



# Maternal and Family Health Priority Overview

## Transition for Children and Youth with Special Health Care Needs



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### Who are the Children and Youth with Special Health Care Needs?

Children and Youth with Special Health Care Needs (CYSHCN) are defined by the Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau 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." CYSHCN include children with chronic conditions such as diabetes, developmen-



tal disabilities such as autism, emotional or behavioral conditions such as ADHD and physical disabilities. Approximately 14.1% or 18,194 children 0-17 years of age in Wyoming have a special health care need.<sup>1</sup>

### What is Transition?

In the medical context, transition for CYSHCN is defined as the "purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from the child-centered to the adult-oriented health care system."<sup>2</sup> Transition services prevent gaps in healthcare and maximize adult health and quality of life.<sup>3</sup> Ideal transition is high quality, developmentally appropriate, family-centered, continuous, comprehensive, coordinated, and culturally competent care that continues uninterrupted as the patient moves from adolescence to adulthood.<sup>3,4</sup> The Consensus Statement on Health Care Transitions



for Young Adults with Special Health Care Needs, supported by the American Academy of Pediatrics, the Society for Adolescent Medicine, the American Academy of Family Physicians, the American College of Physicians, and the American Society for Internal Medicine, recommends that a transition plan be in place by the time an adolescent is 14 years old and that the plan be updated annually.<sup>3</sup> However, transition is a process, not an event, and can begin at the time of diagnosis by encouraging developmentally appropriate activities and setting goals for the future.<sup>5</sup>

### Fast Facts about Transition for CYSHCN

- 14.1% or 18,194 children in Wyoming have a special health care need.
- Transition is the purposeful, planned movement of CYSHCN from the child-centered to the adult-oriented health care system.
- 53% of Wyoming CYSHCN report not receiving services they need to transition into adult healthcare, work and independence.

## **Transition for Children and Youth With Special Health Care Needs: Why Transition Services are Important, Lifecourse Effects, and Contributing Factors**

### **Why Transition Services are Important**

Medical advancement has increased the years and quality of life for CYSHCN, increasing the need for transitional services into adult care.<sup>6-7</sup> Although many CYSHCN are able to negotiate adult systems of healthcare, a substantial population of these individuals need organized, coordinated services to transition to adult care.<sup>2,8</sup> Healthcare transition is critical for economic self-sufficiency, independence, and successful entry into adulthood.<sup>9</sup> A child's pediatrician has experience with the child's condition(s) and a relationship with the child; however, after that child reaches adulthood he or she deserves adult-oriented care. Unless the pediatrician can provide appropriate care for adult health and sexuality issues, new healthcare providers must be found.<sup>10</sup>

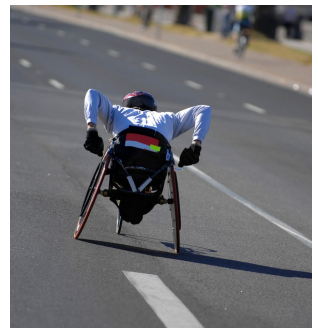


### **Lifecourse Effects**

Unmet transition needs may affect CYSHCN for the rest of their lives. CYSHCN with unmet transition needs are less likely to complete high school, participate in continuing education, gain employment, or live independently.<sup>11</sup> In a study of individuals with disabilities in Massachusetts, 40% had not graduated high school despite all of being over 18 years old.<sup>12</sup> A national study found that people with disabilities are much less likely to be employed (35% vs. 78%) than those without disabilities.<sup>13</sup> Unprepared CYSHCN may lack knowledge about their condition(s) and have limited development of self-care skills and greater financial dependency on their families and society. Lack of preparation of CYSHCN and their families can also lead to gaps in continuity of health care. Gaps in continuity of care can be caused by an inability to find an appropriate source of care and being uninsured or underinsured.<sup>10</sup> A study of young adults 21-24 years of age who had aged out of the Title V CSHCN program in California found an insurance gap was the most prevalent reason for experiencing a problem with access to healthcare.<sup>14</sup> Young adults without insurance are five times more likely to have problems accessing care and seven times more likely to forgo needed care and prescription medication because of cost.<sup>15</sup> Not having a usual source of care causes access problems even if individuals have insurance.<sup>14</sup> Differences in pediatric and adult healthcare systems can lead to non-adherence to treatment plans and, ultimately, an exacerbation of current conditions or development of subsequent health conditions. Besides experiencing complications with their condition(s), CYSHCN who do not receive care and guidance relating to adult health issues may engage in irresponsible sexual behavior and suffer from resulting complications, such as sexually transmitted infections and health compromising unintended pregnancies. They may also experience an increased risk of depression, social problems, stress, and suicide or other premature causes of death in adulthood.<sup>16</sup>

