

## A Comparison of Native and non-Native Children from the National Survey of Children with Special Health Care Needs (NS-CSHCN) Authors: Mike Allgrunn, PhD, Associate Professor, Economics & carole cochran, MSW, Director, South Dakota KIDS COUNT, Beacom School of Business.

### Introduction

This edition of South Dakota Kids Count Quarterly examines results of the 2009/2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). More specifically, it compares and contrasts six outcomes identified by the Maternal and Child Health Bureau for Native Americans/Alaskan Natives in seven states: Arizona, Alaska, Montana, New Mexico, North Dakota, Oklahoma, and South Dakota. The data were obtained from the Data Resource Center for Child & Adolescent Health (2009/10 NS-CSHCN SPSS Indicator Data Set, prepared by the Data Resource Center for Child and Adolescent Health, Child and Adolescent Health Measurement Initiative, www.childhealthdata.org). For the seven states listed above, each core outcome is discussed and data compared.

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

The National Survey of Children with Special Health Care Needs is a national telephone survey, which provides a broad range of information about the health and well-being of U.S. children with special health care needs. The data is collected in a manner that allows for comparison among states.

A total of 40,242 detailed CSHCN interviews were conducted during 2009-2010. At least 750 interviews in each state and the District of Columbia provided detailed information about overall CSHCN populations, and for subgroups such as age, race/ethnicity, family structure and household income.

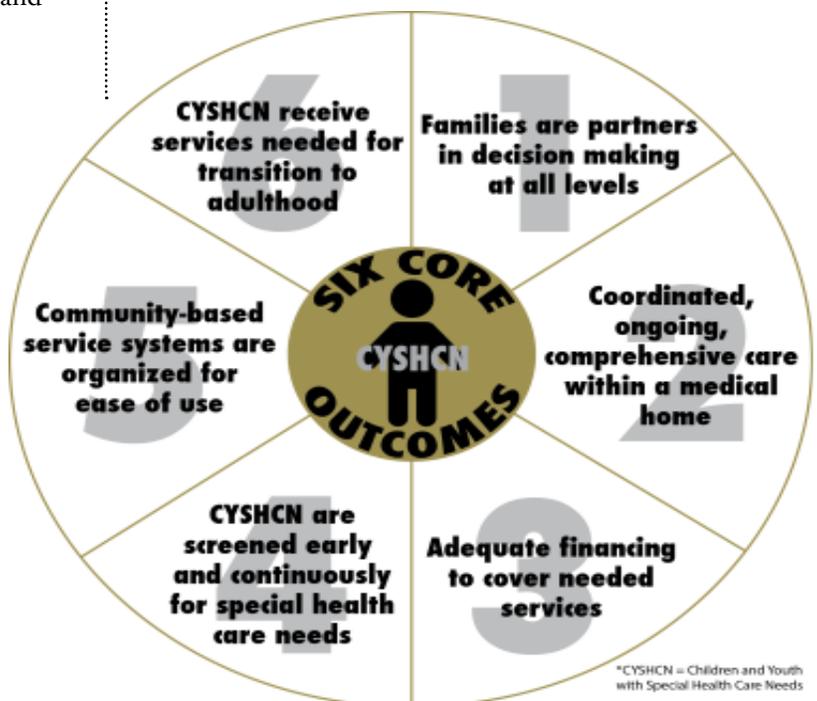
To protect against an individual child being inadvertently identified in states with relatively few children, the National Center for Health Statistics includes individual level data only when a group comprises 5% or more of the total child population in a state. For the NS-CSHCN, seven states have data in the publicly released data files for American Indian or Native Alaskan children (Arizona, Alaska, Montana, New Mexico, North Dakota, Oklahoma, and South Dakota). (2009/10 NS-CSHCN SPSS Indicator Data Set prepared by the Data Resource Center for Child and Adolescent Health, Child and Adolescent Health Measurement Initiative. www.childhealthdata.org)

### About the Maternal and Child Health Outcomes

Effective promotion of health and health services for children and youth with special health care needs (CYSHCN) requires a system of care that is integrated,

comprehensive, coordinated, family-centered and consistent across the lifespan. Working with families, agencies and other key individuals, the Maternal and Child Health Bureau (MCHB) developed six core outcomes families should expect from the service system. They are:

