Financial Burden of Families Raising Children with IDD in the US

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Background: Income poverty and children with disabilities

- Children with disabilities are more likely to grow up in poverty than their non-disabled peers (Emerson & Hatton, 2009)
- The relationship between disability and poverty is likely bi-directional (Elwan, 1999)
- Having a child with a disability is a significant determinant of material hardship (Parish et al, 2008; Emerson & Hatton, 2009)
Background: Elevated costs of care

Families raising children with disabilities incur direct and indirect costs

Direct costs of care:
- Expenses for therapies, rehabilitation, equipment, home modifications, transportation, preventive and emergency services

Indirect costs of care:
- Guardians may need to work fewer hours or give up employment completely to care for the child with a disability
Aim

- There are few current, population-based studies in the US about the costs families incur related to raising their children with intellectual and developmental disabilities.
- Our aim: determine the financial burden of such parents.
Design & Method

- 2009/10 National Survey of Children with Special Health Care needs
  - Fielded by the National Center for Health Statistics
  - Representative of individual US states with ~ 750 special needs children per state
  - Representative of US
  - Cross-sectional
  - Telephone interviews with knowledgeable adult living in household
Measures & Analysis

- Independent variable: Whether child had ID or other special health care needs
  - ID defined as autism, developmental delay, intellectual disability or mental retardation, cerebral palsy, and Down syndrome
- Dependent measures: annual out-of-pocket costs > $500; financial problems caused by child’s needs; parent stopped work to care for child; parent reduced work to care for child; parent avoided changing jobs because of concerns about child’s health insurance
- Covariates: family structure; parental education; income; child’s age, race, ethnicity, condition severity and insurance status
- Analysis: Multivariate logistic regression, weighted for complex sampling design
## Sample characteristics

<table>
<thead>
<tr>
<th>Characteristic (% or Mean)</th>
<th>Households with children with ID N = 7951</th>
<th>Households with other CSHCN N = 32,291</th>
<th>Test Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s race/ethnicity</td>
<td></td>
<td></td>
<td>3.01*</td>
</tr>
<tr>
<td>White</td>
<td>58</td>
<td>60</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>15</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Latino</td>
<td>18</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Child’s sex is female</td>
<td>32</td>
<td>43</td>
<td>102.23***</td>
</tr>
<tr>
<td>Family income &lt;200% FPL¹</td>
<td>51</td>
<td>42</td>
<td>62.49***</td>
</tr>
<tr>
<td>Parent education &lt; high school</td>
<td>13</td>
<td>11</td>
<td>3.70</td>
</tr>
<tr>
<td>Single mother family</td>
<td>26</td>
<td>26</td>
<td>0.26</td>
</tr>
<tr>
<td>Child has no insurance</td>
<td>3</td>
<td>4</td>
<td>0.47</td>
</tr>
<tr>
<td>Child age (years)</td>
<td>9.6</td>
<td>10.0</td>
<td>13.87**</td>
</tr>
</tbody>
</table>

Note: * federal poverty level
Results

Children with IDD | Children with other SHCN

**EXPERIENCED FINANCIAL PROBLEMS**

- **STOPPED WORK**
  - Children with IDD: ***
  - Children with other SHCN: *

- **REDUCED WORK**
  - Children with IDD: ***
  - Children with other SHCN: ***

- **AVOIDED CHANGING JOB**
  - Children with IDD: ***
  - Children with other SHCN: ***

**OUT OF POCKET SPENDING >$500**

- Children with IDD: 44%
- Children with other SHCN: 18%

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Limitations

- Specific disability-related costs of care were unavailable
- Lack of data on the types of services used
- Data are cross-sectional
- No measures of hardship or deprivation, even though these are important indicators of well-being
Conclusions

- The US safety net for families raising children with ID appears inadequate
- Households with children with ID incur significant financial burden, even in comparison to children with other special health care needs
- Employment-related burdens are a concern since it is nearly impossible to avoid poverty in the US without employment
- More effective policies are needed to buffer the costs these families incur, and to ensure their financial well-being
Thank You

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