



Children with Special Health Care Needs in Montana:

Needs Summary

February 2012

Sources of Information

Multiple data sources are available to Montana for assessing the health status and needs of children with special health care needs (CSHCN) in the state. The sources include nationally standardized, phone-based surveys, state-developed mailed surveys, parent/guardian focus groups, and key informant interviews. The variety of data sources provides Montana with a rich range of topics and perspectives on CSHCN. Statewide surveys, such as the National Survey of Children with Special Health Care Needs (NSCSHCN) summarize information on all CSHCN in the state, even those who may not be connected with services or who receive services out of state. More targeted data sources, such as surveys sent out through organizations or contact lists, provide information on specific populations of CSHCN, such as those already receiving services through or connected with a program or organization. Focus groups and key informant interviews often have fewer participants, but may provide more detailed data than what is available through surveys.

The NSCSHCN is a phone survey of randomly selected households conducted every four to five years. Sample sizes are large enough to provide state-level summaries (approximately 750 people surveyed per state). Contacted households are screened for the presence of one or more child with special health care needs and, if a CSHCN resides in the household, parents or guardians are asked a series of questions. The results of the survey include an estimate of the prevalence of CSHCN in each state or locality, demographic factors, types of special needs, unmet needs, health care access and quality, and others. The NSCSHCN also provides state-level data on the core outcomes for CSHCN.

Some information on CSHCN is also collected in the National Survey of Children's Health (NSCH), which follows a similar methodology as the NSCSHCN. The inclusion of CSHCN data in the NSCH allows for some comparisons of health status between children with and without special needs.

State-developed needs assessment surveys were distributed to parents and guardians of CSHCN through early intervention programs and clinics throughout the state in 2005. The recipients were identified because they had been referred to or were clients of the Children's Special Health Services Section, the regional specialty clinics, or other organizations that provide services to children with special health care needs. The results provide a statewide summary of children somehow connected to and identified by the network of specialty services in the state.

The statewide needs assessment survey was limited to two pages (1 sheet of paper-front and back). Respondents were asked to identify the top five health needs for Montana's children with special health care needs (CSHCN). The lists of health needs respondents were asked to select from were based on previous needs assessments and data collection (both in Montana and nationwide), national and state performance measures and health status indicators, and literature reviews. All respondents were asked to indicate the ages of the CSHCN in their household. Two questions were asked about informational resources currently and potentially used by parents and guardians. To attempt to delve into whether children have a medical home, several questions were asked about care coordination, and an open-ended question asking how the child's primary care physician could be more helpful was also included. Respondents were asked to indicate what services they have difficulty accessing, and finally, a question about dental care was included to determine what percentage of children had seen a dentist in the past year, the distance to dental services, and the reasons why children had not received dental care.

As a part of the 2010 Maternal and Child Health (MCH) Needs Assessment, five parent focus groups were held around the state in large, small, and tribal communities in November 2009 and January 2010. The focus group populations were determined based on a review of data sources available for the needs assessment. Populations with the least data available to use in assessing their needs (such as adolescents and parents of children with special health care needs (CSHCN)) were identified as priorities for focus groups. The focus group results provide more in depth and specific information on their experiences with MCH issues in Montana than can be gathered from other data sources.

In October-November 2009-2010, key informant interviews were conducted with public health stakeholders throughout Montana. Those interviewed included public health nurses, directors and managers of local and state public health programs, physicians, public health department staff, school nurses, WIC staff, March of Dimes, dentists, insurance providers, and Head Start staff. The questions in the interviews covered major health issues, how the identified health issues were being addressed, barriers associated with the health issues, and suggested public health interventions to address the needs. The issues and needs of children with special health care needs were included in the “special populations” section.

The data sources included in this assessment are those that provide some statewide perspective on CSHCN. Very targeted data may be collected by specific organizations or providers to provide information for them on their clientele. However, because those data are often not readily available and may not be generalizable to the state overall, they are not included in the following summary.

Children with Special Health Care Needs (CSHCN)¹ in Montana

The NSCSHCN and NSCH provide an overview on all CSHCN in the state. The survey results offer a population-based perspective on the estimated number of CSHCN, the demographics of CSHCN, and what types of services they access and needs they have. Because the surveys are conducted the same way in all states, the results for Montana can be compared to those of other states or the US overall to determine how Montana differs. The following data from these two surveys are a basis for considering the statewide status of CSHCN in Montana.

- ◆ 14.0% of 0-17 year olds in Montana are children with special health care needs, similar to the national prevalence of 15.1%.ⁱ
- ◆ An estimated 30,571 CSHCN 0-17 years of age in Montana.ⁱ
- ◆ Approximately 21,814 Montana households, or 20.9%, have children with one or more special health care needs, not significantly different from the 23.0% of households nationally with CSHCN.ⁱ
- ◆ CSHCN in Montana are spread fairly evenly among urban, suburban, large town, and small town/rural areas, although urban areas have the highest prevalence of CSHCN.ⁱⁱ

