



Children & Youth

with Special Health Care Needs

2005

Washington State Report



Children and Youth with Special Health Care Needs

WASHINGTON STATE REPORT

What is the purpose of this report?

To provide the best information from many data sources about children and youth with special health care needs (CYSHCN) in Washington State.

Who is the intended audience?

Children with Special Health Care Needs Coordinators, policymakers in state and local agencies, families of children and youth with special health care needs and others interested in this population.

What information is in this report?

- Estimated number of children and youth with special health care needs
- Social and economic characteristics
- Services used by this population
- Unmet service needs
- Risk behaviors among adolescents with disabilities

How can this report be used?

- To inform stakeholders about important needs of this population
- To contribute to community-based and statewide assessment activities
- To promote policy discussions
- To guide program planning and grant development

How are children and youth with special health care needs defined in this report?

The federal Maternal and Child Health Bureau defines children with special needs as "...children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally." Data sources used in this report (surveys, vital statistics reports, and public program information) define this population in various ways, but each of these definitions is consistent with the federal definition.

What are the data sources?

Surveys

Information on CYSHCN is from three recent surveys:

- **The 2001 National Survey of Children with Special Health Care Needs** used random parent telephone surveys to identify CYSHCN based on consequences that last or are expected to last 12 months or longer. These consequences are: (1) need for (or use of) prescription medications; (2) need for (or use of) more medical care, mental health, or educational services than other children the same age; (3) limitations in the ability to do the things other children of the same age can do; (4) need for (or receipt of) special therapy, such as physical, occupational or speech therapy, and (5) any kind of emotional, developmental, or behavioral problem that requires treatment or counseling.
- **The 2002 Washington State Healthy Youth Survey** identified youth with disabilities as having "a limitation or inability to perform important life activities in a manner considered appropriate for the age and social role of the person because of a long-lasting (defined as lasting or expected to last 6 months or more) physical, mental, or emotional condition." Students in grades 8, 10 and 12 at select schools were asked to respond to questions about their behaviors and health status.

- **The 2003 Behavioral Risk Factor Surveillance System (BRFSS)** identified children with special health care needs using the same questions as the National Survey of Children with Special Health Care Needs. This telephone survey asked adults to respond to questions about children living in their household.

Vital and Health Statistics

Children with low birth weight (less than 2500 grams, about 5.5 pounds) are at risk for long-term health and developmental problems. The incidence of low birth weight included in this report is from state birth certificates. Data about children hospitalized because of a chronic condition is from the Comprehensive Hospital Abstracts Reporting System, which contains information about every inpatient admission.

Program Participation

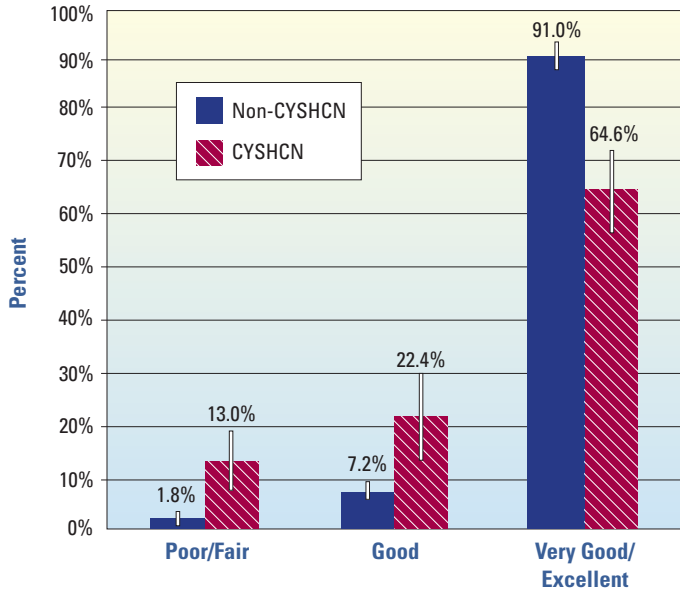
Washington state and federal agencies provide services to children and youth based on a variety of eligibility factors. Program data in this report are from the Washington State Department of Health CSHCN Program, Office of the Superintendent of Public Instruction, Department of Social and Health Services, and Social Security Administration.



