Financial Well-being of Children with Disabilities & their Families

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June 2011
US Context

- Relatively low rates of welfare provision
  - Beliefs about independence and individualistic causes of poverty
  - Entrenched historical patterns of racism
  - Balance of power between state & federal governments: states are largely responsible for welfare spending
- Low corporate and income tax rates; high tax expenditures
- Aging population: competition with the disability field for both resources and labor force
- $13 trillion deficit: driven largely by recession, tax cuts and (to a lesser extent) the wars in Afghanistan and Iraq
Structure of Support for Children with Disabilities in the US

• Early intervention & special education – right to free, public education
  – Local funding & administration creates variability in the quality of services and the extent of inclusion

• Health care – Medicaid
  – For low-income children with disabilities

• Income supports – Supplemental Security Income
  – For low-income families

• Ancillary, limited supports
  – Respite, family support, case management
Unique US Challenges

• Different programs have diverse eligibility criteria, funding streams and governmental administration

• Disability supports are often unpopular
  – Reviews of the SSI program
  – Infighting between parents of “gifted” children and those who have children with disabilities

• Political support for poor families in the US has always been limited
Childhood Disability & Poverty in the United States

- Children with disabilities are significantly more likely to live in poverty
  - 28% of children with disabilities live in poverty (Fujiura)
  - 16% of typically developing children live in poverty

- Childhood poverty is associated with adverse outcomes in:
  - Health
  - Psychological wellbeing
  - Social adjustment
  - Academic achievement
  - Behavior

- Poverty probably has more deleterious impact on children with disabilities but research is scant

- Bidirectional relationship between poverty and disability
Glimpse at the Research

• Low-income families’ spending for their disabled child’s health care
• Material hardship and deprivation in families raising children with disabilities
Low-income Families’ Financial Burden

• 61% of families had out-of-pocket expenses for child's health care
  – 1/3 of those with any costs spent > $500 for the prior year
• Wide state variability
• Fewer families reported high (>$500) spending in states with more generous public health eligibility standards
Spending Relative to Family Income

• 27% of families spent >3% of their total household income on their disabled child’s health care
  – For family of 4 with income at $38,700 (twice the federal poverty level), 3% = $1,161

• State variability in relative burden >3% of income ranged from 6% of families in the District of Columbia to 20% of families in Colorado, Michigan, Minnesota, Montana, New Jersey, North Dakota, Oregon, Tennessee, Utah and Wyoming
  – Families living in states with more generous public health income eligibility standards spend relatively LESS of their total income for their disabled child’s health care
Quartiles of High (>3%) Spending Relative to Total Family Income

LEGEND
1stQ <13.0%  2ndQ 13-15.5%  3rdQ 15.6-19.0%  4thQ >19.0%
Deprivation of Children with Disabilities and Their Caregiving Families
Problematic US Poverty Definition

- Doesn’t address changing patterns of family spending since federal poverty level developed in 1960s
  - Inflation of housing & health care costs
  - Child care costs following women’s entry into work
- Doesn’t address elevated costs some families incur (particularly those with a member with disabilities)
- Doesn’t include noncash income
- Doesn’t address geographic differences in cost of living (median 2010 home price in Syracuse: $125,100; median in Boston: $357,300)
- Federal Poverty Level (FPL) for family of 4 = $22,350 in 2011 (subsistence in the US generally regarded as requiring twice this amount)
- The real issue is not theoretical: the FPL is used to determine eligibility for >100 social welfare programs in the US
How do we understand financial well-being?

• Alternative measures of poverty
  – From the EU relative measures (i.e., income < 40, 50 or 60% of median income nationally)
  – Asset poverty
  – Poverty measures that include the value of income transfers, in-kind goods, medical care
• Material hardship or deprivation: food insecurity, housing instability, health care access
Disabled Children’s Food Insecurity

<table>
<thead>
<tr>
<th>Condition</th>
<th>Odds Ratio</th>
<th>P-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worried food would run out</td>
<td>1.78</td>
<td>**</td>
</tr>
<tr>
<td>Food did not last</td>
<td>1.78</td>
<td>**</td>
</tr>
<tr>
<td>Received emergency food</td>
<td>1.89</td>
<td>**</td>
</tr>
<tr>
<td>Skip meals for lack of money</td>
<td>2.34</td>
<td>**</td>
</tr>
</tbody>
</table>

Families with nondisabled children = 1.0

*p < .05; ** p < .01
Disabled Children’s Housing & Telephone Instability

* p<.05;  ** p<.01; NS not statistically significant

Families with nondisabled children = 1.0
Disabled Children’s Health Care

Uninsured anytime last year
Lacks usual source of health care
Postponed medical care
Postponed dental care

Odds Ratio

Families with nondisabled children = 1.0

* p<.05; ** p<.01
Hardship in 3 Domains: Housing/Utilities, Food, Medical Care

<table>
<thead>
<tr>
<th>Income Relative to the Federal Poverty Level</th>
<th>Disabled</th>
<th>Nondisabled</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 100% FPL</td>
<td>26%</td>
<td>22%</td>
</tr>
<tr>
<td>100-199% FPL</td>
<td>29%</td>
<td>14%</td>
</tr>
<tr>
<td>200-299% FPL</td>
<td>13%</td>
<td>8%</td>
</tr>
<tr>
<td>&gt; 299% FPL</td>
<td>7%</td>
<td>3%</td>
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</tbody>
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Implications for
the US

• It is expensive to parent a child with disabilities in the United States – costs are high and growing, and existing supports are inadequate

• US children with disabilities and their families experience deprivation, even well into middle-income ranges
  – The federal poverty level used in the US to determine eligibility for services is notoriously inaccurate for children with disabilities and their families

• Children with disabilities and their families are particularly at risk for adverse outcomes in the current Congressional budget debates and state budget crises – Medicaid, SSI

• Generosity of state Medicaid policies has particularly large effect on families’ out-of-pocket spending for their children with disabilities
Implications for Japan?

• Defining service eligibility on the basis of an absolute income standard will miss many needy families

• Policymakers interested in targeting resources to those who are most in need should not exclusively rely on an absolute income standard of need

• Disability surveillance is critical, but at the level of government that administers programs – local, county, regional, state
  – Surveillance needs to measure well-being in multiple ways: income, assets, material deprivation
  – Accurate, multi-modal approaches to surveillance are necessary when disability is highly stigmatized and families hide their child’s conditions
Thank you!