

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

Introduction

This edition of the South Dakota Kids Count Quarterly explores results of the 2009/2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). More specifically, it compares and contrasts the Maternal and Child Health Bureau's six outcomes for South Dakota and the nation. The results were obtained from an online resource, the Data Resource Center for Child & Adolescent Health (<http://www.childhealthdata.org>), which is a project of the Child and Adolescent Health Measurement Initiative.

Background

The Maternal and Child Health Bureau* (MCHB) is primarily responsible for promoting and improving the health of children and mothers in the nation. The federal commitment to addressing maternal and child health can be traced first to the Children's Bureau (established in 1912) and then to Title V of the Social Security Act (1935). It serves today as the oldest federal-state partnership. Through Title V the federal government assists states and territories in caring for the health and welfare of the mothers and children served through the Maternal and Child Health (MCH) Services Block Grant. Today, MCHB administers a broad range of programs that address the needs of the nation's MCH population, the largest of which is Title V, The Maternal and Child Health Services Block Grant. (Maternal and Child Health Bureau website <http://mchb.hrsa.gov/about/index.html>)

The Maternal and Child Health Bureau supports both the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN), which are conducted every two years, alternately. The NS-CSHCN takes a close look at the health and functional status of U.S. children with special health care needs—their physical, emotional and behavioral health. It also looks at critical information on access to quality health care, coordination of services, access to a medical home, transition services for youth, and the impact of chronic condition(s) on the child's family (Data Resource Center).

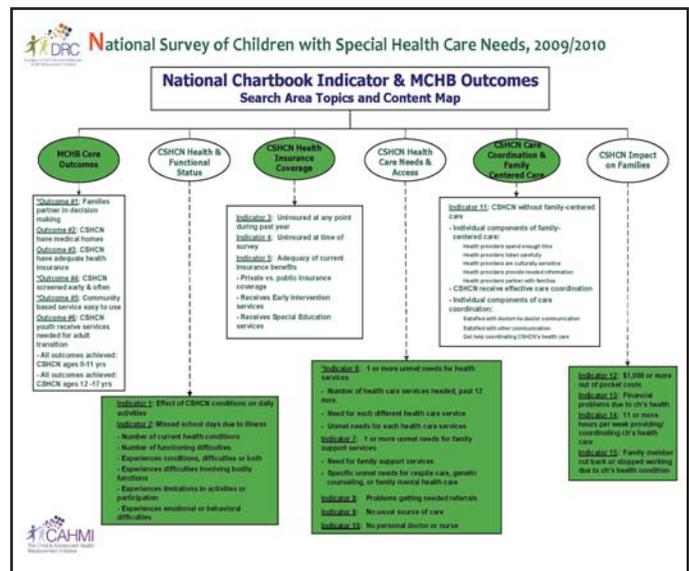
*The Maternal Child Health Bureau is part of the Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS)

Programs for Title V children with special health care needs have moved toward a public health infrastructure-building approach to ensure a seamless system of services and access to care for children and away from providing direct services to children with special health care needs (Strickland, van Dyck, Kogan, Lauver, Blumberg, Bethell, & Newacheck 2011).

Working with families, agencies and other key individuals, the MCHB developed six core outcomes to describe what families should expect from the service system. The six care areas are:

1. Partnering with families in shared decision-making for child's optimal health,
2. Coordinated, ongoing, comprehensive care within a medical home,
3. Consistent and adequate public or private insurance,
4. Early and continuously screening for special health care needs,
5. Easy access to community based services,
6. Receive services for transition to adulthood.

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." In addition to the MCHB core outcomes, the NS-CSHCN survey includes questions related to health and functional status, health insurance coverage, health care needs and access, coordination and family centered care, and impact on families (See graphic below).



MCHB Core Outcomes and South Dakota

The 2009/10 NS-CSHCN survey estimated there are 24,415 children with special health care needs in South Dakota. Their prevalence is 12.5% for South Dakota as compared to 15.1% for the nation. The table below compares South Dakota to the national average for the MCHB core outcomes.