### **Contributing Factors**

Many CYSHCN require coordinated care involving multiple providers often provided by a medical home. The medical home concept is discussed in further detail on page 4. One barrier to transitioning to adult healthcare systems is finding a new set of providers that provide this type of care.<sup>17</sup> Adult providers may be unfamiliar with the condition(s) of the patient and the priorities and concerns of the patient and their family.<sup>18</sup> The difficulty in establishing relationships with new providers is compounded by the difficulty of leaving the familiar pediatric setting and a long standing and close relationship with a pediatrician. The pediatrician or other healthcare provider managing the child's care should play a central role in helping the child and their family find appropriate providers to provide them with a regular source of adult healthcare.<sup>10</sup> This role involves communication with adult healthcare providers and coordination with the healthcare, education, rehabilitation and insurance systems.<sup>10</sup> However, pediatricians and providers face barriers in fulfilling this role, including difficulty in finding adult primary care and subspecialist providers and difficulty in communicating with adult providers. Pediatricians and providers may also face institutional issues, such as lack of institutional support for transition planning, lack of resources, lack of reimbursement for time spent providing transition services and lack of time to provide transitional services.<sup>5, 17</sup>



## Transition for Children and Youth With Special Health Care Needs: National Survey of Children with Special Health Care Needs



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

The NS-CSHCN is a national telephone survey sponsored by the U.S. Department of Health and Human Services, Health Resources and Service Administration's Maternal and Child Health Bureau (MCHB) and conducted by the Centers for Disease Control and Prevention's National Center for Health Statistics (NCHS). 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

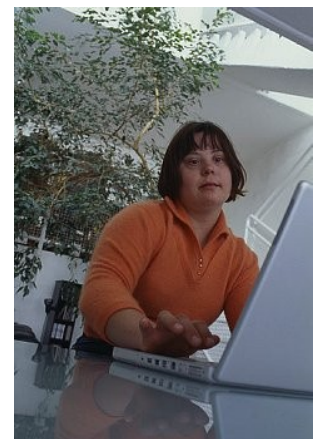
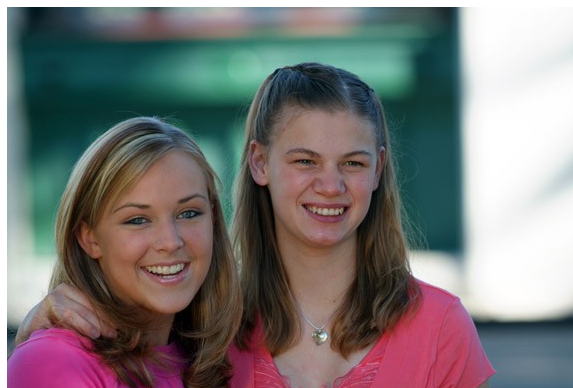
to a medical or health condition expected to last at least 12 months. Independent random samples are taken in all 50 states and the District of Columbia to allow for state specific estimates for information collected.

The parent or legal guardian who knows the most about the health or health care of the children in the household 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. The survey includes children and youth between the ages of 0 and 17 years.<sup>20</sup>



Data from the survey is used to derive measures developed collaboratively through a partnership between MCHB, NCHS and a Technical Expert Panel. These measures include six core performance outcomes developed by MCHB and its partners to promote and measure progress toward a community-based system of services mandated for all CYSHCN under Title V of the Social Security Act. One of the core outcome on transition for CYSHCN states, "youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including health care, work, and independence." The four components used to derive this outcome measure in the NS-CSHCN are listed below<sup>21</sup>

- Doctor or provider has discussed transitioning to adult providers, if necessary
- Doctor or provider has discussed changing health care needs, if necessary
- Doctor or provider has discussed maintaining insurance coverage, if necessary
- Doctor or provider usually or always encourages child to take responsibility for his or her health care needs





## Transition for Children and Youth With Special Health Care Needs: Medical Home

### The Medical Home

The medical home concept was developed by the American Academy of Pediatrics (AAP) in 1992 followed by an updated statement in 2002. A medical home is a physician-based method of managed medical care for children through adulthood, which is accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally sensitive. The physician directing or delivering care should be in a partnership of mutual trust and responsibility with the child and family.<sup>22-24</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.<sup>22-24</sup>



Using the concepts developed by the AAP, MCHB, NCHS, a Technical Expert Panel collaboratively developed a measure of a medical home for the NS-CSHCN and its companion survey, by quantifying seven components of the medical home concept (Table 1). Children must experience all components of the set criteria to be classified as having a medical home for the NS-CSHCN.<sup>21</sup> This quantification of a medical home was developed by the survey's Technical Expert Panel and may not be reflective of all medical home definitions.