Behavioral Risk Factor Surveillance System (BRFSS) and Healthy Youth Survey (HYS) Data

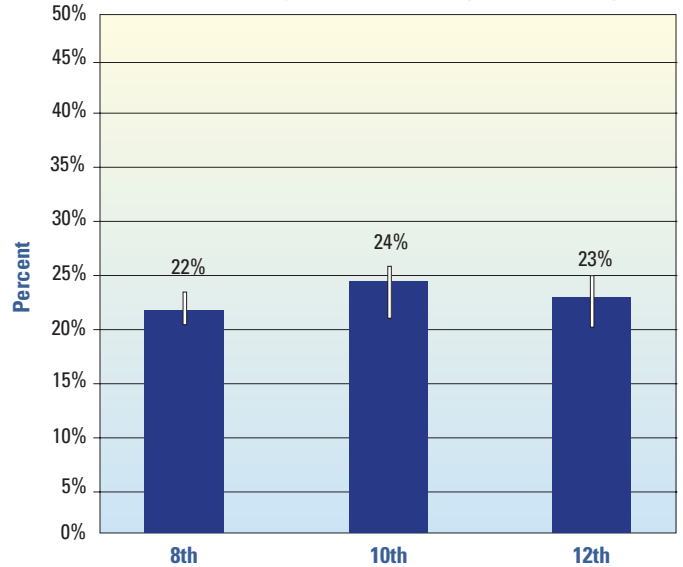
Health Status of CYSHCN vs. Non-CYSHCN

2003 Behavioral Risk Factor Surveillance System



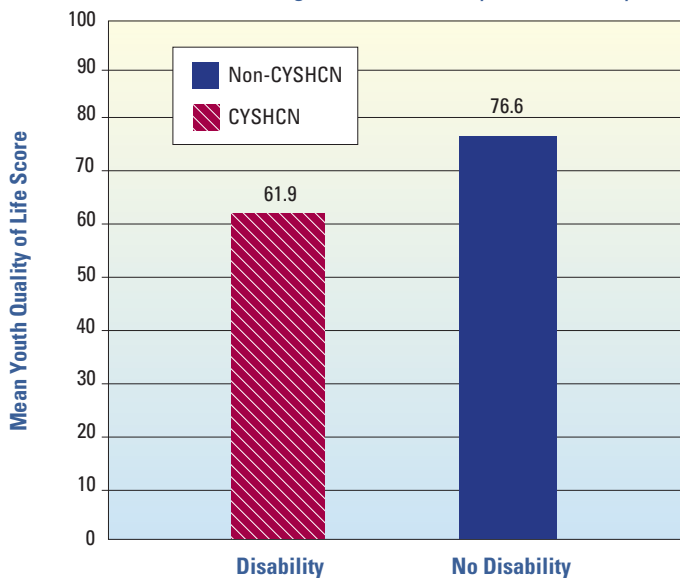
Student-Reported Disability by Grade

2002 Washington State Healthy Youth Survey



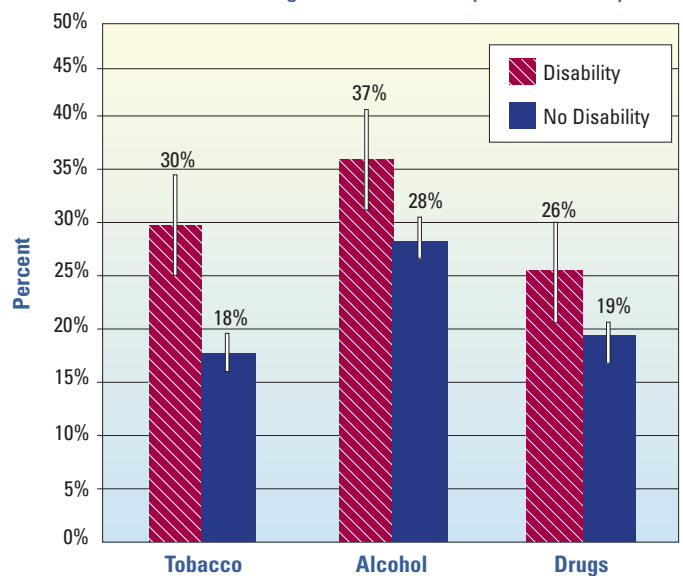
Quality of Life Scores** by Disability Status

2002 Washington State Healthy Youth Survey



Substance Use within the Last 30 Days by Disability Status- 10th Graders

2002 Washington State Healthy Youth Survey



**Quality of life scores based on responses to six questions: get along with parents/guardians; look forward to the future; feel good about myself; satisfied with my life now; feel alone in my life; rating of my life compared to others my age. Scores are based on a scale of 100, higher scores indicating higher quality of life.