1. Partners in Decision-Making
2. Medical Home
3. Adequate Health Insurance
4. Early and Continuous Screening
5. Ease of Community-Based Service Use
6. Transition to Adulthood

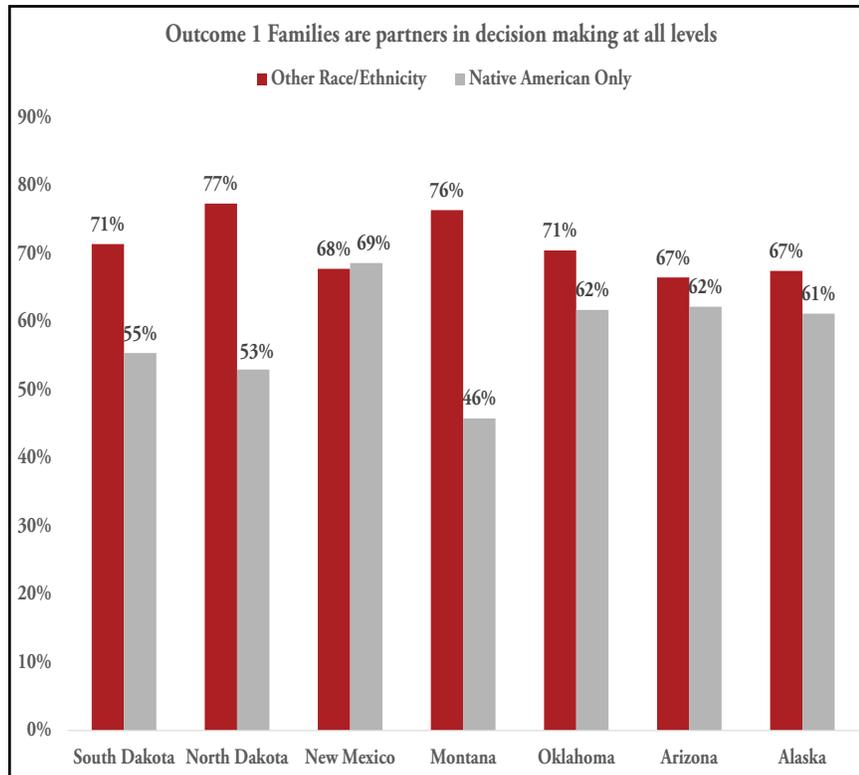


\*CYSHCN = Children and Youth with Special Health Care Needs

Source: Community of Care. Healthy Communities that Work, 2015.

## Core Outcome #1: Families are Partners

*A partnership between a child's family and his/her health care providers allows for an open and intentional dialogue about unique health needs. This leads to individualized care with the ability to identify factors that may negatively affect the child's health. It also gives children and their families needed support during critical periods of development. (Community of Care. Healthy Communities that Work, 2015)*



### Comparison between families of non-Native and Native children with special health care needs

- New Mexico families who have Native children with special health care needs felt part of the decision-making process at a rate slightly higher than non-Native families: 69 percent to 68 percent respectively.
- Families of non-Native Montana children felt more engaged in the decision-making process at a rate of one-and-a-half times that of Native families: 76 percent to 46 percent.
- Conversely, there was a 10 point or lower gap between non-Native families and Native families in Oklahoma, Arizona and Alaska.
- In North Dakota and South Dakota, there was a greater sense of not being included in the decision-making process by Native than non-Native families.

### Comparison among families of Native children with special health care needs

- Of the seven states, Native families with children with special health care needs responded as most involved in the decision-making process in New Mexico (69 percent).
- Native families least likely to feel like partners in their child's health care decision-making were in Montana, 46 percent.
- In three states, almost two-thirds of Native families felt like partners in the decision-making process: Oklahoma (62 percent), Arizona (62 percent), and Alaska (61 percent).
- About half of Native families in North Dakota (53 percent) and South Dakota (55 percent) felt like partners in the decision-making process.

