Breaking the Link Between Special Health Care Needs and Financial Hardship

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The fine print...

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Welcome and introductions

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Speakers

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Learning objectives

• Describe data related to CSHCN number and prevalence, insurance status and data related to insurance inadequacy for CSHCN – all with a focus on demographic differences and inequities

• Define causes and consequences of financial hardship for families raising CSHCN

• Evaluate applicability of specific state strategies in addressing financial hardship among families raising CSHCN

• Identify resources for state-specific data, examples of strategies and other Catalyst Center technical assistance materials
The Catalyst Center: an overview

The National Center on health insurance coverage and financing policy for children and youth with special health care needs

We provide technical assistance, conduct research and policy analysis, create resources, and promote partnerships to improve financing of health care and promote access to care and health equity

A project of the Center for Advancing Health Policy and Practice, Boston University School of Public Health
Breaking the Link Between Special Health Care Needs and Financial Hardship – 2d Ed.

- Section 1: Research data and analysis
- Section 2: Stories of real families raising CSHCN
- Section 3: State strategies for addressing financial hardship

http://cahpp.org/resources/breaking-the-link
Who are children with special health care needs (CSHCN)?

...“those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

(Source: McPherson et al, 1998)
How many children have special health care needs?

Number: 11.2 million children

Percentage: 15.1% of US population under age 18

Measureable outcomes: adequate insurance coverage

National Performance Measure #15: Percent of children ages 0 through 17 who are adequately insured
• All children, including CYSHCN
• Adequate insurance, not just simple coverage

National Outcome Measures
Percent of children without health insurance
Systems of care for children with special health care needs (percent of CYSHCN receiving care in a well-functioning system)

Defining adequacy

Questions from 2011/12 National Survey of Children’s Health (NS-CH):

- Does [CHILD'S NAME]'s health insurance offer benefits or cover services that meet [his/her] needs?
- Does [CHILD'S NAME]'s health insurance allow [him/her] to see the health care providers [he/she] needs?
- How often are these costs reasonable?

Possible responses: never, sometimes, usually, always, don’t know, refused
What we know from the data: Insurance coverage status

<table>
<thead>
<tr>
<th></th>
<th>Not insured</th>
<th>Insured at the time of the survey</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-CSHCN</td>
<td>6.1%</td>
<td>93.9%</td>
<td>100%</td>
</tr>
<tr>
<td>CSHCN</td>
<td>3.2%</td>
<td>96.8%</td>
<td>100%</td>
</tr>
</tbody>
</table>

What we know from the data: Adequacy

<table>
<thead>
<tr>
<th></th>
<th>Current insurance is adequate</th>
<th>Current insurance is not adequate</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-CSHCN</td>
<td>77.9%</td>
<td>22.1%</td>
<td>100%</td>
</tr>
<tr>
<td>CSHCN</td>
<td>70.8%</td>
<td>29.2%</td>
<td>100%</td>
</tr>
</tbody>
</table>

What we know from the data: Elements of adequacy – Coverage allows child to see needed providers?

<table>
<thead>
<tr>
<th></th>
<th>Never/Sometimes</th>
<th>Usually</th>
<th>Always</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-CSHCN</td>
<td>4.3%</td>
<td>9.7%</td>
<td>86.0%</td>
<td>100%</td>
</tr>
<tr>
<td>CSHCN</td>
<td>7.9%</td>
<td>16.3%</td>
<td>75.8%</td>
<td>100%</td>
</tr>
</tbody>
</table>
What we know from the data: Elements of adequacy – Benefits meet child’s needs?

<table>
<thead>
<tr>
<th></th>
<th>Never/ Sometimes</th>
<th>Usually</th>
<th>Always</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-CSHCN</td>
<td>6.6%</td>
<td>13.0%</td>
<td>80.4%</td>
<td>100%</td>
</tr>
<tr>
<td>CSHCN</td>
<td>10.9%</td>
<td>21.2%</td>
<td>67.9%</td>
<td>100%</td>
</tr>
</tbody>
</table>

What we know from the data: Elements of adequacy – Out-of-pocket costs are reasonable?

