



Children and Youth with Special Health Care Needs

From the Campaign for Children's Health Care • April 2007

A significant number of America's children have special health care needs. These children suffer from chronic conditions and require more health care services than other children (for example, more doctor visits, specialized treatments, prescription drugs, and mental health services). Many of them are underinsured or have no health coverage at all, which may mean that their additional needs pose an extreme economic burden for their families and a sizable barrier to their healthy development.

Who Are Children and Youth with Special Health Care Needs?

- Children with special health care needs are defined as children “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.”¹ One in five households with children in the United States includes at least one child with special health care needs.² Nationwide, more than 13.5 million children – 18.5 percent of all children under the age of 18 – have special health care needs.³
- Children with special health care needs have a wide range of chronic illnesses, disabilities, or emotional or behavioral health problems, such as severe asthma, autism, ADHD, cerebral palsy, cystic fibrosis, diabetes, Down syndrome, mental retardation, sensory impairments, sickle cell anemia, and spina bifida.
- Families in every demographic group, including all income levels and ethnicities, have children with special health care needs.
- Families without health insurance are sometimes unable to obtain the health care services their children need. For example, nearly half of all uninsured children with special health care needs reported that they did not receive the care they needed – 29 percent lacked needed dental care, and 14 percent lacked needed mental health services. Furthermore, 15 percent of uninsured children with special health care needs did not receive necessary preventive care, and another 14 percent did not receive needed specialty care.
- Boys are more likely to have special health care needs than girls – 15 percent versus 10.5 percent, respectively.⁴
- The prevalence of special health care needs increases with age. For young children up to age five, the prevalence of special health care needs is just under 8 percent. That percentage increases to 14.6 percent for children aged 6 to 11. And among adolescents (children aged 12-17), the prevalence rises to 15.8 percent.

How Many Children and Youth with Special Health Care Needs Have Health Coverage?

- Although national data indicate that only 5 percent of children and youth with special health care needs were uninsured for the entire year of 2001, 12 percent were uninsured for part of that year. Gaps in private health insurance coverage or lapses in eligibility for public programs leave these children particularly vulnerable.
- Many children and youth with special health care needs are underinsured. About 30 percent of children and youth with special health care needs have unmet health needs due to restrictions on the amount or scope of their health benefits.⁵

Why Is Health Insurance Important for Children and Youth with Special Health Care Needs?

- Lack of insurance or underinsurance creates serious challenges for families. They must make hard choices and substantial sacrifices in other areas to obtain adequate care for their children.
 - Twenty percent of families report that paying for their child's care has led to family financial problems.⁶
 - Nearly one-third of parents cut back on work or stopped working to care for their children with special health care needs.⁷
 - Some families simply do not have the necessary financial resources to meet the health care needs of their children. As a result, children and youth who are uninsured or whose insurance does not pay for critical components of care may suffer from otherwise avoidable problems with their health, development, and capacity to function.
- Comprehensive health insurance is essential for children and youth with special health care needs, helping ensure that they have access to critical care and services such as the following: diagnostic testing, primary care, specialty care, hospital services, prescription drugs, therapies, mental health services, durable medical equipment and supplies, hearing aids, and other health-related services.
- Access to comprehensive care and services is critical for detecting health problems, preventing the deterioration of physical or mental health, and maximizing a child's potential to learn, play, and develop along with his or her peers.
- Some benefits are important only for a small handful of children, but for these children, they can make the difference between life and death. For example, children with metabolic disorders need nutritional supplements, and children with hemophilia require "factors," which are specific proteins that enable the blood to clot.

- Another benefit of comprehensive health insurance is the access it provides to chronic disease management. Chronic disease management is critical for patients with complex conditions that often require multiple types of care from different providers in different kinds of medical settings. Disease management also lowers health care costs, because it allows for better coordination of care.

Medicaid and SCHIP Provide Health Coverage for Children with Special Needs

Comprehensive, affordable health insurance coverage is a vital life-line for children and youth with special health care needs. Nearly two out of five children with special health care needs (38 percent) receive this coverage from Medicaid and the State Children’s Health Insurance Program (SCHIP).⁸

By September 2007, SCHIP must be reauthorized, but the debate in Washington on the future of both SCHIP and Medicaid is already occurring. We need your help. Tell your members of Congress:

- Today, SCHIP provides high-quality, comprehensive, affordable health coverage to more than 4 million children who would otherwise be uninsured.
- To maintain coverage and provide access to treatments for children with special health care needs, states will need approximately \$50 billion in new federal funds over the next five years in addition to the \$25 billion originally allotted to SCHIP.
- Congress must ensure that there is enough money to at least get the children who are already eligible for Medicaid and SCHIP enrolled. And, leaders must act soon so that no child loses health coverage because of a shortage of federal funds.

NOW IS THE TIME TO ACT

The Campaign for Children’s Health Care is a nationwide effort to build awareness on the importance of health coverage for all kids. Join the campaign, sign our petition, and call your Congressional representatives to inform them of the many benefits that Medicaid and SCHIP provide to children and youth with special health care needs.

Go to: <http://www.childrenshealthcampaign.org>

Adapted from materials written by The Catalyst Center, *Improving Financing of Care for Children and Youth with Special Health Care Needs*, Boston University School of Public Health, Health and Disability Working Group.

Endnotes

¹ M. McPherson, P. Arango, H. Fox, C. Lauver, M. McManus, P. Newacheck, J. Perrin, J. Shonkoff, and B. Strickland, "A New Definition of Children with Special Health Care Needs," *Pediatrics* 102 (1998): 137-140.

² U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, *The National Survey of Children with Special Health Care Needs Chartbook 2001* (Rockville, MD: U.S. Department of Health and Human Services, 2004).

³ H. Tu and P. Cunningham, "Public Coverage Provides Vital Safety Net for Children with Special Health Care Needs," Center for Studying Health System Change Issue Brief No. 98 (September 2005):1-4.

⁴ Ibid.

⁵ H. B. Fox, M. McManus, and M. Reichman, *The Strengths and Weaknesses of Private Health Insurance Coverage for CSHCN* (Washington: MCH Policy Research Center, 2002).

⁶ U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, *The National Survey of Children with Special Health Care Needs Chartbook 2001* (Rockville, MD: U.S. Department of Health and Human Services, 2004).

⁷ Ibid.

⁸ H. Tu and P. Cunningham, *op. cit.*



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