Empirical Portrait of Families and Developmental Disabilities in the United States

Susan L. Parish, PhD, MSW
Lurie Institute for Disability Policy
The Heller School for Social Policy and Management
Brandeis University

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Overview

- Unique characteristics of family members who provide care to a loved one with intellectual and developmental disabilities
- Magnitude of the population
- Demographic characteristics
- Health and financial well-being of family caregivers
- Policy context of family caregiving
Unique family caregiving characteristics

- Caregiving is typically lifelong
- Requires specialized knowledge to navigate multiple formal systems of care and service: early intervention, education, pediatric health, adult health, long-term care, vocational, case management
- Caregiving is expensive – insurance often fails to pay for the elevated care needs of people with developmental disabilities
- Caregiving is often chronically stressful and takes a heavy emotional toll
- Emerging evidence suggests caregiving takes a physical toll
- Yet caregivers are resilient, resourceful and feel rewarded by their experiences
Family home or residential services?

- ~2.65 million children and adults with DD (aged >5) in the US, live in community; 80% live with family caregivers (Burke & Fujiura 2013)

- ~613,000 people with developmental disabilities receive residential services in the US (Braddock et al., 2013)

- Residential services waiting list >73,000 Americans with DD (12% of the total number of in residential services; U of Minn RTC, 2013)

- Family support consumes 7% of the $56.7 billion developmental disabilities system expenditures; ~468,000 families (Braddock et al., 2013)
Race and ethnicity of US heads of household that include people with DD

- White, Non-Hispanic: 17%
- Black, Non-Hispanic: 12%
- Hispanic: 66%
- Other, Non-Hispanic: 5%

Source: Pooled SIPP 2004 & 2008 data, author’s calculations, weighted

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Age distribution of US heads of household that include people with DD

- <45 years: 19%
- 45-54 years: 32%
- 55-64 years: 19%
- >64 years: 30%

The number of people living with caregivers aged 65+ is equivalent to 2/3 of the entire DD residential service population.

Source: Pooled SIPP 2004 & 2008 data, author’s calculations, weighted

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Family caregivers report poor health

Source: Burke & Fujiura, 2013
Health impacts of lifelong caregiving

- Marsha Mailick: chronic stress and fatigue take a physical toll on mothers of adult children with autism
- Cortisol studies show hypoactivation, similar to the responses of parents raising children with cancer and people with post-traumatic stress disorder
- Similar findings likely for caregivers of adult children with other developmental disabilities, particularly those with behavior problems and significant health conditions
Racial and ethnic disparities in health effects of caregiving

- Sandy Magaña: Cumulative adverse effects on Latina and Black American mothers who care for adult children with developmental disabilities
  - Arthritis, depression, poor overall health (Magaña & Smith, 2006; Magaña, Seltzer, & Krauss, 2004)
  - Some evidence of more positive emotional health outcomes for African-American caregivers (Magaña, 2004)
Median income and assets among parents of children with DD by parent age cohort

<table>
<thead>
<tr>
<th>Parental Age Cohort</th>
<th>Median Income</th>
<th>Median Assets</th>
<th>Median Net Worth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 45 Years</td>
<td>$0</td>
<td>$0</td>
<td>$7,408</td>
</tr>
<tr>
<td>45-54 Years</td>
<td>$135</td>
<td>$285</td>
<td>$52,364</td>
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<tr>
<td>55-64 Years</td>
<td>$20</td>
<td>$34,908</td>
<td>$47,100</td>
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<tr>
<td>65 and Older</td>
<td>$20</td>
<td>$31,212</td>
<td>$45,288</td>
</tr>
</tbody>
</table>

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

Source: Parish, Rose & Swaine 2010

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Well-being of single and married mothers

- Poor or near poor
- Worked most weeks of month
- Asset poor

*** = significant at p<.001

Source: Parish et al., 2012
Medicaid represents the single largest expenditure for state budgets (24% of total spending in FY13). Medicaid spending growth peaked 2007-2011.

Medicaid and SSI require families to impoverish themselves (the asset cap on eligibility is $3000 for a married couple).

For FY2014, total Medicaid spending was estimated to grow by 13%, state funds increasing by 6%.

State funds continue to be strained and economic recovery remains sluggish.

Projected annual average Medicaid growth between 2013-2022 is 7%, faster than 5% average annual GDP growth.

Few ACA provisions address the needs of caregivers.

Source: NGA & NASBO, 2014; Young 2014
What really matters? Where families live!

- Families living in states with higher income inequality have greater financial burden raising their children with disabilities (Parish et al., 2012)
- 13% of US families receive family support services (but range was 0-34%) (Braddock et al, 2013)
- 22 states provided family support to fewer than 10% of family caregivers (Braddock et al, 2013)
- Families living in states with more generous Medicaid programs have lower out-of-pocket health costs for their children with disabilities (Parish et al., 2009)
In conclusion, some questions...

- How will states address the needs of aging parent caregivers, as individuals with DD live longer than ever before?
- What are the long-term consequences of chronic poverty and deprivation in these caregiving families?
- How will technology help families navigate the difficult world of fragmented service systems?
- How can technology help families meet their obligations to provide increasingly specialized care?
- How can technology help eliminate racial and ethnic disparities in the physical health burdens of caregiving?
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Thank you!

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