could help their families financially. To the extent that SSA offices and these local resources can identify opportunities to collaborate on and streamline information-sharing and referrals for families, through strategies such as developing community resource guides or co-locating agency physical spaces with other community providers, these enhanced networks of support could help bring needed resources into households and improve economic well-being for families.

6. Conclusion

Findings should be considered in light of some caveats and limitations. Though our sample included parents of a range of backgrounds, our interview sample was small and nonrandom. While the information we obtained yields important insights, the perspectives of parents we spoke with are not generalizable to a broader population of parents. Also, our study required parents to consider themselves at least partially retired. Parents who continue working later in life while providing care for a child with disabilities may have different experiences and economic situations than those who identify as retired. Additionally, we conducted interviews with only one parent-respondent per family. Within families, caregiving and work experiences and information about Social Security Administration (SSA) benefits and household finances may vary across parent; thus, our interviews offer only a partial view into family experiences within two-parent families.

Just as our qualitative data balance some of the limitations of what we can learn from our quantitative data, our quantitative data address some of the caveats of our qualitative data collection. Still, our quantitative analysis is not without limitations. Notably, though we use recent nationally representative data, we may be limited in what we can observe due to a limited sample size of households with a retired adult and a child with an identified disability in the household. We do not have sufficient sample size to disaggregate by disability type, and different disability contexts are likely to impact household economic well-being quite differently. Additionally, we use data collected in 2020 and earlier, meaning they do not account for significant economic changes that occurred for households during the pandemic, which may have been particularly salient for households with a child with a disability. As more waves of data are collected via the Survey of Income and Program Participation (SIPP) or other data sources, researchers and policymakers should continue to gather updated evidence about how retired families with a child

with a disability are faring in retirement. Future research can provide additional evidence as more recent data become available.

This study offers important evidence suggesting that SSA benefits are a crucial economic support for households with a retiree and a child with a disability. We find that benefits are an economic lifeline for families across the income spectrum and from a range of social and demographic backgrounds, but particularly for families with limited resources, such as single-parent families, benefits alone may not be sufficient to prevent experiences of hardship for families. In centering parent voices and focusing on families from a variety of backgrounds, this study offers important insight into the current well-being of families, the important role of SSA benefits, and the continuing experiences of economic precarity.

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Appendix A: Quantitative Methodological Supplement

This appendix provides additional detail about our quantitative data and analysis, including additional information about our model specifications and robustness checks. We use data from the Survey of Income and Program Participation (SIPP), a nationally representative, household-based survey that contains detailed measures about household income sources and program participation as well as household composition. We use data from the 2018–2020 panels of the SIPP, meaning we include data from households that were first interviewed in 2018, 2019, and 2020. Households are interviewed annually, for four years, with each annual interview considered a “wave” of data. Though longitudinal, we use the SIPP for cross-sectional analysis in this study and use the first wave of data provided by households (ie., the household interview from 2018, 2018, or 2020). The SIPP provides detailed information about household members, including disability and retirement status. Further, the SIPP collects detailed information about income received from public programs, including Social Security and SSI, as well as private earnings and income, including from private retirement accounts and pensions. Finally, the SIPP includes measures of household economic well-being, including a six-item measure for food security and measures for missing rent or mortgage payments or utility payments. The SIPP data is provided at the month level; we annualize our measures for this analysis and use relevant SIPP weighting. For more information about the SIPP, see <https://www.census.gov/programs-surveys/sipp.html>.

Our quantitative analysis is intended to provide descriptive evidence about the economic well-being of households with a retired adult and a child with a disability. Therefore, our methods are intended to examine associations and are not designed to attribute causality. As such, we rely primarily on bivariate and multivariate analyses. We first use a simple difference in means to compare a variety of measures of income and benefit participation for retired households with typically developing children and retired households with children with an identified disability (Table 3).

Next, we use Ordinary Least Squares (OLS) regression to model the association between having a child with a disability in the household and our economic hardship outcomes (Table 4, Figure 4). We run each model separately and, also use a Westfall-Young (1993) correction to account for multiple hypothesis testing. We note that results are robust to other functional forms, including logit and probit models. Therefore, we opt for using a linear probability model for ease in interpretation of our estimates. After running our main models, we model the association for subgroups of interest (see Appendix Table B1 and Figures 5a–5g. Sample sizes for the subgroups are as follows: White families, $n=1,577$; non-White families, $n=1,279$; metro, $n=2,298$; non-metro, $n=558$; two-parent families, $n=1,589$; single-parent families, $n=1,267$; high school or less, $n=665$; and college degree or higher, $n=1,336$. Though not the focus of our analysis, we used Stata’s *suest* command to test for statistical differences in estimates across subgroup models and can provide results upon request.

