

Maternal and Child Health Issue Brief

January 2015 №12



Children and Youth with Special Health Care Needs in Colorado

Who are children and youth with special health care needs?

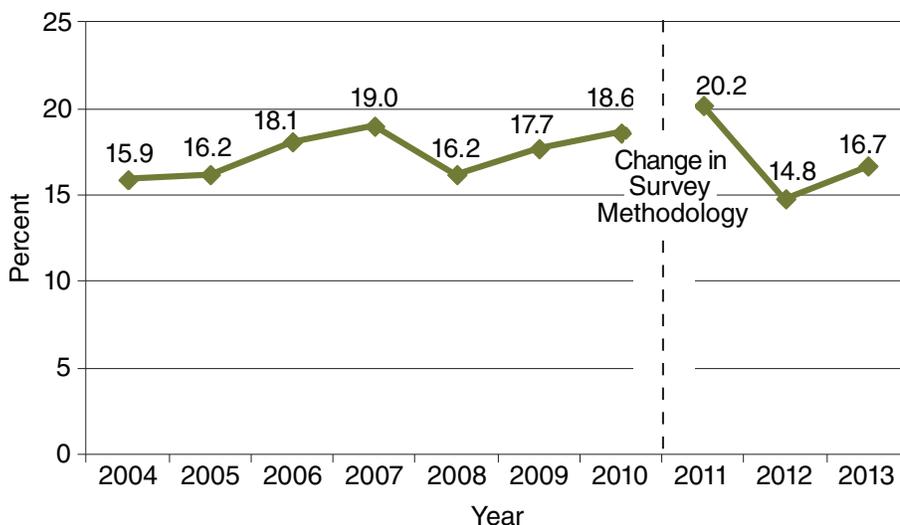
Children and youth with special health care needs (CYSHCN) are “those [children and youth] who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”¹ This is a broad and inclusive definition that does not focus on specific health conditions.² The definition is based on how children’s conditions affect their lives and their need or use of health services.³

What is the prevalence of children and youth with special health care needs?

In Colorado, 13.7 percent of children and youth ages 0-17 years have special health care needs.⁴ The Colorado prevalence for this age group is not significantly different from the prevalence of CYSHCN at the national level (15.1 percent).⁴ This translates to approximately 168,000 children and youth ages 0-17 years with special health care needs in Colorado.

Since national survey data are only available every four years, Colorado added questions to the annual Child Health Survey in order to monitor prevalence more frequently (see note at bottom of page 1). In 2013, 16.7 percent of Colorado children and youth ages 1-14 years had special health care needs.⁵ Data for 2004 to 2010 show an upward trend in the prevalence of CYSHCN, but changes and improvements to the 2011 through 2013 survey methodology prohibit any comparison with data from earlier years.

Figure 1. Prevalence of children and youth with special health care needs ages 1-14 years in Colorado, 2004-2013.⁵



Healthy People Goals⁶

- **By 2020, increase the proportion of children and youth with special health care needs who have access to a medical home to 51.8 percent**

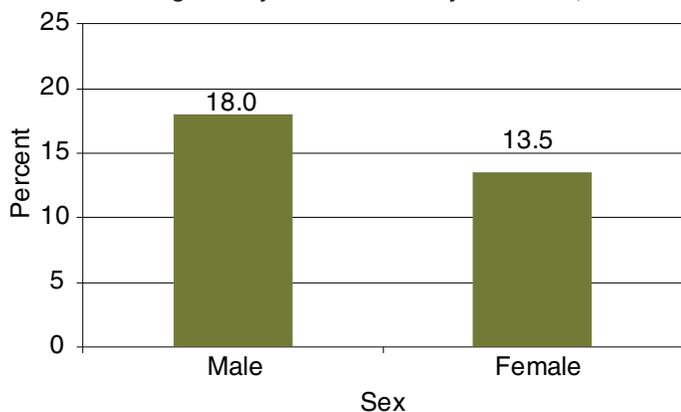
(Colorado data for the HP2020 goal are on page 4.)

