



Department of Public Health and Human Services

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Frequently Asked Questions about the 2016 Montana Children’s Special Health Services Survey

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What is the 2016 Montana Children's Special Health Services Survey?

- This survey is a statewide project, organized in partnership with the Montana Department of Public Health and Human Services (DPHHS), CSHS section and the Rural Institute for Inclusive Communities at the University of Montana. The purpose of the survey is to better understand and meet the needs of Montanan children and youth with special health care needs (CYSHCN) and their families. To do this, we are asking randomly selected CYSHCN caregivers to answer questions about the current care their child or youth with a special healthcare need receives in the healthcare setting.
- The survey consists of items identified as concerns by families and providers for CYSHCN that are focused within the Medical Home and Transition to Adulthood systems of care. Demographic information and your child's health history are also asked in the survey.
- In Montana, 20.0% of 0-17 year olds are Children and Youth with Disabilities (CYSHCN) who are at increased risk of chronic physical, developmental, behavioral, or emotional conditions, and who also require health and related services of a type or amount beyond what is generally required by children. The Montana Disability and Health (MTDH) collaborated with the Children's Special Health Services (CSHS) Program on applications of the concerns report method to rural health care system improvements (e.g., PCORI grant focused on rural hospital discharge; children and youth with special health care needs (CYSHCN)).

Why was I chosen to participate in the survey?

- 1) All families with a child or youth with a special health care need (CYSHCN) with records with DPHHS Children's Special Health Services that were established within the past the past two years (2015 -2016); and 2) a random sample of families with records with DPHHS Children's Special Health Services that were established with CSHS between three and five years ago.

How long do I have to complete and submit the survey?

- Data collection for the surveys ends May 15th, 2017. You may submit your survey online through the Qualtrics platform on May 15th; however, **if you choose to complete the paper version of the survey please submit your completed survey at least 4-5 business days before the May 15th deadline.**

Will my answers be kept private?

- Yes. All answers are kept completely private. No one working with the survey will know your name. Your survey will be identified only by a number to help us keep track of surveys as they are returned. Reports about the results of the survey will combine answers from all the respondents so no one can guess how any individual person answered.

Is it really important that I answer these questions?

- Yes. Because of the small number of CYSHCN caregivers chosen to participate, it is important to have everyone's answers. Every family is different. To get a good picture of the health of children and youth with special healthcare needs in Montana, we need each caregiver selected to return the questionnaire. From the information you give us, we hope to be able to

improve health care for CYSHCN in Montana. We need to learn what goes right in meeting your child's healthcare needs, and what can sometimes go wrong. Your help is important to the success of the Children's Special Health Service program and how we should prioritize our services.

- Participation is voluntary, and responses will be kept anonymous. You may choose to not respond to any question(s) and you may exit the survey at any time. Participation or nonparticipation will not impact your relationship with the University of Montana or with the DPHHS. Submission of the survey will be interpreted as your informed consent to participate and that you confirm you are at least 18 years of age. This survey does not have any anticipated risks. As a token of our appreciation, you will receive a \$5 gas card in the mailed survey.

Some questions do not seem related to health care. Why are they asked?

- Many things in your child's life may affect their health and well-being. These questions will give us a complete picture of things that happened that may have had an effect on your child's health or services that the child should be receiving.

How long will this survey take to complete?

- This survey should take about 20-30 minutes to complete. If you choose to complete the survey, please send it back in the enclosed postage-paid envelope. You may also complete the survey online. Just enter your unique code that is located next to your name on the mailing label.

Can I save and continue my survey at a later time?

- Yes. To do this, every time you click the *Next* or *Back* button in the survey, your current progress is saved automatically. You can come back to your survey if you click on the survey link in the same browser on the same computer.

How does the Survey define a Child or Youth with a Special Health Care Need (CYSHCN)?

- The term, *Child or Youth with Special Health Care Needs (CYSHCN)*, means a child or youth, under the age of 22, who:
 - Has or is at increased risk for chronic physical, developmental, behavioral, and/or emotional conditions; and
 - Needs health and related services of a type or amount beyond that generally required by children.

How come I can't access the online version of the survey?

- Two reasons: 1) You may not have entered in your unique 4-digit code; or, 2) You may have incorrectly entered the survey link.
- Solution: 1) Enter in your unique 4-digit code that can be found on the cover of your survey; or, 2) enter in the simplified survey link, ri.umt.edu/cshs2016, that was included on the follow-up postcard you should have received in the mail.
- If you prefer to enter the survey link that was included with your survey please see the solutions below to correctly enter in your survey link:

- You may have entered a number one, “1”, where a lowercase L, “l”, is needed between the number “6” and letter “Y”.
- You did not include an underscore, “_”, between the letter “V” and number “6”.
- You may have entered the letter, “i”, where a lowercase J, “j”, is needed between the letters “t” and “N”.
- If you are still not able to access the online version of the survey, please **call or email Helen Russette at (406) 243-4860 or helen.russette@mso.umt.edu**.

How was this Survey developed?

- The following input shaped the design of the Survey: rapid literature reviews, systems-level key informants, providers, and families of children or youth with a special health care needs. Survey items were structured according to the Association of Maternal and Child Health Program (AMCHP) standards for medical home and transition to adulthood by value perspectives (e.g., equity, safety, welfare). The resulting menu of concerns (over 300 concerns) were vetted and voted on by our partners (see “Partners” section below) for inclusion on the Survey.