Finally, to examine the role of receipt of SSA benefits and SSI payments in moderating experiences of hardship, we run interaction models. We interact benefit receipt—specifically, indicators for whether the household reports receipt of any OASDI benefits, SSA retirement benefits, and SSI payments—with the indicator for child disability. We use the same covariates and general analytic models as in our non-interaction models described above. We then estimate interaction models for each subgroup. For brevity, we present estimates only for the interaction term for the subgroups but can provide the main effects upon request.

Appendix B: Detailed SIPP Results Tables

Table B1. Ordinary Least Squares (OLS) Estimates of Economic Well-Being Measures by Child Disability Status and Variation in Social and Geographic Characteristics

	Full Sample	Race/Ethnicity		Urbanicity		Family Structure		Education	
		White	Nonwhite	Metro	Nonmetro	Two-Parent	Single Parent	4-Year Degree +	<HS
<100% Poverty	0.015 (0.010)	0.018	0.011	0.012	0.025	0.019	0.006	-0.003	0.017
<200% Poverty	0.092*** (0.017)	0.106***	0.714*	0.092***	0.099**	0.039+	-0.725*	0.093***	0.112**
Income to poverty ratio	-0.858*** (0.179)	-0.989***	-0.675**	-0.814***	-1.053**	-0.989***	-0.954***	-1.142**	-0.609***
Food hardship	0.056*** (0.012)	0.038**	0.082***	0.054**	0.059*	0.036*	0.077***	0.073***	0.011
Utility hardship	0.043*** (0.011)	0.030*	0.064***	0.051***	0.015	0.051***	0.033*	0.040**	0.011
Mortgage/rent hardship	0.020* (0.009)	0.024*	0.020	0.026*	-0.001	0.027*	0.013	0.231+	0.013
SSA as Percent of Income	0.136** (0.013)	0.141***	0.132***	0.141***	0.124***	0.089***	0.178***	0.120***	0.174***

Source: Authors' calculations using the 2018–2020 SIPP.

Notes: Standard errors in parentheses. ***p<.001 **p<.01 *p<.05 +p<.10. Models include the following covariates: number of retired adults in household, number of children under 18 in household, race/ethnicity of householder (not included in race/ethnicity subgroup models), highest level of education, sex of focal child, census region of household, marital status of household (not included in family structure subgroup models), indicator for additional household members with a disability, urbanicity (not included in urbanicity subgroup models).

Table B2. Interaction Estimates: The Role of SSA Benefits and SSI Payments in Moderating Measures of Hardship

	Income to Poverty			Food Hardship	Utility Hardship	Mortgage/Rent Hardship	
	<100% Poverty	<200% Poverty	Ratio				
Child with disability (main effects)	0.066** (0.021)	0.041 (0.035)	-0.192 (0.216)	0.061* (0.025)	0.080*** (0.023)	0.033+ (0.019)	
Receipt of any OASDI benefits	-0.060* (0.024)	-0.635** (0.021)	-0.216 (0.229)	-0.014 (0.014)	0.016 (0.014)	0.006 (0.011)	
OASDI Receipt X Child with disability	-0.058* (0.021)	0.070+ (0.040)	-0.808 (0.431)	-0.007 (0.028)	-0.047+ (0.025)	-0.016 (0.021)	
Child with disability (main effects)	0.047** (0.017)	0.083** (0.029)	-0.497 (0.312)	0.087*** (0.020)	0.073*** (0.018)	0.031* (0.015)	
Receipt of SSA retirement benefits	-0.071*** (0.012)	-0.074*** (0.020)	0.001 (0.218)	-0.004 (0.014)	0.004 (0.013)	0.004 (0.011)	
SSA Retirement Receipt X Child with disability	-0.041* (0.021)	0.019 (0.034)	-0.521 (0.373)	-0.045+ (0.024)	-0.043+ (0.022)	-0.016 (0.019)	
Child with disability (main effects)	0.021+ (0.011)	0.104*** (0.018)	-0.891*** (0.198)	0.057*** (0.013)	0.037** (0.012)	0.015 (0.010)	
Receipt of SSI Payments	0.056** (0.019)	0.190*** (0.031)	-0.864* (0.344)	0.035 (0.023)	0.032 (0.020)	-0.005 (0.017)	
SSI Receipt X Child with disability	-0.062* (0.027)	-0.168*** (0.045)	0.674 (0.490)	-0.028 (0.032)	0.012 (0.029)	0.026 (0.024)	

