



# ‘IT’S HARD TO KNOW WHAT TO EXPECT’: PARENTS OF CHILDREN WITH DISABILITIES IN RETIREMENT

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Income from the Social Security Administration (SSA) has the potential to provide substantial economic support for the increasing number of families with retirement-age adults who have caregiving responsibilities for their children with disabilities. Despite the potentially crucial role of SSA benefits, the economic well-being experiences of retired parents of children with disabilities and their experiences related to economic well-being have largely been excluded from the research literature.

## **Economic Well-Being in Retirement for Parents of Children with Disabilities**

In order to inform our understanding about how families with retirement-age adults caring for a child with a disability are faring financially, the extent to which they rely on SSA benefits, and their perceptions of benefit adequacy, we explore the following research questions: (1) How are households with retired caregivers for children with disabilities faring economically? Are there differences based on social characteristics or where families live?; and (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?

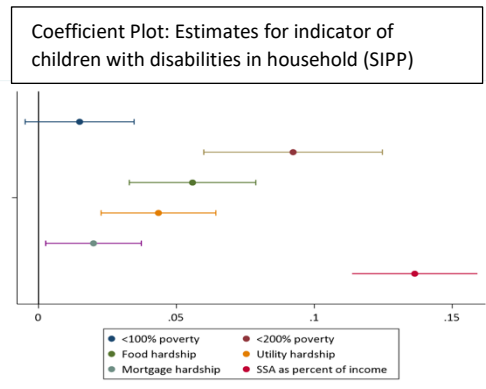
We use an explanatory, sequential mixed-methods design with data from the 2018–2020 Survey of Income and Program Participation (SIPP) to descriptively explore the overall economic well-being of households with a retired adult and a child with a disability, the role of SSA benefits, and the extent to which social characteristics matter for these outcomes. We then build on our quantitative analysis using data gathered from semi-structured interviews with retired parents who provide care for children with disabilities and whose households receive SSA benefits. Interviews provide a deeper, more nuanced understanding of quantitative findings and answering questions that could not be addressed through the survey data.

## **Caregiving for a Child with a Disability Affects Work and Retirement Savings and is Associated with Increased Experiences of Economic Hardship**

We find retired households with a child with a disability in the SIPP are more economically disadvantaged across a variety of measures compared to retired households with other children, including annual income; poverty rates; use of means-tested safety net programs; and likelihood of experiencing economic hardship including food insecurity, missed utility payments, and missed rent or mortgage payments. We also find



that retired parents of children with disabilities rely on SSA benefits as a larger share of their retirement income than parents of typically developing children, are less likely to have non-SSA sources of retirement income than other parents. We find differences in family economic experiences by family social dimensions, including race, education, geography, and single parenthood across many measures of hardship, underscoring the role of structural disadvantages for these families' experiences in retirement.



Our qualitative interviews provided some additional nuance. Parents reported that their children's caregiving needs affected when, where, and how much they worked, with important implications for income and ability to save for retirement. Further, parents of children with disabilities often provided financial supports for children, as SSA benefits and children's income alone was generally inadequate for meeting children's financial needs. Single parent households faced compounding hardships balancing caregiving, work, and saving for retirement.

## SSA Benefits Are "Crucial," but Insufficient for Fully Addressing the Needs of Many Families

SSA benefits played a role in economic well-being across families but were especially crucial for families that lacked other income sources in retirement, and single-parent families in particular. In these families, SSA benefits played a critical role for family survival and the ability of parents to meet children's care needs. Our quantitative analyses support these findings. Estimates indicate that SSA benefits play a role in supporting the economic well-being of retired households with a child with a disability; benefits may be modestly adequate in providing support for families overall and especially important for families living in non-metro areas and single-parent families.

Parents worried about their children's future economic and caregiving needs, and the adequacy of SSA benefits for addressing these needs in the future. Feelings of considerable uncertainty across many domains affected parents' perceptions of adequacy and fears for their children's futures. Parents called for more information, guidance, and case management support from SSA to navigate these challenges.

## Implications

- Our findings demonstrate that economic well-being for retired parents of children with disabilities is precarious, and the importance of SSA rules and broader policy for supporting these families.
- Outreach to families about available SSA benefits and eligibility criteria could help promote family economic well-being and support families as they plan for children's futures.

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