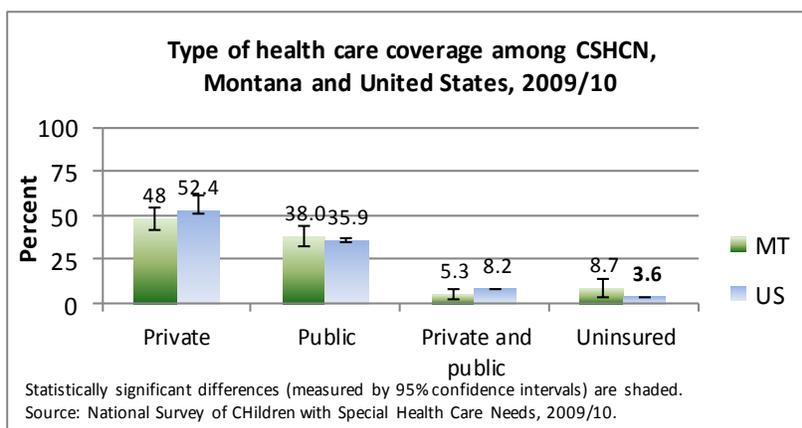
¹ National Survey of Children with Special Health Care Needs: “CSHCN are defined as those children who met at least one of 5 screening criteria for CSHCN, including those whose conditions result in functional limitations, those whose conditions are managed with prescription medications only, those whose conditions result in above routine use of medical, mental health, or other services, and those whose conditions require prescription medicine and above routine use of services.”

- ◆ Neighborhood environments in Montana are similar for CSHCN and non-CSHCN in terms of overall safety, school safety, neighborhood amenities (sidewalks, recreation centers, libraries, parks), and the presence of rundown housing, litter, and graffiti.ⁱⁱ
- ◆ School-age CSHCN indicate they are less likely to care about doing well in school and do all required homework than children without special needs (31.4% compared to 48.7%). However, CSHCN and non-CSHCN had similar rates of being involved in volunteer activities (13.2% and 15.8%, respectively) and working for pay outside the home 10 or more hours (19.1% and 18.8%).ⁱⁱ
- ◆ 7.4% of Montana CSHCN receive SSI benefits because of a disability.ⁱ
- ◆ In 2005/06, the majority (52.2%) of CSHCN in Montana lived in households with incomes below 200% of the federal poverty level, significantly different than the 41.2% of CSHCN nationwide.ⁱⁱⁱ
- ◆ 16.1% of CSHCN in Montana were without insurance at least once during the previous year, significantly more than the 9.3% of CSHCN nationwide.ⁱ
- ◆ 8.7% of CSHCN in Montana are uninsured.ⁱ
- ◆ Among all children in Montana, both CSHCN and non-CSHCN have similar levels of health care coverage, although CSHCN are more likely to be covered by public insurance (33.8% compared to 20.3%).ⁱⁱ

CSHCN with certain types of special health care needs

	MT Est. # of children % of 0-17 year olds [95% confidence interval]	US % of 0-17 year olds [95% confidence interval]	Differences*
Functional limitations	7,338 24.2% [19.1-29.2]	23.5% [22.7-24.3]	None
Managed with prescription medications only	9,522 31.4% [26.3-36.5]	39.3% [38.4-40.1]	MT has lower prevalence
Above routine use of medical, mental health, or other services	7,037 23.2% [17.4-29.0]	15.8% [15.1-16.5]	MT has higher prevalence
Require prescription medicine AND above routine use of services	6,454 21.3% [16.8-25.8]	21.4% [20.7-22.1]	None

* Statistically significant differences as measured by 95% confidence intervals.
Source: National Survey of Children with Special Health Care Needs 2005/06



- ◆ 10.5% of CSHCN in Montana do not have a usual source of care when sick, and 13.4% do not have a personal doctor or nurse, significantly more than the 6.9% of CSHCN nationwide.ⁱ
- ◆ Parents' general health and mental/emotional health were significantly lower among households with CSHCN compared to those without CSHCN.ⁱⁱ
- ◆ CSHCN were significantly more likely to have parents who reported usually or always feeling they were hard to care for or bothersome, or were angry with them during the past month (22.8% compared to 5.2%).ⁱⁱ

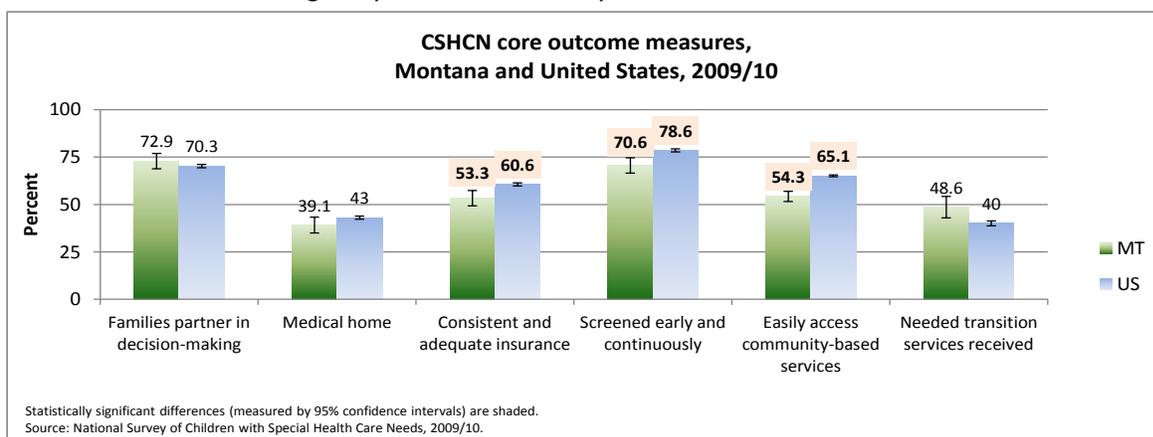
CHSCN Outcome Measures

The Federal Maternal and Child Health Bureau developed six core outcome measures to indicate the progress towards family-centered and community-based systems of care for children with special health care needs:

1. Families of children and youth with special health care needs partner in decision-making at all levels and are satisfied with the services they receive;
2. Children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home;
3. Families of CSHCN have adequate private and/or public insurance to pay for the services they need;
4. Children are screened early and continuously for special health care needs;
5. Community-based services for children and youth with special health care needs are organized so families can use them easily;
6. 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.

