

Children and Youth with Special Health Care Needs & Disabilities

Publicly funded services to identify and address Children and Youth with Special Health Care Needs (CYSHCN) and Disabilities are described in Care Coordination Services, Early and Periodic Screening, Diagnosis and Treatment, Family Support Services, Early Hearing Loss Detection, Diagnosis and Intervention, and Immunization Program CHILD Profile

Key Findings:

- Between 14 and 18 percent of children and youth in Washington had a special health care need in 2005-2007, which is similar to the US rate.^{1,2} A significantly higher proportion of school-age children had a special health care need compared to children 0-5 years. This may be the result of increased identification when children enter school. Males were more likely to have a special health care need than females.¹
- Spanish-speaking Hispanics were less likely to report a child with a special health care need compared with English-speaking Hispanics (4%, $\pm 2\%$ vs. 12%, $\pm 4\%$, respectively).¹ Studies suggest that limited English skills are associated with difficulties accessing health care,⁴ children not receiving needed medical care,⁵ and medical misdiagnoses.⁵ These difficulties might influence parents' abilities to report their children's conditions accurately. In addition, culture can affect interpretation of survey questions.⁶
- No significant differences in the prevalence of CSHCN by poverty level were observed.¹

Definitions: Children with Special Health Care Needs: Children and youth with special health care needs are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally. (MCHB, 2001)

Disabilities: Children having an activity limitation, who use assistance or perceive themselves as having a disability. (Healthy People 2010)

National Performance Measures: Children with Special Health Care Needs Program

Six National Performance Measures (NPM) track progress in the development of a system of services for children with special health care needs (Table 1).

Table 1. National Performance Measures, 2005/06
NS-CSHCN¹

	WA	US
1. CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	56% (± 4)	57% (± 1)
2. CSHCN who receive coordinated, ongoing, comprehensive care within a medical home ^b	48% (± 4)	47% (± 1)
3. CSHCN whose families have adequate private and/or public insurance to pay for the services they need	65% (± 4)	62% (± 1)
4. CSHCN who are screened early and continuously for special health care needs ^a	69% (± 4)	64% (± 1)
5. CSHCN whose services are organized in ways that families can use them easily ^a	85% (± 3)	89% (± 1)
6. Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence ^a	47% (± 6)	41% (± 1)

- The Washington rates of early and continuous screening, and youth who receive adequate transition services are significantly higher than the US rates. The percent of parents in Washington reporting services are organized in a way families can use them easily is significantly lower than the US rate.

Youth with Disability

The 2008 Healthy Youth Survey contained questions about physical disability, long-term emotional problems, learning disabilities, and activity limitations.³ Disability is defined differently from special health care need. But, it is likely that youth with a disability in the Healthy Youth Survey are a similar population to the youth with special health care needs identified in other surveys.⁴

Disability Prevalence:

- In 2008, about 19 percent of Washington 8th graders, 24 percent of 10th graders and 25 percent of 12th graders reported they had a disability.^{3, c}

Health Risk Behaviors

- In 2008, about 26 percent of Washington 10th graders with a disability reported smoking in the past 30 days compared to 12 percent of those without a disability.
- About 28 percent of Washington 10th graders with a disability reported using marijuana in the past 30 days compared to 16 percent of those without a disability.
- About 25 percent of Washington 10th graders with a disability reported binge drinking within the past two weeks compared to 16 percent of those without a disability.

Harassment, Violence, and Suicide Attempts

- 10th graders with disabilities in Washington were more likely than other youth to report being bullied at school in the past 30 days (35 percent and 19 percent respectively).
- Washington students with disabilities were more likely to report physical fighting in the past year (44 percent vs. 27 percent) and carrying a weapon at school (10 percent vs. 5 percent) compared to students without disabilities.
- Students with disabilities were also more likely to attempt suicide within the past year compared to those without disabilities (19 percent vs. 6 percent, respectively)

Access to Care:

- In Washington, youth with a disability were less likely to report a dental visit in the past year compared to youth without a disability. (Data not shown)³
- According to the 2007 National Survey of Children's Health, children with special health care needs in Washington were less likely to receive care within a medical home, compared with children without special health care needs. (Data not shown).²

Table 2. Health Risk Behaviors, Grade 10 HYS 2008, Washington State ³

	Youth with disabilities	Youth without disabilities
Smoking in past month	26% ± 3%	12% ± 2%
Marijuana in past month	28% ± 3%	16% ± 2%
Binge drinking in past two weeks	25% ± 3%	16% ± 2%
Bullied at school in past month	35% ± 3%	19% ± 2%
Fighting in past year	44% ± 4%	27% ± 2%
Weapon to school in past month	10% ± 3%	5% ± 1%
Suicide attempt in past year	19% ± 3%	6% ± 1%

Data Sources

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 5/15/09 from <http://www.childhealthdata.org/learn/NS-CSHCN>
2. Child and Adolescent Health Measurement Initiative. 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. Retrieved 6/16/09 from www.nschdata.org
3. Washington State Healthy Youth Survey 2008. Washington State Office of Superintendent of Public Instruction, Department of Health, Department of Social and Health Services, and Department of Community, Trade, and Economic
4. Ngui, E. M., & Flores, G. (2006). Satisfaction with care and ease of using health care services among parents of children with special health care needs: the roles of race/ethnicity, insurance, language, and adequacy of family-centered care. *Pediatrics*, 117(4), 1184-1196.
5. Flores, G., Abreu, M., & Tomany-Korman, S. C. (2005). Limited English proficiency, primary language at home, and disparities in children's health care: how language barriers are measured matters. *Public Health Reports*, 120(4), 418-430.
6. Shenkman, E., Vogel, B., Brooks, R., Wegener, D. H., & Naff, R. (2001). Race and ethnicity and the identification of special needs children. *Health Care Financing Review*, 23(2), 35-51.
7. Stein, R. E., & Silver, E. J. (2002). Comparing different definitions of chronic conditions in a national data set. *Ambulatory Pediatrics*, 2(1), 63-70.

Endnotes

- a. State and national rates are significantly different, based on chi-square test, $p \leq 0.05$.
- b. Medical home: "An approach to providing health care services in a high-quality and cost-effective manner. Care is received from a pediatric health care profession whom the family trusts. Care is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective. (American Academy of Pediatrics)
- c. The Youth Disability Screener used in the Healthy Youth Survey 2008 administration (for grades 8, 10, 12) is a 4-item measure based on self-reported disability status developed by the Seattle Quality of Life Group at the University of Washington. Youth were classified as having a disability if they answered "Yes" to any of the following questions 1) Do you have any physical disabilities or long-term health problems lasting or expected to last 6 months or more? 2) Do you have any long-term emotional problems or learning disabilities lasting or expected to last 6 months or more? 3) Would other people consider you to have a disability or long-term health problem including physical health, emotional, or learning problems? 4) Are you limited in any activities because of a disability or long-term health problem including physical health, emotional, or learning problems expected to last 6 months or more?

Other Resources

Children with Special Health Care Needs National Performance Measure Fact Sheets, Washington State Department of Health
Children and Youth with Special Health Care Needs, Health of Washington State, Washington State Department of Health, 2007
Care Coordination for Children with Special Health Care Needs Data Monograph, Washington State Department of Health
Medical Home Data Monograph, Washington State Department of Health, 2007
Youth with Disabilities: Risk Factors for Injury Data Monographs, Washington State Department of Health, 2007

For persons with disabilities, this document is available on request in other formats. To submit a request, please call 1-800-525-0127 (TDD/TTY 1-800-833-6388).