

## FINANCIAL HARDSHIP IN FAMILIES RAISING CYSHCN

Inadequate insurance coverage and financing results in significant financial hardship for many families raising children and youth with special health care needs<sup>1</sup> (CYSHCN).



### CYSHCN

Most CYSHCN have insurance, but having health insurance does not necessarily mean the coverage is adequate or affordable. Being insured is only part of the story. Many families make difficult sacrifices to help ensure adequate care for their CYSHCN.



### FAMILIES



Inadequate health care coverage is a serious problem for a large percentage of families raising CYSHCN. Not every service or support CYSHCN need is paid for by insurance and as a result, families often incur large out-of-pocket (OOP) costs, resulting in financial hardship and medical debt.<sup>2</sup>

### PAYERS & POLICYMAKERS

Adequacy is a problem for both publicly and privately insured CYSHCN. Implementing financing strategies aimed at covering more services and reducing families' OOP expenses could help address higher costs later as the result of absent or delayed care.



### PROVIDERS

Adequacy is composed of three elements: benefits (what a child needs is covered), access (children can get the services they need by being able to see appropriate providers) and affordability (OOP expenses are reasonable).



## CATALYST CENTER RESOURCES



### Breaking the Link Between Special Health Care Needs and Financial Hardship

This report examines the impact that health care financing and coverage gaps have on the lives of families and highlights innovative policy solutions that can improve care for CYSHCN.

<http://cahpp.org/resources/breaking-the-link-between-special-health-care-needs-and-financial-hardship/>



### Family Stories

These personal stories help illustrate the challenges families face raising CYSHCN and demonstrate what is possible when additional financing and services are available.

<http://cahpp.org/projects/the-catalyst-center/stories/>



### Information for Families

This directory provides links to a range of national and state-based direct service organizations and to information related to Title V Maternal and Child Health programs.

<http://cahpp.org/projects/the-catalyst-center/info/>



### State Financing Strategies

This page links to examples of the innovative strategies states are using to improve and finance care for CYSHCN, like relief funds, benefits counseling, and more.

<http://cahpp.org/projects/the-catalyst-center/financing-strategies/>

**DEFINING CYSHCN:** According to the federal Maternal and Child Health Bureau, CYSHCN are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions, and who also require health and related services of a type or amount beyond that required by children generally.<sup>1</sup>

## CITATIONS

1. McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P., Perrin, J., Shonkoff, J., & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, 102(1):137-140.
2. Dworetzky, B., Wilson, K., Koppelman, E., Comeau, M., Charmchi, P., Ablavsky, E., ... Bachman, S. (2017). *Breaking the link between special health care needs and financial hardship (2nd ed.)*. Boston. Retrieved from [http://cahpp.org/wp-content/uploads/2017/04/Catalyst\\_Center\\_Breaking\\_The\\_Link-2nd-ed.pdf](http://cahpp.org/wp-content/uploads/2017/04/Catalyst_Center_Breaking_The_Link-2nd-ed.pdf)

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