Panel 2: Race												
	White	Non-white	White	Non-white	White	Non-white	White	Non-white	White	Non-white	White	Non-white
OASDI Interaction	-0.025	-0.103*	0.112*	0.006	-1.323*	0.021	-0.004	-0.003	0.028	-0.125**	0.007	-0.044
Retirement Interaction	-0.029	-0.065+	0.047	-0.034	-1.084*	0.456	-0.042	-0.040	-0.024	-0.052	-0.002	-0.031
SSI Interaction	-0.041	-0.078**	-0.174*	-0.164**	0.715	0.668	0.028	-0.080+	-0.042	0.024	0.030	0.013

Panel 3: Urbanicity												
	Metro	Non-metro	Metro	Non-metro	Metro	Non-metro	Metro	Non-metro	Metro	Non-metro	Metro	Non-metro
OASDI Interaction	-0.047+	-0.082	0.065	0.078	-0.850+	-0.48	0.028	-0.140*	-0.017	-0.151*	-0.003	-0.056
Retirement Interaction	-0.025	-0.089+	0.000	0.103	-0.415	-0.757	-0.024	-0.114+	-0.016	-0.130*	-0.002	-0.047
SSI Interaction	-0.072*	-0.018	-0.147**	-0.281*	0.356	1.981+	-0.025	-0.062	0.051	-0.125+	-0.054*	-0.067

Panel 4: Family Structure												
	Two Parent	Single Parent	Two Parent	Single Parent	Two Parent	Single Parent	Two Parent	Single Parent	Two Parent	Single Parent	Two Parent	Single Parent
OASDI Interaction	-0.082**	-0.016	0.046	0.08	-0.881	-1.091+	-0.022	-0.001	0.014	-0.131**	0.007	-0.039
Retirement Interaction	-0.062*	-0.006	0.014	0.021	-0.466	-0.951*	-0.030	-0.062	0.000	-0.081*	0.007	-0.032
SSI Interaction	-0.066+	-0.055	-0.112+	-0.201**	0.19	0.922	-0.080+	-0.004	0.033	-0.013	0.082*	-0.029

Panel 5: Education												
	≥ 4 Year Degree		≥ 4 Year Degree		≥ 4 Year Degree		≥ 4 Year Degree		≥ 4 Year Degree		≥ 4 Year Degree	
	≥ 4 Year Degree	≤ HS	≥ 4 Year Degree	≤ HS	≥ 4 Year Degree	≤ HS	≥ 4 Year Degree	≤ HS	≥ 4 Year Degree	≤ HS	≥ 4 Year Degree	≤ HS
OASDI Interaction	0.021	-0.111+	0.086+	0.169+	-1.095	-0.673	-0.028	0.068	-0.035	-0.026	-0.018	-0.018
Retirement Interaction	0.010	-0.086	0.017	0.164*	-0.802	-0.626+	-0.076**	0.039	-0.067*	0.026	-0.030	0.033
SSI Interaction	-0.038	-0.083	-0.009	-0.249**	-0.193	0.782+	0.001	-0.028	0.022	-0.011	0.031	0.039

Source: Authors' calculations using the 2018–2020 SIPP.

Notes: Standard errors in parentheses. ***p<.001 **p<.01 *p<.05 +p<.10. Models include the following covariates: number of retired adults in household, number of children under 18 in household, race/ethnicity of householder (not included in race/ethnicity subgroup models), highest level of education, sex of focal child, U.S. Census region of household, marital status of household (not included in family structure subgroup models), indicator for additional household members with a disability, urbanicity (not included in urbanicity subgroup models). Estimates in bold in first panel are the interaction estimates for the interaction of having a child with a disability and receipt of benefit as noted. In the following panels, we present only the interaction estimates without the main effect.



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