

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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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

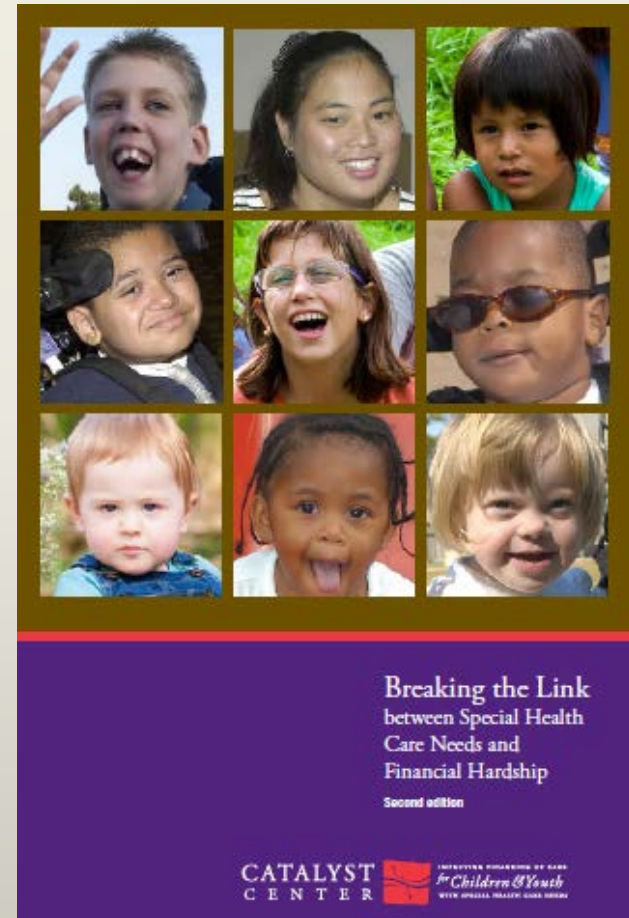


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Breaking the Link Between Special Health Care Needs and Financial Hardship – 2d Ed.

- 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>



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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

(Source: National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 4/23/17 from www.childhealthdata.org)



Measurable 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)

Kogan, et al. (2015). A New Performance Measurement System for Maternal and Child Health in the United States. *Maternal and Child Health Journal*, 19(5), pp. 945-57.
doi:10.1007/s10995-015-1739-5 ; NS-CH (2011/12)



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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

	Not insured	Insured at the time of the survey	Total
Non-CSHCN	6.1%	93.9%	100%
CSHCN	3.2%	96.8%	100%

National Survey of Children's Health. NSCH 2011/12. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 4/23/17 from www.childhealthdata.org



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What we know from the data: Adequacy

	Current insurance is adequate	Current insurance is not adequate	Total
Non-CSHCN	77.9%	22.1%	100%
CSHCN	70.8%	29.2%	100%

National Survey of Children's Health. NSCH 2011/12. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 4/23/17 from www.childhealthdata.org



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

	Never/ Sometimes	Usually	Always	Total
Non- CSHCN	4.3%	9.7%	86.0%	100%
CSHCN	7.9%	16.3%	75.8%	100%

National Survey of Children's Health. NSCH 2011/12. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 4/23/17 from www.childhealthdata.org



What we know from the data: Elements of adequacy – Benefits meet child's needs?

	Never/ Sometimes	Usually	Always	Total
Non-CSHCN	6.6%	13.0%	80.4%	100%
CSHCN	10.9%	21.2%	67.9%	100%

National Survey of Children's Health. NSCH 2011/12. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 4/23/17 from www.childhealthdata.org



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

	No OOP Expenses	Never/ Sometimes	Usually	Always	Total
Non- CSHCN	44.2%	16.7%	17.6%	21.6%	100%
CSHCN	43.5%	23.1%	18.6%	14.7%	100%

National Survey of Children's Health. NSCH 2011/12. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 4/23/17 from www.childhealthdata.org



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

	Did not have problems paying medical bills	No medical expenses	Yes, had problems paying or were unable to pay medical bills	Total
Non-CSHCN	90.5%	0.5%	8.9%	100%
CSHCN	80.0%	0.5%	19.5%	100%

National Survey of Children's Health. NSCH 2011/12. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 4/23/17 from www.childhealthdata.org



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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

Source: Catalyst Center (2009): Breaking the Link Between Special Health Care Needs and Financial Hardship (1st edition)



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What we know from the data: Impact on families

Out-of-pocket spending > than \$1000 per year	22.1%
Financial difficulties reported	21.6%
11 or more hours per week of caregiving (related to child's SHCN)	13.1%
1 or more family member has cut back on work or stopped working (due to child's SHCN)	25.0%

Source: NS-CSHCN (2009/10)



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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

- [*Breaking the Link Between Special Health Care Needs and Financial Hardship 2d. Ed.*](#)
- [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>

Breaking the Link Between Special Health Care Needs and Financial Hardship 1st edition (2009)

- http://cahpp.org/wp-content/uploads/2015/04/Catalyst_Center_Breaking_The_Link.pdf



Questions and Discussion



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**For more information,
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