Resultsⁱ

- ◆ For CSHCN outcome measures 1, 2, and 6, Montana indicators are not significantly different than the nation as a whole.
- ◆ CSHCN in Montana are significantly less likely than CSHCN nationwide to have consistent and adequate public or private insurance, to be screened early and continuously for special health care needs, and to be able to easily access community based services.
- ◆ CSHCN in Montana are significantly less likely to be insured at the time of the survey and to be consistently insured during the past 12 months than CSHCN nationwide.
- ◆ 19.3% of CSHCN in Montana had no preventive visit, such as a well-child check-up, significantly more than 9.6% of CSHCN nationwide.
- ◆ CSHCN in Montana were significantly more likely to experience difficulties or delays in accessing services due to eligibility, lack of availability of services, or cost, than CSHCN nationwide.



Needs and Strengths

Indications of needs and strengths can be pulled from multiple sources. The following section summarizes the data on needs and strengths from each of the statewide sources of data on children with special health care needs.

National Survey of Children with Special Health Care Needs and National Survey of Children's Health

The comparison of CSHCN in Montana to those nationwide offers perspective on how our state compares to other locations. Because some factors specific to the state can also affect the health status of CSHCN and their access to care, another important consideration is how children with special needs in Montana compare to those without special needs. Appendices A and B include tables with confidence intervals for the data from 2005/06. The tables will be updated with data from the 2009/10 survey within the first half of 2012.

CSHCN in Montana compared to nationwideⁱ

- ◆ In Montana, 68.9% of CSHCN had no unmet needs for 14 specific health services in 2009/10, significantly lower than the 76.4% of CSHCN nationwide.
- ◆ In 2009-2010, 12.9% of Montana families reported needing respite care, significantly higher than 6.7% of families throughout the US.
- ◆ CSHCN in Montana are significantly more likely than CSHCN nationwide to use a clinic, health center, or other entity instead of a doctor's office as their usual source of sick care, 32.1% in Montana compared to 15.7% of CSHCN throughout the US.
- ◆ 57.4% of CSHCN in Montana use a doctor's office as their usual source of sick care, significantly lower than 74.8% of CSHCN throughout the US.
- ◆ 93.1% of CSHCN nationwide have a personal doctor or nurse, significantly higher than 86.6% of CSHCN in Montana.
- ◆ CSHCN in Montana are significantly more likely to have been uninsured at least once in the last year than CSHCN nationwide, 16.1% compared to 9.3%.
- ◆ Almost the same proportion of CSHCN in Montana and nationwide had at least one preventive dental visit in the last year: 85.7% and 85.9%, respectively.
- ◆ 19.3% of CSHCN in Montana had no preventive visits, such as a well child check-up, during the past year, significantly more than the 9.6% of CSHCN nationwide.
- ◆ Families of CSHCN in Montana are significantly more likely to have financial problems related to the health conditions and to have paid over \$1,000 in out of pocket expenses during the last year than families nationwide (29.8% of Montana families had financial problems, compared to 21.6% of all US families, and 31.3% of Montana families paid more than \$1000 out of pocket, compared to 22.1% nationwide).
- ◆ The proportion of Montana parents of CSHCN whose child's health care professional helps them feel like a partner in their child's care is 68.2%, very similar to the 67.4% of parents nationwide.
- ◆ 57.2% of Montana parents are less than satisfied with the communication between their child's doctor and school or other programs when needed, higher, but not significantly different than the 46.9% of parents who are less than satisfied nationwide.

CSHCN in Montana compared to non-CSHCN in Montanaⁱⁱ

- ◆ Not surprisingly, CSHCN were significantly less likely to have excellent or very good health status and CSHCN 6-17 years of age were significantly more likely to have missed 11 or more school days due to illness or injury compared to children without special needs. CSHCN were also

significantly less likely to have teeth in excellent or very good condition and more likely to have had two or more oral health problems in the past six months.

- ◆ CSHCN are significantly more likely than children without special health care needs to have unmet needs for medical, dental, mental health, or other health care (20.2% compared to 5.9%).
- ◆ More CSHCN saw health care specialists than non-CSHCN, which is not surprising, however, CSHCN who needed specialist care were significantly more likely to have problems getting it than non-CSHCN who needed specialist care (44.3% compared to 13.7%).
- ◆ In terms of standard care by providers, parents of both CSHCN and non-CSHCN in Montana had similar frequencies of being asked by health care providers whether they had concerns about their child's learning, development or behavior (approximately 48%). However, throughout the US, parents of CSHCN were more likely than parents of non-CSHCN to be asked about concerns.
- ◆ Among children who needed referrals, CSHCN and non-CSHCN had very similar rates of being able to access the referrals they needed (85.5% and 85.2%).
- ◆ CSHCN in Montana are significantly less likely to have a medical home than children without special needs (53.2% and 63.4%, respectively), however, over 90% of both CSHCN and non-CSHCN have a usual source of care for both well and sick care (95.9% and 93.6%, respectively).
- ◆ Among Montana children, 28.2% of children without special health care needs did not receive needed care coordination, while 43.1% of children with special needs did not receive the care coordination they needed.
- ◆ Among Montana children who received needed care coordination, CSHCN were significantly less likely to receive effective coordination than non-CSHCN (56.9% and 71.8%).