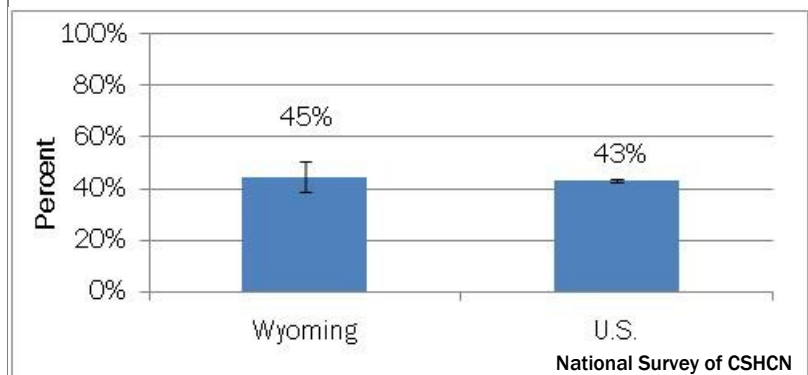
**Table 1: Components that make up the Medical Home Outcome on the NS-CSHCN, 2009/10**

| Component   | Questions used to assess component  |
|---|---|
| Established relationship with a specific provider | <ul style="list-style-type: none"> <li>Has a personal doctor or nurse</li> </ul>  |
| Accessible  | <ul style="list-style-type: none"> <li>None</li> </ul>  |
| Family-Centered                                   | <ul style="list-style-type: none"> <li>Doctor or provider spends enough time with the child</li> <li>Doctor or provider listens carefully to parent</li> <li>Doctor or provider provides needed information</li> <li>Doctor or provider helps parents feel like partners in child's care</li> </ul>     |
| Continuous  | <ul style="list-style-type: none"> <li>None</li> </ul>  |
| Comprehensive                                     | <ul style="list-style-type: none"> <li>Has no problems getting referrals to see any doctors or receive any services</li> <li>Has a usual source of care for sick and routine preventative care</li> </ul>   |
| Coordinated                                       | <ul style="list-style-type: none"> <li>Has help with care coordination, if needed</li> <li>Satisfied with communication between child's doctors and other providers</li> <li>Satisfied with communication between child's doctors or other providers and school or other programs, if needed</li> </ul> |
| Culturally Effective                              | <ul style="list-style-type: none"> <li>Doctor or provider sensitive to family's values and customs</li> </ul>   |

CYSHCN are less likely to have a medical home than children without a special health care need. Differing standards defining a "medical home" and reimbursement structures that fail to recognize and support all components of a medical home are a compounding barrier to CSHCN receiving transition services. CYCHSN without a medical home have double the odds of failing to meet the transition outcome in comparison to CYCHSN with a medical home.<sup>25</sup>

In 2009/10, 45% of Wyoming CYSHCN received coordinated, ongoing, comprehensive care within a medical home. This was not significantly different than the U.S. estimate of 43%.<sup>1</sup>

**Figure 1: Percent of Wyoming and U.S. CYSHCN ages 12-17 who Receive Coordinated, Ongoing, Comprehensive Care within a Medical Home, NS-CSHCN 2009/10**



## Transition for Children and Youth With Special Health Care Needs: Healthy People 2020 and Data on Transition in Wyoming

"Healthy People provides science-based, 10-year national objectives for improving the health of all Americans."<sup>26</sup> Healthy People 2020 established four overall goals for this decade:

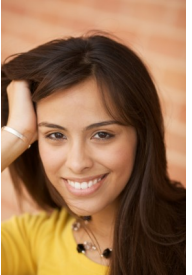
1. Attain high-quality, longer lives free of preventable disease, disability, injury, and premature death;
2. Achieve health equity, eliminate disparities, and improve the health of all groups;
3. Create social and physical environments that promote good health for all;
4. Promote quality of life, healthy development, and healthy behaviors across all life stages.<sup>26</sup>

To achieve these goals, objectives have been set for a variety of indicators that are used to measure progress. Some of these objectives are also priorities set by the Wyoming Department of Health's Maternal and Family Health Section to improve the health of Wyoming women and families.