## Core Outcome #2 – Medical Home

*A medical home recognizes the family as a constant in a child’s life, emphasizes partnership between health care professionals and families, and ensures children have easy and timely access to appropriate, individualized and comprehensive preventive care with a focus on integrated services and positive long-term outcomes. (Community of Care. Healthy Communities that Work, 2015).*

“Medical home” refers to medical care for infants, children, and adolescents that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. The medical home concept was first proposed by the American Academy of Pediatrics (AAP) in a 1992 policy statement that was updated in 2002. The AAP definition of medical home emphasizes that a medical home is “not a building, house, or hospital, but rather an approach to providing continuous and comprehensive primary pediatric care from infancy through young adulthood, with availability 24 hours a day, 7 days a week, from a pediatrician or physician whom families trust.”

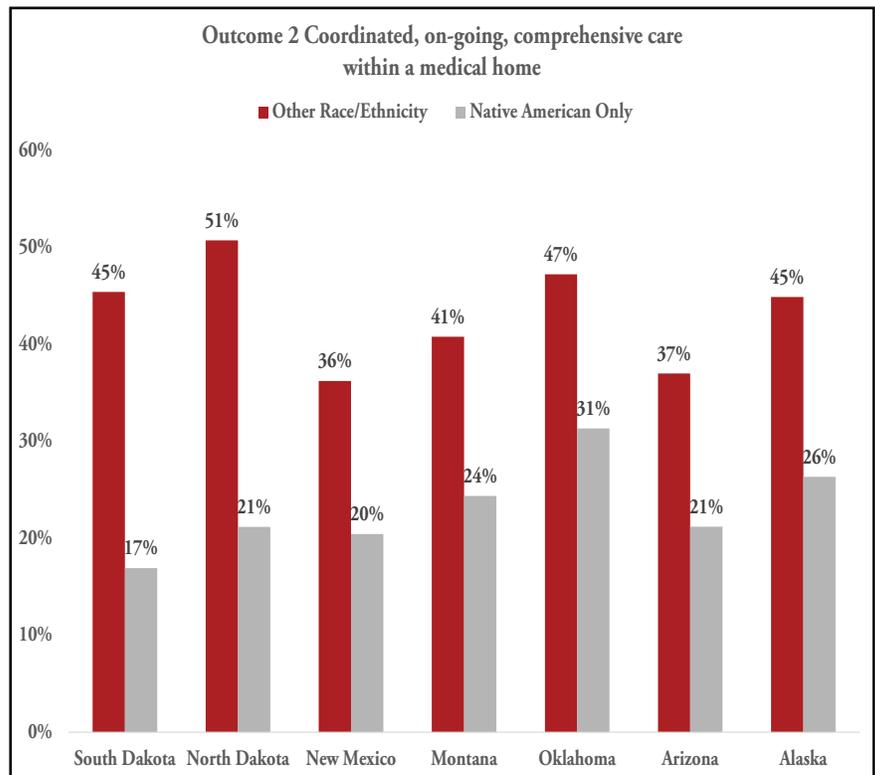
The need for an ongoing source of health care—ideally a medical home—for all children has been identified as a priority for child health policy reform at the national and local level. The U.S. Department of Health and Human Services’ Healthy People 2010 and 2020 goals and objectives state that “all children with special health care needs will receive regular ongoing comprehensive care within a medical home” and multiple federal programs require that all children have access to an ongoing source of health care.

### Comparison between families of non-Native children and Native children with special health care needs

- Non-Native families were much more likely than Native families to feel their children received coordinated, ongoing, comprehensive care within a medical home. This was the only MCHB core outcome that showed these results.
- The greatest difference between non-Native families and Native families for care within a medical home were North Dakota and South Dakota, with a 30 percent and 28 percent difference respectively.
- The remaining five states showed half that difference, Alaska 19 percent, Montana 17 percent, and New Mexico, Oklahoma, and Arizona each at 16 percent.

