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Dear Legislative Members and Concerned Parties:

Good day, I would like to address several concerns I have as a parent of a child with Cystic Fibrosis and dealing with Children Special Health Services. These concerns stem from the multidisciplinary clinics that the state contracts for Cystic Fibrosis and the Regional Pediatric Clinics as well as the use of the Rural Institute's Consumer Advisory Council as the statutory advisory council for the MCHB Title V Block Grant Program which funds these programs.

The Children's Special Health Services (CSHS) is charged by the Federal Maternal Health Bureau to: "Support development and implementation of comprehensive, culturally competent, coordinated systems of care for children and youth who have or at risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally."

1. The Multidisciplinary Cystic Fibrosis Clinics have been provided in three geographic regions to provide access to health care in the region that the families reside. Recently the clinics have been cancelled due to the state not signing a new contract (regionally) to provide these services. Who decided this? Why and what were the reasons for the change? This greatly affects families, why are families not consulted when these contracts are assigned? Without the regional multidisciplinary Cystic Fibrosis clinics these children are at greater risk for hospital stays, decrease in lung function and decline in overall health.
2. As a parent of a child with a physical disability this infringes on her civil rights to not have access to these clinics.
Please see state law http://leg.mt.gov/bills/mca_toc/50_19_2.htm and <http://leg.mt.gov/bills/2007/BillHtml/SB0162.htm> which ensures that rights of children with genetic diseases and the state profile on Cystic Fibrosis <https://dphhs.mt.gov/Portals/85/publichealth/documents/MPH/2011/MPHSeptember2011.pdf>.
3. The Regional Pediatric Clinics were defunded and the care coordination that occurred with them at the regional sites were terminated. Where did the budget for this go? Who made this decision and how did they notify the families? In the state of Montana where we do not have a Children's Hospital, this care coordination is key to the health care of children with special health care needs. As a parent of a child with special health care needs this care coordination in our community is key to the continued good health of our child. I am concerned about the lack of oversight or meaningful family involvement for families in this kind of decision. Now that there is the loss of the regional clinics there will be less care given to children with special health care needs because of the added cost and time of travel.

4. In 2012-13 the Advisory Council consisted of parents of children with special health care needs, Pediatricians, Nurse Coordinators and stakeholders who had knowledge or experience working with families and children with special health care needs. It was disbanded by the administration and in the 2016 Annual Application and 2014 Grant report http://dph.gov/Portals/85/publichealth/documents/MCH/MT_MCHBG_FINAL_2016application2014Report.pdfhs.mt stated that it was replaced by the Rural Institutes Consumer Advisor Council <http://ruralinstitute.umt.edu/consumer-advisory-council-intro> this council is for the purpose of transition and outcomes for developmental disabilities. As a parent of a child with a physical disability (Cystic Fibrosis) this precludes me having a voice for my child as she does not qualify under that subset of a disability. It is concerning that the administration would choose an advisory council that knowingly marginalizes the voice of families it serves and not allow active CYSHN families participation. There was no public notice that this was the advisory council. The former advisory council was set up to meet the varying needs of CYSHN and under what authority was it disbanded and replaced? How was it communicated? Where is the transparency?

It is for these reasons that the CSHS is not meeting its mission as charged by the Federal Health Bureau as stated above.

Thank you for your consideration.

Sincerely,

Rebecca Richards