Family Caregiving for Children and Adults with Intellectual Disabilities in the United States

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February 25, 2015
Overview

- Socio-political context of family caregiving
- The importance of Medicaid
- Unique characteristics of family caregivers
- Financial well-being of family caregivers
- Health of family caregivers
- State variability
- Racial and ethnic disparities
- Conclusion
**Socio-political context of US caregiving**

- **Graying of the population**
  - Relatively small working population = fewer resources for our Social Security and public health systems

- **Rising income inequality**
  - Hollowing out of the middle class – low median income & high unemployment persist after Great Recession (not for richest)
  - US income inequality at the extreme end of the global scale – 50% of income held by top quintile of population (doing better than Namibia, Botswana, South Africa)

- **The war on our (fragile, limited) safety net**
  - Proposed cuts to food stamps, disability income transfers
  - Legacy of slavery, Jim Crow segregation, persistent racism – the perceived face of US poverty is Black

- **Health care spending = 16.9% GDP in 2012 (highest in world; UK - 9.3%; France is #2 - 11.6%)**
  - But health outcomes are poor: infant mortality, obesity
"Browning" of America

4 states, including California & Texas today have no majority; by 2050 – white minority across the US

Source: U.S. Census Bureau, 2014; 2012

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Medicaid & the policy context

- Medicaid is the largest payer for the ID service system
- Medicaid represents the single largest expenditure for state budgets (24% of total spending in FY13)
- Medicaid requires families to impoverish themselves (asset cap 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

Source: NGA & NASBO, 2014; Young 2014
Medicaid Expansion and The States

- In 2010, The Patient Protection and Affordable Care Act, known as The Affordable Care Act or Obamacare, was passed
- Obamacare outlined expansions in eligibility for Medicaid
- However, the Supreme Court ruled that each of the 50 states should make its own decision about expanding Medicaid eligibility
- So, where you live matters!
Current Status of State Medicaid Expansion Decisions

Note: The federal (not state) government currently pays the full cost of Medicaid expansion, and will begin paying 90% of the costs in 2020
King v. Burwell

- Supreme Court case – challenge to the Affordable Care Act (ObamaCare)
- Argues federal subsidies for the exchanges are wrong
- An estimated 13.4 million Americans could lose federal aid for insurance premiums (and most are expected to lose health insurance coverage) (Kaiser Family Foundation, 2015)
- Arguments begin next week
- Decision: summer 2015
Unique family caregiving characteristics

- Caregiving is typically lifelong
  - Life course perspective: disrupted and delayed transitions
- Specialized knowledge is needed to navigate multiple formal systems of care and service: early intervention, education, pediatric health, adult health, long-term care, vocational, case management
- Fragmentation is a hallmark of the US service systems
- Caregiving is expensive – insurance often fails to pay for the elevated care needs of people with intellectual disabilities
- Caregiving is chronically stressful and emotionally difficult
- Emerging evidence: caregiving takes a physical toll
- Yet caregivers are resilient, resourceful and feel rewarded by their experiences, despite a seemingly hostile policy climate
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)
Who are family caregivers?

- Sibling caregiver: 5%
- Parent caregiver: 3%
- Grandparent caregiver: 5%
- Other relative caregiver: 87%

Source: SIPP 2008 data, author’s calculations, weighted

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

Source: Pooled SIPP 2004 & 2008 data, author’s calculations, weighted
## Sibling caregivers are disadvantaged

<table>
<thead>
<tr>
<th>Trait</th>
<th>No one with ID in household</th>
<th>Sibling Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women Household Head</td>
<td>51%</td>
<td>59%</td>
</tr>
<tr>
<td>Median Age</td>
<td>44</td>
<td>59</td>
</tr>
<tr>
<td>White</td>
<td>80%</td>
<td>67%</td>
</tr>
<tr>
<td>Black</td>
<td>13%</td>
<td>25%</td>
</tr>
<tr>
<td>Latino</td>
<td>13%</td>
<td>9%</td>
</tr>
<tr>
<td>Married</td>
<td>54%</td>
<td>48%</td>
</tr>
<tr>
<td>No High School Degree</td>
<td>8%</td>
<td>16%</td>
</tr>
<tr>
<td>Health status is fair or poor</td>
<td>12%</td>
<td>26%</td>
</tr>
<tr>
<td>Employed</td>
<td>77%</td>
<td>73%</td>
</tr>
<tr>
<td>Unable to meet essential expenses</td>
<td>18%</td>
<td>31%</td>
</tr>
</tbody>
</table>

All differences statistically significant, $p < .05$ or better

*Source: Authors’ calculations, SIPP 2008 data*
State variability in family support

- What is family support?
  - In- or out-of-home respite, in-home services, support groups, cash assistance
- States control their own ID service systems – no service is mandated by our federal government
- Wide variability in states’ family support generosity
- 13% of US families receive family support services (but range was 0-34% across states)
- 22 states provided support to fewer than 10% of family caregivers

Source: Braddock, States of the States (2013)
Median income and assets among parents of children with DD by parent age cohort

**Source:** Parish et al., 2010

### Median Income
- **Under 45 Years:** $7,408
- **45-54 Years:** $135
- **55-64 Years:** $285
- **65 and Older:** $20

### Median Assets
- **Under 45 Years:** $0
- **45-54 Years:** $135
- **55-64 Years:** $285
- **65 and Older:** $20

### Median Net Worth
- **Under 45 Years:** $34,908
- **45-54 Years:** $52,364
- **55-64 Years:** $78,897
- **65 and Older:** $75,156

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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 of children and adult children with ID

***= significant at p<.001

Source: Parish et al., 2012

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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
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
Racial disparities in health care quality and access for children with ID

Source: Magaña et al., 2012

* *p<.05. **p<.01. ***p<.001.
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)

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What really matters? Where families live!

- Families in states with higher income inequality have greater financial burden raising their children with disabilities (Parish et al., 2012)
- 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 ID live longer than ever before?
- What are the long-term consequences of chronic poverty and deprivation in these caregiving families?
- How can we eliminate racial and ethnic disparities in the health burdens of caregiving?
- How will families weather further cuts to the safety net?

- **The need for family advocacy has never been more urgent in the US**
Acknowledgements

- Co-authors: Sandy Magaña (University of Illinois at Chicago), Esther Son (CUNY-Staten Island), Kathleen Thomas (University of North Carolina at Chapel Hill), Leah Igdalsky & Rajan Sonik (Brandeis University), Subharati Ghosh (Tata Institute)

- Partial support was provided by the grant #H133B130007 from the National Institute on Disability and Rehabilitation Research, US Department of Education. The opinions and conclusions are solely mine and should not be construed as representing the sponsor.

Thank you!

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Where People with IDD Live

- 58% Lives alone or is HoH
- 18% Lives only with people with IDD
- 6% Spouse/partner is caregiver
- 3% Sibling caregiver
- 3% Parent caregiver
- 4% Grandparent/other relative caregiver
- 7% Non-relative caregiver
- 2% Residential

Source: SIPP 2008 data, author’s calculations, weighted

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How Many Americans Could Lose Subsidies in 2016?

If the Supreme Court sides with the plaintiffs in King v. Burwell, millions could lose federal aid for insurance premiums.

Total = 13.4 million

Source: Kaiser Family Foundation estimates based on projected national totals from the Congressional Budget Office.