Note: Data in this issue brief come from the National Survey of Children with Special Health Care Needs (NS-CSHCN) and the Colorado Child Health Survey (CHS). These two population-based surveys use the same validated, non-condition specific, consequences-based screening tool to identify CYSHCN.¹ However, comparisons between the two sets of survey results should not be made because the age groups are different: the NS-CSHCN covers children and youth ages 0-17 years and the CHS covers children and youth ages 1-14 years.^{4,5}

Demographics of Children and Youth with Special Health Care Needs

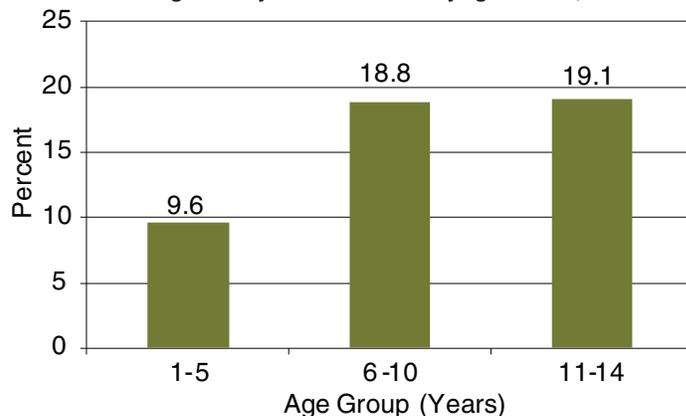
The prevalence estimates shown below are from the Colorado Child Health Survey (ages 1-14 years) and represent the proportions of the total child population that have special health care needs.

Figure 2. Prevalence of children and youth with special health care needs ages 1-14 years in Colorado by sex of child, 2012-2013.⁵



Almost one in five (18.0 percent) males ages 1-14 years in Colorado has special health care needs. This is not significantly different from females (13.5 percent).

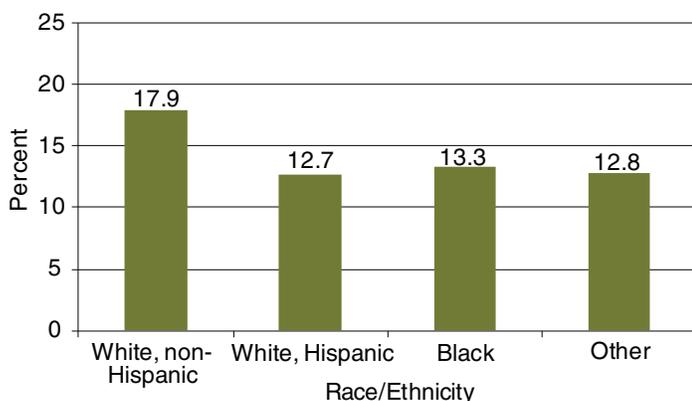
Figure 3. Prevalence of children and youth with special health care needs ages 1-14 years in Colorado by age of child, 2012-2013.⁵



One in ten (9.6 percent) Colorado children ages 1-5 years has special health care need. This is significantly different from children ages 6-10 years (18.8 percent) and youth ages 11-14 years (19.1 percent).

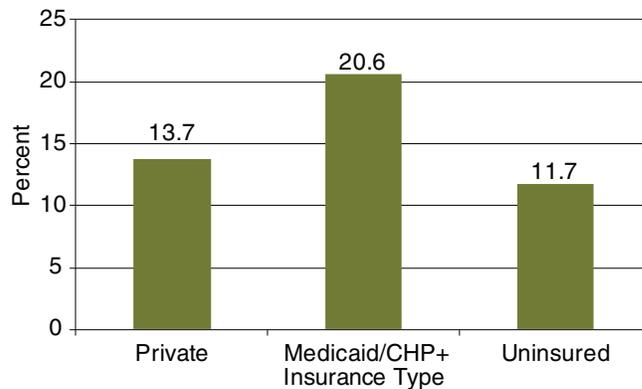
The Child Health Survey did not reveal any significant difference in the prevalence of children and youth with special health care needs based on household poverty level or on urban/rural residence.

Figure 4. Prevalence of children and youth with special health care needs ages 1-14 years in Colorado by race/ethnicity, 2012-2013.⁵



Almost one in five (17.9 percent) White, non-Hispanic children and youth has special health care needs. There are no significant differences between different racial/ethnic groups.