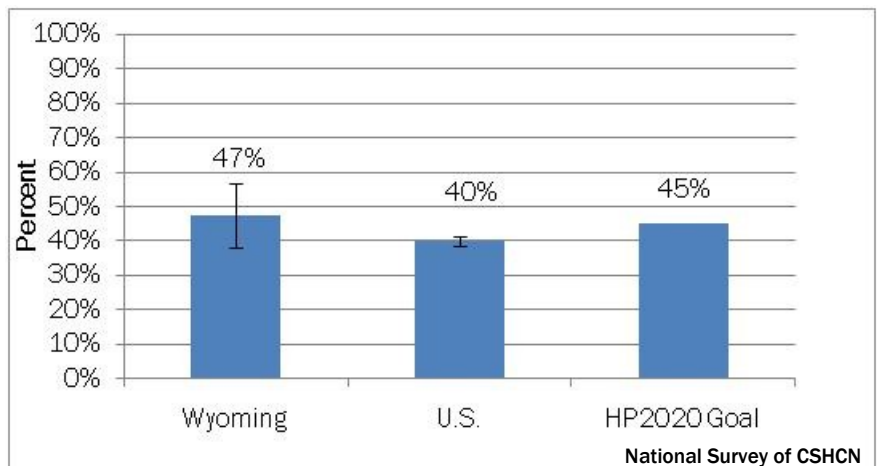
The HP2020 objective related to transition is: increase the proportion of youth with special healthcare needs whose healthcare provider has discussed transition planning from pediatric to adult healthcare from 41.2% to 45.3%. This objective is measured using the transition outcome from the NS-CSHCN.<sup>27</sup>



In 2009/10, the percent of Wyoming CYSHCN that received the services necessary to make appropriate transitions to adult healthcare, work and independence (47%), exceeded the HP2020 goal (45.3%). However, the percent of Wyoming CSHCN receiving services necessary to make appropriate transitions was not significantly different than the HP2020 goal or the U.S. percent (40%).<sup>1</sup>



**Figure 2: Percent of Wyoming and U.S. CYSHCN ages 12-17 who Received the Services Necessary to make Appropriate Transitions to Adult Health Care, Work, and Independence, NS-CSHCN 2009/10**



**Figure 3: Percent of Wyoming and U.S. CYSHCN ages 0-17 who were Never, Moderately, or Consistently Affected in their Daily Activities by their Health Condition, NS-CSHCN 2009/10**

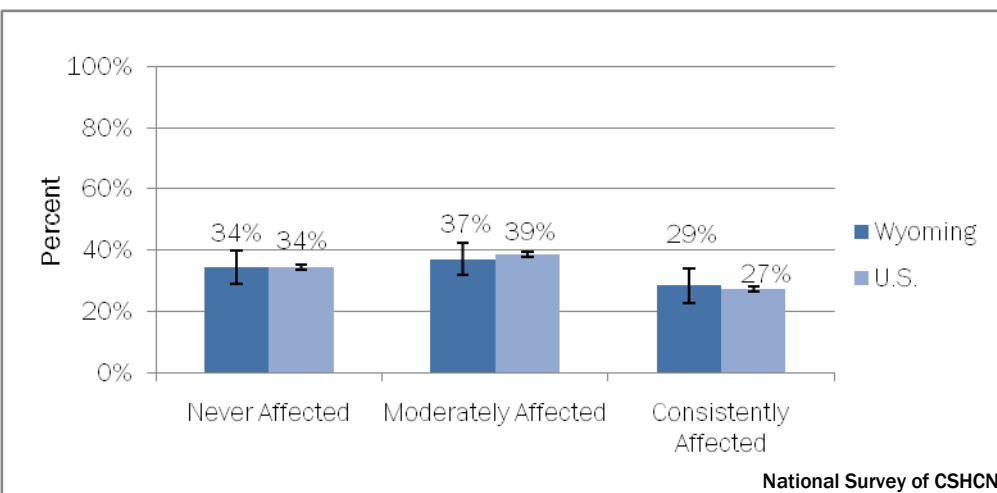


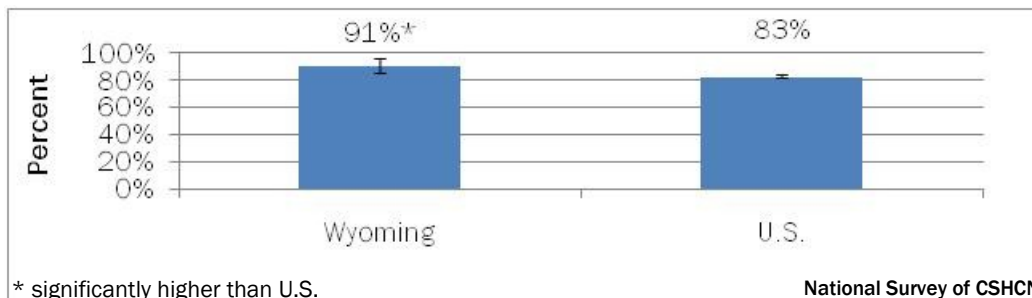
Figure 3 shows the percentages of CYSHCN never (34%), moderately (37%), and consistently (29%), affected by their conditions were not significantly different than the national percentages of CYSHCN never (34%), moderately (39%), and consistently (27%), affected by their conditions.<sup>1</sup>

