

# National Survey of Children with Special Health Care Needs (NS-CSHCN)



## Program description

The Children and Youth with Special Health Care Needs (CYSHCN) program is housed in the Maternal and Child Health Section of the Bureau of Community Health Promotion. The CYSHCN program also includes staff at five regional CYSHCN centers and CYSHCN statewide agencies and collaborating partners (see the Resources list at the end of this report). For more information on CYSHCN contact Amy Whitehead, MHA, at 608-267-3861 or by email at [Amy.Whitehead@dhs.wisconsin.gov](mailto:Amy.Whitehead@dhs.wisconsin.gov). For more information on the SLAITS CSHCN Survey or other data, contact Elizabeth Oftedahl, MPH, at 608-261-9304 or by

email at [Elizabeth.Oftedahl@dhs.wisconsin.gov](mailto:Elizabeth.Oftedahl@dhs.wisconsin.gov).

## Demographics of population served

Children with special health care needs (CSHCN) are defined by the Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) 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." The survey shows that 13.9% of U.S. children and 15.3% of Wisconsin children have special health care needs. For Wisconsin, that translates into an estimated 198,000 children under age 18.

## Data description

The National Survey of Children with Special Health Care Needs (NS-CSHCN) conducted in 2005-2006 represents the second round of the survey originally conducted in 2001. However, in an effort to improve the survey, many of the questions were revised or reordered and some of the indicators redefined precluding direct comparisons to the 2001 survey. The survey provides national and state-level data on the size and characteristics of the CSHCN population including detailed information on the prevalence of CSHCN, the demographic characteristics of these children, the types of health and support services they and their families need, and their access to and satisfaction with the care they receive.

## Prevalence of CSHCN

Percent of children in the population who have special health care needs

	<u>State %</u>	<u>National %</u>
<b>Total</b>	<b>15.3</b>	<b>13.9</b>
<b>By Age</b>		
• 0-5 years	9.5	8.8
• 6-11 years	17.5	16.0
• 12-17 years	18.3	16.8
<b>By Sex</b>		
• Male	17.6	16.1
• Female	12.9	11.6
<b>By Poverty Level</b>		
• 0-99% FPL	17.7	13.9
• 100-199% FPL	14.8	14.0
• 200-399% FPL	14.7	13.6
• 400% FPL or more	15.0	14.0

**By Hispanic Origin and Race**

	<u>State %</u>	<u>National %</u>
• Non-Hispanic	15.6	15.0
White	15.1	15.5
Black	19.0	15.0
Asian	*	6.3
American Indian/Alaska Native	*	14.5
Native Hawaiian/Pacific Islander	*	11.5
Multiple Races	18.1	17.9
• Hispanic	10.0	8.3
Hispanic, Spanish language household	**	4.6
Hispanic, English language household	16.9	13.1

**Indicators:**

**Child Health**

	<u>State %</u>	<u>National %</u>
• CSHCN whose conditions affect their activities usually, always or a great deal	23.2	24.0
• CSHCN with 11 or more days of school absences due to illness	11.4	14.3

**Health Insurance Coverage**

• CSHCN without insurance at some point in the past year	6.4	8.8
• CSHCN without insurance at time of survey	1.6	3.5
• Currently insured CSHCN whose insurance is inadequate	34.4	33.1

**Access to Care**

• CSHCN with any unmet need for specific health care services	15.5	16.1
• CSHCN with any unmet need for family support services	5.9	4.9
• CSHCN needing a referral who have difficulty getting it	15.1	21.1
• CSHCN without a usual source of care when sick (or who rely on the ER)	5.1	5.7
• CSHCN without any personal doctor or nurse	5.2	6.5

**Family-Centered Care**

• CSHCN without family-centered care	28.8	34.5
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**Impact on Family**

• CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year for the child	20.2	20.0
• CSHCN whose conditions cause financial problems for the family	17.2	18.1
• CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care	9.6	9.7
• CSHCN whose conditions cause family members to cut back or stop working	21.7	23.8

**Core Outcomes**

	<u>% of CSHCN achieving outcome in the state</u>	<u>% of CSHCN achieving outcome in the nation</u>
• Families of CSHCN partner in decision making at all levels and are satisfied with the services they receive	65.3	57.4
• CSHCN receive coordinated ongoing comprehensive care within a medical home	54.6	47.1
• Families of CSHCN have adequate private and/or public insurance to pay for the services they need	63.0	62.0
• Children are screened early and continuously for special health care needs	62.0	63.8
• Community-based services for CSHCN are organized so families can use them easily	90.0	89.1
• Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence	44.5	41.2

\* Due to the small size of the group in the state population, data have been suppressed to protect respondents' confidentiality.  
 \*\*Estimate suppressed as it does not meet the standard for reliability or precision.

