Financial well-being of US parents raising children with developmental disabilities

Susan L. Parish
October 2013
Background

- Caregiving research is replete with studies on emotional burden, stress and coping, depression
- Patterns of lifelong caring for a child (and then adult child) with developmental disabilities – delayed or deferred launching of the child from the family home
- Bidirectional relationship between maternal stress & depressive symptoms
- Some evidence of greater likelihood of physical health problems as caregivers age (in contrast to same-age adults without responsibility for a child with DD)
- Some evidence that adverse health effects are elevated for Black and Latina mothers than for White mothers of adult children with DD
Background

- Most children and adults with developmental disabilities live at home with family caregivers in the US
- Regardless of age, the caregiving “system” rests on the backs of family caregivers, typically mothers
- Ongoing deinstitutionalization, special education mandates since 1975
- In the US, family support and income transfers are exceptionally limited:
  - $4b spent in 2011 for family support vs. $56.7b (7%) for total DD service system
  - $US 710 monthly max for Supplemental Security Income in 2013, income transfer program for people with disabilities (~75% of the US federal poverty level)
Background, continued

- Bidirectional relationship between poverty and disability
- Lifelong care needs for people with developmental disabilities
- Launching stage delayed (often for decades)
- Reduced maternal employment -> increased poverty, reduced saving to buffer hardships and temporary setbacks
Living Arrangement of Individuals with Developmental Disabilities, 2011

- With family caregiver: 72%
- Alone or with roommate: 13%
- Supervised residential setting: 16%

Individuals with DD Living with Family by Caregivers’ Age Cohort, 2011

- 41% Caregiver <41
- 35% Caregiver Age 41-59
- 24% Caregiver Age 60+

Research Questions

- What is the financial well-being of single mothers of children with developmental disabilities, in comparison to other single mothers?

- How does the financial well-being of parents of children with developmental disabilities change across the parental lifecourse?
Data & Analyses

Survey of Income and Program Participation (SIPP; US Census Bureau)

- Longitudinal & nationally representative
- High quality information on income, assets, program participation

Multivariate logistic & linear regression models

- Covariates: age, race, ethnicity, education, age of child, and income for the asset-based indicators
- Cross-sectional analyses
- SIPP is longitudinal, but data on disability is only collected in 1-2 waves
Measures of Financial Wellbeing

- Assets
  - Net worth: assets from all sources excluding home equity
  - Liquid assets
  - Retirement accounts from all sources
  - Net worth < $0

- Income
  - Income from all sources (earned & unearned; including income transfers)

- Poverty
  - US income poverty: absolute measure of poverty equivalized for household size; in 2012, $US 11,170 was annual poverty level for individual
  - US asset poverty (net worth < 3 months of income at poverty level)
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>6,547 single mothers of children w/o DD</th>
<th>242 single mothers of children with DD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% or mean</td>
<td>% or mean</td>
</tr>
<tr>
<td>Age</td>
<td>34 years</td>
<td>34 years</td>
</tr>
<tr>
<td>Black**</td>
<td>29%</td>
<td>38%</td>
</tr>
<tr>
<td>Latina</td>
<td>19%</td>
<td>14%</td>
</tr>
<tr>
<td>Graduated high school**</td>
<td>84%</td>
<td>74%</td>
</tr>
<tr>
<td># of other adults living in HH***</td>
<td>0.9</td>
<td>1.2</td>
</tr>
<tr>
<td># of children living in HH</td>
<td>1.4</td>
<td>1.5</td>
</tr>
<tr>
<td>No job and not looking***</td>
<td>23%</td>
<td>44%</td>
</tr>
<tr>
<td># of jobs held by adults in HH***</td>
<td>1.4</td>
<td>1.1</td>
</tr>
</tbody>
</table>

Notes: * p<.05; ** p<.01; *** p<.01

HH = household
## Sample 2: Single and married mothers of children with DD

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>345 married mothers of children with DD % or mean</th>
<th>242 single mothers of children with DD % or mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age***</td>
<td>46 years</td>
<td>34 years</td>
</tr>
<tr>
<td>Black***</td>
<td>11%</td>
<td>38%</td>
</tr>
<tr>
<td>Latina*</td>
<td>17%</td>
<td>14%</td>
</tr>
<tr>
<td>Graduated high school***</td>
<td>84%</td>
<td>74%</td>
</tr>
<tr>
<td># of other adults living in HH***</td>
<td>1.8</td>
<td>1.2</td>
</tr>
<tr>
<td># of children living in HH</td>
<td>1.6</td>
<td>1.5</td>
</tr>
<tr>
<td>No job and not looking</td>
<td>40%</td>
<td>44%</td>
</tr>
<tr>
<td># of jobs held by adults in HH</td>
<td>1.7</td>
<td>1.1</td>
</tr>
</tbody>
</table>