## Transition for Children and Youth With Special Health Care Needs: Data on the Four Components of the Transition Outcome in Wyoming

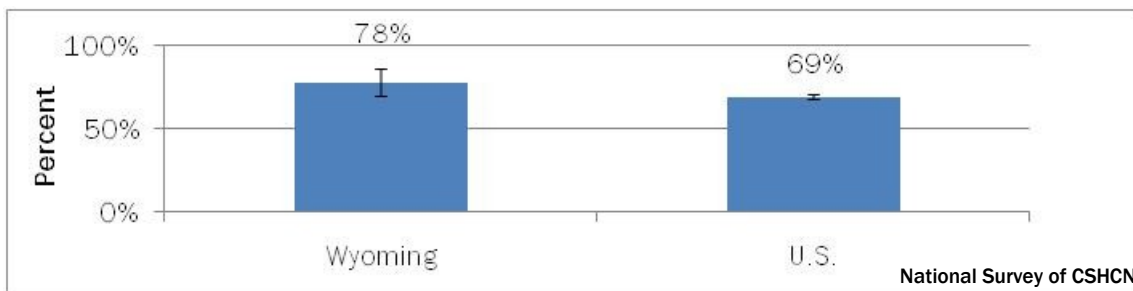
As described on page 3, the NS-CSHCN transition outcome is made up of four components. The following graphs compare the percent of Wyoming versus the percent of U.S. children who are meeting each of these.

The percentage of Wyoming CYSHCN who needed to discuss, but did not discuss a shift to adult health providers (91%) was significantly higher than the national percentage (83%).<sup>1</sup>

**Figure 4: Percent of Wyoming and U.S. CYSHCN ages 12-17 who Needed but Did Not Discuss Shift to Adult Healthcare Providers, NS-CSHCN 2009/10**



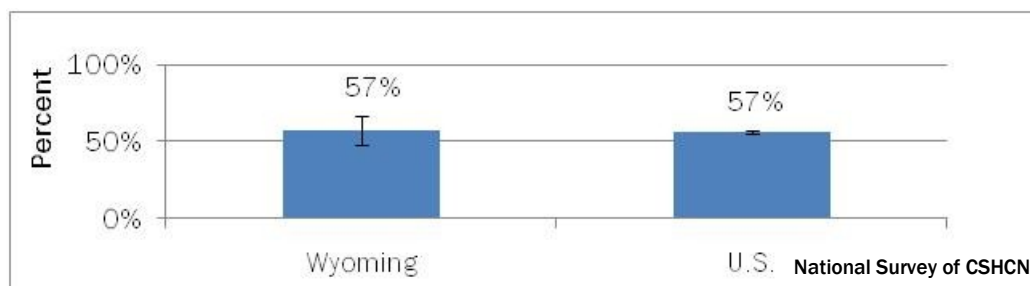
**Figure 5: Percent of Wyoming and U.S. CYSHCN ages 12-17 who Needed and Discussed Changing Healthcare Needs as He/She becomes an Adult, NS-CSHCN 2009/10**



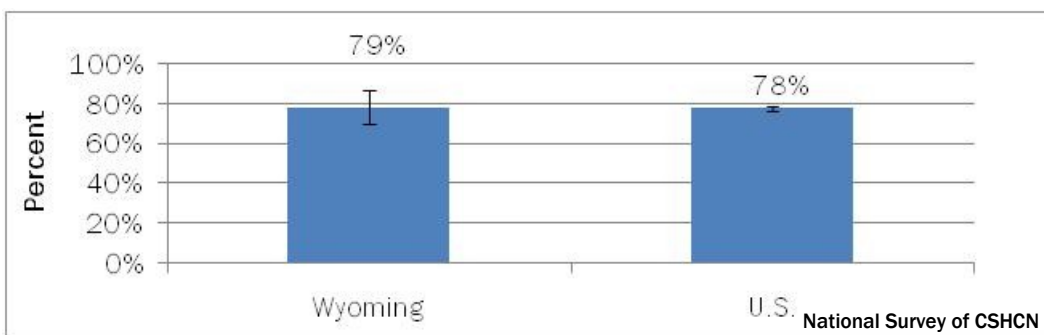
The percentage of Wyoming CYSHCN who needed to discuss, and did discuss changing health care needs (78%) was not significantly higher than the national percentage (69%).<sup>1</sup>

The percentage of Wyoming CYSHCN who needed to discuss, and did discuss how to maintain insurance coverage (57%) was not significantly different than the national percentage (57%).<sup>1</sup>