Results from the National Survey of Children with Special Health Care Needs, 2001

Prevalence

Child-Level Prevalence: WA State% Nation%

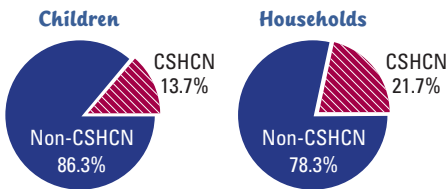
Percentage of Children & Youth with Special Health Care Needs (CYSHCN), 0 - 17 yrs old

13.7 12.8

Household-Level Prevalence: WA State% Nation%

Percentage of Households with Children that have one or more CYSHCN, 0 - 17 yrs old

21.7 20



Prevalence by Age:

Children 0-5 years of age: **8.6** 7.8

Children 6-11 years of age: **15.4** 14.6

Children 12-17 years of age: **16.7** 15.8

Prevalence by Sex:

Female: **11.7** 10.5

Male: **15.6** 15.0

Prevalence by Poverty Level:

0% - 99% Federal Poverty Level (FPL): **15.4** 13.6

100% - 199% FPL: **15.9** 13.6

200% - 399% FPL: **13.6** 12.8

400% FPL or greater: **12.8** 13.6

Prevalence by Race/Ethnicity:

Hispanic: **9.6** 8.5

White (non-Hispanic): **15.0** 14.2

Black (non-Hispanic): **13.3** 13.0

Multi-racial (non-Hispanic): **13.2** 15.1

Asian (non-Hispanic): **6.4** 4.4

Native American/Alaskan Native (non-Hispanic): **16.6**

Native Hawaiian/Pacific Islander (non-Hispanic): **9.6**

Indicators

Child Health: WA State % Nation %

1) % of CYSHCN whose health conditions consistently and often greatly affect their daily activities. **27.2** 23.2

2) % of CYSHCN with 11 or more days of school absences due to illness. **17.0** 15.8

Health Insurance Coverage:

3) % of CYSHCN without insurance at some point during the past year. **9.1** 11.6

4) % of CYSHCN currently uninsured. **5.0** 5.2

5) % of currently insured CYSHCN with coverage that is not adequate. **30.2** 33.8

Access to Care:

6) % of CYSHCN with 1 or more unmet needs for specific health care services. **20.4** 17.7

7) % of CYSHCN whose families needed but did not get all respite care, genetic counseling and/or mental health services. **31.1** 23.1

8) % of CYSHCN needing specialty care who had problems getting a referral. **20.5** 21.9

9) % of CYSHCN without a usual source of care (or who rely on the emergency room). **9.5** 9.3

10) % of CYSHCN without a personal doctor or nurse. **11.0** 11.0

Family-Centered Care:

11) % of CYSHCN without family-centered care. **29.7** 33.2

Impact on Family:

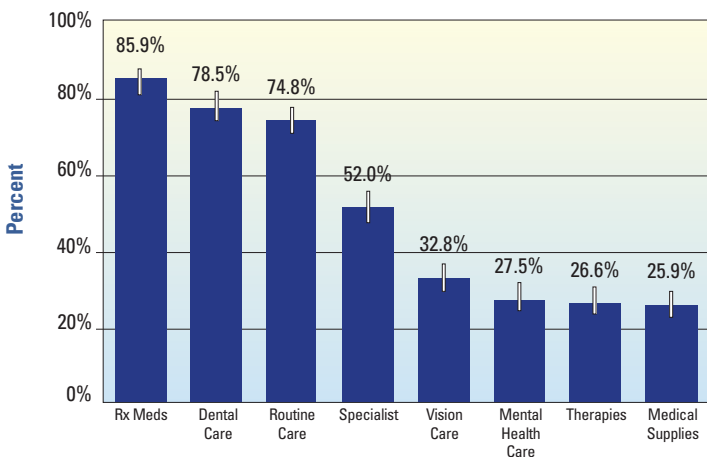
12) % of CYSHCN whose families pay \$1,000 or more in medical expenses per year. **11.7** 11.2

13) % of CYSHCN whose families experienced financial problems due to child's health needs. **20.8** 20.9

14) % of CYSHCN whose families spend 11 or more hours per week providing and/or coordinating health care for child. **12.6** 13.5