2005 CSHCN Needs Assessment

The 2005 Montana CSHCN Needs Assessment included information from families that were already connected with services or programs for CSHCN in Montana. The results provide a summary of the needs and recommendations of CSHCN in Montana who are currently accessing some type of health resource.

Most important needs of CSHCN in Montana and primary barriers to addressing the needs

Need	Primary barrier
Clinics to address the special needs of children	Limited availability of services
Health insurance	Cost of services
Access to dental care	Cost of services
Access to health care	Cost of services
Safe and affordable child care/day care	Cost of services

Source: 2005 Montana CSHCN Needs Assessment

Over 86 percent of parents stated that their child or children's health care is well-coordinated. Eighty-three percent were satisfied with the care their child receives from his or her primary care physician. Ten percent of parents were neutral and less than six percent were dissatisfied with the care their child receives. Seventy-nine percent of respondents said that their child's primary care doctor helps them with their child or children's special needs. Approximately 23 percent said their child or children's primary care doctor does not help them with their child's special needs.

How satisfied are you with the care your child receives from his or her primary care doctor?

<i>Very satisfied</i>	59.8%
<i>Somewhat satisfied</i>	23.3%
<i>Neutral</i>	10.1%
<i>Somewhat dissatisfied</i>	3.7%
<i>Very dissatisfied</i>	1.8%
<i>No response</i>	1.3%

The second care coordination question asked parents about who coordinated their child's care. Many respondents indicated more than one care coordinator. The most commonly listed care coordinator listed was a parent, grandparent, guardian or foster parent, with approximately sixty-five percent of respondents listing themselves or a parent figure as the coordinator. Medical providers such as doctors, specialists and nurses were listed as a care coordinator by just under half of the respondents. The state's early intervention centers and social workers and case managers were noted as care coordinators for just under 20 percent of the children included in the survey. Hospitals or clinics were considered a care coordinator by approximately 11 percent of the parents who responded to the survey.

Parents were asked to indicate how their child or children's primary care physician could be more helpful to them. 518 respondents (52 %) did not respond to the question, were unsure of how their physician could be more helpful, or noted that they were very happy with their primary care physician. The most common suggestions for how primary care physicians could be more helpful fell into several categories: 1) availability/accessibility, which includes having difficulty scheduling appointments and seeing other medical providers in a practice instead of the primary care physician; 2) knowledge about the child/children's condition(s); 3) communication with parents/guardians, which includes time spent and method of communication, and; 4) coordination with other providers and specialists.

Seeing the primary care physician instead of a nurse practitioner or another physician in the practice was noted by several parents as a concern because a new provider is not always aware of the potentially complex needs or medical history of their child, and educating a new provider takes time, and he or she may still not be familiar with the child's needs.

Comments that fell into the communication category included not using as much medical terminology. Many parents also noted that more time to talk and respond to their questions would be helpful.

Focus Groups

Focus group data provide some depth on the experiences of parents of CSHCN. The discussions are somewhat structured, so standard questions were asked of each of the five groups, and the summary is based on the parents' discussions of the issues and concerns they encounter.

Challenges and concerns (listed in priority order):

1. *Finding treatment*
 - a. Scarcity of local, competent providers
 - b. Insufficient access to local providers
 - c. Lack of specialists in Montana
 - d. The manner in which providers treat parents

The primary concern for all of the focus groups was finding treatment for their children. Parents in smaller communities in particular noted the difficulties of finding local physicians with the up-to-date knowledge and expertise necessary to provide care for their children. Parents in all communities also noted that access to local providers was a challenge due to limited appointments or service providers, or a lack of providers who accept Medicaid. Parents also expressed frustration with the way providers treat them. Participants noted that providers discount what they say or don't listen to them. Parents on Medicaid noted that they felt looked down on.

2. *Emotional toll*

Emotional challenges ranged from the stress of the daily responsibilities of caring for a CSHCN to the lack of adequate respite care and finding care for the entire family. Caregiver of foster or adopted children noted that they did not receive the support and information they needed to provide appropriate care.

3. *Insurance coverage/finances*

All parents noted that they worry about financial issues. Parents and caregivers cited the frustrations of applying for Medicaid, the limited coverage it provides, the difficulty of getting reimbursements, the fear of losing coverage, and the lack of choice in where to go. Parents with private insurance said that they pay too much out of pocket.

4. *School*

Parents with children in school said that they don't get enough help from schools and that school professionals don't welcome their input.

5. *Future of their children*

Parents and caregivers were concerned about what would happen to their children in adulthood, especially when the parents cannot care for them. Another concern was the lack of resources and services available to their children after high school and the difficulty in accessing continuous care.

Assistance at the time of diagnosis and services after the initial diagnosis

Most caregivers said they were offered no or very little help at the time of their child's diagnosis and found the help they needed through their own research and family and friends. After the initial diagnosis caregivers had a variety of experiences, some with too many referrals and some with not enough. The consistent theme was a lack of coordination of referrals

When asked about what they would change, participants noted the following, listed in priority order:

1. More help finding resources, services and information.
2. Help with finances, "*money*".
3. More health care specialists in Montana.
4. More pediatricians and other providers that accept Medicaid.
5. Coordination of services, "*an advocate*".
6. Disabled children should have services regardless of age.
7. Respect and courtesy from all professionals.
8. Medicaid coverage for all disabled children, children who are chronically ill or have life-threatening illnesses without regard to income.
9. Family therapy with a therapist who understands how disability affects the whole family.
10. More support from the school system.

One parent suggested a list of diseases or conditions on the state website with available resources (support groups, agencies, non-profits) for each condition that would appear if you clicked on a condition.