Figure 5. Prevalence of children and youth with special health care needs ages 1-14 years in Colorado by insurance type, 2012-2013.⁵



Based on Child Health Survey data, among children and youth insured by Medicaid or CHP+, an estimated one in five (20.6 percent) has special health care needs. Among children insured by private insurance at the time of the survey, an estimated one in seven (13.7 percent) has special health care needs. These are significant differences.

What are the challenges experienced by children and youth with special health care needs and their families?

Fifteen national indicators are used to describe the well-being of CYSHCN and their families.⁷ These key indicators are grouped into five areas: child health, health insurance coverage, access to care, family centered care, and impact on family.

Table 1. National indicators for children and youth with special health care needs ages 0-17 years, Colorado and the Nation, 2009-2010.⁴

Indicator	Colorado (%)	Nation (%)
Child Health		
CYSHCN whose conditions affect their activities usually, always, or a great deal	26.1	27.1
CYSHCN with 11 or more days of school absences due to illness	17.7	15.5
Health Insurance Coverage		
CYSHCN without insurance at some point in past year	10.6	9.3
CYSHCN without insurance at time of survey	4.6	3.5
Currently insured CYSHCN whose insurance is inadequate	44.8*	34.3
Access to Care		
CYSHCN with any unmet need for specific health care services	26.1	23.6
CYSHCN with any unmet need for family support services	8.1	7.2
CYSHCN needing a referral who have difficulty getting it	30.5	23.4
CYSHCN without a usual source of care when sick (or who rely on the emergency room)	10.4	9.5
CYSHCN without any personal doctor or nurse	8.6	6.9
Family Centered Care		
CYSHCN without family centered care	33.5	35.4
Impact on Family		
CYSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year for the child	30.3*	22.1
CYSHCN whose conditions cause financial problems for the family	29.2*	21.6
CYSHCN whose families spend 11 or more hours per week providing or coordinating child's health care	11.0	13.1
CYSHCN whose conditions cause family members to cut back or stop working	25.9	25.0

*Colorado estimate is significantly different from the national estimate



Colorado prevalence estimates were significantly different compared to national estimates for three key indicators. In Colorado, 44.8 percent of CYSHCN have insurance that is inadequate compared to 34.3 percent of CYSHCN nationally. Three in ten (30.3 percent) CYSHCN in Colorado live in families who pay \$1,000 or more out of pocket in medical expenses compared to two in ten (22.1 percent) CYSHCN nationally. Three in ten (29.2 percent) CYSHCN in Colorado have conditions that cause financial problems for the family compared to two in ten (21.6 percent) CYSHCN nationally. These data demonstrate that some CYSHCN in Colorado, as well as throughout the nation, experience barriers to care and lack a well-functioning system of services. These data also demonstrate that families of CYSHCN in Colorado experience financial stressors beyond that reflected in the national data.

Systems Outcomes for the CYSHCN Population

There are six national core outcomes considered critical for a well-functioning system of services for the population of children and youth with special health care needs.² All data in this section are from the National Survey of Children with Special Health Care Needs and refer to children and youth with special health care needs ages 0-17 years.

- Families of CYSHCN partner in decision-making regarding their child's health: Two-thirds (66.5 percent) of CYSHCN in Colorado live in families who are partners in shared decision-making for the child.
- CYSHCN receive coordinated, ongoing, comprehensive care within a medical home: Less than half (43.7 percent) of CYSHCN in Colorado receive coordinated, on-going, comprehensive care within a medical home. This outcome does not meet the Healthy People 2020 goal of 51.8 percent.
- Families of CYSHCN have adequate private and/or public insurance to pay for needed services: Half (49.9 percent) of CYSHCN in Colorado have adequate private and/or public insurance to pay for the services they need. This is significantly different compared to 60.6 percent of CYSHCN with adequate private and/or public insurance nationwide.
- Children are screened early and continuously for special health care needs: Eight in ten (81.7 percent) CYSHCN in Colorado are screened early and continuously for special health care needs.
- Community-based services are organized so families can use them easily: Six in ten (60.1 percent) CYSHCN in Colorado can easily access community based services.
- Youth with special health care needs (YSHCN) receive the services necessary to make appropriate transitions: Four in ten (42.1 percent) YSHCN in Colorado receive the services necessary to make appropriate transitions to adult health care, work, and independence.⁴



