Children and Youth with Special Health Care Needs

Definition: Children and youth with special health care needs are those who have chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children and youth generally.

Summary

An estimated 14%–17% of children in Washington State ages 17 and younger have a special health care need (about 214,000–260,000 children). Special health care needs are more common among older children.

Children and youth with special health care needs can benefit from early diagnosis and access to a variety of medical, community, social, and school services. While children and youth with special health care needs use more health services than those without special needs, they are also more likely to report unmet health care needs. Receiving services in a health care setting that coordinates care and facilitates partnerships (a "medical home") might help ensure the best health outcomes for all children.

Background Note

Children and youth with special health care needs have many types of ongoing health, neurobehavioral, and developmental problems. These problems can include cancer, asthma, autism, mental retardation, or attention deficit hyperactivity disorder (ADHD). Despite the variation in their diagnoses, many of these children have similar health and educational service needs. As a result, it is useful to consider them as a group rather than by specific medical conditions.[1]

Rates

Historically, experts estimated the prevalence of children with special health care needs by focusing on specific conditions. A 1997 study conducted by the Washington State Health Care Policy Board estimated that 18% of children and youth had special health care needs. This estimate, obtained from analysis of clinical diagnoses, includes only children and youth who had health insurance and a medical encounter in 1993. This study categorized children by severity of their conditions. About 11% of children had relatively mild conditions such as asthma or ADHD, which require limited services. About 6% had moderate conditions such as cleft lip and palate or diabetes. Only 1% of children had severe conditions such as leukemia or chronic ventilator dependency, which require frequent and intensive services.[2]

More recently, experts have focused on a functional definition. This definition requires that the child or a parent characterize a condition as lasting 12 months or longer, limiting ability to engage in daily activities, and requiring specific medical, social, or educational services and/or prescriptions. The estimated range of children and youth with special health care needs in Washington State is from 14% (±1%) to 17% (±2%). The 14% estimate is based on data from the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN), and the 17% estimate is from the 2003 National Survey of Children's Health (NSCH). The 2003 Washington estimate is similar to the national rate of 18% (±0.4%).

Year 2010 Goals

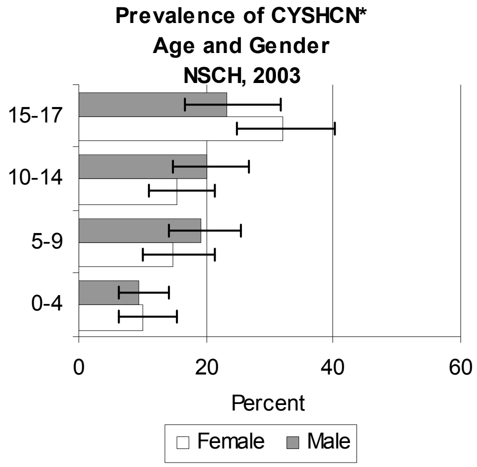
Healthy People 2010 goals are that all children with special health care needs will receive care in a family-centered, comprehensive, and coordinated system and within a medical home. In 2003, 45% (±7%) of children with special health care needs had a medical home, so it is unlikely this goal will be met.

Age and Gender

In Washington in 2003, the older children were, the greater the proportion with special health care needs. This finding suggests some health conditions may not be identified until children reach certain developmental stages.

Overall, about 18% (±3%) of boys and 17% (±3%) of girls had special health care needs in

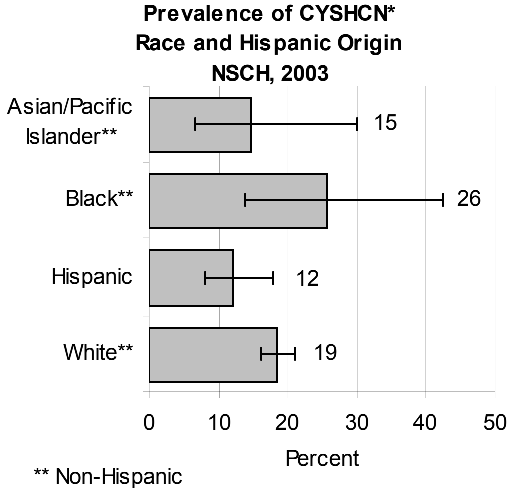
Washington in 2003.[3] These patterns are similar to those of the United States.



