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PROGRAMS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS - SURROUNDING STATES AND SURVEY RESULTS

This memorandum summarizes the state programs for children with special health care needs in North Dakota, Minnesota, Montana, and South Dakota. Also presented are selected results from a 2004 United States Department of Health and Human Services report of a 50-state national survey of parents of children with special health care needs.

SUMMARY OF STATE PROGRAMS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

North Dakota

The annual budget for North Dakota's children's special health services program is approximately \$960,000. Of this amount, \$396,000 is from the general fund and \$564,000 is from federal and other funds. The federal and other funds consist of approximately \$500,000 of federal maternal and child health block grant funds.

The program is administered by the Department of Human Services and has a medical advisory council. The program employs eight full-time equivalent (FTE) positions, including a director, nurse, program administrator, two eligibility and claims staff members, and two administrative support positions.

The program serves approximately 1,400 children per year. Approximately 300 to 325 families receive financial assistance from the program. Those with incomes at or below 185 percent of the federal poverty level receive services at no cost. Those with incomes above 185 percent of the federal poverty level share in the cost of services. The maximum financial assistance a family may receive each year on behalf of a child is \$20,000. The department spends approximately \$160,000 per year providing financial assistance to families for diagnostic and treatment services.

The primary responsibilities of the program are to:

1. Plan, organize, and manage specialty clinics for children with special health care needs by bringing in specialists to provide services for the children - The state provides for the cost of the services.
2. Provide financial assistance to families - Families with incomes up to 185 percent of the federal poverty level receive specialty care services at no cost.
3. Coordinate with county and public health staff to assist families access services and resources for their child with special health care needs.
4. Provide information and resources to assist families, including offering a toll-free telephone line for families to use to obtain information.
5. Distribute food and formula for children with phenylketonuria and maple syrup urine disease.
6. Provide payment for services relating to children with Russell-Silver Syndrome.

Minnesota

The annual budget for Minnesota's children's special health needs program is approximately \$3 million. Of this amount, \$487,000 is from the general fund, \$1.9 million from federal maternal and child health block grant funds, and \$600,000 from other funds.

The program is administered by the Minnesota Department of Health and does not have an advisory board. The program employs 23.3 FTE positions, including a director, nurses, social workers, and support staff. The state is divided into six districts where the special health services nurses and social workers are located.

The program serves approximately 5,200 children annually. Because of state budget constraints, beginning in 2003 the program discontinued providing financial assistance to families. Prior to 2003 financial assistance was provided to families primarily to assist in paying health insurance premiums to keep the families from applying for Medicaid. The program provided financial assistance to approximately 2,100 families at a cost of approximately \$1.5 million per year.

The primary responsibilities of the program are to:

1. Build health systems in the state, primarily involving the private sector, to provide services for children with special health care needs.
2. Conduct specialty clinics outside the Minneapolis/St. Paul area by planning and organizing the clinics and contracting with private providers for services.
3. Focus on expanding early intervention services that have been provided from birth to age 3 to birth to age 21 for children with special health care needs.
4. Assist local public health and school nurses to identify children with special health care needs and coordinate services with the medical team and others involved with the child.

Montana

The annual budget for Montana's children's special health services program is \$769,000, of which \$744,000 is from the federal maternal and child health block grant and \$25,000 from tobacco tax revenue.

The program is administered by the Montana Department of Public Health and Human Services and has an advisory committee consisting of providers, consumers, and state agency personnel. The program employs 6 FTE positions, including 1 supervisor, 2 nurse consultants, 2 program specialists, and 1 fiscal specialist.

The program serves approximately 2,600 children each year and provides financial assistance of approximately \$200,000 each year to an estimated 100 families. Financial assistance is available to eligible families with incomes less than 200 percent of the federal poverty level. The financial assistance is limited and primarily assists in providing reimbursement for excessive costs not covered by another payer, such as private health insurance, Medicaid, or the state children's health insurance program. The maximum allowable financial assistance each recipient may receive is \$12,000 per year.

The primary responsibilities of the program include:

1. Assist in building systems of care in the state involving private providers, community programs, and state agencies and programs to meet the needs of children with special health care needs and their families.
2. Organize specialty clinics by bringing in specialists to provide services to children with special health care needs.
3. Provide financial assistance to eligible families with incomes less than 200 percent of the federal poverty level.
4. Assist families to obtain needed services and provide advocacy and educational services relating to children with special health care needs.

South Dakota

The annual budget for South Dakota's children's special health services program is approximately

\$1 million per year, of which \$400,000 is from the state general fund and \$600,000 from federal maternal and child health block grant funds.

