

Who are Children with Special Health Care Needs (CSHCN)?

What challenges do they face in the current system of health care coverage and financing?

What do they need from health care reform?

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Who are CSHCN?

- CSHCN have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and also require health and related services of a type or amount far greater than required by children generally.*

10.2 Million

• Children in the US have special health care needs**

1 in 7 (13.8%)

• Children in the US have special health care needs**

*McPherson, M, et al. *A new definition of children with special health care needs* (Elk Grove Village, IL: Pediatrics, 1998),102: 137-140

**Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2005–2006*. (Rockville, MD: U.S. Department of Health and Human Services, 2007).

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Currently, there are major gaps in the health care coverage and financing system that cause significant problems for CSHCN in accessing care and financial hardship for their families....

Children with special health care needs – aren't they taken care of?

- Common policy perception – as long as you cover uninsured children (e.g. expand CHIP) CSHCN should be okay.....
- Especially given:
 - Poverty \longrightarrow Medicaid \longleftarrow Disability
 - Medicaid TEFRA/HCBS waiver programs
 - SSI = Disability = Medicaid
 - CHIP: the Children's Health Insurance Program

Not quite.....

While most CSHCN do have health care coverage

| Type of insurance | % of CSHCN by insurance category – National Average |
|-------------------------|---|
| Private insurance only | 60.3% |
| Public insurance only | 28.6% |
| Both public and private | 7.5% |
| Uninsured | 3.6% |

Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Retrieved 1/22/11 from www.cshcndata.org

**Simple coverage
is not enough.....**

Currently insured CSHCN whose coverage is inadequate (according to their families)

National Average

33.1%

Child and Adolescent Health Measurement Initiative. *2005/06 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Retrieved 1/22/11 from www.cshcndata.org

Underinsurance: typical gaps in coverage that impact CSHCN

- Habilitative therapies: physical, occupational, speech/language
- Prescription medications
- Durable medical equipment
- Eye glasses, hearing aids
- Consumable supplies: diapers, wipes, hearing aid batteries, disposable dressings, etc.
- Mental health services
- Dental care

When families are the 'payer of last resort,' continued....

- Family as a whole is affected – fewer funds for food, clothing, housing, etc.
- Worst case scenario: Child may not receive needed care and services

Material Hardship in US Families Raising Children with Disabilities. Parish, S., et al. *Exceptional Children*, Vol. 75, No. 1, pages 71-92. Retrieved 9/27/09 from <http://bhrp.sowo.unc.edu/susanparish/files/2008%20Except%20Children%20material%20hardship.pdf>

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So what do CSHCN need from health care reform?

The starting point is coverage that is:

- Universal and continuous
- Adequate
- Affordable