**Figure 6: Percent of Wyoming and U.S. CYSHCN ages 12-17 who Needed and Discussed How to Maintain Insurance Coverage, NS-CSHCN 2009/10**



**Figure 7: Percent of Wyoming and U.S. CSHCN ages 12-17 whose Doctors Usually or Always Encouraged Self Management Skills, NS-CSHCN 2009/10**



The percentage of Wyoming CYSHCN whose doctors usually or always encouraged self management skills (79%) was not significantly different than the national percentage (78%).<sup>1</sup>

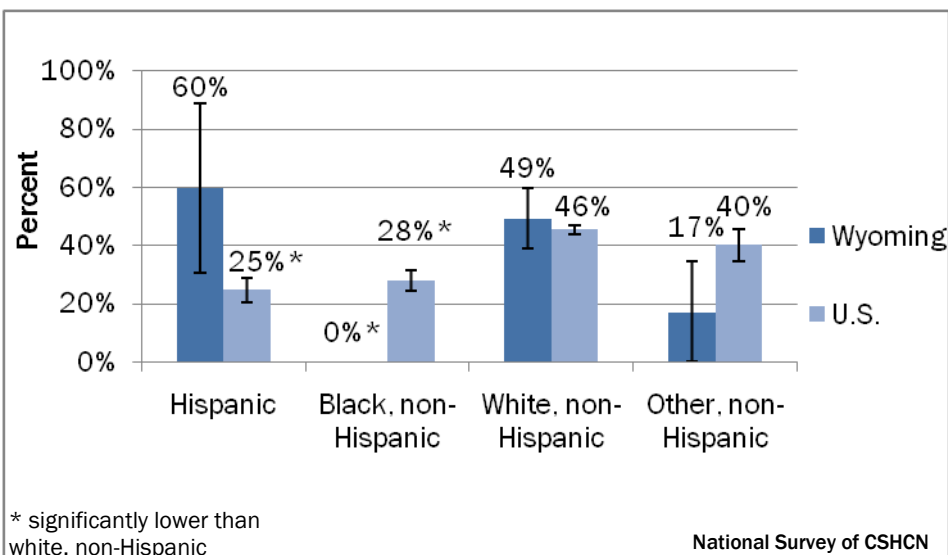
## Transition for Children and Youth With Special Health Care Needs: Disparities

HP2020 defines a health disparity as “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.”<sup>29-30</sup>

CYSHCN from ethnic and racial minorities and lower income levels experience poorer access and quality of care than their white counterparts; results from the NS-CSHCN 2009/10 show that CYSHCN who are non-Hispanic black or Hispanic, have a lower income and/or do not speak English at home are less likely to have a medical home.<sup>28, 31</sup> Nationally, Non-Hispanic black youth were 1.5 times and Hispanic youth were 1.4 times less likely to receive services needed for transition than non-Hispanic white youth. CYSHCN with a primary language other than English were 2.5 times less likely to receive services needed for transition compared to those with English as a primary language.<sup>28</sup>



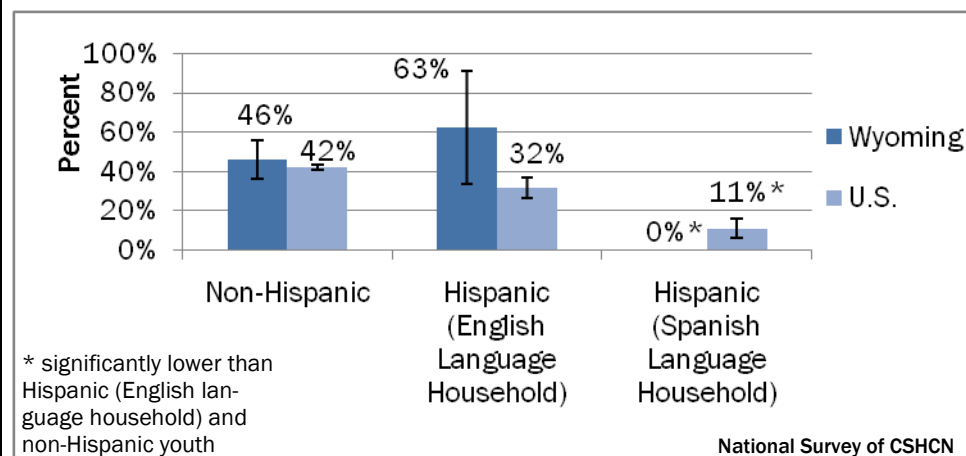
**Figure 8: CYSHCN ages 12-17 who Received Services Needed for Transition to Adult Healthcare, Work and Independence by Race/Ethnicity, 2009/10**



