# Cleft Clinic Assessment & Recommendation Report

Children's Special Health Services

Montana DPHHS

2022

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**A note about citations:** Throughout the document, citations are marked using abbreviated codes associated with the source material, but these codes do not follow a specific citation format. A list of the codes and their corresponding source material are found at the end of the document.

## Glossary of Acronyms & Terms

Several acronyms and medical terms will be used throughout this report. Please refer back to this section for definitions/explanations.

**ACPA**: American Cleft Palate-Craniofacial Association. A non-profit association of individuals and healthcare professionals who are interested in clinical care and research advancements for those affected by cleft and craniofacial conditions. ACPA works to support the care of individuals affected by cleft and craniofacial conditions. They also serve as a national accrediting organization for cleft palate and craniofacial teams. More information at: https://acpa-cpf.org/

**BCBS**: Blue Cross Blue Shield insurance company

**CFC:** Cystic Fibrosis Clinic. Clinics in Montana of interdisciplinary providers who care for patients with cystic fibrosis.

**CHRIS**: Children's Health Resource and Information System

**CL:** Cleft lip. A cleft lip is a separation of the two sides of the lip. The separation often includes the bones of the upper jaw and/or upper gum.

**Cleft Clinics:** Term used in this report to refer to the interdisciplinary team clinics contracted through Children's Special Health Services to serve children with cleft lip and/or palate in Montana.

**Clinic Coordinator:** The Clinic Coordinator is the primary individual employed by each health system that is contracted by Children's Special Health Services to coordinate the Cleft Clinics at that location each quarter.

**CL/P:** Cleft lip and palate. Cleft lip and cleft palate can occur on one side (unilateral cleft lip and/or palate) or on both sides (bilateral cleft lip and/or palate). Because the lip and the palate develop separately, it is possible for the child to have a cleft lip, a cleft palate, or both cleft lip and cleft palate.

**CP**: Cleft palate. A cleft palate is an opening in the roof of the mouth in which the two sides of the palate did not fuse, or join together, as the unborn baby was developing.

**CPT:** Current Procedural Terminology (CPT®) codes are used by healthcare professionals as a uniform language for coding medical services and procedures.

**CSHS**: Children's Special Health Services. The CSHS section is within the Montana Department of Public Health & Human Services. Since some children and youth

require more healthcare resources than others because of a medical condition, CSHS works to help children and families in Montana receive the healthcare and supportive services they need to live happy, healthy lives in their communities. More information at: https://dphhs.mt.gov/ecfsd/cshs/index

**CYSHCN**: Children and Youth with Special Health Needs. CYSHCN are children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions. They also require health and related services of a type or amount beyond that required by children generally. More information at: https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn

**DPHHS**: Montana Department of Public Health & Human Services

**ENT**: A physician who has specialized training in diagnosing and treating diseases of the ear, nose, and throat. Also called an otolaryngologist.

**EPSDT**: Early and Periodic Screening, Diagnostic, and Treatment. The EPSDT benefit provides comprehensive and preventive health care services for children under age 21 who are enrolled in Medicaid. Specifically, this benefit ensures timely screenings, dental, mental health, developmental, and specialty services. More information at: https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html

**FCHB:** Family and Community Health Bureau. Located within the Early Childhood and Family Support Division of DPHHS and houses the CSHS Section.

**HCPCS**: Healthcare Common Procedure Coding System. HCPC codes most commonly used in the Cleft Clinics for billing are T1024 & T1025.
*American Academy of Professional Coders:*

- **T1024:** “Evaluation and treatment by an integrated, specialty team contracted to provide coordinated care to multiple or severely handicapped children, per encounter as maintained by CMS falls under Screenings, Assessments, and Treatments, Individual and Family”
- **T1025:** “Intensive, extended multidisciplinary services provided in a clinic setting to children with complex medical, physical, mental and psychosocial impairments, per diem as maintained by CMS falls under Screenings, Assessments, and Treatments, Individual and Family”

**HMK**: Healthy Montana Kids. A free or low-cost health insurance plan that provides coverage to eligible Montana children up to age 19. Financial eligibility is based on a household's gross income. Medical benefits are administered through the BCBS of Montana Provider Network.

**HMK *Plus***: Healthy Montana Kids *Plus*. HMK *Plus* and Montana Medicaid (MT Medicaid) are healthcare benefits for eligible low-income Montanans.

**ICT**: Interdisciplinary Care Team. ICTs are a team of healthcare professionals from different professional disciplines who work together to manage the needs of the patient. The group usually includes surgeons, dental specialists, speech-language pathologists, social work, nutrition, and others who meet regularly to evaluate and discuss the patients under their care.