Participant Benefits of Focus Group Participation

“Participants showed tremendous enthusiasm for participating in these focus groups. Many parents were thankful to the state of Montana for providing a forum in which they could voice their concerns. Many of the participants asked what was going to happen next and if they could be involved. If more focus groups or other events are planned, they said they would like to participate again.

Participants in every focus group said they learned about services and agencies from other participants. Several parents in each focus group exchanged contact information so they can continue to share information or initiate a support group.”

Key informant interviews

Key informant interviews collect information from individuals or organizations who coordinate programs for or provide services to children with special health care needs. The results provide information on the needs of CSHCN from a service delivery perspective.

Major health issues of special populations	Ways that identified health issues are being addressed	Top barriers associated with health issues	Top public health interventions to improve the health of special populations
<ul style="list-style-type: none"> • Limited availability of/access to health care services • Lack of/Access to specialized health care in area/Montana • Mental health issues • Developmental disabilities • Early intensive intervention for autistic children • Dental issues • Chronic illnesses 	<ul style="list-style-type: none"> • Referrals • Recruiting specialty providers to Montana • Specialized clinics • Special education departments/special education teachers • Individual or group support • Interventions • Education 	<ul style="list-style-type: none"> • Distance to travel for specialized services • Money/financial/cost • Lack of specialists • Access to specialty care • Referral issues (where to refer, lack of funding) 	<ul style="list-style-type: none"> • One-stop-shopping for information, advice, referrals, services, available support systems, and programs • Increase the number of school nurses in State • Education • Access to specialty health care and services

Themes/Summary**Access to primary and specialty care**

All of the data sources on CSHCN in Montana indicate that availability of and access to health services are a major concern. This was expressed by parents of CSHCN throughout the state, whether already linked to services or not, as well as key informants.

The majority of parents reported being satisfied with the care they received from their primary care physician (over 50% for all sources that measured this topic). However, the data indicate that it may take parents and caregivers significant time to find such a provider and potentially for both to become educated on the child’s needs and appropriate resources.

The data show that CSHCN are more likely to have unmet need for care and services. This suggests that those parents who are not satisfied with the care they receive, or those who do not have a consistent source of care are struggling to meet their child’s needs. Focus group participants cited difficulties in

finding and/or accessing local, competent providers, particularly those who accept Medicaid. Since approximately 34% of CSHCN in Montana have public health insurance coverage, the challenges in finding providers who will accept their coverage is a cause for concern.

A lack of routine preventive medical care is the primary factor contributing to Montana's need for early and continuous screening (according to the NSCSHCN). Improved coordination of care – in addition to better access to providers – could assist families in making sure preventive services are provided (medical and dental) and all appropriate screenings are completed in a timely manner.

Specialty care is an acknowledged challenge in Montana. The state may not have the client base to support even one of some types of specialties in the state, let alone specialists in more than one location. Twenty percent of CSHCN who needed specialty care had trouble getting it.

Effective care coordination

Related to the difficulty in accessing quality care in Montana is the need for effective care coordination. Parents and caregivers – and possibly providers – need more support to find and coordinate information about children's conditions and treatment. The focus groups indicate this was particularly a need at the time of and soon after diagnosis. Key informant interviews indicate that service delivery agencies and providers are aware of this need and that a source of information on resources, services and support programs was one of the top public health interventions that could help improve the health of CSHCN.

A centralized effort at care coordination for CSHCN could potentially provide valuable, ongoing data on the gaps and challenges in coordinating care for CSHCN. Such an effort could also offer more details on the types of specialty care or specifics of referrals that are difficult to follow through on.

Effective care coordination could address all three of the CSHCN core outcome measures that are significantly lower in Montana: consistent and adequate public or private insurance, early and continuous screening for special health care needs, and families able to easily access community based services. The elements of consistent and adequate public or private health insurance that are issues in Montana are a lack of health insurance and gaps in health insurance coverage. Parents also indicate challenges in covering the out of pocket costs of care. Care coordination could identify potential gaps in coverage for CSHCN and explore ways to bridge the gaps, help families access other coverage options, and facilitate parent's efforts to get services for their children.

ⁱ Child and Adolescent Health Measurement Initiative. 2009/10 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health [Web site]. <http://www.childhealthdata.org/browse/survey?s=1>. Accessed 2-15-12.

ⁱⁱ Child and Adolescent Health Measurement Initiative. 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health [Web site]. <http://www.childhealthdata.org/browse/survey?s=2>. Accessed 11-8-11.

ⁱⁱⁱ Child and Adolescent Health Measurement Initiative. 2005/06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health [Web site]. <http://www.childhealthdata.org/browse/survey?s=1>. Accessed 11-8-11.