* Children and youth with special health care needs

Race and Hispanic Origin

Children of Hispanic origin are less likely to have an identified special health care need than white children. There are no statistically significant differences among the other racial or ethnic groups for which data are available. Data are not available for the American Indian and Alaska Native population.[3]



* Children and youth with special health care needs

Children of Hispanic origin whose primary language at home was Spanish were less likely to have a parent report a special health care need than children of Hispanic origin whose primary language was English. When the comparison was limited to English speakers, the difference between children of Hispanic origin and whites was no longer significant.[3] National 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 the survey questions.[6]

Income and Education

In Washington in 2003, there were no significant differences in the prevalence of children and youth with special health care needs by income or educational level of parent.[3] Nationally, however, children among lower-income groups more often reported activity limitations than those with higher incomes.[7]

Other Measures of Impact and Burden

Use of health care. By definition, children and youth with special health care needs use more health services than other children and youth. These services include emergency services, prescription medication, and urgent care. In 2003, 25% (±6%) of children with special health care needs in Washington used emergency departments within the past year compared with 15% (±2%) of other children. These children also used prescription medicine more often than other children (74% ±6% and 7% ±2% respectively) and were more likely to see a health care provider for an illness (74% ±6% and 55% ±3% respectively). Children and youth with special health care needs are more likely to need specialist services or equipment compared with other children (59% ±1% and 18% ±2%, respectively). In addition, among those who had a personal doctor or nurse and needed specialty care or equipment, children with special health care needs were less likely to have easy access compared with other children and youth (77% ±8% and 91% ±4%, respectively).[3]

Having health insurance decreases the likelihood of having unmet health care need among children with special health care needs.[8] According to the NSCH, about 97% (±3%) of these children in Washington had some form of health insurance coverage in 2003.

Many of these children have continuous coverage that is inadequate to meet all of their health care needs. In a 2001 national study, fewer than 60% of U.S. children with special health care needs had parents who said their health insurance always met their children's needs.[9] In a different study, underinsured children with special needs were more likely to be from low-income families, have unmet medical needs, and to have difficulty obtaining referrals to specialists compared with children with more complete coverage. The families of these children also experienced more financial problems, and parents were more likely to reduce or stop work due to the child's health condition.[10]

Nationally from 1994–1995, non-white children with special health care needs were more likely to have unmet prescription, eyeglass, or mental health care needs than white children. This association was apparently due to differences in health insurance status and family income, because it became non-significant after adjusting for these factors.[11]

Cost of health care. Washington children with chronic conditions have medical costs about six times those of children without chronic conditions. Costs increase with the severity of conditions.[2] In 1997, the 18% of children with special health care needs accounted for 60% of the medical costs for all children.[2]

Effects on families. Families provide most of the care for their children with special health care needs. Depression, psychological distress, and declines in physical health are more common among parents and siblings of these children. Such conditions result from increased financial strain, uncertainty about the future, social isolation, and fatigue related to meeting their child's health care needs.[12] Effects on the family can vary. Low-income families and families whose children have severe functional limitations are more likely to experience distress.[13] In a study conducted in Minnesota and Washington from 1991–1997, two-adult families including children with chronic conditions functioned in areas such as communication and accomplishing tasks as well as families with healthy children.[14] In a 2003 survey in Washington, about 35% (±3%) of children who did not have special needs had parents who said they were giving up more of their lives than they had expected to meet their children's needs. Fifty-one percent (±7%) of children with special needs had parents who reported similarly.[3]

In 2001, 21% (±4%) of children with special health care needs in Washington had families that experienced financial problems because of their conditions. Nationally, about 22% of families of children with special health care needs spent more than $2,000 a year on their children's medical needs in 2000 and 2001.[15]

Out-of-pocket medical costs are higher for children with special health care needs than for other children,[15] and families with lower incomes feel an especially heavy financial burden from these costs. After accounting for health insurance status, families with children with special health care needs who had incomes of less than 200% of the federal poverty level were ten times more likely to report that out-of-pocket costs exceeded 5% of family income than families who had higher incomes.[16]