**MCHBG**: Maternal and Child Health Block Grant (Title V). The Title V Maternal and Child Health (MCH) Block Grant Program is a partnership between the federal government and states. Their goal is to support the health and well-being of all mothers, children, and families. More information at: https://mchb.hrsa.gov/programs-impact/title-v-maternal-child-health-mch-block-grant

**SLP**: Speech-Language Pathologist. SLPs work to prevent, assess, diagnose, and treat speech, language, social communication, cognitive-communication, and swallowing disorders in children and adults. More information at: https://www.asha.org/

**SPA**: State Plan Amendment. There is a specific SPA to EPSTD program within MT Medicaid that allows for CSHS to bill the HCPCs to MT Medicaid for ICT services rendered as part of the three CSHS-supported Cleft Clinics.

## Executive Summary

Access to pediatric specialty care in Montana has evolved profoundly in the past two decades, and within this healthcare landscape, care of cleft lip and palate (CL/P) and craniofacial conditions has proven itself both the rule and the exception. Since the 1940s, when Cleft Clinics are thought to have been initiated in Montana, they have taken a variety of shapes, but today remain very similar to the shape they were given in the 1990s. In 2007, a Montana Medicaid State Plan Amendment (SPA) made the Cleft Clinics a billable service under Medicaid. This action solidified the Cleft Clinics in their current state not only financially but also in a model that no longer aligns with the newer clinic recommendations of the American Cleft Palate-Craniofacial Association (ACPA). When the current Clinics were established, Montana had far fewer pediatric specialty providers who worked within a healthcare system that was less connected and coordinated than it is today. Today, the Clinics still provide a convenient way for 150 patients each year to see approximately 8-10 providers in a single day, receive basic evaluations from each, and then receive a plan of care for CL/P or other craniofacial conditions based on the team of providers seen. Within Montana there are approximately 800-850 people aged 0-17 years old with CL/P who would benefit from annual team-based care planning. While ACPA still recommends team-based care as best practice, there are alternative and improved ways to achieve an interdisciplinary approach to CL/P that would fit more naturally into the existing healthcare landscape. Montana now has greater access to pediatric specialists across the state, improved availability to these specialists outside of Clinics, increasing telehealth capacity, and larger, more complex medical systems forming networks across the state that coordinate and maintain care within those systems. Together, all these factors create the opportunity to improve patient CL/P care and access. **When considering a redesign of the Cleft Clinics statewide, however, the numerous differences across communities and healthcare systems within those communities make it unlikely that one model would be the best option across all communities in Montana.** Each major population center has a unique mixture of specialists, some of whom are employed by the major hospital or healthcare system in the community, and some of whom work in private practice. A number of these population centers don't actually have access to all of the specialists necessary for CL/P, such as plastic surgeons who are trained in CL/P care. Additionally, some specialists, such as orthodontia, are harder for many patients to access due to low or non-existant Medicaid reimbursement rates for their services. People from rural areas are always in a unique situation when they have complex medical needs and have to travel to major medical centers to receive care. Alternatively, the rise in pediatric specialists across the state and improved telehealth services may make it possible to better serve people in their rural areas. All of these considerations need to be addressed before choosing the best Cleft Clinic model for a specific community.

In conducting this assessment of the current Cleft Clinics in Montana and considering future models of care for CL/P, multiple viewpoints were considered, including patients and families, participating Cleft Clinic providers, Cleft Clinic Coordinators, healthcare system administrators, Montana Medicaid as the primary payer for children's healthcare in the state, and current and past staff at the Department of Health and Human Services (DPHHS) Children's Special Health

Services (CSHS) involved in the Clinics. There is a resounding recognition that patients with CL/P are best served by a team of specialists who are able to seamlessly coordinate their care with the patient, the patient's family, and within the context of the patient's life circumstances. It is understood that a considerable volume of care needs to be delivered over decades, and it is imperative that the care is affordable to patients, is comprehensive, is convenient to access, and creates trust within the patient-provider relationships.