Appendix A

Summary of data from the 2005/06 National Survey of Children with Special Health Care Needs

Needs of CSHCN, by type					
	CSHCN who needed care-MT	CSHCN who needed care-US	CSHCN with unmet need-MT	CSHCN with unmet need-US	Differences*
Routine preventive medical care	70.5% [66.7-74.3] 19,604	77.9% [77.2-78.5]	3.8% [2.2-5.4] 1,065	1.9% [1.7-2.1]	MT has higher <u>unmet</u> need
Specialist care	50.4% [46.3-54.4] 13,993	51.8% [50.9-52.6]	5.0% [3.1-6.9] 1,388	2.8% [2.5-3.1]	None
Preventive dental care	79.5% [76.0-82.9] 22,097	81.1% [80.4-81.8]	9.7% [7.3-12.1] 2,701	6.3% [5.9-6.7]	MT has higher <u>unmet</u> need
Other dental care	24.7% [21.4-28.1] 6,875	24.2% [23.5-24.9]	5.0% [3.2-6.7] 1,379	2.6% [2.3-2.8]	MT has higher <u>unmet</u> need
Prescription medications	84.8% [81.9-87.7] 23,591	86.4% [85.8-87.0]	2.9% [1.5-4.3] 801	1.6% [1.4-1.8]	None
Physical, occupational, or speech therapy	23.1% [19.6-26.6] 6,441	22.8% [22.1-23.5]	3.1% [1.5-4.8] 867	3.1% [2.8-3.4]	None
Mental health care or counseling	29.3% [25.5-33.1] 8,161	25.0% [24.3-25.7]	6.6% [4.5-8.7] 1,839	3.7% [3.4-4.0]	MT has higher <u>unmet</u> need
Vision care or eyeglasses	35.2% [31.4-39.0] 9,782	33.3% [32.6-34.1]	2.3% [1.1-3.5] 633	1.4% [1.2-1.6]	None
Respite care	8.5% [5.8-11.1] 2,360	4.5% [4.2-4.9]	3.6% [1.7-5.5] 999	2.2% [1.9-2.4]	MT has higher need.
Genetic counseling	7.5% [5.4-9.6] 2,097	5.7% [5.3-6.1]	1.7% [0.7-2.8] 486	1.3% [1.1-1.5]	None
Mental health care or counseling	15.4% [12.3-18.5] 4,286	12.3% [11.7-12.8]	4.2% [2.5-5.9] 1,175	2.4% [2.1-2.6]	None

* Statistically significant differences as measured by 95% confidence intervals.
Source: 2005/06 National Survey of Children with Special Health Care Needs

Needs of CSHCN, by core outcome measure

Families partnering and satisfied with services

	MT	US	Differences*
Somewhat or very dissatisfied with services received	11.9% [9.1-14.7] 3,258	8.7% [8.3-9.2]	None
Sometimes or never felt like a partner in child's care during last year	12.6% [9.8-15.4] 3,295	12.4% [11.8-12.9]	None

Medical home

	MT	US	Differences*
Among those who needed referrals,	23.4%	21.1%	None

had problems getting them for specialist care or services	[17.2-29.5] 2,241	[19.9-22.4]	
CSHCN who do not have usual sources for both sick and well care	9.8% [7.3-12.2] 2,705	7.1% [6.6-7.5]	None
CSHCN who do not have a personal doctor or nurse	9.5% [7.1-11.9] 2,637	6.5% [6.1-6.9]	MT higher
CSHCN does not get family-centered care	34.9% [30.9-38.8] 9,502	32.5% [31.7-33.3]	None
Among those who needed care coordination, did not meet 1 or more elements of care coordination **	37.2% [32.7-41.7] 7,790	40.8% [39.9-41.8]	None
Health insurance			
	MT	US	Differences*
No health insurance at time of survey	10.3% [7.7-13.0] 2,875	3.5% [3.2-3.8]	MT higher
One or more periods without insurance in last year	17.4% [14.2-20.7] 4,823	8.8% [8.3-9.3]	MT higher
Current insurance is not adequate***	33.0% [29.1-37.0] 8,085	33.1% [32.3-33.9]	None
Early and continuous screening			
	MT	US	Differences*
Did not receive routine preventive medical care during past year	30.9% [27.1-34.7] 8,585	22.9% [22.2-23.6]	MT higher
Did not receive preventive dental care during past 12 months	25.5% [21.8-29.2] 6,969	21.5% [20.8-22.2]	None
Transition services			
	MT	US	Differences*
CSHCN did not receive all needed anticipatory guidance	48.0% [42.3-53.8] 6,089	52.6% [51.3-53.9]	None
Youth's doctors did not discuss health needs as he/she becomes adult	27.6% [22.6-32.7] 3,694	28.2% [27.0-29.3]	None
Did not discuss how to maintain insurance coverage	40.8% [35.2-46.3] 5,476	42.0% [40.8-43.3]	None
Doctors sometimes or never encourage age appropriate self management skills	17.0% [12.7-21.2] 2,342	22.0% [20.9-23.1]	None

* Statistically significant differences as measured by 95% confidence intervals.

**Elements of care coordination include communication between child's doctors, communication by doctors with child's schools and other programs, and receiving help coordinating a child's care.

*** Adequacy measured as coverage that offers benefits or covers services that meet CSHCN's needs, have a reasonable level of uncovered costs, and allow CSHCN to see the health care providers that they need.