Secondary health conditions and other outcomes. Children and youth with special health care needs can experience secondary health conditions including decubitus ulcers, obesity, chronic loss of joint motion, difficulty breathing, and depression. These children might also be more likely to be abused and neglected than other children.[17,18] The National Center on Child Abuse and Neglect found that children with disabilities were about twice as likely to be maltreated as other children; some children were disabled as a result of abuse whereas for others a pre-existing disability might have contributed to maltreatment.[18] Possible factors underlying an increased risk of abuse include the characteristics of their disabilities, psychological and social effects of care-giving on families, and the children's dependence on others for both social interaction and basic needs. Other factors associated with child maltreatment, such as domestic violence and poverty, might also play a role in these associations.

Adolescent transition. More adolescents with chronic conditions are surviving into adulthood. Few adult providers are willing and able to accept youth with special needs into their practices.[19] In 2001, only 6% of U.S. youth with special health care needs ages 13–17 years received the services they needed to transition to adult health care services.[20]

Transition planning is more common in schools than in health care systems. Among U.S. youth who receive special education, approximately 75% of 14 year-olds and 96% of 17–18 year-olds began educational and vocational transition planning. Two years after secondary school, about 80% of youth who received special education were employed or receiving postsecondary education or job training.[21,22] Although many youth with special health care needs will be able to live and work independently as adults, others will be unemployed, socially isolated, or unable to live independently.[23]

Child care and school system effects. The federal 1990 Americans with Disabilities Act (ADA) guarantees that children with special health care needs cannot be excluded from "public accommodations" because of their special need. Because of the ADA, children with special needs are entitled to participate with other children in child care and after-school programs. But families of children with special health care needs can face several constraints when seeking services. These include facilities' reluctance to enroll children with special needs, insufficient or inadequately trained staff, difficulty adapting physical facilities, and high costs.

Children with special needs enrolled in school along with their families, and schools face additional challenges in meeting health, educational, and social needs. Children ages 3 to 21 who are in special education programs are eligible for health and educational services including nursing care, physical therapy, speech therapy, and occupational therapy. In 2001, about 32% of Washington's children with special health care needs were reported by their parents to be enrolled in special education programs. In 2003, children with special health care needs in Washington had about twice as many school absences as other children.[3]

Health-risk behaviors. The 2004 Healthy Youth Survey (HYS) contained questions about physical disability, long-term emotional problems, learning disabilities, and activity limitations. Disability is defined differently from special health care need. But it is likely that youth with a disability in the HYS are a similar population to the youth with special health care needs identified in other surveys.[24]

Both national research and Washington HYS data from 2004 show that youth with disabilities were more likely to engage in risk-taking behaviors and to experience mental health problems than other youth.[17, 25, 26, 27, 28, 29] On the HYS, youth who reported having a disability were more likely to report cigarette smoking, marijuana use, binge drinking, and suicide attempts compared to other youth. Behavioral problems such as substance use and violence might be more strongly associated with emotional problems than with disabilities caused by a disease such as cancer.

Health-risk Behaviors, HYS 2004

	Youth with disabilities	**Youth without disabilities**
Smoking in past month	21% ± 3%	10% ± 2%
Marijuana in past month	23% ± 4%	15% ± 2%
Binge drinking in past two weeks	25% ± 3%	18% ± 2%
Fighting in past year	38% ± 4%	25% ± 2%
Weapon to school in past month	9% ± 4%	4% ± 1%
Suicide attempt in past year	20% ± 2%	6% ± 1%

Harassment and violence. [18] In 2004, 10th-grade youth with disabilities in Washington were more likely than other youth to report being bullied at school in the past 30 days (34% ±4% and 19% ±3% respectively). Fourteen percent (±3%) of 10th-graders with self-reported disabilities reported that they were harassed in the past year about having a disability. Youth with disabilities also reported more harassment about their gender, race, and sexual orientation compared to other youth.

