



## Why Health Insurance is Important to Children and Youth with Special Health Care Needs

### Children and Youth with Special Health Care Needs

The Maternal and Child Health Bureau defines children and youth with special health care needs (CYSHCN) as 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.”<sup>1</sup>

They include children with a wide range of conditions, including chronic illnesses such as diabetes, sickle cell anemia, cystic fibrosis, and heart disease; developmental disabilities such as mental retardation, sensory impairments and autism spectrum disorders; emotional or behavioral health needs including ADHD and mental health conditions; and physical disabilities such as cerebral palsy, spina bifida, or muscular dystrophy.

Federal research indicates that nearly 9.4 million children in the United States — 13% of all children under 18 — had special health needs in 2001.<sup>2</sup> One in five households in the U.S. includes at least one child with special health care needs.<sup>3</sup>

While families of all income levels and ethnicities may have a child with special health needs, there is a link between special needs and poverty. Boys are more likely to have special health care needs than girls, and the prevalence of special needs increases with age.

### Health Insurance — and Underinsurance

Health insurance is essential for CYSHCN, permitting access to 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 these 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 with his or her peers. Some services generally covered by health insurance, such as nutritional supplements for children with metabolic disorders or clotting factor for children with hemophilia, are only important for a small handful of children, but for these children they can make the difference between life and death.

Two thirds of CYSHCN have private insurance and nearly a quarter have public coverage through Medicaid or SCHIP. Although national data indicate that only 5% of CYSHCN were uninsured in 2001, 12% 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.

The far more common problem for children with special health care needs, however, is underinsurance. Restrictions on the amount or scope of health benefits create unmet needs for about 30% of children and youth with special health care needs.<sup>4</sup>

While national trends suggest that insurance coverage for children has increased in recent years, largely due to expansion of public programs,<sup>5</sup> these gains may be undercut by reductions in private coverage or restricted benefit packages that have a disproportionate impact on CYSHCN of all income levels.

### **Impact on Families**

Lack of insurance or underinsurance creates serious challenges for families. Twenty percent report that their child's care leads to family financial problems,<sup>6</sup> and nearly one-third of parents have cut back on or stopped work to care for their CYSHCN.<sup>7</sup>

Some families must make hard choices and substantial sacrifices to ensure adequate care for their children. But for other families, the resources to pay for care are simply not there: children and youth who are uninsured or whose insurance does not pay for critical components of care may experience adverse outcomes in relation to health, development and capacity to function.

Both the national Healthy People 2010 objectives and the President's New Freedom Initiative recognize adequate coverage as critical to the care of CYSHCN. It is vital that policymakers consider CYSHCN when making health care financing decisions.

## At a Glance: Health Insurance and Children and Youth with Special Health Care Needs

- 9.4 million children in the United States have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition.
- One in five households in the U.S. includes at least one child with special health care needs.
- Twenty percent of families caring for children with special health care needs report that paying for their care has caused financial problems.
- Nearly one-third of parents of children with special health care needs have cut back on or stopped work to provide care.
- Two thirds of children with special health care needs have private insurance and nearly a quarter have public coverage through Medicaid or SCHIP. Twelve percent were uninsured for at least part of 2001.
- Nearly a third of children with special needs who *do* have health insurance require care that isn't covered.

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### References:

<sup>1</sup> 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 :137-140.

<sup>2</sup> Blumberg SJ, Olson L, Frankel M, Osborn L, Becker CJ, Srinath KP, Giambo P (2003). Design and operation of the National Survey of Children with Special Health Care Needs, 2001. *Vital Health Stat 1*. Jun;(41):1-136.

<sup>3, 6-7</sup> National Survey of Children with Special Health Care Needs (2005). Retrieved July 6, 2006 from [www.cshcndata.org](http://www.cshcndata.org).

<sup>4</sup> Fox HB, McManus M and Reichman, M. (2002). The strengths and weaknesses of private health insurance coverage for CSHCN. MCH Policy Research Center. Washington, DC.

<sup>5</sup> Blewett LA, Davern M, & Rodin H. (2004). Covering kids: Variation in health insurance coverage trends by state, 1996-2992. *Health Affairs*. 23(6): 170-180).