Coordination of this care and the services by providers involved in the care are imperative—and costly. Currently, CSHS contracts with three major healthcare systems which provide the clinic coordination services. Due to changes in Maternal and Child Health Block Grant (MCHBG) funding, stagnant Medicaid reimbursement rates, declining patient attendance and minimal state budget support, CSHS can no longer cover these contract costs in the same way that it has been able to historically. For example, in SFY 2022, CSHS paid $175,490.26 to contract with the three healthcare systems and all of the supporting providers to run the Clinics. During that same time period, $87,935.01 was received through reimbursement for those services. There is $25,000 from the State Tobacco Settlement available to support the Cleft Clinics each year. Still, this pattern, in which expenses for the Clinics exceeds the revenue created from the Clinics began prior to COVID, was then exacerbated by the COVID-19 pandemic, and still persists. In SFYs 2024, 2025, 2026, $300,000 ($100,000 / year) from the State Genetic Fund revenue surplus has been obligated to support the Cleft Clinics as they transition into a new model that will allow them to continue in a more financially sustainable manner. Additionally, though the state funding has been essential to the healthcare systems coordinating Cleft Clinics, the role of CSHS in the Clinics has become increasingly burdensome to the healthcare systems through reporting requirements, outdated record-keeping systems, and maintenance of a rigid Clinic model that doesn't allow for innovation to meet the changing healthcare landscape. The Cleft Clinics also place an incredible amount of administrative overhead on the staff of CSHS, who are maintaining 25+ contracts with healthcare systems and providers, paying those contracts quarterly, managing a contractor to conduct the medical billing for patient care at all of the Cleft Clinics across the state, and closely monitoring to ensure that the contract obligations of the healthcare systems are being met. Additionally, providers who participate in the Cleft Clinics often volunteer their time. Those who are paid for their services are paid so minimally, that it indicates that altruism, dedication to patient care, and professional fulfillment are the primary reasons for provider participation in the Clinics. Some providers are paid through their normal salaries within their health system, but in these cases, their participation is made possible through the generosity of their employers who are accepting the same limited stipends for the services of their providers as all other providers involved are receiving.

It is difficult to build a sustainable healthcare model on the assumption of altruism. Despite this, some of the recommendations for future models continue to rely on donations of time, energy, and expertise from providers and healthcare systems. When considering which model to adopt in a community, careful attention will need to be paid to health systems' internal system capacity, the community's array of private practice providers, and the mission and capacity of each health system to provide resources to the Cleft Clinic. The Clinic Coordinator position is the single most difficult position to fund due to the way that healthcare payers reimburse for

services. In the current model, CSHS has been funding the Clinic Coordinator's position but relying on considerable donations from providers and health systems who employ those providers for their participation. This model could continue in the future—in a way—with CSHS paying for Coordination services with the reimbursement received from the Clinics, but would continue to rely on donations of provider time and energy. Additionally, this option would rely on the continuation of a burdensome bureaucracy for CSHS and considerable efforts to reform and update MT Medicaid HCPC reimbursement rates.

If health systems were to implement a model that relied on reimbursements based on traditional service provision (each provider bills independently for each service they provide), then the services of each provider would be reimbursed more appropriately. However, the role of the Clinic Coordinator funding would be less clear as CSHS transitions away from its ability to fund this position. In health systems where all or most of the providers are employed by the health system, it may be easier to justify the role and payment of the Coordinator position, as this is similar to any specialty coordinator who is coordinating care within the enclosed healthcare system. For CL/P care specifically, it is less clear who should financially support the role of the Coordinator because the providers involved are often employed by different systems or in private practice. Though primary pediatricians generally fill the role of the Coordinator for their patients across all types of medical care needs, CL/P care is so specialized and rare within a pediatrician's patient panel that it becomes inefficient for every coordinator of every pediatrician in an area to attempt to coordinate team-based care among a few area specialists. That said, there are likely creative models within larger organizations that fold the pediatrician into the Clinics. For example, Benefis in Great Falls has recently begun organizing their Cleft Clinics so that a pediatrician from their system sees all of the patients at the Cleft Clinic and could, in theory, become the primary pediatrician for a majority of those patients, streamlining the coordination in that area. In Vermont, the state Department of Health recently shifted out of the role of coordinating Cleft Clinics and transitioned them to the University of Vermont (UVM) Health Network. The person coordinating their Clinics is employed by the office of the plastic surgeon within the UVM Health Network, and in their model, each provider bills separately for their services.

There is also likely room for innovation within the Cleft Clinic format itself. While there is great convenience in being able to see so many providers at one time, patients and providers both noted that patients don't always need to see every provider at each Clinic. For young CL/P patients in particular, the Clinics are sometimes too long and exhausting. Evaluations are sometimes too basic for those who need more time with certain specialists and too involved for those patients who don't need to see a particular specialist. ACPA recommendations for team-based care offer flexibility to meet best practice guidelines, including the requirement for fewer specialists to mandatorily take part in team-based recommendations, the flexibility of spreading out appointments over a 30-day period, and the ability for evaluations to take place at the specialists' office, where treatment or more in-depth evaluations can be adequately completed. To meet APCA standards, providers still need to meet in real time to discuss and plan care for patients, but this meeting could be done outside of Cleft Clinic dates and spaces that are more convenient for providers. This meeting could even be conducted remotely using

videoconferencing or telehealth platforms. For example, a Coordinator could ensure that a patient sees the three required specialists under ACPA team-based care (surgeon, speech and language pathologist, orthodontia) at each of their respective offices within a 30-day period; then, at an agreed-upon time, those three specialists (plus any others who saw the patient during that time frame) would meet to discuss the plan of care for the patient. In this example, there isn't an extensive "Cleft Clinic" to plan and organize, but patient care is still being considered through a team-based lens and care coordination is taking place.