### Comparison among families of Native children with special health care needs

- Native families in Oklahoma (31 percent) were somewhat more likely to have a medical home than Native families in the other six states.
- Similar responses showed about one-fifth to one-fourth of Native families felt they had a medical home: Alaska (26 percent), Montana (24 percent), Arizona (21 percent), North Dakota (21 percent) and New Mexico (20 percent).
- Native families in South Dakota (17 percent) were least likely to feel their child had a medical home.



### Core Outcome #3: Adequate Financing

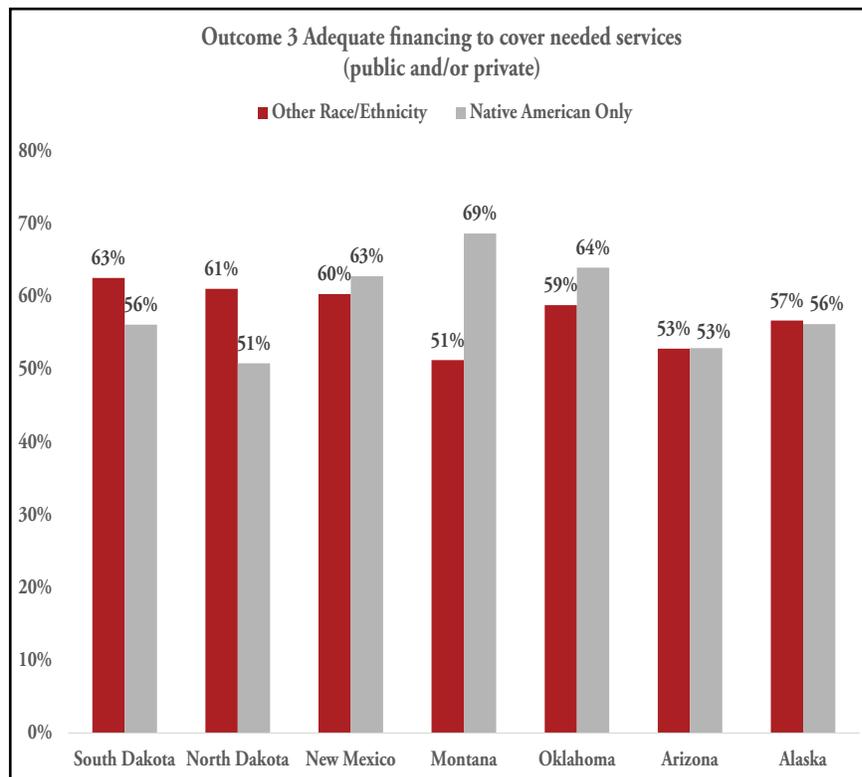
*Children with nonexistent, inconsistent or inadequate health insurance are less likely to receive the care they need, and suffer greater health and psychological consequences as a result of their unmet needs. Adequate insurance plays a substantial role in ensuring access to family-centered care and a medical home. (Community of Care. Healthy Communities that Work, 2015)*

#### Comparison between families of non-Native and Native children with special health care needs

- Native families in Montana (69 percent), Oklahoma (64 percent), and New Mexico (63 percent) were more likely than non-Native families to say they had adequate financing to cover needed services for their children with special health care needs.
- One state, Arizona, showed no difference between non-Native and Native families with children with special health care needs. Native families in Alaska (56 percent) were slightly less likely than non-Native families (57 percent) to say their children had adequate financing to cover needed services.
- Native families compared to non-Native were least likely to feel their children had adequate financing to cover needed services in North Dakota (51 to 61 percent) and South Dakota (56 to 63 percent).

#### Comparison among families of Native children with special health care needs

- Almost 7 in 10 Native families in Montana with children with special health care needs were likely to report they had adequate financing to cover needed services.
- Almost two-thirds of Native families in New Mexico (63 percent) and Oklahoma (64 percent) reported they had adequate financing to cover needed services.
- Over half of Native families in the remaining states reported they had adequate financing for needed services.



