Parents of children with disabilities face unique constraints and tradeoffs in retirement decisions. Mothers of children with disabilities—the focus of this study—are particularly likely to face challenges in preparing for retirement as they disproportionately bear the responsibility of caregiving for their child. Benefits from the Social Security Administration (SSA), including retirement and childhood disability benefits, have the potential to support economic stability for these families.

Assessing retirement for mothers of children with disabilities

Anticipating that the context of retirement for mothers of children with disabilities is unique from that of other mothers, we aim to understand: (1) Are there differences in retirement savings and timing for mothers of children with disabilities compared to other mothers?; and (2) How do mothers of children with disabilities think about retirement options, and what is the role of SSA benefits in their retirement planning?

We use an explanatory, sequential mixed-methods design with nationally representative data from the National Longitudinal Survey of Youth (NLSY) 1979 and the related Child and Young Adult sample to understand patterns, trends, and associations between a child’s disability status and various retirement outcomes for mothers. Our quantitative sample is comprised of an initial 11,545 mother/child dyads (based on a sample of 4,941 mothers), including 8% of dyads in which the child reports a health limiting condition for at least two consecutive waves, and 7% where the mother reports significant caregiving responsibilities. We use inverse probability of treatment weighting (IPTW) to account for initial differences in families with typically developing children and children with disabilities.

We then build on our quantitative analysis using data gathered from semi-structured interviews with mothers of children with disabilities. We interviewed 12 mothers, all of whom were 45 or older and provided care for a child with a disability. Interviews focused on gathering a deeper, more nuanced understanding of quantitative findings and answering questions that could not be addressed through the survey data.

Mothers Report Caregiving Impacts Retirement Timing
Using our NLSY sample, we find no significant differences in most measures of retirement timing, with one exception. Using a Cox proportional hazard model, we find that mothers with significant caregiving responsibilities are less likely to report retiring than other mothers through 2018, the last year of available data. We also find that mothers of children with disabilities, across all measures of disability, have lower labor market participation than other mothers. Further, mothers with significant caregiving responsibilities were less likely to have any employer-sponsored retirement savings, and, those who did have savings reported significantly less savings.

Our qualitative interviews provided some additional nuance. Mothers reported that caregiving responsibilities affected where, when, and how much they worked, with mothers making career trade-offs in order to provide care. Some mothers reported needing to work longer than they planned prior to becoming a parent of a child with a disability due to the amount of savings they anticipated needing for their child’s care in addition to their own retirement; others reported exiting the paid labor force early due to caregiving responsibilities. Families headed by single mothers faced different considerations and tradeoffs than mothers in two-parent, dual-earner households.

Caregiving Influences Mothers’ Conception of Retirement and SSA Benefit Receipt

In our interviews, mothers had varying definitions of what it would mean to “retire”, but, most concurred that the end of paid employment did not signal the end of “work.” This echoed a finding from our NLSY sample, which suggested that mothers with significant caregiving responsibilities are more likely than other mothers to report needing to continue working due to economic necessity. In interviews, mothers noted that they figured SSA benefits into their retirement planning but did not expect to rely on them, though quantitative analyses suggest mothers with significant caregiving responsibilities are more likely to receive retirement benefits at an early age.

Implications

- Our findings demonstrate the importance of broad policies that provide support for families and targeted policies to provide specific support for families with a child with a disability.
- Outreach to families about available SSA benefits and eligibility criteria could help support family economic stability.

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