Other possible models for structuring the Cleft Clinics are outlined in this document and include: continuing to run Cleft Clinics in the same way they are currently being run, but with an effort to increase the HCPCS reimbursements rates to create a sustainable model; and the option to enlist a full time RN who could coordinate Cleft Clinics across the state, independent of any healthcare systems.

This document provides historical context, contemporary considerations, and recommendations for a host of different scenarios. **The primary focus of any future best-practice model for CL/P care is that it exists and it meets the needs of the people of Montana.**

## Acknowledgements

For the Montana patients and families who are affected by cleft lip, cleft palate, and other craniofacial conditions, it is our sincere hope that this document will help to improve the care you receive and the outcomes you experience across our state.

This assessment would not have been possible without countless patients, families, healthcare providers, and health systems across Montana, whose dedication, expertise, and contribution of energy and firsthand knowledge have been invaluable. Our thanks also to the staff of Montana DPHHS, who envisioned this assessment and showed unwavering dedication to maintaining access to care.

The goal of this assessment is to provide a better understanding of the needs and system possibilities surrounding CL/P care in Montana so that we may use the resources available to us to move forward with informed and data-driven approaches to change.

## Purpose of the Assessment

The current system of state-funded Cleft Clinics (the Clinics) was established many decades ago, and the landscape of healthcare and available providers has changed significantly since then. In recent years, several trends have emerged that prompted the need for this assessment. These concerns include a lack of consistent state-based funding, a burdensome administrative system, decreasing ability for providers to volunteer their services at the Clinics, and a decreasing number of participants attending the Clinics.

The Children's Specialty Services Needs Assessment was conducted to accomplish the following:

- Conduct a basic assessment of the CL/P population and demographic characteristics in Montana.
- Understand both strengths and weaknesses of the current state-funded Cleft Clinic care model.
- Compare current state-funded Cleft Clinic structure at each site to ACPA clinic standards.
- Identify perceptions of the CL/P patient population in Montana who utilize the current state-funded Cleft Clinics regarding the gaps, needs, and strengths of the Cleft Clinics.
- Assess the benefits and limitations of the current state-funded Cleft Clinic structure from the perspective of participating healthcare providers.
- Evaluate the costs and revenue associated with maintaining the state-funded Cleft Clinics.
- Provide suggestions of alternative options for state-funded Cleft Clinics to improve service delivery and establish financial stability.

## Methods

The Cleft Clinic Needs Assessment was conducted during the summer and fall of 2022 by DPHHS CSHS and Yarrow, a contracted public health consulting organization. Main sources of data for this analysis include unpublished data from the CSHS Children's Health Resource and Information System (CHRIS) database; CSHS epidemiologists' unpublished reports; data from CSHS contracted biller database (Aspen Billing (Aspen); and interviews and surveys conducted with CSHS state staff, current registered nurse (RN) Clinic Coordinators, participating cleft healthcare providers, and parents/caregivers of patients that participate in the Cleft Clinics.

At the outset of the Assessment, time was spent identifying the Assessment's purpose, which then guided the activities and information gathered for this project. Development of the activities undertaken in conducting this assessment and the methods for these activities are generally described within the corresponding section of the report, but those methods that are more general and/or span the entirety of the document are outlined below.

**CHRIS System and Epidemiological Data**

The CHRIS system is a proprietary database used by CSHS as a way for each hospital system that facilitates Cleft Clinics to maintain all Cleft Clinic patients' relevant health information. This system tracks the patient, dates of service, and the specific provider seen by the patient at each Cleft Clinic (it does not house all patient health information). The Family and Community Health Bureau (FCHB) epidemiology team reviewed data from the CHRIS system internally to gain an overview of basic patient demographic and clinic utilization information.

**Interviews with DPHHS Staff**

Interviews were conducted with the following DPHHS staff to understand the management, administration, history, financial support, Medicaid coverage, and other nuanced information about the Cleft Clinics, as well as available options to ensure the sustainability of its ongoing operation.