## Core Outcome #4: Early Screening

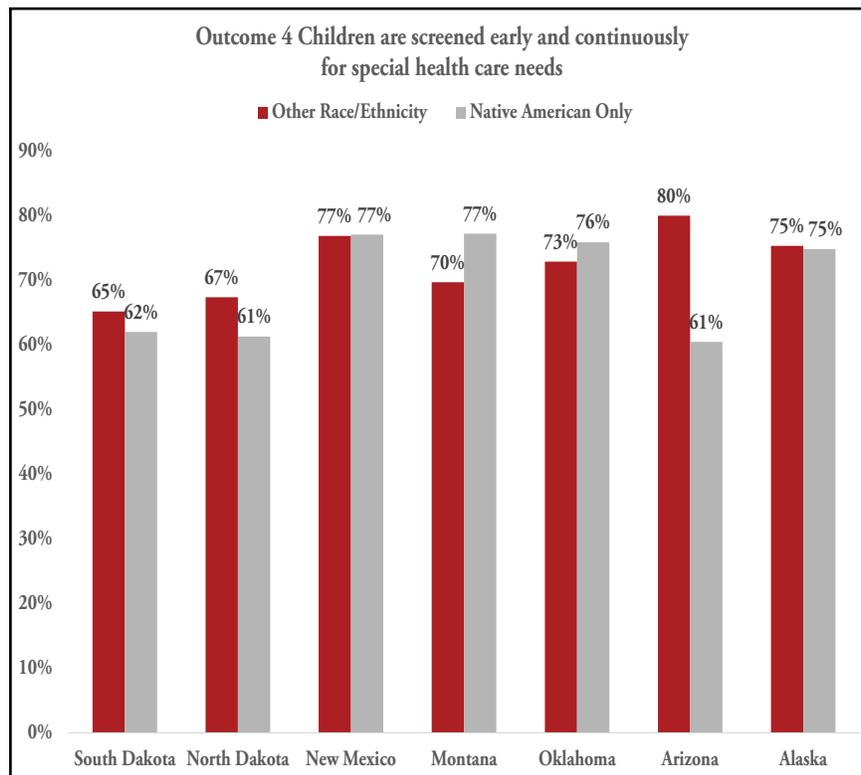
*Early and continuous screening, from birth through the teen years, allows emerging needs to be identified as early as possible, which is critical to addressing them appropriately and minimizing long term consequences. (Community of Care. Healthy Communities that Work, 2015)*

### Comparison between families of non-Native and Native children with special health care needs

- Non-Native families were much more likely than Native families in Arizona to report their children were screened early and continuously for special health care needs (80 percent to 61 percent).
- Conversely, Native families in Montana and Oklahoma were more likely than non-Native families to report their children were screened early and continuously for special.
- There were no differences found between non-Native and Native families reporting their children being screened early and continuously in New Mexico (77 percent) and Alaska (75 percent).
- Non-Native families were slightly more likely than Native families in North Dakota and South Dakota to report their children were screened early and continuously.

### Comparison among families of Native children with special health care needs

- Three-fourths or more of Native families in four states, Alaska, Oklahoma, Montana, and New Mexico, reported their children were screen early and continuously for special health care needs.
- The remaining three states, South Dakota, Arizona, and North Dakota, showed slightly less than two-thirds of Native families reporting their children were screen early and continuously for special health care needs.



