



What do Children with Special Health Care Needs Require from Health Care Reform?

As we move to reform our healthcare system we need to keep in mind the unique needs of the over ten million children in the United States who have special health care needs. These children require “health and related services of a type or amount beyond that required by children generally.”¹ Health care reform, especially universal and continuous insurance coverage, is essential for these children who by definition need and use the vast majority of health care services among children. Other essential components of health care reform for children with special health care needs (CSHCN) include:

1. **ADEQUATE** coverage. Nearly one third of CSHCN have health insurance that does not meet their needs due to benefit limits (e.g. lack of coverage, dollar limits or visit limits), exclusions for pre-existing conditions or limited access to health care providers. Most of these children live in families with private insurance coverage. Mechanisms exist for some privately insured CSHCN to “buy into” Medicaid coverage to supplement their private coverage. This safety net option – or something similar – must be part of health care reform and include families at *all* income levels who can purchase the coverage on a sliding scale.
2. **AFFORDABLE** coverage. More than half of all bankruptcies in the United States are the result of medical debt or lost employment due to illness². Visit and medication co-payments mount quickly for children with chronic health conditions, and many plans have lifetime benefit caps. Families of CSHCN need health policies that protect them from runaway out-of-pocket health care expenses to avoid financial hardship.
3. **CONTINUOUS** coverage. A 2005 national survey indicated that over 900,000 CSHCN were uninsured at some point in the year in which the survey was administered³. About 1/3 of these children had no insurance at all during the year and the other 2/3 experienced gaps in coverage during the year. These are children who cannot afford to go one week or one month without health care coverage. Health care reform must offer a safety net for children whose coverage is dropped due to changes in family employment or income.

For more in-depth information and analysis, see the following Catalyst Center publications at www.catalystctr.org

- *Breaking the Link Between Special Health Care Needs and Financial Hardship*
- *Reducing Underinsurance for Children and Youth with Special Health Care Needs Through Medicaid Buy-in Programs*
- *Frequently Asked Questions about the Family Opportunity Act's Medicaid Buy-in Option*

¹ McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland F (1998). A new definition of children with special health care needs. *Pediatrics* 102:137-140.

² Himmelstein D, Thorne D, Warren E, Woolhandler S (2009). Medical bankruptcy in the United States, 2007: Results of a national study. *American Journal of Medicine*. In Press.

³ National Survey of Children with Special Health Care Needs (2005). Retrieved June 20, 2009 from www.cshcndata.org.

About the Catalyst Center

The Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs is located at the Boston University School of Public Health. The Catalyst Center provides research and technical assistance support to the efforts of stakeholders at the federal, state and local levels in assuring adequate health insurance coverage and financing to meet the diverse needs of children and youth with special health care needs and their families.

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