Core Outcome	South Dakota %	United States %
1. Partners in Decision-Making	69.7%	70.3%
2. Medical Home	42.2%	43%
3. Adequate Health Insurance	62%	60.6%
4. Early and Continuous Screening	64.9%	78.6%
5. Ease of Community-Based Service Use	64.9%	65.1%
6. Transition to Adulthood	48.3%	40%

Comparing MCHB core outcomes from the 2005/06 NS-CSHCN shows a lower percentage of CSHCN achieving the outcome for both South Dakota and the nation.

Core Outcomes	South Dakota		United States % of CSHCN Achieving Outcome	
	% of CSHCN Achieving Outcome		Outcome	
	2005/06	2009/10	2005/06	2009/10
1. Partners in Decision-Making	NC	NC	NC	NC
2. Medical Home	53.80%	42.20%	41.70%	43.00%
3. Adequate Health Insurance	66.70%	62.40%	62.00%	60.60%
4. Early and Continuous Screening	NC	NC	NC	NC
5. Ease of Community-Based Service Use	NC	NC	NC	NC
6. Transition to Adulthood	50.60%	48.30%	41.20%	40.00%

NC – Not comparable across survey years because the method of measurement is sometimes modified between survey years to accommodate changing definitions and priorities.

Core Outcome #1

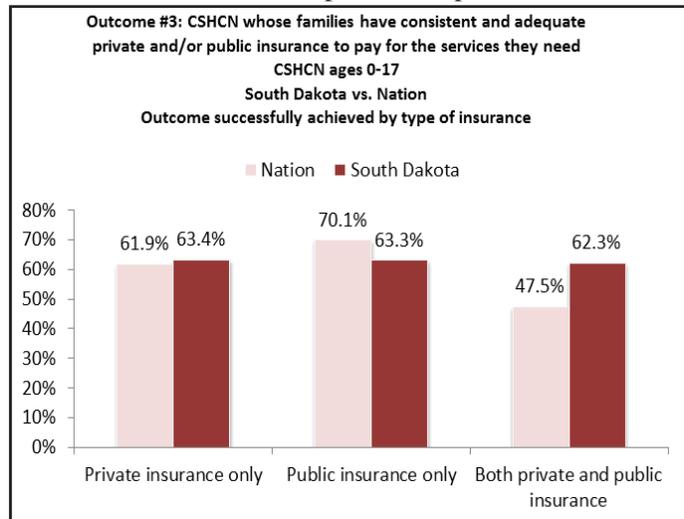
The first core outcome assesses the degree to which health professionals engage families in decision-making about their child’s health care. Based on data from the 2009/10 NS-CSHCN, 70.3% of CSHCN nationwide meet Outcome #1; South Dakota followed closely at 69.7%. States ranged from 61.8% - 77.6% (DRC, 2011).

Core Outcome #2

Outcome #2 assesses if CSHCN receive care within a medical home. Having a medical home is a priority of the American Academy of Pediatrics. Measurements of this outcome include: has at least one personal doctor or nurse, has no problems getting referrals when needed, and families that receive effective care coordination. As measured in the 2009/10 NS-CSHCN, nationally, 43.0% of CSHCN meet this outcome and 42.2% of South Dakota CSHCN met it. States ranged from 34.2-50.7% (DRC, 2011).

Core Outcome #3

The third core outcome assesses adequate insurance to cover needed services of the CSHCN and was measured by questions regarding the child’s: health insurance offered benefits that usually or always meet the child’s needs; the child was insured and had no gaps in coverage in the past year, and non-covered charges are usually or always reasonable, and the child’s health insurance usually or always allows the child to see needed providers. The 2009/10 survey showed 60.6% of the nation’s CSHCN and 62.4% of South Dakota CSHCN met this outcome. State ranged from 49.9% to 72.6% (DRC, 2011). The chart below shows the percentage of families with adequate and consistent insurance for the services they need. South Dakota ranks higher than the nation in the number of families that have both public and private insurance.