## Core Outcome #5: Easy-to-use systems

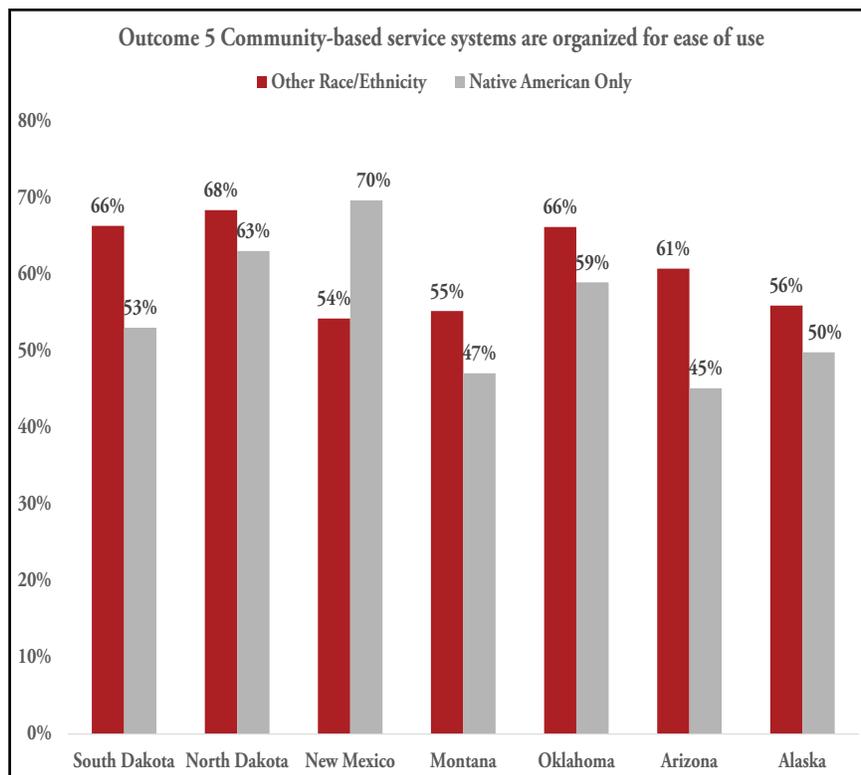
*Children and youth with special health care needs have complicated needs which often require services from multiple providers as well as schools and other community based organizations. Services must be organized and integrated in a way that reduces frustration to reduce the barriers to access that leave children without needed services. (Community of Care. Healthy Communities that Work, 2015)*

### Comparison between families of non-Native and Native children with special health care needs

- Native families in New Mexico reported community-based services were easy to use at a rate 24 percent higher than non-Native families (70 percent versus 54 percent).
- Non-Native families, in Arizona and South Dakota, reported community based services were easy to use at a higher rate than Native families (Arizona 61 percent versus 45 percent; South Dakota 66 percent versus 53 percent).
- For the remaining states, the gap between non-Native and Native families reporting community-based services were easy to use was less than 10 points (Montana 55 percent versus 47 percent; Alaska 56 percent versus 50 percent; and North Dakota 68 percent to 63 percent).

### Comparison among families of Native children with special health care needs

- Native families in New Mexico (70 percent) reported community-based services were easy to use at a rate 1.5 times higher than Native families in Arizona (45 percent) or Montana (47 percent).
- Almost two-thirds of Native families in North Dakota (63 percent) reported community-based services were easy to use.
- Three in five Native families in the remaining states reported community-based services were easy to use (South Dakota 53 percent; Oklahoma 59 percent; and Alaska 50 percent).