How was this Survey designed?

- The Survey is modeled after two Concerns Report Indices for how important and how satisfied the participant is with that item and a health belief model framework that incorporates the Parent Patient Activation Measurement Tool (P-PAM).

What is the Parent Patient Activation Measurement Tool (P-PAM)?

- Patient activation is frequently used a measurement of self-efficacy in healthcare settings. In pediatric populations such as children and youth with special health care needs, the self-efficacy of the parents is a critical predictor of overall treatment outcomes due to the role of parents in providing and accessing care (Pennarola et al., 2012). The Patient Activation Measure (PAM) has been adapted for use with parents who provide care to children with chronic illnesses. This tool, the Parent Patient Activation Measurement Tool (P-PAM) has been cross culturally validated and determined to be a reliable measure of parent activation (Decamp et al., 2016).
- Research using the P-Pam investigated relationships between individual parent characteristics (healthcare status, age, etc.) and parent activation (Pennarola et al., 2012; Pennarola et al., 2015). Higher parent activation was associated with never having been married. In addition, it was found that the age of the parent was correlated with activation as was illness severity although the relationship between severity and activation changed overtime. (Pennarola et al., 2012; Pennarola et al., 2015).

What if I have questions about the survey?

- If you have any questions about your rights as a research subject, contact the UM Institutional Review Board (IRB) at (406) 243-6672.
- If you have questions about the survey methodology, please **contact Dr. Meg Traci, meg.traci@mso.umt.edu, 406-243-4956**.

- If you have questions about the Montana Children’s Special Health Services Program, please contact **Rachel Donahoe**, rdonahoe@mt.gov , **406-444-3617**.

Community Discussion Forums. What are they and how do I get involved?

- **Background and Purpose**
 - Community discussion forums will occur April to May, 2017. These forums will consists of parents and primary caregivers of children and youth with a special health care (CYSHCN) to discuss and interpret the Montana Children’s Special Health Services Survey findings. That is, attendees will discuss the meaning of survey results and will be asked for their input on an agenda to improve the services, supports, and lives of Montana children and youth with special health care needs. In sum, our goals is to set an agenda for the future of services and supports for families of children and youth with special health care needs.
- **Dates and locations of Community Discussion Forums**
 - **Helena:** Wednesday, May 4th, 2017, TBD
 - **Butte:** Wednesday, May 4th, 2017, 4:00pm – 5:30pm at MILP and 6:30-7:30 at 4cs
 - **Great Falls:** TBD
 - **Missoula:** TBD, Headwaters Park and Rec Meeting Room, Currents Aquatics Center in McCormick Park, 600 Cregg Ln, Missoula 59801
 - **Kalispell:** TBD
 - **Billings:** Tuesday, May 23rd, 2017,
 - 9:30-11:00 A.M. LIFTT, Address: 1201 Grand Ave, Billings, MT 59102, Phone: (406) 259-5181
 - 12pm – 1:00 P.M. at Billings Clinic
 - 1:30-3:00 P.M. LIFTT, Address: 1201 Grand Ave, Billings, MT 59102, Phone: (406) 259-5181
 - **Miles City:** Wednesday, May 24th, 2017, 4:30pm – 6pm, TBD
- **Support to participate in discussion forms**
 - We are able to provide families with a \$25 reimbursement for expenses related to taking part in the discussion forum. If you would need to travel more than 50 miles to attend the event, or if you need accommodations or an interpreter, please contact Severin Studer from the Rural Institute at the University of Montana, severin.studer@mso.umt.edu. For interpreters especially, please try to give us at least one week before the scheduled event to schedule an interpreter. Food and refreshments will be provided.
- **Interested in participating in the Community Discussion Forum?**
 - Please contact **Dr. Meg Traci**, meg.traci@mso.umt.edu, **406-243-4956**.

- Unable to attend?
 - In the event that you will not be able to attend the forum but would still like to be involved and receive the information provided, please **contact Severin Studer, severin.studer@mso.umt.edu.**

Partners involved in this Survey:

- This survey is a statewide project, organized in partnership with the Montana Department of Public Health and Human Services (DPHHS), CSHS section and the Rural Institute for Inclusive Communities at the University of Montana.

Acknowledgments:

- The Assessment Design Team, parents of a child or youth with special health care needs, and the Rural Institute Consumer Advisory Council have provided a tremendous amount of time and energy to the development of the Survey and we are forever grateful to the work these groups have accomplished
 - Assessment Design Team (ADT) is comprised of numerous members, such as the HALI Project, the Children’s Clinic, St. Vincent’s Healthcare, Shodair Children’s Hospital, PLUK, University of Montana School of Extended & Lifelong Learning, Providers, Community Medical Center, and Benefis Pediatric Specialty Clinic.
 - Web link to list of ADT members: See the webpage for the link.
 - The Rural Institute Consumer Advisory Council (CAC) consists of parents of and youth with developmental disabilities (DD); Vocational Rehabilitation, Disability Rights Montana, PLUK, MYLF, schools, MonTECH, the Social Security Administration, and CSHS. All five regions of the state are represented.
 - Web link to list of CAC members: <http://ruralinstitute.umt.edu/consumer-advisory-council-intro>.