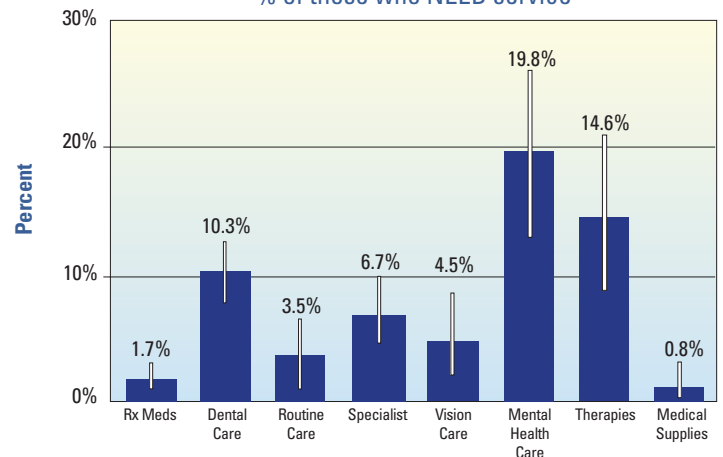
15) % of CYSHCN whose health needs caused family members to cut back or stop working. **27.6** 29.8

Services Needed by WA CYSHCN



Unmet Health Needs of WA CYSHCN

% of those who NEED service

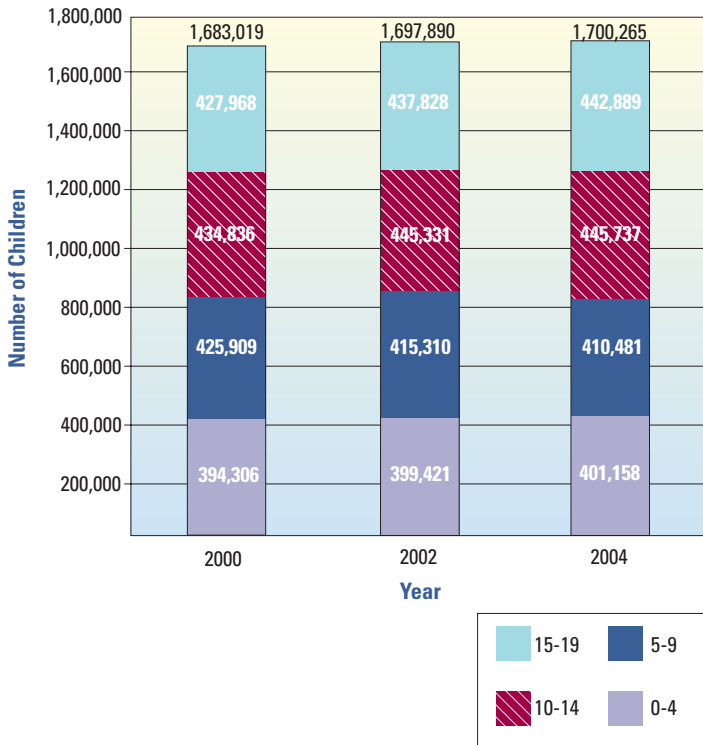




Program & Vital Statistics Data

Population of Children Ages 0-19 Years by Age Group in Washington 2000-2004

Office of Financial Management



Children Served by Public Programs

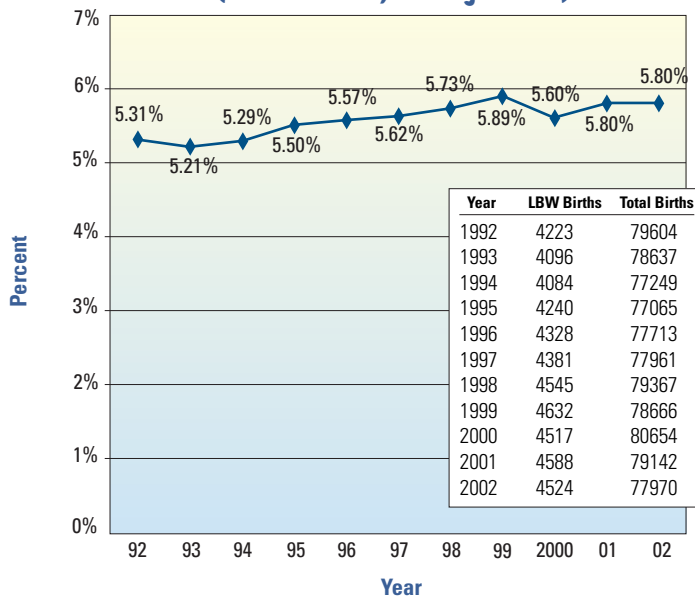
Estimated Number of CSHCN in Washington in 2001: **211,000***