Nationally, compared to the percentage of non-Hispanic white youth (54%), the percentages of Hispanic youth (25%), and non-Hispanic black youth (28%) who received transition services were significantly lower, and the percentage of other, non-Hispanic youth (40%) was not significantly different than the percentage of non-Hispanic white youth. In Wyoming, compared to the percentage of non-Hispanic white youth (49%), the percentage of non-Hispanic black youth (0%) who received transition services was significantly lower, the percentage of Hispanic youth (60%) was not significantly different, and the percentage of other, non-Hispanic youth is not reported because the estimate was not reliable.<sup>1</sup>

Nationally, the percentage of Hispanic youth in a Spanish language household (11%) who received transition services was significantly lower than the percentages of Hispanic youth in an English language household (32%) and non-Hispanic youth (42%). In Wyoming, the percentage of Hispanic youth in a Spanish language household (0%) who received transition services was significantly lower than the percentages of Hispanic youth in an English language household (63%) and non-Hispanic youth (46%).<sup>1</sup>

**Figure 9: CYSHCN ages 12-17 who Received Services Needed for Transition to Adult Healthcare, Work and Independence by Language Spoken, 2009/10**



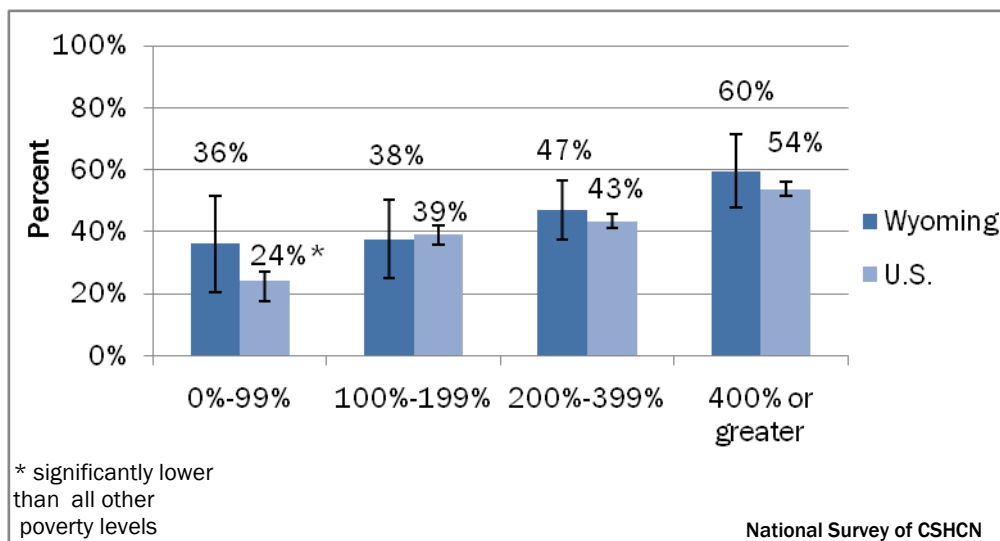


## Transition for Children and Youth With Special Health Care Needs: Disparities

Multiple studies have shown that fewer young adults are insured than other population groups and that ethnic and racial minorities and low income individuals have less access to insurance.<sup>31</sup> Studies have shown that CSHCN also experience age-related loss of insurance, gaps in insurance coverage, losing a usual source of care, and forgoing or delaying care similar to the general population, except that they may experience more severe consequences. Although all CYSHCN experience difficulty in maintaining access to care as they become adults, it may be especially difficult for those of low income, low educational attainment and/or racial and ethnic minorities.<sup>28</sup> Compared to CYSHCN at or above 400% of the federal poverty level, those at 99% of the poverty level or below were 2.2 times less likely to meet the transition outcome, and compared to CYSHCN who had insurance coverage, while CYSHCN without insurance coverage were 2.1 times less likely to meet the core outcome.<sup>25</sup>

