



Special Healthcare Needs Fact Sheets

CHILDREN WITH SPECIAL HEALTHCARE NEEDS in Rhode Island

May 2008

INTRODUCTION

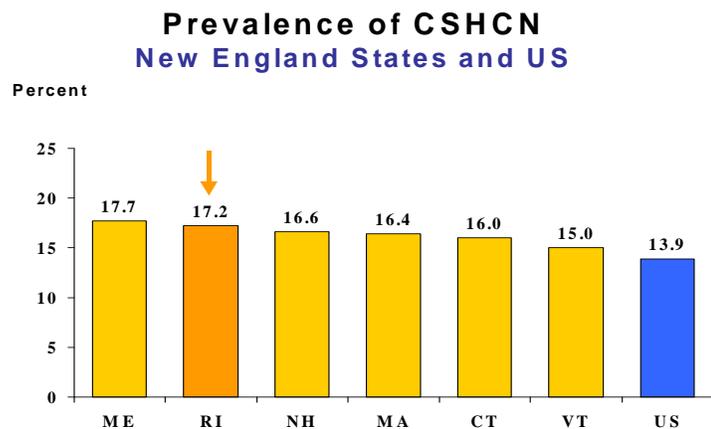
This report provides information about major health indicators for Children with Special Healthcare Needs (CSHCN) living in Rhode Island. It presents the findings from the 2005-06 and national data. Topics included in this report are the prevalence of CSHCN, Health Insurance Coverage, Access to Care, Care Coordination, Family-Centered Care, and Impact on Family.

The National Survey of Children with Special Healthcare Needs (CSHCN), first conducted in 2001, was designed to produce prevalence estimates of CSHCN using a standard battery of screening questions, to describe the types of services CSHCN need and use, and to assess areas of improvement in the system of care for CSHCN. The second National Survey of CSHCN was conducted in 2005 and 2006, which added the benefit of comparisons over time. In RI, a total of 3,704 household screening interviews were completed from April 2005 to February 2007, which resulted in 851 completed special needs interviews. Survey methods and screening for CSHCN are presented on the last page.

Definition of Special Healthcare Needs: The Maternal and Child Health Bureau (MCHB) define children with special healthcare needs as "... those who have or are at increased risk for 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."

PREVALENCE

- The rate of CSHCN in Rhode Island increased from 14.1% (an estimated 35,265 children) in 2001 to 17.2% (an estimated 41,783 children) in 2006.
- In 2006, Rhode Island had the 2nd highest rate of children with special healthcare needs among the 6 New England states, and the 6th highest rate among the 50 states and DC.
- All NE states, including RI, have higher prevalence rates of children with special healthcare needs than the national rate of 13.9%. The national rate also increased from 12.8% in 2001 to 13.9% in 2006.



WHO ARE RHODE ISLAND'S CSHCN POPULATION?

- Teenagers (ages 12-17) had the highest rate of special healthcare needs (20.7%) followed by children aged 6-11 (20.0%). The youngest age group (birth-5) had the lowest rate of special healthcare needs (10.1%) in RI.
- Special healthcare needs were more prevalent among boys (20.8%) than among girls (16.1%).
- Special healthcare needs were less prevalent among Hispanic children (12.4%) than non-Hispanic children (17.7%). Among Hispanics, children living in Spanish-language households were much less likely to have special healthcare needs (8.5%) than children living in English-language households (21.0%). White non-Hispanic children had a higher rate of special healthcare needs (18.3%) than black non-Hispanic children (14.6%).
- Children with family incomes 100-199% federal poverty level (FPL) had the highest rate of special healthcare needs (21.3%). The rate of special healthcare needs was the lowest among children with the highest family income group (14.5%).

Prevalence by Demographics	RI	US
Percent of Children with Special Healthcare Needs (CSHCN).	17.2	13.9
Prevalence of children 0-5 years of age.	10.1	8.8
Prevalence of children 6-11 years of age.	20.0	16.0
Prevalence of children 12-17 years of age.	20.7	16.8
Percent of CSHCN that are male.	20.8	16.1
Percent of CSHCN that are female.	13.5	11.6
Percent of families raising CSHCN at 0%-99% Federal Poverty Level	19.5	14.0
Percent of families raising CSHCN at 100%-199% Federal Poverty Level	21.3	14.0
Percent of families raising CSHCN at 200%-399% Federal Poverty Level	16.0	13.5
Percent of families raising CSHCN at 400% Federal Poverty Level or greater	14.5	14.0
Percent of CSHCN who are Non-Hispanic	17.7	15.0
Percent of CSHCN who are Hispanic	12.4	8.3
Percent of CSHCN who are White	18.3	15.5
Percent of CSHCN who are Black	14.6	15.0
Percent of CSHCN who are of Multiple Races	23.2	17.9
Percent of Hispanic CSHCN of a Spanish Speaking Household	8.5	4.6
Percent of Hispanic CSHCN of an English Speaking Household	21.0	13.1