**Mackenzie Petersen**, MSW-MPH, She/Her/Hers
Children with Special Health Needs State Director/Section Supervisor
Early Childhood & Family Support Division

**Katie Sheehy,** BSN, RN
CSHS Nurse Consultant
Early Childhood and Family Support Division

**Joshua Clement**
Fiscal and Operations Bureau Chief
Early Childhood & Family Support Division

**Miriam Naiman-Sessions, PhD**
Senior Epidemiologist Supervisor
Early Childhood and Family Support Division

**Miranda Prevel**
Montana Medicaid
DPHHS Health Resources Division

**Katie Hawkins**
Montana Medicaid
DPHHS Health Resources Division

**Mary LeMieux**
Montana Medicaid
DPHHS Health Resources Division

**Site Visits and Clinic Coordinator Interviews**
A site visit was conducted at each of the three clinic sites:

- St. Vincent's Healthcare in Billings, MT: June 30, 2022
- Benefis Health System in Great Falls, MT: July 15, 2022
- CMC in Missoula, MT: July 18, 2022

Each site visit was scheduled on days when Cleft Clinics were not running. At each site visit a Yarrow team member met with the site Clinic Coordinator and other staff involved in the Cleft Clinic to further understand the Clinic Coordinators' perspectives, to learn how each site's clinic delivery compares using ACPA accreditation standards, and to gain general insight about the Clinics' operations. Detailed notes were taken during these interviews, the resulting insights have been used to inform the entirety of this assessment.

**System Administration Consultation**
Meetings were held with hospital leadership who play a role in the administration of the Cleft Clinics in their respective health systems.

- Benefis Health System in Great Falls, MT: Oct 10, 2022
- CMC in Missoula, MT: Sept 27, 2022

In these meetings, various scenarios of Cleft Clinic models were offered to the leadership to solicit feedback regarding the feasibility of each from the perspective of the health systems. No specific model was clearly identified as being preferable than others by health system leadership.

During the process of conducting this assessment, St. Vincent's Healthcare merged with Intermountain Health (Salt Lake City, Utah), which has maintained an ACPA-accredited Cleft Palate and Craniofacial Program for more than 20 years. St. Vincent's leadership was made

aware of the process of identifying alternative Cleft Clinic models and declined any meetings at this time as they understand the resources that will be made available to their CL/P patients through the existing Intermountain Health Cleft Palate and Craniofacial Program.

A robust mixture of providers who care for patients with CL/P in the Kalispell area were contacted as part of this assessment in an attempt to understand CL/P care delivery in that area. Representatives of Logan Health Kalispell stated their desire to develop and host Cleft Clinics in the future.

**Other Interviews and Consultations**

**Former State Cleft Employees.** Three former CSHS nurse consultants involved in the statewide specialty clinics over the last several decades were interviewed separately. Marylynn Donnelly, Meghan Kiser, and Caitlyn Patera all provided invaluable clinical perspective and historical context on the Cleft Clinics in Montana.

**Other State Clinics.** Additionally, a number of out-of-state providers associated with CL/P care were interviewed. Specifically, information about different CL/P clinic models was gathered from Seattle Children's Craniofacial Clinic Team, the University of Vermont Cleft and Craniofacial Program, and the Wyoming Department of Health Children’s Special Health Program.

**Providers.** Interviews were conducted with Antonio Santin, MD, plastic surgeon in Great Falls, Rachel Amthor, MD pediatrician in Great Falls, and Courtney Patterson, MD, internist in Kalispell.

# Introduction

## Overview of Cleft Lip and/or Palate and Patient Treatment Needs

CL/P are a heterogeneous group of disorders affecting the structure of the face and oral cavity. They are among the most common congenital anomalies occurring in the United States. Specifically:

- About 1 in every 1,600 babies is born with cleft lip with cleft palate in the United States.
- About 1 in every 2,800 babies is born with cleft lip without cleft palate in the United States.
- About 1 in every 1,700 babies is born with cleft palate in the United States *(CDCF).*

CL/P can be diagnosed either prenatally (via ultrasound) or postnatally. Additionally, the diagnosis may be associated with one of many syndromes that could further complicate a child's needs *(CCCLCP)*. Certain racial groups, including those from American Indian / Alaska Native and Asian populations, have a higher incidence of CL/P compared to other races *(CCCLCP)*.

A child born with a cleft or other craniofacial condition often requires specialized healthcare from infancy to young adulthood. An interdisciplinary team approach is recommended for these patients, with teams composed of professionals from a variety of healthcare disciplines who work with the family on an individual treatment plan. Services and treatment for children with CL/P can vary depending on a number of factors, including the severity of the cleft(s) and other associated syndromes. Examples of common services and treatments include:

- Surgical interventions starting in infancy and continuing through adolescence
- Ongoing dental and orthodontic needs beginning in infancy and lasting into adulthood
- In infancy, special bottles, feeding education, and/or lactation consultation may be provided by an occupational therapist, registered dietitian, physical therapist, lactation specialist, and/or nurse.
- Speech and language therapy (SLT)
- Audiology evaluations and interventions
- Ophthalmology evaluations and interventions
- ENT evaluations and interventions
- Consultation or evaluation by genetics
- Neurodevelopmental and cognitive assessment by a psychologist
- Assistance with insurance and additional financial needs by a social worker or other trained professional
- Routine pediatric care from a primary care provider, such as a pediatrician or family practice provider