Core Outcome #4

Outcome #4 assesses early and continuous screening for CSHCN. That is the precursor to early identification, diagnosis and treatment of special health care needs, which leads to more efficient and comprehensive care. Measurements of this outcome include children who have had a well-child check up and preventive dental visits in the past 12 months. Discovering abnormalities as soon as possible will minimize long-term consequences of a special health care need. South Dakota's Well-Child Care Program helps foster the health and well-being of children and youth on Medicaid or the Children's Health Insurance Program (South Dakota, 2011). In South Dakota, the suggested check-up schedule includes general health, dental vision, hearing, lead, and immunizations (South Dakota, 2011). Nationally, 78.6% of CSHCN and 64.9% of South Dakota CSHCN met this outcome. State ranged from 64.9% - 89.1% (DRC, 2011).

Core Outcome #5

Outcome #5 assesses integration of services for CSHCN. Key measurements include difficulties or delays receiving services and parental frustrations in getting services for their child. Nationally, 65.1% of CSHCN and 64.9% of South Dakota CSHCN met this outcome; and States ranged from 54.3% - 73.5% from the 2009/10 NS-CSHCN (DRC, 2011).

Core Outcome #6

The final outcome assesses services for CSHCN ages 12-17 as they transition from 'child' health services to "adult" services. Measurements include guidance for transition to adult health care (e.g. transitioning to doctors who treat adult patients, changing health care needs of adults, and maintaining health insurance as an adult); and if the child's doctor encourages self-management skill. The 2009/10 NS-CSHCN showed nationally, 40.0% and 48.3% of South Dakota's CSHCN met this outcome. States range from 31.7% - 52.7% (DRC, 2011).

Conclusion

This article provides an introduction to the National Survey for Children with Special Health Care Needs, reviewing Maternal and Child Health of the data from the 2009/10, and comparing MCH data from the 2005/06 NS-CSHCN. The NS-CSHCN provides important data that can be used to plan for services and/or programs for children with special health needs and their families.

The six core MCH outcomes provide South Dakota with knowledge of the care currently provided to children with special health care needs. The 2009/2010 NS-CSHCN survey showed that South Dakota was lower (-14%) than the nation in the fourth outcome (CSHCN who are screened early and continuously for special health care needs). South Dakota had a higher percentage (+8%) than the nation on the sixth core outcome (CSHCN who receive services for transition to adulthood).

References

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About the Data Resource Center for Child & Adolescent Health

The mission of the Data Resource Center for Child and Adolescent Health (DRC) is to advance the effective use of public data on the status of children's health and health-related services for children, youth and families in the United States. The DRC does this by providing hands-on access to national, state, and regional data findings from large population-based surveys. Data are collected from parents and thus contribute a much needed voice in the drive to improve the quality of health care for children and youth.

Frequently asked questions about the Data Resource Center Indicator Sets for the NS-CSHCN are on its main website: <http://childhealthdata.org/learn/faq>. The site provides further details including data files available to public, collection of data, and the techniques used to analyze the data found.



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This Facts on KIDS is based on research by Kylie M. McCarthy, a MBA student with a concentration in Health Services Administration and a South Dakota Leadership Education Excellence in Caring for Children with Neurodevelopmental and Related Disorders (LEND) Program trainee.

LEND is a one year specialized training which focuses on the interdisciplinary training of professionals for leadership roles in the provision of health and related services to infants, children and adolescents with neurodevelopmental and related disabilities and their families. The South Dakota LEND Program is supported by a grant from the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), of the United States Department of Health and Human Services - grant number T73MC00037-13-04.

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The South Dakota KIDS COUNT Project (www.sdkidscount.org) The South Dakota KIDS COUNT project is part of a network of projects supported and coordinated by the Annie E. Casey Foundation. Data and information are collected and published about the demographics, health, education, economic and safety of children. The data provide South Dakotans a broad picture of how the state’s children are doing and provide parents, policymakers, advocates and others interested in the well-being of children with information they need to make informed decisions about policies and programs for children and families. Additional funding for the state project comes from the South Dakota Departments of: Education & Social Services.

Thank you to:

Kylie M. McCarthy for her work on this monograph. She will be receiving her Masters of Business Administration (MBA) degree from the Beacom School of Business, The University of South Dakota in December 2013.

Betsy Rice, SD Voices for Children