



CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN)

Children with special health care needs (CSHCN) are defined 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."¹ This broad definition is used by the federal Department of Health and Human Services and allows state CSHCN programs to create programs for a variety of special health care needs, and customize those programs to meet the needs within a state. This issue of *Montana Public Health* describes CSHCN activities in Montana.

Montana CSHCN in Perspective

Rates of conditions which may identify a child as having a special health care need vary from state to state. For example, for the time period 2001-2005, Montana had a higher rate of infants born with cleft lip and palate, and a lower rate of premature births than did the U.S. as a whole. (Table 1)

Table 1. Incidence of cleft lip or palate and premature birth in the Montana and U.S., 2001-2005

PLACE	CLEFT LIP/PALATE		PREMATURE BIRTH	
	#	rate per 1000	#	rate per 100
Montana	82	1.5	6,387	11.3
U.S.	15,761	0.8	2,487,339	12.2

The federal Maternal Child Health Bureau developed and conducted a telephone survey of families with children, including those with special health care needs, in 2001, and again in 2005-2006. This survey, the National Survey of Children with Special Health Care Needs (NS-CSHCN), provides information on:

- Prevalence of CSHCN in the Nation and in each State
- Demographic characteristics of CSHCN
- Types of health and support services needed
- Family perceptions about access to and satisfaction with care received.

Approximately 750 interviews regarding a child with special health care needs were conducted in each of the 50 States and the District of Columbia. Families with CSHCN were queried regarding their child's health and functional status, access to care, care coordination, satisfaction with care, health insurance coverage, adequacy of health care coverage, and impact of the child's special needs on the family.

Based on the results of this survey, Montana had an estimated 27,853 children with special health care needs in 2006, up somewhat from an estimated 26,981 in 2001. Examples of conditions that qualify children with special health needs in Montana are listed in Table 2.

Table 2. Examples of conditions among children with special health needs, Montana

- Cystic fibrosis
- Diabetes
- Cleft lip/palate
- Asthma
- Seizure disorder
- Juvenile rheumatoid arthritis

(for more information: <http://www.cshs.mt.gov>)

Children with special health care needs in Montana are more likely to be very poor, miss more school, and more likely to have inadequate or no health insurance than CSHCN in the U.S. as a whole. (Table 3)

Table 3. Findings from the national survey of children with special health care needs, Montana and U.S., 2001 and 2006

INDICATOR FOR CSHCN	PERCENT WITH INDICATOR			
	2001		2006	
	MT	US	MT	US
family at 0-99% federal poverty level	14.6	13.6	18.0	13.9
≥11 days school absence due to illness	21.1	15.8	18.7	14.3
no health insurance at some point during year	19.8	11.6	17.4	8.8
no personal doctor	13.7	11.0	9.5	6.5
condition causes financial problem for family	26.6	20.9	25.3	18.1

The Montana Children's Special Health Services (CSHS) Program Children with special health care needs in Montana may be eligible to receive services from the CSHS Program, DPHHS. The program's mission is to develop and support systems of care for CSHCN. The program can offer the following services to CSHCN and their families:

1. **Pediatric clinic services** The CSHS program supports regional clinics located in Missoula, Great Falls and Billings. Clinics provide service to children with conditions that include cleft/craniofacial, metabolic, neurological, genital-urinary, pulmonary, cystic fibrosis, genetic, and endocrine disorders. These clinics increased services from 1219 clinic visits in 2001 to 2731 in 2007.

2. **Financial Assistance** Financial assistance for medical care is available on a limited basis. Program policy allows up to \$2000 per year per child with covered conditions. During 2007, 70 clients received an average of \$1309 per child for medical services.

3. **Resource and Referrals** CSHS staff provides resource and referral information to families and providers who contact the program. Through clinic services, financial assistance and resource and referral contacts, the CSHS program provided services to 3876 CSHCN during 2007.

Recommendations for Montana clinicians:

Contact the Children's Special Health Services (CSHS) for information about specialty clinics in your community.

Refer families with CSHCN to CSHS for eligibility assessment and possible financial assistance for medical services.

Assess impact of condition on school attendance and on family support needs.

For more information regarding Children's Special Health Services, call 406-444-3620 or visit the website at <http://www.cshs.mt.gov>

References:

¹ McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics* 1998;102:137-140.

² CDC. VitalStats. <http://www.cdc.gov/nchs/vitalstats.htm>. Accessed 7/22/08.

³ U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2005-2006*. Rockville, Maryland: U.S. Department of Health and Human Services, 2008.

2,600 copies of this public document were published at an estimated cost of \$0.45 per copy, for a total cost of \$1,170.00, which includes \$403.00 for printing and \$767.00 for distribution.



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