



# Maternal and Family Health Priority Overview

## Build and Strengthen Data Capacity for Children and Youth with Special Health Care Needs



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## Children and Youth with Special Health Care Needs in Wyoming

### Who are Children and Youth with Special Health Care Needs (CYSHCN) ?

The Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) within the U.S. Department of Health and Human Services defines CYSHCN as, "those 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."<sup>1</sup> CYSHCN often have conditions such as allergies, asthma, ADD/ADHD, depression, anxiety, emotional problems, migraines, intellectual disabilities, autism, autism spectrum disorder, seizures, heart or blood problems, diabetes, Down syndrome and cerebral palsy.<sup>2</sup> According to the National Survey of Children with Special Health Care Needs (NS-CSHCN), these conditions are often associated with one or more functional difficulties that include, but are not limited to, respiratory problems, learning or behavior problems, speaking or communicating, seeing even with glasses, hearing, chronic pain, digesting food, gross and fine motor functioning, making and keeping friends, and self-care.<sup>2</sup> Compared to other children, CYSHCN are more likely to have an overall health status of fair/poor, one or more unmet healthcare needs,



inadequate health insurance, no medical home, repeat a grade in school, and miss 11 or more days of school annually.<sup>2</sup> It is also estimated that health costs for CYSHCN account for at least 40% of total medical care costs for all children.<sup>3</sup>

Approximately 14.4% of Wyoming children ages 0-17 years (95% CI 13.5%-15.4%) have a special health care need.<sup>3</sup> The prevalence is higher among children in poverty. One in five Wyoming children living below 100% of the Federal Poverty Level (FPL) have a special health care need compared to one in eight children who live at or above 400% of the FPL.



### Fast Facts about Children & Youth with Special Health Care Needs

- In 2005–06, approximately 14.4% of Wyoming children and youth had a special health care need.
- Approximately 30% of Wyoming CYSHCN reside in Natrona and Laramie Counties.
- Less than half of Wyoming CYSHCN received coordinated, ongoing, comprehensive care within a medical home.

## Why Data for CYSHCN in Wyoming are Important, Acronyms, and Data Sources

### **Why Data for CYSHCN are Important**

It is the goal of Maternal and Family Health (MFH), Wyoming's Title V Agency, to assure that resources are made available to Wyoming CYSHCN and their families. Data that identify the prevalence of CYSHCN and their needs help MFH to plan services. There are few current data sources for CYSHCN in Wyoming. Gaining an in-depth understanding of CYSHCN through exploring existing data sources, identifying missing data, and developing new data sources will allow MFH to identify gaps in services and to better assist the CYSHCN community throughout the state.



### **ACRONYMS:**

CSH = Children's Special Health

CYSHCN = Children and Youth with Special Health Care Needs

MCHB = Maternal and Child Health Bureau (United States Government)

MFH= Maternal and Family Health (Wyoming Department of Health)

NS-CSHCN = National Survey of Children with Special Health Care Needs

WDH = Wyoming Department of Health

### **DATA SOURCES**

Data specific to the needs and services of Wyoming CYSHCN currently come from two main sources: the Children's Special Health program (CSH) at the Wyoming Department of Health (WDH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN).

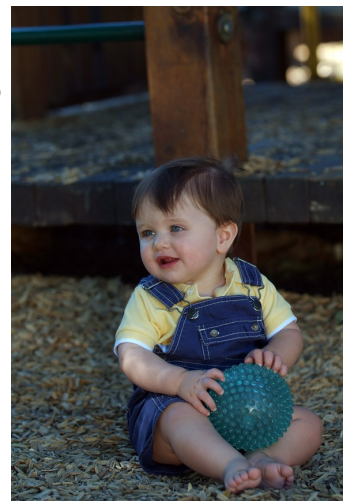
#### **Children's Special Health Program**

The CSH Program is located in MFH, Community and Public Health, Public Health Division, WDH. CSH is a program for income and condition eligible Wyoming CYSHCN who require more than routine medical care and support services. Due to limited resources, CSH provides services and financial assistance to approximately 13% of the estimated 16,456 CYSHCN in Wyoming. The CSH program is described in greater detail on page three.

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

The NS-CSHCN is a national telephone survey conducted by the National Center for Health Statistics and sponsored by MCHB. Households with CYSHCN are identified through a random-digit dial selection process. Children are classified as having special health care needs if they have health services needs or functional limitations related to a medical or health condition expected to last at least 12 months. Independent random samples are taken in all 50 states and the District of Columbia to allow for state specific estimates for information collected.