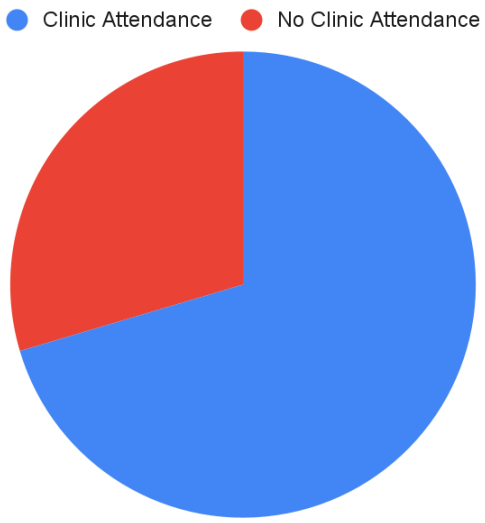
## Demographics of Cleft Lip and Palate in Montana

The DPHHS Maternal and Child Health Epidemiology team estimated the prevalence of cleft anomalies in children in the state of Montana. These estimates were sourced from three primary databanks, including Montana Vital Records, Medicaid claims, and Children's Special Health Services (CSHS) Speciality Cleft Clinic participation data.

During the six-year span between 2015-2021, there were a total of 287 children born that were identified to have cleft anomalies. This predicts that approximately 48 children were born each year with CL/P. If those 48 children attend the Cleft Clinics over 17 years, **this would predict an estimated 820 potentially eligible children requiring CL/P care and coordination in the state each year.**

Of the 287 patients reviewed for this project, 70.4% were identified as having participated in the CSHS Cleft Clinics at least once. Around 19.6% have not participated in the Cleft Clinics. To increase future participation in the Clinics, beneficial next steps would include further investigation into this population, including identifying existing barriers or ways to capture them in future outreach. Of these 287 patients, 56.4% were identified through Medicaid data, and 45.8% were identified through birth records. It is noted that these percentages should be interpreted with caution, as the CSHS Cleft Clinic identifies a broader pool of participants than Vital Records and Medicaid claims. The Cleft Clinics include patients with specific craniofacial conditions the other data sources do not *(SEPI)*.

**Figure 1: CSHS Specialty Clinic Participation.**




*(SEPI)*

## Recent Changes to Cleft Clinics in Montana

Several changes over the past few decades have impacted the funding, billing, locations, attendance, and accreditation of the Cleft Clinics.

### Shift in Title V Block Grant Funding

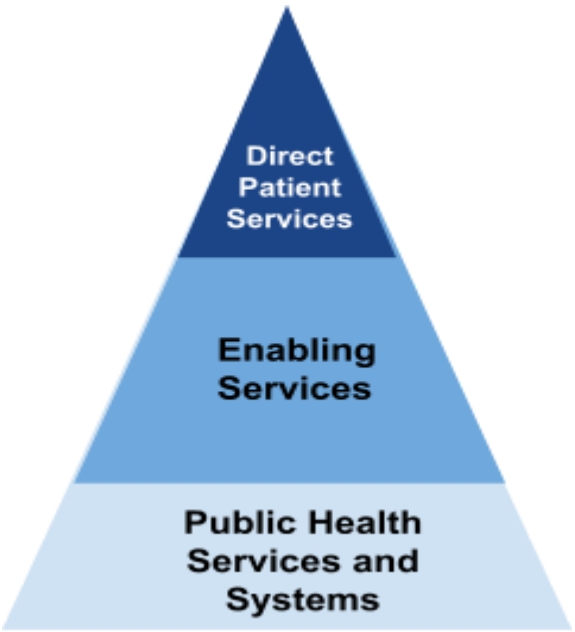
CSHS has historically received regular funding from the federal Title V Maternal and Child Health Block Grant (MCHBG). The Title V MCHBG is responsible for promoting the health of all mothers and children, including Children and Youth with Special Health Needs (CYSHCN) and their families. As defined in section 501(a)(1) of the Title V legislation, the purpose of the MCHBG is to enable each state to offer multiple services, including "to provide and to promote family-centered, community-based, coordinated care (including care coordination services, as defined in subsection (b)(3)) for children with special health care needs and to facilitate the development of community- based systems of services for such children and their families" *(USDHHS)*.

CSHS has traditionally used this funding to support the Cleft Clinics, but in recent years, the federal government has provided guidance directing more of these funds away from direct patient services and towards services focused more on overall population health.

More specifically, since its original authorization in 1935, Title V of the Social Security Act has been amended several times to reflect an ongoing commitment to improving the health and well-being of mothers, children, and families. As recently as 2020, the 10 Essential Public Health Services were revised. **Figure 2** *(USDHHS)* demonstrates how the updated 10 Essential Public Health Services align with the goals of the MCHBG .