<table>
<thead>
<tr>
<th></th>
<th>No OOP Expenses</th>
<th>Never/Sometimes</th>
<th>Usually</th>
<th>Always</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-CSHCN</td>
<td>44.2%</td>
<td>16.7%</td>
<td>17.6%</td>
<td>21.6%</td>
<td>100%</td>
</tr>
<tr>
<td>CSHCN</td>
<td>43.5%</td>
<td>23.1%</td>
<td>18.6%</td>
<td>14.7%</td>
<td>100%</td>
</tr>
</tbody>
</table>

What we know from the data: Families who had problems paying medical bills

<table>
<thead>
<tr>
<th></th>
<th>Did not have problems paying medical bills</th>
<th>No medical expenses</th>
<th>Yes, had problems paying or were unable to pay medical bills</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-CSHCN</td>
<td>90.5%</td>
<td>0.5%</td>
<td>8.9%</td>
<td>100%</td>
</tr>
<tr>
<td>CSHCN</td>
<td>80.0%</td>
<td>0.5%</td>
<td>19.5%</td>
<td>100%</td>
</tr>
</tbody>
</table>

What we know from the data: Inequities

Source: 2009/10 NS-CSHCN

Only 60.6% of CSHCN met the Core Outcome (+ response to all 5 items related to insurance adequacy)

The 5 items:

- Have insurance
- Have consistent insurance
- Can see needed providers
- Benefits meet child’s needs
- Out-of-pocket costs are reasonable

What we know from the data:
Inequities

CSHCN who were more likely to meet the Core Outcome:

• Younger children (63.2% ages 0-5 years vs. 59.4% ages 12-17 years)
• Non-Hispanic White (62.9% vs. 58.8% non-Hispanic Black and 53.7% Hispanic)
• Family completed the survey interview in English (61.3% vs. 47.7%)
• Daily activities less impacted by SHCN (70.0% vs. 52.0% who reported usually/always/a great deal impacted)

Pathways to financial hardship

- Higher health care costs
- Higher routine expenses
- Loss of employment income

What we know from the data: Impact on families

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>22.1%</td>
<td>Out-of-pocket spending &gt; than $1000 per year</td>
</tr>
<tr>
<td>21.6%</td>
<td>Financial difficulties reported</td>
</tr>
<tr>
<td>13.1%</td>
<td>11 or more hours per week of caregiving (related to child’s SHCN)</td>
</tr>
<tr>
<td>25.0%</td>
<td>1 or more family member has cut back on work or stopped working (due to child’s SHCN)</td>
</tr>
</tbody>
</table>

Source: NS-CSHCN (2009/10)
What we know from families

On the impact of higher health care costs:

“Most people assumed that a family like ours, because we had two college-educated parents, would have the resources they needed to take care of their family’s medical conditions. It wasn’t until [he] was two and we were in major medical debt that we learned from another parent that we’d been income-eligible the whole time for [financial assistance through a state program for CSHCN].”
What we know from families

On financial hardship related to **routine expenses**:

“The shoes are $100, which I can’t afford. And ([he] has to wear shoes with the AFOs [ankle-foot orthoses]. He doesn’t wear the AFOs because I can’t afford shoes. Every day [he] can’t wear the AFOs is another day we can’t work on walking.”
What we know from families

On the consequences of loss of income:

“We started getting bills and garnishments [of wages] that first year [due to medical bills]. It was a nightmare. [My husband’s] wages continue to be garnished and we are taking a huge hit.”
Examples of state strategies to address financial hardship

Relief funds
Examples of state strategies to address financial hardship

Prior authorization/approval
Examples of state strategies to address financial hardship

Medical/therapeutic daycare
Examples of state strategies to address financial hardship

Care coordination
Examples of state strategies to address financial hardship

Telemedicine
Examples of state strategies to address financial hardship

Health transformation
Catalyst Center resources

- State-at-a-glance Chartbook pages and childhealthdata.org for more state specific data
- General financing strategies section website
- Family stories section of Catalyst website
- *Health Care Coverage and Financing for Children with Special Health Care Needs: A Tutorial to Address Inequities*
Citations

McPherson et al, 1998
• https://www.ncbi.nlm.nih.gov/pubmed/9714637#
National Survey of CSHCN, 2009/10 and National Survey of
Children’s Health, 2011/12
• www.childhealthdata.org

Kogan, et al, 2015
• https://www.ncbi.nlm.nih.gov/pubmed/25823557

Ghandour, et al, 2010
• https://www.ncbi.nlm.nih.gov/pubmed/25864809

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• http://cahpp.org/wp-content/uploads/2015/04/Catalyst_Center_Breaking_The_Li
nk.pdf
Questions and Discussion
For more information, please contact us at:

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