Parents of CYSHCN who participate are asked questions pertaining to their child's health status, health insurance coverage, access to care, and the impact of their child's condition on the family. Other information collected includes age, sex, income level, race and ethnicity.<sup>5</sup> The survey includes children and youth between the ages of 0 and 17 years. Page four details important information from the NS-CSHCN specific to Wyoming CYSHCN.



# The Children's Special Health Program in Wyoming

## CHILDREN'S SPECIAL HEALTH

The WDH CSH Program, which serves approximately 13% of Wyoming's CYSHCN, collects information on the CYSHCN and their families enrolled in the CSH program as well as for those who apply for services. From 2006 through 2010, 1675 families applied for assistance through CSH. Of those, 93.2% met the eligibility guidelines for services. While CSH program data are available, data needed to assess the quality of coordinated care that CSH clients receive are not available. Eligibility guidelines, available services, covered medical, data highlights and limitations to the data for the CSH Program are described below.

### CSH Eligibility Guidelines:

To be eligible for services covered under CSH, an applicant must meet the following criteria:

- Be a Wyoming resident
- Be a US Citizen or Legal Resident
- Have a household income at or below 200% of the federal poverty level
- Have a condition covered under the CSH program
- Have insurance or have applied for Medicaid or Kid Care
- Have a completed and signed application

### Some of the services CSH provides include:

- Coordination of care by assisting families with services needed in the community or state
- Referrals to parent support groups
- Financial assistance for qualifying medical conditions and diseases
- Financial assistance for diagnostic evaluation to determine diagnosis
- Genetic counseling services and specialty care clinics
- Funds for translation services required by CSH clients
- Funds for transportation

### Covered Medical Conditions

Eligible conditions are specified by the CSH program, and range from developmental to functional to chronic medical conditions.

### Children's Special Health Client Data

From 2006 through 2010:

- 93.2% of families that applied for CSH met the eligibility guidelines for services
- 94.9% of CSH participants had a primary care provider identified
- 76.8% of children on CSH were covered by Medicaid
- 5.0% of children on CSH were covered by Kid Care CHIP
- 93.6% of children on CSH were covered by some form of private health insurance
- The five most frequently approved conditions among CSH enrollees are:
  - Diagnostic Evaluation (47.7%)
  - Congenital Anomalies (17.8%)
  - Disease of the Nervous System and Sense Organs (12.0%)
  - Autism Spectrum Disorders (9.7%)

### Limitation to CSH Client Data

CSH client data are only representative of those CYSHCN who meet eligibility guidelines and receive services under the CSH program. As the data represent only those enrolled in CSH, this information may not represent the needs and services required by the majority of the Wyoming CYSHCN population and their families.



# National Survey of Children with Special Health Care Needs

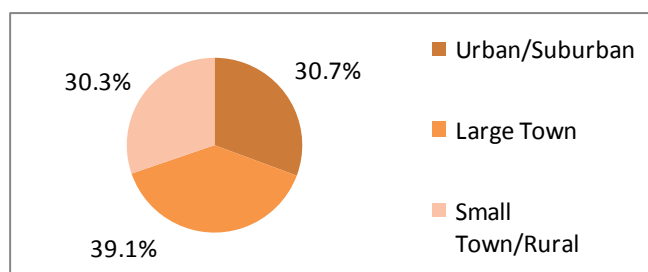
## NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS (NS-CSHCN)

Information collected through the NS-CSHCN enables Wyoming to better assess the needs of all CYSHCN and not just those who qualify for CSH Program services. With this information, Wyoming can better understand the CYSHCN population and access to care issues which may help identify gaps in services. Some of the Wyoming data from the NS-CSHCN are described below.

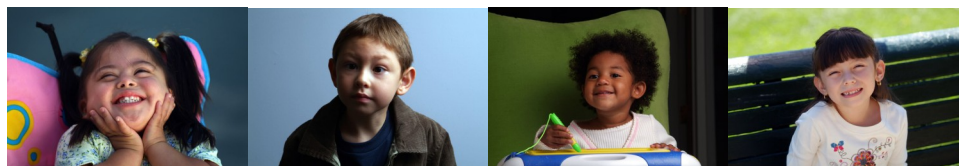
### Location

CYSHCN in Wyoming are not concentrated into one area of the state. Figure 1 illustrates that the largest portion of CYSHCN (39.1%) reside in large town areas, while the remaining reside equally in urban/suburban areas (30.7%) and small town/rural areas (30.3%).<sup>5</sup> It should be noted that the Urban/Suburban category only included two areas in Wyoming: Natrona and Laramie counties.