## For more information:

### SLAITS National Survey of Children with Special Health Care Needs:

- First survey conducted in 2001-2002; data released early in 2004  
<http://www.cdc.gov/nchs/about/major/slaits/cshcn.htm>
- Second survey conducted in 2005-2006; data released early 2008  
[http://www.cdc.gov/nchs/about/major/slaits/cshcn\\_05\\_05.htm](http://www.cdc.gov/nchs/about/major/slaits/cshcn_05_05.htm)

## Additional Resources:

### Bureau of Community Health Promotion (BCHP) Websites

#### Maternal and Child Health (MCH) Program

[http://dhs.wisconsin.gov/DPH\\_BFCH/MCH/index.htm](http://dhs.wisconsin.gov/DPH_BFCH/MCH/index.htm)

#### Children and Youth with Special Health Care Needs (CYSHCN) Program

[http://dhs.wisconsin.gov/DPH\\_BFCH/cshcn/index.HTM](http://dhs.wisconsin.gov/DPH_BFCH/cshcn/index.HTM)

### Regional CYSHCN Centers

#### Northern Regional CYSHCN Center

Marathon County Health Department, 1200 Lake View Dr., Rm. 200, Wausau, WI 54403-6797  
Phone: 715/ 261-1900 Fax: 715/ 261-1901 Toll-Free: 1 866/ 640-4106  
Website: [www.co.marathon.wi.us/cyshcn.asp](http://www.co.marathon.wi.us/cyshcn.asp)

#### Northeastern Regional CYSHCN Center

Children's Hospital of Wisconsin-Fox Valley, 325 N. Commercial St., Ste. 400, Neenah, WI 54956  
Phone: 920/ 969-5325 Fax: 920/ 969-7975 Toll-Free: 1 877/ 568-5205  
Website: [www.northeastregionalcenter.org](http://www.northeastregionalcenter.org)

#### Southern Regional CYSHCN Center

Waisman Center, 1500 Highland Ave., Rm. 102, Madison, WI 53705-2280  
Phone: 608/ 265-8610 Fax: 608/ 265-3441 Toll-Free: 1 800/ 532-3321  
Website: [www.waisman.wisc.edu/ciu/cshcn/index.html](http://www.waisman.wisc.edu/ciu/cshcn/index.html)

#### Southeastern Regional CYSHCN Center

Children's Hospital of Wisconsin, PO Box 1997 - MS 939, Milwaukee, WI 53201-1997  
Phone: 414/ 266-6333 Fax: 414/ 266-2225 Toll-Free: 1 800/ 234-5437 (1 800/ 234-KIDS)  
Website: [www.southeastregionalcenter.org](http://www.southeastregionalcenter.org)

#### Western Regional CYSHCN Center

Chippewa County Department of Public Health, 711 N. Bridge St., Rm 222, Chippewa Falls, WI 54729  
Phone: 715/ 726-7900 Fax: 715/ 726-7910 Toll-Free: 1 800/ 400-3678 (1 800/ 400-FORU)  
Website: [www.co.chippewa.wi.us/ccdph/cyshcn/](http://www.co.chippewa.wi.us/ccdph/cyshcn/)

### CYSHCN Statewides and Collaborating Partners

#### ABC for Health, Inc.

32 N. Bassett St., Madison, WI 53703-2606  
Phone: 608/ 261-6939 Fax: 608/ 261-6938 Toll-Free: 1 800/ 585-4222  
Website: [www.abcforhealth.org](http://www.abcforhealth.org) / [www.healthwatchwisconsin.org](http://www.healthwatchwisconsin.org)

#### ABC for Rural Health

100 Polk County Plaza, Ste. 18, Balsam Lake, WI 54810  
Phone: 715/ 485-8525 Fax: 715/ 485-8501

#### CYSHCN Oral Health Project

Children's Health Alliance of Wisconsin, 620 S. 76<sup>th</sup> St., Ste. 120, Milwaukee, WI 53214  
Phone: 414/ 292-4015 Fax: 414/ 231-4972  
Website: [www.chawisconsin.org](http://www.chawisconsin.org)

**Family Voices of Wisconsin**

P.O. Box 55029, Madison, WI 53705  
Phone: 608/ 239-1364 / 608/ 233-3726  
Website: [www.wfv.org](http://www.wfv.org)

**Great Lakes Inter-Tribal Council**

P.O. Box 9, Lac du Flambeau, WI 54538  
Phone: 715/ 588-3324 Fax: 715/ 588-7900  
Website: [www.glitc.org](http://www.glitc.org)

**Parent to Parent of Wisconsin**

Family Resource Connection, 1020 Kabel Ave., Rhinelander, WI 54501  
Phone: 715/ 361-2890 Fax: 715/ 361-2892  
General email: [Get-Connected@p2pwi.org](mailto:Get-Connected@p2pwi.org)  
Website: [www.p2pwi.org](http://www.p2pwi.org)

**Wisconsin First Step**

c/o Gundersen Lutheran Medical Center, 1900 South Ave., LaCrosse, WI 54601-9980  
Phone: 608/ 775-5586 Fax: 608/ 775-4766 Toll-Free: 1 800/ 642-7837 (1-800/ 642-STEP)  
Website: [www.mch-hotlines.org](http://www.mch-hotlines.org)