Agencies and Programs	Number of Children Served
Department of Health	
CSHCN Program (January 1 – December 31, 2004)	10,185
Office of Superintendent of Public Instruction	
Special Education - IDEA Part B (as of December 1, 2004)	124,091
Social Security Administration	
Supplemental Security Income program (SSI) December 2003	13,105
Department of Social and Health Services Programs (DSHS) (July 2002- June 2003)	
Medical Assistance	664,983
Economic Assistance	339,629
Children's Administration	92,750
Mental Health	37,175
Developmental Disabilities Infant Toddler Early Intervention Program (October 2003-September 2004)	6,806** 16,225
Alcohol & Substance Abuse	9,366
Total DSHS Program Participation (Unduplicated Count)	713,814

*From National Survey of Children with Special Health Care Needs, 2001

** This number reflects subset of Developmental Disabilities total.

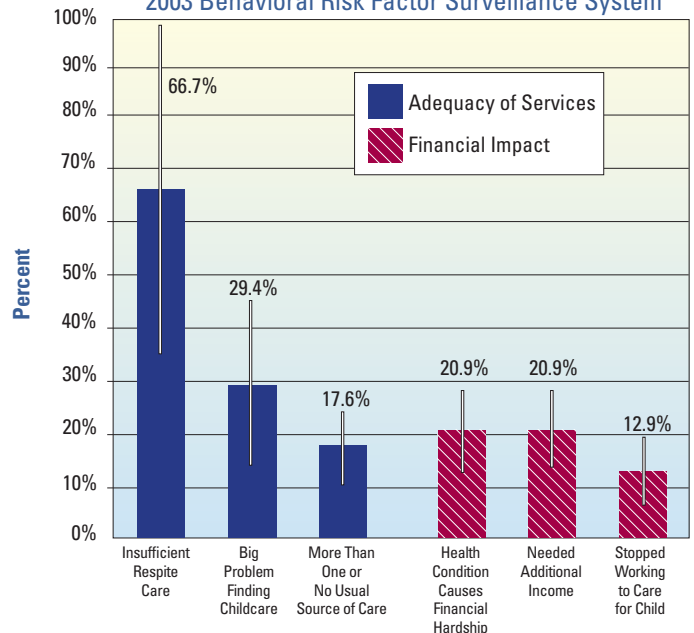
Percent of Births with Low Birth Weight (LBW) (less than 2,500 grams*)



*Rate per 100 births among births for which the birth weight is known.

Adequacy of Services for CYSHCN and Financial Impact on Families of CYSHCN

2003 Behavioral Risk Factor Surveillance System





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Sources

- Maternal and Child Health Bureau, National Survey of Children with Special Health Care Needs
- Washington State Healthy Youth Survey
- Washington State Department of Health, Behavioral Risk Factor Surveillance System
- VistaPHweb 5.0
- Washington State Department of Health, Child Health Intake Forms, Children with Special Health Care Needs Program
- Washington Department of Social & Health Services Client Database
- Office of the Superintendent of Public Instruction IDEA Part B Program Data
- Social Security Administration SSI Recipients by State and County
- Washington Department of Social & Health Services Infant-Toddler Early Intervention Program Data
- Office of Financial Management, State of Washington

Endnotes

- **Small Numbers.** To ensure confidentiality and provide relatively stable estimates of rates, this report in some cases combines more than one year of data, e.g., age-specific hospitalizations and CHIF data, and is noted on the particular charts to which this applied. Zeros are also used to represent fewer than five or no cases in a particular category or subgroup.
- **Confidence Intervals.** Confidence intervals provide a range estimate for hospitalization rates within a county, and tend to be wider when there are smaller numbers of cases, and narrower when there are larger numbers of cases. If the confidence interval is outside of either the lower or upper bound of the statewide average, which itself has a very narrow confidence interval, then the county-specific hospitalization rate should be considered statistically significantly higher or lower than the statewide average.
- **Hospitalization Data.** The rates of hospitalizations reported are based on children's zip code of residence as reported in their hospital record contained in the Comprehensive Hospital Abstract Reporting System (CHARS). CHARS excludes children hospitalized in military facilities, children who reside in institutions and Washington State children hospitalized in other states. Classification of chronic condition status is based on the principal diagnosis matching one of the list of pediatric chronic conditions defined in the National Committee for Health Care Quality HEDIS 2002 Quality – Protocols for Administering CAHPS 2.0H Survey. Analyses were performed using VistaPHw5.0.

Acknowledgements

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For additional information

Contact the Washington State Department of Health CSHCN Program at 360-236-3571 or email cshcn.support@doh.wa.gov