Figure 1: CYSHCN Population Distribution within the State of Wyoming, 2005-2006



Source: NS-CSHCN 2005-06



### Age and Gender

Twice as many youth ages 6-17 years were diagnosed with a special health care need than children younger than 6 years of age. The prevalence of CYSHCN by age is similar in Wyoming and the U.S. (Table 1).<sup>5</sup>

More males are affected by a special health care need than females. In Wyoming, 16.6% of boys had a special health care need compared to 12.2% of girls.<sup>5</sup> This disparity was similar to the national distribution of 16.1% of males and 11.6% of females.<sup>5</sup>

Table 1: The Percent of Wyoming Children and Youth with Special Health Care Needs by Age Group, 2005-2006

CYSHCN Age Group	Wyoming	U.S.
0 to 5 Years	8.6%	8.8%
6 to 11 Years	17.6%	16.0%
12 to 17 Years	17.0%	16.8%

Source: NS-CSHCN 2005-06

### Race and Ethnicity

Prevalence data from the 2005-2006 NS-CSHCN was reported on the percentage of CYSHCN for racial and ethnic populations that made up at least 5% of a state's population.<sup>5</sup> This minimum population requirement was needed to maintain a high level of accuracy for the data reported. For Wyoming CYSHCN, race and Hispanic origin were reported for non-Hispanic for all races, non-Hispanic white, non-Hispanic multiple races, and Hispanic CYSHCN.

Results are presented and compared to the national estimates in Table 2. There were no significant differences between Wyoming and the U.S. in CYSHCN prevalence by race or ethnicity.<sup>5</sup>

Table 2: The Percent of Wyoming Children with Special Health Care Needs by Race and Ethnicity, 2005-2006

CYSHCN Prevalence by Hispanic Origin and Race	Wyoming	U.S.
Non-Hispanic	14.5%	15.0%
White	14.4%	15.5%
2 or more races	20.8%	17.9%
Hispanic	12.6%	8.3%

Source: NS-CSHCN 2005-06

## National Survey of Children with Special Health Care Needs (continued)

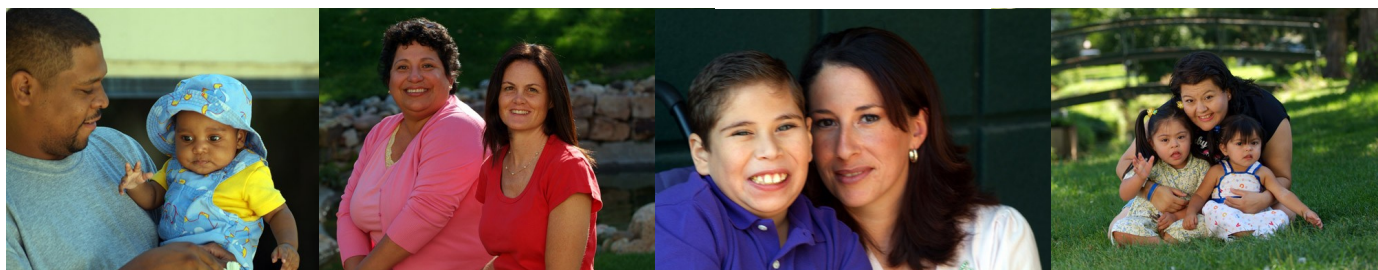
### Health Insurance

By definition, the population of CYSHCN requires more services than children without special health care needs. As such, these families can expect to pay more for health costs and services. Adequate insurance is necessary for families of CYSHCN to pay for routine primary care and other medical services in order to keep out of pocket expenses down. Continuous coverage is also important for CYSHCN so that gaps can be avoided in receiving needed care. Maintaining adequate health coverage may be difficult, however. In 2005-2006, 8.8% of Wyoming families of CYSHCN reported that their child went without health insurance at some point in the past year, which was similar to the U.S. percentage of 8.8%.<sup>5</sup> At the time of the survey, 34.9% of CYSHCN with health insurance were determined to have inadequate coverage.<sup>5</sup> The U.S. estimate for inadequate health insurance was 33.1%.