Source: 2005/06 National Survey of Children with Special Health Care Needs

Appendix B

Summary of data from the 2007 National Survey of Children's Health

Selected child health indicators, by CSHCN status, MT and US

Physical and dental health				
	MT CSHCN	MT Non-CSHCN	US CSHCN	Differences*
Children age 0-17 with overall health status excellent or very good	62.9% [55.8 - 69.9] 25,652	93.9% [92.2 - 95.5] 175,539	69.2% [67.5 - 70.9] 9,780,669	MT CSHCN ↓ then non-CSHCN
Children age 1-17 whose teeth are in excellent or very good condition	56.3% [49.1 - 63.4] 22,515	78.6% [75.9 - 81.3] 137,985	64.7% [62.9 - 66.5] 8,965,849	MT CSHCN ↓ then non-CSHCN
Children age 1-17 who have two or more oral health problems (toothache, decay, broken teeth, bleeding gums) in the past six months	16.2% [10.6 - 21.7] 6,463	8.5% [6.5 - 10.5] 14,942	12.0% [10.8 - 13.2] 1,664,927	MT CSHCN ↑ then non-CSHCN
Children age 6-17 who missed 11 or more school days due to illness or injury in the past 12 months	26.5% [19.0 - 34.0] 8,636	5.3% [3.3 - 7.2] 6,372	13.5% [12.2 - 14.9] 1,503,840	MT CSHCN ↓ then non-CSHCN
Health insurance coverage				
	MT CSHCN	MT Non-CSHCN	US CSHCN	Differences*
Currently have health insurance coverage	86.0% [79.6 - 92.5] 35,250	87.0% [85.0 - 89.0] 162,363	93.9% [93.0 - 94.9] 13,272,593	MT CSHCN ↓ than US CSHCN
Currently uninsured or were uninsured at some time during the previous 12 months	22.2% [15.3 - 29.2] 9,070	19.3% [16.9 - 21.8] 36,054	12.3% [11.0 - 13.5] 1,734,220	MT CSHCN ↑ than US CSHCN
Currently have public health insurance coverage	33.8% [26.9 - 40.6] 13,534	20.3% [17.5 - 23.1] 37,477	35.7% [34.0 - 37.4] 5,003,032	MT CSHCN ↑ then non-CSHCN
Currently have private health insurance coverage	51.9% [44.8 - 59.1] 20,789	66.6% [63.5 - 69.6] 122,977	58.2% [56.4 - 60.0] 8,161,416	MT CSHCN ↓ then non-CSHCN
Among currently insured children, those whose insurance does NOT usually or always meet their needs; cover needed providers; or have reasonable costs	35.5% [28.8 - 42.1] 12,497	30.3% [27.3 - 33.2] 49,110	29.4% [27.6 - 31.1] 3,895,577	None
Health care access and quality				
	MT CSHCN	MT Non-CSHCN	US CSHCN	Differences*
Children age 0-17 with one or more preventive medical visits in the past 12 months	86.2% [81.2 - 91.2] 34,403	79.3% [76.9 - 81.7] 147,577	91.4% [90.2 - 92.6] 12,802,108	None
Children age 1-17 with one or more preventive dental visits in the past 12 months	80.4% [74.7 - 86.1] 31,588	75.6% [72.7 - 78.5] 132,216	84.1% [82.8 - 85.5] 11,636,399	None
Among children age 2-17 needing mental health care in the past 12 months, those who received treatment from a mental health professional	68.4% [57.9 - 78.9] 10,710	61.9% [31.7 - 92.1] 907	61.7% [58.6 - 64.7] 2,731,910	None
Children who had unmet needs for medical, dental, mental health or other health care at some time during the previous 12 months	20.2% [13.8 - 26.6] 8,234	5.9% [4.3 - 7.6] 11,104	13.6% [12.3 - 14.9] 1,914,496	MT CSHCN ↑ then non-CSHCN
Children who have a Medical Home: continuous, coordinated, comprehensive, family-centered, and compassionate health care services (NOTE: Several other measures listed below are included in this indicator).	53.2% [46.1 - 60.3] 21,288	63.4% [60.4 - 66.4] 114,213	49.8% [48.0 - 51.6] 6,805,059	MT CSHCN ↓ then non-CSHCN

Children who have a usual source for well and sick care (component of Medical Home measure)	95.9% [92.8 - 98.9] 39,278	93.6% [92.0 - 95.1] 174,859	94.8% [93.9 - 95.8] 13,390,478	None
Children who receive family-centered health care (component of Medical Home measure)	67.8% [61.1 - 74.6] 26,233	71.1% [68.2 - 74.0] 121,515	65.5% [63.7 - 67.3] 9,017,569	None
Among children needing referrals during the past 12 months, those who had no problem getting needed referrals (component of Medical Home measure)	85.8% [75.0 - 96.7] 11,688	85.2% [77.2 - 93.1] 14,584	78.4% [75.7 - 81.1] 3,547,822	None
Among children needing care coordination in the past 12 months, those who received effective care coordination (component of Medical Home measure)	56.9% [48.4 - 65.4] 16,992	71.8% [66.3 - 77.2] 35,286	59.3% [57.3 - 61.4] 6,055,589	MT CSHCN ↓ then non- CSHCN
Needed and had problems getting specialist care during the past 12 months	17.2% [11.5 - 22.9] 6,994	3.4% [2.4 - 4.4] 6,358	14.3% [13.0 - 15.6] 2,019,929	MT CSHCN ↑ then non- CSHCN
Children who saw health care specialists during the previous 12 months	44.3% [37.4 - 51.3] 18,167	13.7% [11.8 - 15.7] 25,655	44.9% [43.1 - 46.7] 6,338,865	MT CSHCN ↑ then non- CSHCN
Among children age 0-5 who had health care in the past 12 months, those whose parents were asked by health care providers if they have concerns about their child's learning, development, or behavior	48.6% [30.5 - 66.7] 3,523	47.7% [42.2 - 53.3] 28,797	55.4% [51.3 - 59.4] 1,563,476	None