HEALTH INSURANCE COVERAGE

- Health insurance is essential to access care for children with special healthcare needs.
- Without health insurance, children are more likely to forgo necessary preventative healthcare. Acute care, when children are sick, can leave families with overwhelming medical bills.

ACCESS TO CARE

- Children with special healthcare needs require a broad range of services, from primary and specialty medical care to prescription medications, medical equipment and therapies.
- In addition to the needs of the child, families of CSHCN may need additional services, such as respite care, family counseling, or genetic counseling.
- There has been a significant improvement in usual source of care from 10.3% (2001) to 4.7% (2006).

FAMILY-CENTERED CARE

- Family-centered care is an approach to the planning, delivery, and evaluation of healthcare whose cornerstone is active participation between families and professionals. Family-centered care was measured using core elements of time spent, listening, information, sensitivity, and partnering.
- Overall, 30.1% of CSHCN in RI received care that lacks at least one of these five components, compared to 34.4% of CSHCN in the nation.

CSHCN...	RI	US
... without insurance at some point in past year	6.2	8.8
... without insurance at time of survey.	1.4	3.5
... whose insurance is inadequate.	26.8	33.1
... whose insurance benefits sometimes / never meet child's needs	7.0	12.7
... whose non-covered charges are sometimes / never reasonable	23.2	28.1
... whose insurance sometimes / never allows child to see needed providers.	4.9	9.3
CSHCN...	RI	US
... with any unmet need for specific healthcare services.	12.6	16.1
... with any unmet need for family support services.	4.3	4.9
... without a usual source of care when sick (or rely on the emergency room).	4.7	5.7
... without a personal doctor or nurse.	2.3	6.5

CSHCN...	RI	US
... without family-centered care.	30.1	34.4
... whose doctors never / sometimes spend enough time with child.	16.6	21.3
... whose doctors never / sometimes listen carefully.	8.4	11.2
... whose doctors never / sometimes provide enough information.	15.4	16.9
... whose doctors are never / sometimes sensitive to family's values.	9.0	11.1

CARE COORDINATION

- Care Coordination for children with special healthcare needs is a process that links children with special healthcare needs and their families to services and resources in a coordinated effort to maximize the potential of children.

IMPACT ON FAMILY

- Having a child with special healthcare needs can affect a family's finances and employment status. The demands on families may require that parents cut down their work hours or give up a job, at the same time as facing burdensome out-of-pocket healthcare costs.
- There was a marked increase in families paying \$1,000 or more in personal medical expenses from 5.2% in 2001 to 12.6% in 2006.

Survey Methods in Screening for Special Healthcare Needs: The survey screening questions include five stem questions about general healthcare needs that could be the consequence of chronic health conditions. If a child currently experiences one of these consequences, follow-up questions determine whether this healthcare need is the result of a mental, behavioral, or other health condition, and whether the condition has lasted or is expected to last for 12 months or longer. Those with affirmative answers to the stem and both follow-up questions are considered to have a special healthcare need.

For more information about the 2005-2006 National Survey of Children with Special Healthcare Needs, go to: http://www.cdc.gov/nchs/about/major/slait/ncshcn_05_06.htm

CSHCN...	RI	US
... needing a referral who have difficulty getting it.	10.2	21.1
... whose families had no help with coordinating child's healthcare.	62.5	66.8
... whose families reported dissatisfaction with communication among child's doctors and other health providers.	4.8	7.4
... whose families experienced difficulties in using health services.	12.4	10.9
... whose families reported dissatisfaction with health services their child receives.	6.8	8.7
CSHCN...	RI	US
... whose families pay \$1,000 or more out of pocket medical expenses per year for the child.	12.6	20.0
... whose condition caused financial problems for the family.	14.0	18.1
... whose families spend 11 or more hours per week providing or coordinating child's healthcare.	9.6	9.7
... whose condition cause family members to cut back or stop working.	26.8	29.9

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