### Access to Care

Accessing needed care is important for all children but even more critical for CYSHCN. Receiving needed health services helps to ensure that new and existing health problems are diagnosed and treated to prevent further complications and to maximize the child's potential in life.<sup>6</sup> In 2005-2006, nearly 1 in 5 CYSHCN in Wyoming who needed a referral to services had difficulty getting it. In addition, 15.7% of Wyoming CYSHCN have unmet needs for specific health services.<sup>3</sup>



### Impact on Family

Many families of CYSHCN experience challenges in managing care for their child with special health care needs. Table 3 illustrates that time commitments for providing and coordinating care affect the ability of a caregiver to work, which decreases family income and adds to financial stress. In Wyoming, a significantly higher percentage of families of CYSHCN pay \$1,000 or more in out of pocket expenses for medical care than do families nationally.<sup>5</sup>

**Table 3: The Percent of Wyoming Families with CYSHCN who Face Specific Challenges in Managing Care for CYSHCN compared to the United States, NS-CSHCN, 2005-2006**

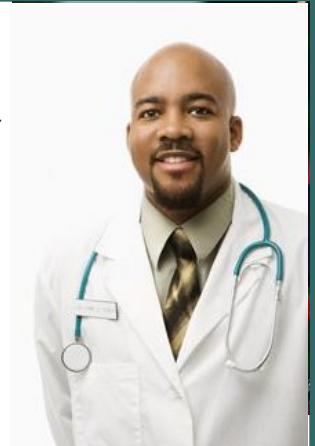
Impact on the Family	Wyoming	U.S.
CSHCN whose families pay \$1,000 or more out of pocket in medical expenses per year for the child	*29.2%	20.0%
CSHCN whose conditions cause financial problems for the family	21.3%	18.1%
CSHCN whose families spend 11 or more hours per week providing or coordinating child's healthcare	12.0%	9.7%
CSHCN whose conditions cause family members to cut back or stop working	22.8%	23.8%

\* Represents a statistically significant difference from the U.S. percent.

## CYSHCN Medical Home and Transition

### MEDICAL HOME & CARE COORDINATION

The medical home concept was developed by the American Academy of Pediatrics (AAP) in 1992. It is characterized as a primary care physician-based method of managed medical care for all children, including CYSHCN, that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally sensitive.<sup>6-8</sup> Medical homes require a collaboration of families, healthcare workers, schools, employers, insurers and interested parties to ensure that quality healthcare and necessary services are received by CYSHCN and all children.<sup>7-9</sup>



There is no direct way to accurately assess medical home. Using the six of the eight concepts developed by the AAP (accessible care and continuous care were not addressed), the 2005-2006 NS-CSHCN included questions on the components of a medical home including:

- A relationship with a specific provider
- Family-centered, compassionate, and culturally effective care
- Comprehensive care
- Coordinated care

This created a standard method to measure coordinated, ongoing, comprehensive care in a medical home for all children. Children must experience all components of the set criteria to be identified as having a medical home.<sup>5</sup> In 2005-2006, only 49.1% of Wyoming CYSHCN received coordinated, ongoing, comprehensive care within a medical home, which was similar to the U.S. estimate of 47.1%.<sup>5</sup>

### TRANSITIONING INTO ADULT SERVICES

“Transition planning creates a coordinated set of activities as part of a process focused on improving the child’s academic and personal life skills and helping the child move from school to adult life.”<sup>10</sup> Because special health care needs are unique to each individual child, transition planning for CYSHCN must be tailored in order to meet the needs and interests of the child and the goals set by the child and their family.

While there is a suggested timeline for steps in transitioning for various ages throughout childhood for CYSHCN, transitioning into young adulthood has special consequences and key components that must be addressed for each CYSHCN.<sup>10-13</sup>



Components of transition planning for adulthood should include employment, housing, transportation, education, social/recreation, daily living, money, insurance and health.<sup>11, 14</sup> It is recommended that all CYSHCN have a transition plan in place to address these issues by the age of 16 years so there are no gaps in necessary services when a child turns 18 years of age. In Wyoming, parents are no longer considered legal guardians once a child turns 18 years of age, although they may file to maintain guardianship.<sup>15</sup> In addition, CYSHCN may not be eligible to receive services from previous medical providers, and they may “age-out” of some assistance programs. Coming of age, however, may allow CYSHCN to become entitled to new assistance programs such as Vocational Rehabilitation or Supplemental Security Income. By engaging in transition planning, CYSHCN and families can be prepared to apply for and receive services.