Focus on Medical Home Systems Outcome for the CYSHCN Population

The medical home is considered one of the most promising approaches to delivering high-quality and cost-effective health care.⁸ Because the CYSHCN population requires care beyond that of a typical child/youth, the components of a medical home approach are essential in order to fully meet the needs of the child/youth and their family. The medical home approach refers to health care that is patient/family-centered, comprehensive, coordinated, accessible, continuous, and culturally effective.⁹ This approach to care improves quality of care, reduces costs, and improves patient/family experience in receiving care.¹⁰

Colorado added the set of medical home questions from the National Survey of Children's Health to the Child Health Survey in order to measure the prevalence of medical home at both the state and regional levels, among all children and youth, as well as among children and youth with special health care needs. All the data below are from the Colorado Child Health Survey and are for children and youth with special health care needs ages 1-14 years.

Based on data from 2010-2012, 54.8 percent of CYSHCN in Colorado received coordinated, ongoing, comprehensive care within a medical home. This is significantly different from the 67.2 percent of non-CYSHCN in Colorado who received care in a medical home.⁵

The medical home measure includes five components. Having a personal doctor or nurse is one component of a medical home approach that supports accessibility to care. In Colorado, 96.1 percent of CYSHCN have a personal doctor or nurse.

A usual source of sick and well care is a medical home component that supports comprehensive care. Almost all CYSHCN (96.0 percent) have a usual source for both sick and well care.⁵ Obtaining needed referrals is an additional comprehensive care component. Among CYSHCN who needed a referral, 22.6 percent had difficulty getting it.⁵

Family centered-care is another critical medical home component. One-third (32.2 percent) of CYSHCN in Colorado did not receive family-centered care.⁵

Effective cross-system care coordination is a component of the medical home approach that supports coordinated and continuous care. Among CYSHCN in Colorado who needed care coordination, 46.6 percent failed to receive all needed care coordination.⁵ Of the five medical home components, the prevalence of effectively coordinated care is the lowest.

References

1. Child and Adolescent Health Measurement Initiative (2012). "Who Are Children with Special Health Care Needs (CSHCN)." Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Available at www.childhealthdata.org. Revised 4/2/12. http://childhealthdata.org/docs/nsch-docs/whoarecshcn_revised_07b-pdf.pdf.
2. NS-CSHCN Chartbook 2009-2010. United States Department of Health and Human Services website. <http://mchb.hrsa.gov/cshcn0910/core/co.html>. Accessed November 11, 2014.
3. Children with Special Health Care Needs A Profile of Key Issues in California. Lucile Packard Foundation for Children's Health website. <http://www.lpfch.org/cshcn/fullreport.pdf>. Prepared November 2010. Accessed November 11, 2014.
4. 2009-2010 National Survey of Children with Special Health Care Needs, Maternal and Child Health Bureau, U.S. Department of Health and Human Services
5. Colorado Child Health Survey, Health Statistics and Evaluation Branch, Colorado Department of Public Health and Environment
6. Maternal Infant and Child Health Objectives. Healthy People 2020. United States Department of Health and Human Services website. <http://www.healthypeople.gov/2020/topics-objectives/topic/maternal-infant-and-child-health/objectives>. Accessed October 30, 2014.
7. Blumberg SJ, Carle AC. The well-being of the health care environment for CSHCN and their families: A latent variable approach. *Pediatrics* 2009;124:S361-367.
8. Patient-Centered Medical Homes. *Health Affairs*. September 14, 2010.
9. American Academy of Pediatrics. Policy statement: The medical home. *Pediatrics*. 2002;110:184-186.
10. Patient-Centered Primary Care Collaborative. Benefits of implementing the primary care patient-centered medical home: A review of cost and quality results, 2012. <https://www.pcpc.org/guide/benefits-implementing-primary-care-medical-home>. Published September 2012. Accessed December 9, 2014.

This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number H18MC00006, State Systems Development Initiative (SSDI) for \$95,374. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Maternal and Child Health Program, Prevention Services Division
Telephone: 303-692-2503
www.mchcolorado.org



Colorado Department
of Public Health
and Environment