



The Essential Components of Health Care Reform for Children with Special Health Care Needs

Over 10 million children in the United States (nearly 14%) have special health care needs¹ that require “health and related services of a type or amount beyond that required by children generally.”² Health care reform is essential for these children, who by definition need and use the vast majority of health care services among children. They are, in many respects, the canaries in the coal mine: if health care reform works for these children, it will work for all children.

President Obama has asked Congress to present him with a health care reform bill with the goal of passing legislation by the end of this year. As various proposals emerge, we highlight the essential components of health care reform for children with special health care needs (CSHCN) and recommend criteria by which these proposals can be judged:

1. Universal, CONTINUOUS Coverage.

In 2005, a national survey indicated that over 900,000 CSHCN were uninsured at some point over the course of the year.³ About one third of these children had no insurance at all during the year and the other two thirds experienced gaps in coverage during the year, most likely because they lost eligibility for Medicaid or SCHIP or their parents lost their jobs or changed jobs with a gap in insurance coverage. 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.

Things to look for:

- No coverage exemptions based on health status, age, national origin, or immigration status
- Safety net coverage for CSHCN whose parents experience a gap in coverage
- No waiting period for SCHIP or other public coverage for CSHCN
- Premium assistance based on family income for low income families
- Guaranteed issue and guaranteed renewability
- Transition coverage to allow CSHCN entering adulthood to remain on their family coverage.

2. ADEQUATE coverage.

Nearly one third of CSHCN have insurance coverage that does not meet their needs, primarily due to the limited scope of benefits available through private insurance or some SCHIP programs (e.g. lack of coverage for dental care or medical supplies; dollar limits on durable medical equipment; visit limits for physical therapy or mental health). Exclusions for pre-existing conditions and limited access to essential health care providers also contribute to the inadequacy of coverage experienced by the families of 300,000 CSHCN. Currently, these families **cannot** access broader benefits that are available under Medicaid because their income is too high, and they cannot access benefits available through many SCHIP programs because they have private insurance. Most of these children live in families with private insurance coverage.

Mechanisms exist for some privately insured CSHCN to “buy into” Medicaid coverage on a sliding scale based on family income to supplement their private coverage. The CommonHealth program in Massachusetts functions as a safety net for privately insured children with disabilities by allowing families of any income to buy into the Medicaid program for their child with a disability on a sliding fee scale. The Family Opportunity Act (FOA) allows states to implement similar programs for families with incomes up to 300% of the FPL.⁴ The cost of these programs to states is relatively small because private insurance covers some of the most expensive services such as hospitalizations and pharmaceuticals. This safety net option – or something similar – must be part of health care reform and include families at *all* income levels who can then purchase the coverage on a sliding scale.

Things to look for:

- Keep what is working intact – the Medicaid program, with its provisions for Early Periodic Screening Diagnosis and Treatment (EPSDT) provides the breadth of coverage needed by CSHCN
- Extend EPSDT provisions to any expansion of coverage for CSHCN
- Ensure that a safety net option – whether FOA or a similar program with less restrictive income limits – is available **nationally** to CSHCN based on a sliding fee scale
- Eliminate pre-existing conditions provisions
- Provide minimal creditable coverage
- Promote medical home

3. AFFORDABLE coverage.

A recent study found that over 60% of all bankruptcies in American are the result of medical debt or lost employment due to illness, even though three quarters of these individuals have health insurance and most own their own homes.⁵ In addition to uncovered medical expenses, co-pays and deductibles add up very quickly for families

of CSHCN with chronic health conditions. While the average child may require 2-3 copays/year for physician visits, it is not uncommon for a child with special health care needs to need 2-3 copays a **week** for therapy or physician visits. Nearly a quarter of families of CSHCN cut back on employment to care for their child, and 18% report that caring for their child has created financial hardship for the family.⁶ Far too many families live on the brink of financial solvency, trying to balance the needs of their child with their ability to borrow money or spend out-of-pocket for medical care. Few private health insurance plans cap the out-of-pocket copayment costs for a family, and many still contain lifetime benefit caps. Families of CSHCN need a national plan that will cap their out-of-pocket expenditures for health care services and protect them from financial ruin.

Things to look for:

- Eliminate life-time benefit caps and implement reforms that include stop-loss coverage for catastrophic illness
- Cap annual deductibles **and** copayments at a reasonable level, based on family size and income
- A cap on the difference in premium price among health insurance plans

Regardless of family income, financial hardship is common among families of CSHCN. Financial hardship results from three intertwined pathways: higher health care costs; higher costs for expenses every family has; and loss of employment income and access to employer-sponsored health insurance. The Catalyst Center's publication *Breaking the Link between Special Health Care Needs and Financial Hardship* provides extensive information and real-life stories about families that have been financially devastated by caring for their child with special needs. **Any national health reform proposal that is passed must have provisions that prevent families from suffering the serious financial hardship that currently results from caring for their child with special needs and which allow CSHCN to grow, play and learn so that they may reach their fullest potential.**

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

² 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

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

⁴Part of the Deficit Reduction Act of 2007

⁵ 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

⁶ National Survey of Children with Special Health Care Needs (2005). Retrieved June 20, 2009 from www.cshcndata.org.

For more information, please see the following Catalyst Center publications at www.catalystctr.org

[*Breaking the Link between Special Health Care Needs and Financial Hardship*](#)

[*Reducing Under-Insurance 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*](#)

[*Health Care Reform and the Massachusetts Commonhealth Program: An Important Foundation to Build on for Children with Disabilities*](#)

About the Catalyst Center

The Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs is a national center funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration, and is located at the Boston University School of Public Health. The Catalyst Center provides 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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