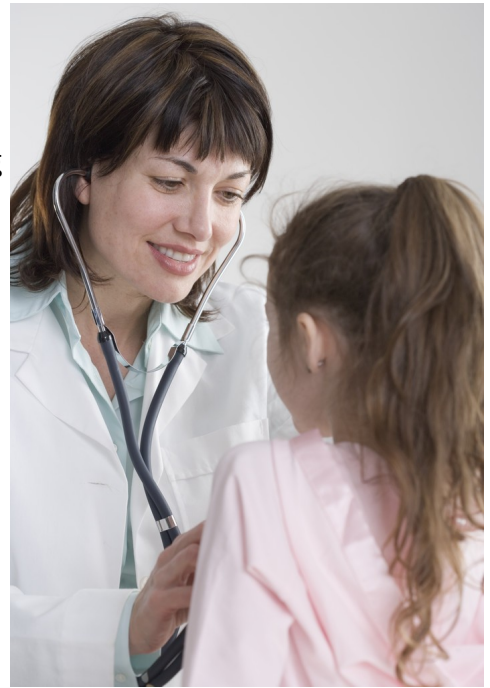
Unfortunately, not all CYSHCN in Wyoming are receiving adequate transition services. According to the 2005-2006 NS-CSHCN, only 47.0% of Wyoming youth with special health care needs received the services necessary to make appropriate transitions to adult healthcare, work and independence.<sup>5</sup> While this was similar to the national estimate of 53.0%, there is an obvious need to improve transition planning for CYSHCN in Wyoming.

## Strategies to Increase Data Capacity for CYSHCN

### STRATEGIES TO INCREASE CYSHCN DATA CAPACITY IN WYOMING

Maternal and Family Health, Wyoming's Title V agency, selected increasing capacity to collect and analyze CYSHCN data as a state priority for the 2011-2015 Maternal and Child Health Needs Assessment. The needs assessment is federally mandated for Title V funding, and once the needs assessment is complete, organizations identify state priorities for maternal and child health improvement for the next five years. The plan to address this priority includes several steps:

1. Identify data sources for CYSHCN and analyze existing data
2. Create a comprehensive report on CYSHCN
3. Identify data gaps
4. Assess capacity to address data gaps
5. Create a plan to address data gaps



#### Identify data sources for CYSHCN in Wyoming and analyze existing data

While some data from the NS-CSHCN and the CSH program have been analyzed, a more thorough exploration of these data sources is planned. In addition, data from other existing sources including data from Genetics clinics, hospital discharge data, Medicaid, and Kid Care data will be explored. MFH will also evaluate the need for and effectiveness of specialty clinics through provider surveys and by examining data from the NS-CSHCN to determine if the clinics offered match the medical needs of CYSHCN in the state.

#### Create a comprehensive report on CYSHCN

When data analysis is complete, a comprehensive report on CYSHCN in Wyoming will be prepared and distributed to stakeholders. Special reports focusing on transition services and medical home will also be created. An Advisory Committee will be convened to guide the development of the report and to determine next steps.

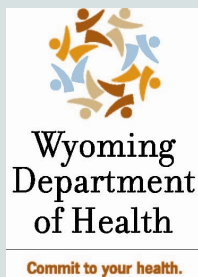


#### Identify data gaps, assess capacity to address data gaps, and create a plan

Once the comprehensive report on CYSHCN in Wyoming has been completed, the Advisory Committee will meet to identify gaps in the existing data and to prioritize the data gaps. MFH will work with the Advisory Committee to assess the capacity to address data gaps. This includes examining structural resources, data systems, organizational relationships, and competencies and skills in the current workforce. The Advisory Committee and MFH will then create and implement a plan to address the data gaps. This entire process is expected to be complete by July 2015.

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### Maternal and Family Health Mission

Maternal and Family Health provides leadership to ensure that all Wyoming women, children and families, including those with special health care needs, have access to prevention services and public health programs to create a strong foundation for optimal lifelong health.

Web address: <http://health.wyo.gov>

### Maternal and Family Health Priorities for 2011-2015

1. Promote healthy nutrition among women of reproductive age.
  - \*Promote folic acid intake among Wyoming women of reproductive age.
  - \*Promote a healthy prepregnancy body mass index and adequate weight gain during pregnancy.
2. Promote healthy nutrition and physical activity among children and adolescents.
3. Build and strengthen services for successful transitions for children and youth with special health care needs.
4. Reduce the rate of unintentional injury among children and adolescents.
5. Design and implement initiatives that address sexual and dating violence.
6. Reduce the rate of teen births.
7. Reduce the percentage of women who smoke during pregnancy.
8. Build and strengthen capacity to collect, analyze, and report on data for children and youth with special health care needs.
9. Support behaviors and environments that encourage initiation and extend duration of breastfeeding.