Youth with special health care needs were less likely than other youth to report having people to turn to for help when they felt sad or hopeless (6% ±1% and 13% ±2% respectively). In a national study, youth with disabilities who were close to their parents reported less emotional distress, fewer suicide attempts, and less violence than those who were not close to their parents.[28]

Intervention Strategies

Key public health interventions for children and youth with special health care needs follow U.S. Maternal and Child Health Bureau goals.[30] These interventions attempt to link families and children to community-based services that help them meet their needs, improve family and provider partnerships, obtain more comprehensive care within a medical home, have adequate health insurance, and help adolescents make the transition to adult care.

Medical home. A medical home is a health care setting that facilitates partnerships between health care providers, children with special needs, and their families and ideally provides care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.[31] In 2003, 45% (±7%) of Washington's children with special needs had a medical home. This rate is similar to children and youth without special needs (49% ±3%).

Among children with special health care needs, children with a medical home have less delayed care, less problems getting care, fewer unmet health care needs, and fewer unmet needs for family support services.[32] Parents of children with a medical home also reported improved care delivery, a decrease in the number of missed work days, and a decrease in hospitalizations.[33] Children who receive care in a medical home are half as likely to visit an emergency room or be hospitalized.[32]

Public policy. Having health insurance decreases the likelihood of having unmet medical, dental, prescription, eyeglass, or mental health care need among children with special health care needs.[34] Thus, public policy initiatives that increase health insurance coverage for children with special health care needs should improve their access to health care.

In March 2007, Washington Governor Christine Gregoire signed into law Senate Bill 5093, which outlines improvements including expanded access to health care coverage for children with linkages to a medical home. A proactive outreach campaign to enroll uninsured children will be implemented. At present, public health nurses and other community partners, such as WithinReach, work with families to help enroll children in Medicaid and other public insurance programs.

Other strategies. Other interventions for children with special health care needs are aimed at increasing screening,[35] assisting youth with special health care needs in the transition to adult health care services, [20] increasing family satisfaction with partnerships with health care providers,[36] and organizing community-based services so that families with children with special health care needs can use them more easily.[4] But researchers have not systematically evaluated these approaches.

See Related Chapters: People With Disabilities, Access to Primary Health Care Services, and Medical Homes for Children and Adults.

Data Sources

Washington Healthy Youth Survey (HYS): Office of Superintendent of Public Instruction, Washington State departments of Health, Social and Health Services, and Community, Trade, and Economic Development, and the Family Policy Council, 2004.

National Survey of Children's Health (NSCH) Health Resources and Services Administration, U.S. Maternal and Child Health Bureau. 2003.

National Survey of Children with Special Health Care Needs (NS-CSHCN) Health Resources and Services Administration, U.S. Maternal and Child Health Bureau. 2001.

For More Information

Washington State Department of Health, Children with Special Health Care Needs Program, (360) 236-3571

The Center for Children with Special Needs, Children's Hospital and Regional Medical Center: http://www.cshcn.org/resources/resources.cfm.

Technical Notes

Definition of children with special health care needs:

The definition of children with special health care needs used in this chapter is a combination of the definition provided by the U.S. Maternal and Child Health Bureau (MCHB) and the criteria used to create the children with special health care needs screening measure. The MCHB definition includes children who are at risk for having a special health care need; but since the screener does not measure children at risk, they were not included in the definition.

Children with special health care needs screener:

The children with special health care needs screener, developed by the Child and Adolescent Health Measurement Initiative was used in the 2001 National Survey of Children with Special Health Care Needs and the 2003 National Survey of Children's Health. To be classified as having a special health care need, the parent must report that the child has one or more of the following needs or limitations, due to a medical or health condition and expected to last 12 months or longer: 1) use or need of prescription medication, 2) above average use or need of medical, mental health, or educational services, 3) functional limitations compared with others of same age, 4) use or need of specialized therapies (occupational therapy, physical therapy, speech, etc.), or 5) treatment or counseling for emotional or developmental problems.

Prevalence of children with special health care needs, 2001 and 2003:

The 2001 National Survey of Children with Special Health Care Needs and the 2003 National Survey of Children's Health used the same survey questions and screener to identify children with special needs. The change in the estimates from 14% to 17% could be due to modifications in the order in which the questions were asked, a true increase in the rate of children with special health care needs, or an unknown reason.

Endnotes

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