The program is administered by the Department of Health and does not have an oversight or advisory committee. The program employs 2.5 FTE positions and contracts with nonprofit organizations to provide regional teams across the state.

The state is divided into four regions. Each region has a team made up of one or two registered nurses, a social worker, dietitian, and clerical support. The state contracts with private, nonprofit organizations to provide these teams. Contract costs are approximately \$200,000 per year for each region.

The program serves approximately 7,600 children and budgets approximately \$82,000 per year for financial assistance for families. Families with incomes of up to 225 percent of the federal poverty level are eligible for financial assistance based on a sliding fee scale. A family may not receive more than \$20,000 in financial assistance each year.

The primary responsibilities of the program are to:

1. Plan and organize specialty care clinics for children with special health care needs across the state by bringing in specialists to provide care.
2. Provide financial assistance for families with incomes of up to 225 percent of the federal poverty level based on a sliding fee scale.
3. Coordinate care for children with special health care needs and their families.

CHILDREN WITH SPECIAL HEALTH CARE NEEDS - NATIONAL SURVEY RESULTS

The following schedule presents the results of a national survey regarding children with special health care needs conducted in 2001 by the United States Department of Health and Human Services and released in 2004. The information is based on surveys of parents. Results are shown for North Dakota, Minnesota, Montana, South Dakota, and the United States.

Prevalence Statistics					
	North Dakota	Minnesota	Montana	South Dakota	United States
Number of self-reported children with special health care needs	19,651	160,946	26,981	22,669	Not reported
Percent of children with special health care needs	12.4%	12.4%	11.8%	11.3%	12.8%
Prevalence by age					
Children 0-5 years of age	6.8%	6.5%	6.9%	7.1%	7.8%
Children 6-11 years of age	14.3%	12.5%	11.7%	12.3%	14.6%
Children 12-17 years of age	15.3%	17.4%	15.6%	13.9%	15.8%
Prevalence by sex					
Male	14.7%	13.7%	13.2%	12.7%	15%
Female	10%	11.1%	10.3%	9.8%	10.5%

	North Dakota	Minnesota	Montana	South Dakota	United States
Prevalence by poverty level					
0-99 percent federal poverty level	18.5%	11.3%	14.6%	14.6%	13.6%
100-199 percent federal poverty level	11.8%	16.1%	11.7%	12.4%	13.6%
200-399 percent federal poverty level	11.5%	11.2%	10.7%	9.6%	12.8%
400 percent federal poverty level	12.3%	13.6%	13.5%	12.1%	13.6%
Indicator					
	North Dakota	Minnesota	Montana	South Dakota	United States
Child health					
Percentage of children with special health care needs whose conditions affect their activities usually, always, or a great deal	17.4%	19.2%	28.7%	19.4%	23.2%
Percentage of children with special health care needs with 11 or more days of school absences due to illness	13.6%	11.2%	21.1%	11.8%	15.8%
Health insurance coverage					
Percentage of children with special health care needs without insurance at some point in the last year	12.9%	7.6%	19.8%	9.1%	11.6%
Percentage of children with special health care needs currently uninsured	4.7%	4.4%	12.1%	5%	5.2%
Percentage of currently insured children with special health care needs with insurance that is not adequate	30.7%	25.8%	38.5%	32.8%	33.5%
Access to care					
Percentage of children with special health care needs with any unmet need for specific health care services	12.8%	14.1%	22.3%	11%	17.7%
Percentage of children with special health care needs with any unmet need for family support services	3.5%	7.4%	9.2%	3.9%	5.1%
Percentage of children with special health care needs needing specialty care who had difficulty getting a referral	19.1%	23.5%	23.6%	13.6%	21.9%
Percentage of children with special health care needs without a usual source of care (or who rely on the emergency room)	11.5%	11%	10.7%	10.8%	9.3%
Percentage children with special health care needs without a personal doctor or nurse	11.2%	15.4%	13.7%	11.2%	11%
Family-centered care					
Percentage of children with special health care needs without family-centered care	29.5%	30.8%	32.6%	29.5%	33.5%
Impact on family					
Percentage of children with special health care needs whose families pay \$1,000 or more in medical expenses per year	14%	11.6%	15.2%	13.2%	11.2%
Percentage of children with special health care needs whose condition caused financial problems for the family	24%	19.5%	26.6%	20.4%	20.9%
Percentage of children with special health care needs whose families spend 11 or more hours per week providing for coordinating care	14.7%	8.5%	14.9%	12.4%	13.5%
Percentage of children with special health care needs whose condition affected the employment of family members	21.8%	27.1%	27.3%	27%	29.9%