Health Care of Children with Autism: A Policy View from the US

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Presentation overview

- Context of health care services for US children with autism
  - Importance of Medicaid and states’ financial prospects
- Costs of health care for children with autism are expensive
  - To the public health system
  - To families, which have limited capacity
- Marked inadequacies in health care access for children with autism
  - Particularly troubling racial and ethnic disparities in quality of care
- “New” autism insurance mandates in the states: are they working?
Health care access of children with autism and other special health care needs

Note: p<.05 for all; SHCN=special health care needs

Source: Kogan et al., 2008

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Children with autism are more expensive than those with other special needs

Note: *p*<.05 for all; SHCN=special health care needs

Source: Kogan et al., 2008
Families raising children with autism and other developmental disabilities lack adequate financial resources
Median income and assets among parents of children with DD by parental age cohort

<table>
<thead>
<tr>
<th>Parental Age Cohort</th>
<th>Median Income ($)</th>
<th>Median Liquid Assets ($)</th>
<th>Median Net Worth ($)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 45 Years</td>
<td>$0</td>
<td>$0</td>
<td>$0</td>
</tr>
<tr>
<td>45-54 Years</td>
<td>$135</td>
<td>$285</td>
<td>$47,100</td>
</tr>
<tr>
<td>55-64 Years</td>
<td>$285</td>
<td>$45,288</td>
<td>$78,897</td>
</tr>
<tr>
<td>65 and Older</td>
<td>$20</td>
<td>$31,212</td>
<td>$75,156</td>
</tr>
</tbody>
</table>

Source: Parish et al., 2010

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Public health insurance is vital for children with autism
Insurance coverage of children with autism in the US

Medicaid: State administered health insurance for low-income people and those with disabilities in the US; funded jointly by the federal & state governments

Private only 47%
Public or Public & Private 47%
Other Uninsured 3%
Uninsured 3%

Source: Chiri & Warfield (2011)
State Medicaid spending & families’ financial burden

- State Medicaid spending for children with disabilities is critically important
- Families of children with autism in states with higher per capita Medicaid spending are less likely:
  - To have ANY out-of-pocket expenses for their child’s health care
  - To have out-of-pocket > $500 for the year
  - To have spending that > 3% of their total annual income
  - To need additional income to care for their child

Source: Parish et al., forthcoming
Average annual Medicaid growth

Source: National Governors Association & National Association of State Budget Officers

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Number of states proposing Medicaid cost containment strategies, FY 2012

Source: National Governors Association & National Association of State Budget Officers, 2012
How are the states doing?

- The recovery is underway, but not as robust as previous recoveries – high unemployment continues
- 42 states projected to have FY2014 spending above FY2013
  - But 19 states have not recovered to pre-recession levels
  - State spending is still below 2008 pre-recession levels for the aggregated 50 states; mid-year increases may take nominal (not inflation-adjusted) spending above 2008 levels
- Expiration of the 2009 American Recovery & Reinvestment Act funds challenges states, particularly in Medicaid ($87 billion)
- Increasing demand for state services has not been fully offset by increasing revenue projections
- Medicaid (still) represents the single largest expenditure for state budgets (24% of total spending in FY12)

Source: NASBO & NGA, 2013
Relationship between insurance type & families’ financial burden?

- 82% of all families had any out-of-pocket expenditures
- Mean out-of-pocket spending $US 730; median $US 215
- Mean relative burden $US 9.70 per $US 1000 of income; median $US 2.60 per $US 1000

Source: Parish et al., under review (data from the Medical Expenditure Panel Survey, 2000-09)
Median out-of-pocket spending among families with any spending by income and insurance type

<table>
<thead>
<tr>
<th>Income Level</th>
<th>Medicaid/SCHIP</th>
<th>Private</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;200% FPL</td>
<td>$171</td>
<td>$169</td>
</tr>
<tr>
<td>≥200% FPL</td>
<td>$623</td>
<td>$287</td>
</tr>
</tbody>
</table>

Note: Excludes families that reported no out-of-pocket spending; FPL is the federal poverty level ($US 22,350 for family of 4 in 2013)
Racial disparities in quality of care for children with autism

Source: Magaña et al, forthcoming; all comparisons with White children p<.05
States with private autism insurance reform laws

Source: Autism Votes
New autism mandates reduce families’ financial burdens

Families living in states with autism health insurance mandates:

- Are less likely to spend >$500 annually for out-of-pocket health care costs of their child with autism
- Are less likely to have any out-of-pocket costs

Source: Parish et al., 2012
Implications

- Families raising children with autism incur substantial financial burdens.
- Out-of-pocket spending incurred by families of children with autism are higher for children who lack public insurance, even after controlling for socio-economic status and family income.
- Families incur out-of-pocket expenses for a varied range of health care services.
Conclusion

The time for advocacy has never been more pressing

- State budgets will continue to be strained
- Families continue to struggle to
  - Secure services for their children with autism
  - Stay afloat financially
- Interventions to improve health care access for racial and ethnic minority children with autism are urgently needed
  - Policies must promote high-quality care
- The Affordable Care Act (Obamacare) may increase access to services; the DSM-5 diagnostic changes may or may not reduce access to services
Acknowledgements

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Thank you!