**Notes:** *p<.05; **p<.01; ***p<.01

*HH = household*
## Sample 3: Age cohorts of parents with children with DD (% or mean)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>&lt; 45 Yrs</th>
<th>45-54 Yrs</th>
<th>55-64 Yrs</th>
<th>&gt;64 Yrs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female**</td>
<td>69%</td>
<td>51%</td>
<td>55%</td>
<td>55%</td>
</tr>
<tr>
<td>Black</td>
<td>19%</td>
<td>16%</td>
<td>18%</td>
<td>20%</td>
</tr>
<tr>
<td>Latina*</td>
<td>15%</td>
<td>11%</td>
<td>13%</td>
<td>14%</td>
</tr>
<tr>
<td>Graduated high school***</td>
<td>82%</td>
<td>81%</td>
<td>78%</td>
<td>69%</td>
</tr>
<tr>
<td>Married**</td>
<td>53%</td>
<td>65%</td>
<td>47%</td>
<td>41%</td>
</tr>
<tr>
<td># of other adults living in HH***</td>
<td>1.0</td>
<td>1.8</td>
<td>1.7</td>
<td>1.7</td>
</tr>
<tr>
<td># of children living in HH***</td>
<td>2.0</td>
<td>1.2</td>
<td>0.3</td>
<td>0.3</td>
</tr>
<tr>
<td>No job and not looking***</td>
<td>29%</td>
<td>23%</td>
<td>41%</td>
<td>86%</td>
</tr>
<tr>
<td># of jobs held by adults in HH*</td>
<td>1.4</td>
<td>1.6</td>
<td>1.4</td>
<td>0.6</td>
</tr>
</tbody>
</table>

Notes: * p<.05; ** p<.01; *** p<.01

HH = household; Head of household is referent
Income and Assets of Single Mothers with and without children with DD

<table>
<thead>
<tr>
<th>Category</th>
<th>Without DD</th>
<th>With DD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual income</td>
<td>$40,417</td>
<td>$61,336</td>
</tr>
<tr>
<td>Net worth</td>
<td>$4,681</td>
<td>$54,467</td>
</tr>
<tr>
<td>Liquid assets</td>
<td>$32,450</td>
<td>$3,128</td>
</tr>
<tr>
<td>Retirement saving</td>
<td>$5,794</td>
<td>$2,935</td>
</tr>
</tbody>
</table>

*p<.05; **p<.01; ***p<.01
Poverty and Debt of Single Mothers of Children with and without DD

Notes: * p<.05; ** p<.01; *** p<.01
Income and Assets of Single & Married Mothers of Children with DD

*p<.05; **p<.01; ***p<.001
Poverty and Debt of Single & Married Mothers of Children with DD

Notes: * p<.05; ** p<.01; *** p<.01
Median Income and Assets among Parents of Children with DD by Parental Age Cohort

Source: Parish et al., 2010
Families of children and adult children with DD with zero or negative liquid assets

Source: Survey of Income & Program Participation, 2001 & 2004

THE LURIE INSTITUTE FOR DISABILITY POLICY
Income and Asset Poverty Among Parents of Children with DD by Parents’ Age Cohort

Percent of Households

- Asset Poverty
- US Income Poverty

Parental Age Cohort

- < 45 Yrs
- 45-54 Yrs
- 55-64 Yrs
- > 64 Yrs
Limitations

- Data are cross-sectional, cannot infer causality
- Does not explore racial/ethnic disparities
- Reliance on self-reported information for disability status of children (no independent or clinical corroboration of child’s diagnosis or health care)
- Longitudinal analyses of financial well-being not possible
Implications

- It is expensive to raise children with developmental disabilities in the US and the financial consequences are enduring.
- Single mothers of children with developmental disabilities are highly vulnerable.
- Low assets are particularly worrisome because children with developmental disabilities often have unexpected health care costs.
- Limited assets also fail to provide parents with a safety net if their own health declines.
- Policy interventions are warranted to improve the financial wellbeing of parents of children with developmental disabilities.
- Existing income transfer programs (SSI, SSDI) are inadequate.
- Limited assets particularly worrisome for elderly caregivers who will face health problems.
- Single mothers need targeted support to enable them to work (accessible child care, subsidies, training to child care providers in disability issues).
Acknowledgements

- Co-authors: Rod Rose, Jamie Swaine, Sarah Dababnah (University of North Carolina), Ellen Tracy Marya (Brandeis University),
- Funding support: Lurie Institute for Disability Policy at Brandeis University
Sources


Thank you!
Income and Assets Among Parents of Children with DD by Parents’ Age Cohort

- **Net Worth ($)**
- **Annual Income of Household ($)**
- **Liquid Assets ($)**

- **Parental Age Cohort**:
  - Under 45 Years
  - 45-54 Years
  - 55-64 Years
  - 65 and Older

- **Dollar Amount ($)**:
  - $0
  - $20,000
  - $40,000
  - $60,000
  - $80,000
  - $100,000
  - $120,000
  - $140,000
  - $160,000
  - $180,000
  - $200,000

Lurie Institute for Disability Policy