Community and school activities

	MT CSHCN	MT Non-CSHCN	US CSHCN	Differences*
Children age 6-17 who have ever repeated a grade in school	15.2% [8.2 - 22.2] 5,083	7.6% [5.2 - 10.0] 9,228	18.5% [16.8 - 20.2] 2,084,373	None
Children age 6-17 for whom it was always true during the previous month that they cared about doing well in school and that they did all required homework	31.4% [24.7 - 38.0] 10,523	48.7% [45.1 - 52.4] 59,568	38.6% [36.7 - 40.6] 4,352,882	MT CSHCN ↓ then non- CSHCN
Children age 6-17 who participated in sports, clubs, or other organized activities outside of school during the past 12 months	81.0% [74.8 - 87.3] 26,664	91.0% [88.8 - 93.1] 111,170	77.2% [75.4 - 79.0] 8,707,351	MT CSHCN ↓ then non- CSHCN
Youth age 12-17 who were involved in volunteer or community service work once a week or more over the past 12 months	13.2% [7.0 - 19.4] 2,750	15.8% [12.2 - 19.4] 9,720	15.2% [13.0 - 17.5] 895,116	None
Youth age 12-17 who worked for pay outside the home 10 hours or more in the previous week	19.1% [11.5 - 26.7] 4,121	18.8% [15.0 - 22.6] 11,600	10.7% [9.1 - 12.2] 630,834	None
Children age 6-17 who spend one hour or more reading for pleasure on an average weekday	19.4% [13.3 - 25.5] 6,396	16.9% [14.1 - 19.7] 20,458	15.9% [14.5 - 17.2] 1,740,895	None

Family health and activities

	MT CSHCN	MT Non-CSHCN	US CSHCN	Differences*
Among children currently living with their mother, those whose mothers' general health is excellent or very good	53.9% [46.5 - 61.4] 19,353	70.2% [67.3 - 73.1] 121,287	56.4% [54.6 - 58.3] 7,346,616	MT CSHCN ↓ then non- CSHCN
Among children currently living with their mother, those whose mothers' mental and emotional health is excellent or very good	60.6% [53.1 - 68.1] 21,748	76.8% [74.0 - 79.6] 132,597	63.1% [61.3 - 64.9] 8,208,657	MT CSHCN ↓ then non- CSHCN
Among children currently living with their	43.6%	63.3%	47.8%	MT CSHCN ↓

mother, those whose mothers' general health and mental/emotional health are both excellent or very good	[36.5 - 50.7] 15,644	[60.2 - 66.3] 109,243	[46.0 - 49.7] 6,217,337	then non- CSHCN
Among children currently living with their father, those whose fathers' general health is excellent or very good	59.0% [50.9 - 67.1] 17,513	75.3% [72.4 - 78.1] 117,338	66.3% [64.3 - 68.3] 6,452,872	MT CSHCN ↓ then non- CSHCN
Among children currently living with their father, those whose fathers' mental and emotional health is excellent or very good	69.1% [61.4 - 76.8] 20,512	80.3% [77.5 - 83.0] 125,016	73.4% [71.5 - 75.3] 7,133,746	MT CSHCN ↓ then non- CSHCN
Among children currently living with their father, those whose fathers' general health and mental/emotional health are both excellent or very good	49.0% [41.0 - 57.0] 14,547	69.3% [66.2 - 72.4] 107,947	58.2% [56.1 - 60.3] 5,652,682	MT CSHCN ↓ then non- CSHCN
Children age 5 or younger who were read to by family members every day during the previous week	42.4% [25.5 - 59.3] 3,146	58.4% [53.0 - 63.8] 37,291	56.2% [52.1 - 60.2] 1,595,278	None
Children age 5 or younger who were sung to or told stories by family members every day during the previous week	62.9% [45.6 - 80.2] 4,666	68.9% [63.9 - 73.9] 44,463	65.4% [61.7 - 69.2] 1,860,828	None
Children whose families ate a meal together on every day of the previous week	45.9% [38.8 - 52.9] 18,791	52.9% [49.9 - 55.9] 98,583	43.3% [41.5 - 45.1] 6,102,810	None
Children age 6-17 who spend four hours or more on an average weekday watching television or videos or playing video games	12.7% [6.6 - 18.8] 4,262	7.7% [5.7 - 9.6] 9,288	12.8% [11.5 - 14.0] 1,438,118	None
Children whose parents usually or always felt they were hard to care for or bothersome, or were angry with them during the past month	22.8% [16.8 - 28.8] 9,332	5.2% [3.7 - 6.7] 9,705	20.0% [18.4 - 21.5] 2,816,263	MT CSHCN ↑ then non- CSHCN
Neighborhood environment				
	MT CSHCN	MT Non-CSHCN	US CSHCN	Differences*
Children living in neighborhoods in which people are supportive, trustworthy and helpful	79.5% [73.2 - 85.8] 32,263	89.2% [87.2 - 91.1] 161,483	80.4% [78.9 - 81.9] 11,154,315	MT CSHCN ↓ then non- CSHCN
Children living in neighborhoods their parents feel is usually or always safe	87.0% [81.1 - 93.0] 35,323	93.2% [91.5 - 94.9] 169,919	84.4% [83.1 - 85.7] 11,824,646	None
Children age 6-17 attending schools their parents feel is usually or always safe	88.6% [82.3 - 94.9] 28,172	95.2% [93.3 - 97.0] 108,156	88.8% [87.5 - 90.1] 9,649,949	None
Children living in neighborhoods with sidewalks, libraries, recreation centers, and parks	45.1% [38.0 - 52.2] 18,107	41.2% [38.3 - 44.2] 74,022	47.9% [46.1 - 49.7] 6,567,719	None
Children living in neighborhoods with rundown housing, litter, and graffiti	10.1% [4.3 - 15.8] 4,083	4.5% [3.1 - 5.9] 8,184	5.4% [4.4 - 6.4] 753,983	None

* Statistically significant differences as measured by 95% confidence intervals.

Source: 2007 National Survey of Children's Health