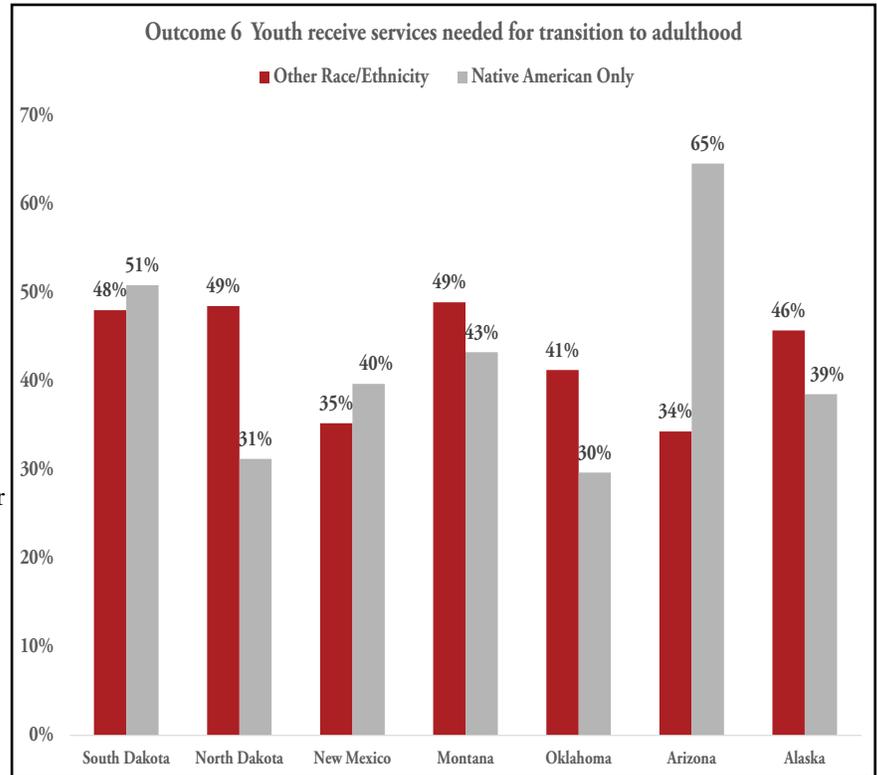


## Core Outcome #6: Youth with special health care needs receive services needed for transition to adulthood

*Historically, less than half of youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. (Community of Care. Healthy Communities that Work, 2015)*

### Comparison between families of non-Native and Native children with special health care needs

- Native families with youth transitioning to adulthood in Arizona reported a much higher rate of receiving services than non-Native youth in Arizona (31 points higher, 65 percent versus 34 percent).
- Families with Native youth in South Dakota and New Mexico reported a slightly higher rate than non-Native families of receiving services for youth transitioning to adulthood (South Dakota 51 percent versus 48 percent; New Mexico 40 percent to 35 percent).
- Non-Native families with youth reported receiving services as they transitioned to adulthood at a higher or slightly higher rate than families with Native youth (Oklahoma 41 percent versus 30 percent; North Dakota 49 percent versus 31 percent; Montana 49 percent versus 43 percent; and Alaska 46 percent versus 39 percent).



### Comparison among families of Native children with special health care needs

- Arizona families were far more likely than families in the other six states to report receiving services as youth transitioned to adulthood. The rate for Arizona (65 percent) was 14 points higher than the next highest state, South Dakota (51 percent).
- Native families showed similar rates for youth transitioning to adulthood in Montana (43 percent), New Mexico (40 percent), and Alaska (39 percent).
- Rates for Native families in North Dakota (31 percent) and Oklahoma (30 percent) also show similar but lower rates for youth receiving services transitioning to adulthood.

### Conclusion

The monograph looked at the MCHB six core outcomes from the National Survey of Children with Special Health Care Needs (2009/10). Specifically it examined results for non-Native and Native children in seven states; Arizona, Alaska, Montana, New Mexico, North Dakota, Oklahoma, and South Dakota. These outcomes, measured by questions asked in the NS-CSHCN survey, determine the nation’s progress toward achieving “seamless system of services and access to care.”

Comparing non-Native children to Native children, the data showed that Core Outcome #2-Medical Home, was the only core outcome where non-Native families with children reported higher rates than Native families.

For the remaining core outcomes, New Mexico families whose Native children have special health care needs had outcomes better or the same as non-Native children with the same needs. This was similar for comparisons with other Native children from the other states compared in the article. Oklahoma and Montana Native families whose children have special health care needs also had higher percentages than non-Native children with Core Outcomes #3 and #4; and higher percentages than Native children for Core Outcomes #2-Medical Home, #3-Adequate Health Insurance, and #4-Early & Continuous Screening. Native children in South Dakota had a higher percentage than non-Native children for Core Outcome #6-Transition to Adulthood.



UNIVERSITY OF  
SOUTH DAKOTA

SD KIDS COUNT Project  
Beacom School of Business  
The University of South Dakota  
414 East Clark Street  
Vermillion, SD 57069

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ORGANIZATION  
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VERMILLION, SD  
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## References

2009/10 NS-CSHCN SPSS Indicator Data Set prepared by the Data Resource Center for Child and Adolescent Health, Child and Adolescent Health Measurement Initiative. [www.childhealthdata.org](http://www.childhealthdata.org). (n.d.).

Community of Care. Healthy Communities that Work. (2015). Retrieved from [www.cocsd.org](http://www.cocsd.org)

Data Resource Center for Child & Adolescent Health. (2016). Retrieved from <http://www.childhealthdata.org/home>

National Survey of Children with Special Health Care Needs. (2016). Retrieved from <http://www.childhealthdata.org/learn/NS-CSHCN>

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