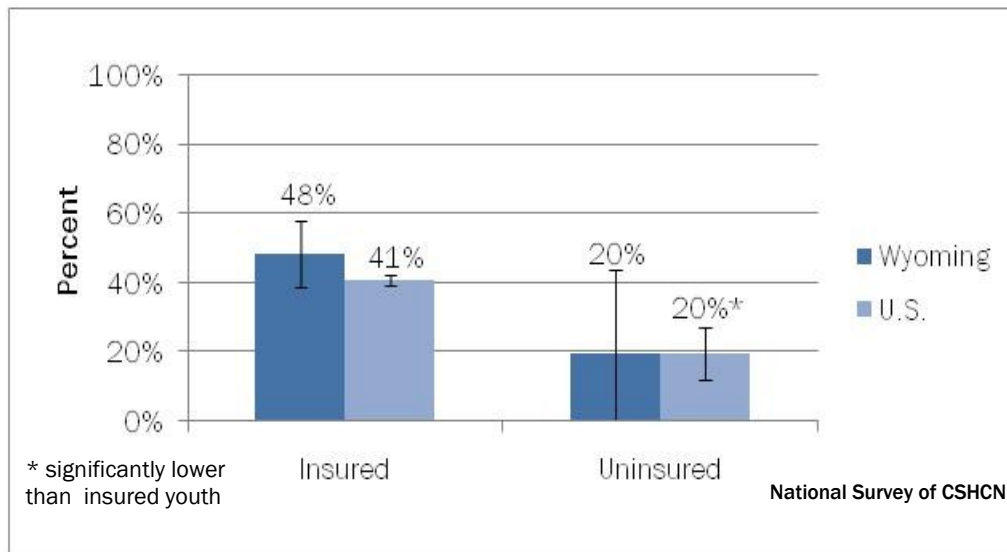


**Figure 10: CYSHCN ages 12-17 who Received Services Needed for Transition to Adult Healthcare, Work, and Independence by Income Level, 2005/06**



Nationally, the percentage of CYSHCN at or below 99% of the poverty level (24%) who received transition services was significantly lower than CYSHCN at any income above 99% of the poverty level. However, in Wyoming the percentage of CYSHCN at or below 99% of the poverty level (36%) who received transition services was not significantly different than CYSHCN at any income above 99% of the poverty level.<sup>21</sup> These data were not available for 2009/10.

**Figure 11: CYSHCN ages 12-17 who Received Services Needed for Transition to Adult Healthcare, Work and Independence by Insurance Status, 2009/10**



Nationally, the percentage of uninsured CYSHCN who met the transition outcome (20%), was significantly lower than the percentage of insured CYSHCN who did not meet the transition outcome (41%). However, in Wyoming, the percentage of uninsured CYSHCN who did not meet the transition outcome (20%) estimate was not reliable, and is not comparable to the percentage of insured CYSHCN who did not meet the transition outcome (48%).<sup>1</sup>



## Transition for Children and Youth With Special Health Care Needs: Strategies



The Children's Special Health (CSH) program is a program for children and youth with special health care needs (CYSHCN) requiring something beyond routine and basic care. The program's goal is to help CYSHCN receive the best possible medical care. CSH provides payment for specialty medical care and coordination of care for CYSHCN. Maternal and Family Health (MFH) oversees the CSH program and case management occurs in Public Health Nursing (PHN) offices. MFH provides block grants to Wyoming counties for PHNs to assist families who qualify for MFH services. Case management would include helping clients obtain needed care and forward referrals to appropriate community resources, including transition services.

At 18 years of age, CSH clients and their families receive a document with resources and considerations for transitioning from youth to adult services. The document provides talking points addressing guardianship, finances (and financial assistance), healthcare, and sexuality. In addition, a transitioning tool for families—Packaging Wisdom—is available on the MFH website (<http://www.health.wyo.gov/familyhealth/csh/index.html>). Packaging Wisdom allows families of CYSHCN to compile and store health and behavior records in a single binder or electronic folder.

MFH attends, participates in, and funds various conferences around the state. During these events, MFH has a booth containing information about MFH programs. MFH participates in various webinars as a means to increase staff knowledge and resources regarding transition. In an effort to improve public access to transition information, MFH updated their website and transition related documents.

MFH also partners with a variety of entities to address CYSHCN transition needs. MFH collaborates with the Governor's Council on Developmental Disabilities (GCDD) and Vocational Rehabilitation to assure effort is made for CYSHCN transitioning to all aspects of adult life.

MFH works with a strong network of parent advocacy organizations to ensure that the needs of CYSHCN and their families are being met. Wyoming Parents Helping Parents (PHP) is a private non-profit organization that supports children through advocacy, education, and referral. PHP houses two projects: the Parent Information Center (PIC) (<http://www.wpic.org>) and Parent Education Network (PEN) (<http://www.wpen.net>). PIC is a statewide parent center for families of children with disabilities and PEN is the Wyoming State Parent Information Resource Center (PIRC). MFH collaborates with a third program, the Family 2 Family Health Information Center (F2FHIC) (<http://www.uwyo.edu/wind/f2f/index.html>) with the Wyoming Institute for Disabilities (WIND). F2FHIC is a resource center for families of CYSHCN. MFH and WIND support F2FHIC efforts to ensure CYSHCN receive the services necessary to make transitions to all aspects of adult life, including adult healthcare, work, and independence. MFH also partners with UPLIFT (<http://www.upliftwy.org>). UPLIFT is an association that provides education and advocacy for parents, families, and the community, focusing on emotional, behavioral, and learning needs of children and youth.



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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.

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