**Figure 2. Public Health Services for MCH Populations: Title V MCH Services Block Grant.**

1. Assess and Monitor Health Status
2. Investigate, Diagnose, and Address Health Problems and Hazards
3. Communicate Effectively to Inform and Educate the Public on Health
4. Strengthen, Support, and Mobilize Community Partners to Improve Health
5. Develop and Implement Supportive Health Policies, Plans, and Laws
6. Improve and Protect the Public's Health through Legal and Regulatory Actions
7. Assure Effective and Equitable Health Systems
8. Build and Support a Diverse and Skilled Public Health Workforce
9. Improve and Innovate Public Health Functions through Program Evaluation, Research, and Continuous Quality Improvement
10. Build and Support a Strong Public Health Organizational Infrastructure



Specifically, the updated Essentials yielded the following strategy for states to use in their program planning specific to CYSHCN: "#7: Promote the effective and efficient organization and utilization of resources to ensure access to necessary comprehensive services for CSHCN and families through public health services, systems, and population health efforts" *(USDHHS)*.

**Clinic Locations**: Three Cleft Clinic contractors remain in operation today through Community Medical Center (CMC) (Missoula), Benefis Health System (Great Falls), and St. Vincent's Healthcare (Billings). However, outreach clinics used to be held at various other locations across the state, including Browning, Wolf Point, Kalispell, and Helena. Both Browning and Wolf Point outreach clinics were discontinued in 2016. Kalispell's clinics were discontinued in 2018, and Helena held its last clinic in 2019. Outreach clinics hosted by St. Vincent's in Bozeman are offered 1 time per year.

**Attendance**: As expected, attendance dipped significantly with the onset of the COVID-19 pandemic starting in 2020. In FY2021, Cleft Clinics restarted with COVID-19 precautions in place. Overall, however, attendance records demonstrate a trend in decreased patient attendance over the past several years. Please refer to the section Cleft Clinic Site Specific Attendance Data for more specific information on statewide patient attendance numbers and trends.

**Accreditation**: Previously, the Cleft Clinics in Montana were accredited by the ACPA as a whole at the state level. Re-accreditation was attempted again in 2021, but given changes to ACPA accreditation standards, a state program with a current structure like Montana's can no longer recertify for accreditation. Accreditation must occur at the clinic level. Specifically, accredited clinics need to have one nurse coordinator and one surgeon that attend each clinic, whereas currently in Montana, there are different coordinators and different surgeons at each site. Thus, the three current Cleft Clinics (as a whole) are not accredited by the ACPA.

# Current Cleft Clinic Operation in Montana

## Contracting and Administration

Cleft Clinics in Montana are overseen by the CSHS section of the DPHHS and administered in partnership with three major health systems: St. Vincent Healthcare (Billings), CMC (Missoula), and Benefis Health System (Great Falls), as well as a number of private practices and their providers in those areas. To accomplish this, CSHS maintains the following contracts, which are updated annually and paid quarterly *(CCIT)*:

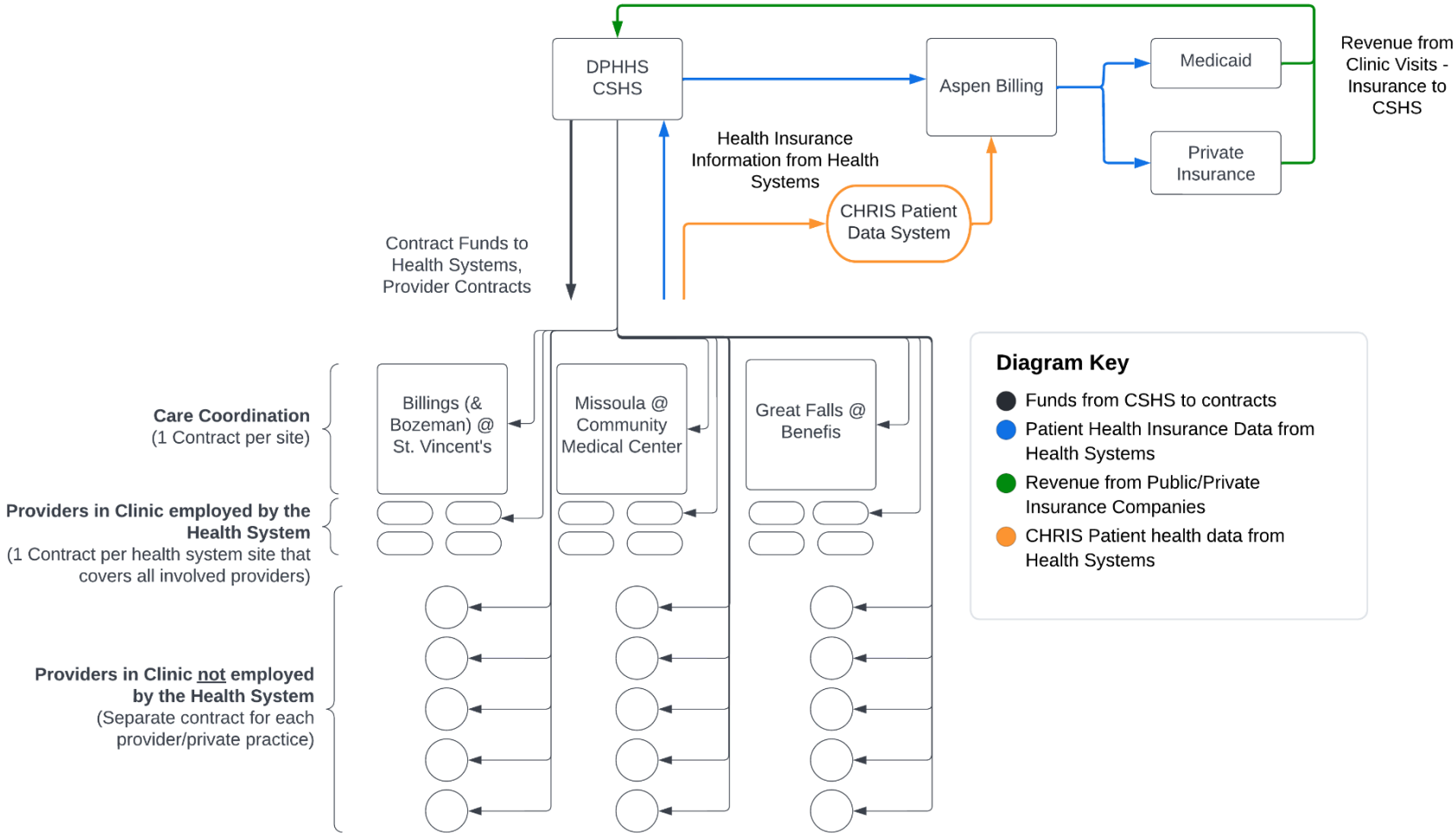
- One contract with each of the three health systems for care coordination and space to run the Clinics (a total of three contracts)
- One contract with each of the three health systems to compensate their employed providers that participate in the Clinics
- 15-20 individual contracts with private practices and providers across all three sites and the annual outreach clinic in Bozeman, MT. The exact number of contracts with private practices and providers fluctuates throughout the year as providers leave or begin work with the Clinics.

The contracts with each of the health systems for care coordination are significantly different and were established many years ago. For example, one Clinic bills a flat rate each quarter. The other two sites bill hourly, but they have considered different factors and estimate time worked and other billing factors such as space and centralized management differently. Since CSHS handles all clinic-associated costs, if a Clinic is canceled and there is no revenue or if a patient's insurance does not cover the charges, CSHS covers the charges at a loss.

Each of the three health systems runs one Cleft Clinic each quarter, and St. Vincent's offers one additional annual Cleft Clinic in Bozeman. After each health system has completed their quarterly Cleft Clinic, patient health information is entered into the CHRIS system, which indicates the number of providers seen by each patient and includes a summary note from the patient's clinic day. Complete patient records are maintained at each individual site, not by CSHS. Separately, the health system Clinic Coordinator collects each patient's health insurance information and sends this to CSHS staff through a secure information exchange portal, mail, or fax. CSHS staff then sends health insurance information via a secure file transfer to Aspen, a private company that provides billing services for CSHS. Aspen has its own unique login to access CHRIS for pertinent patient information necessary for billing. Revenue from this process is mailed to the CSHS via checks, and those funds are applied toward payment of contracts to the health systems and private provider contracts.

More information about Cleft Clinic financing is available in the section: Financial Assessment

**Diagram 1.** Visual of current Cleft Clinic model in Montana as administered by CSHS.



## Cleft Clinic Description

### Referrals to the Cleft Clinics

Most patients referred to the Cleft Clinics in Montana are identified prenatally or immediately after delivery. In communities where the Cleft Clinics are held, primary care providers, including pediatricians, are often familiar with these resources and are able to connect patients to the Cleft Clinics' Clinic Coordinators. If a primary care provider or pediatrician is not familiar with the Cleft Clinics, then patients are connected to the Clinics later through other specialists who are aware of the Clinics. For example, this scenario may happen for patients born in rural areas where primary care providers or pediatricians may not be familiar with the Clinics but who refer to one of the state's few plastic surgeons, who are then able to connect the patients with the Cleft Clinics.

### Care Coordination

According to the Agency for Healthcare Research and Quality (AHRQ), "care coordination involves deliberately organizing patient care activities and sharing information among all of the participants concerned with a patient's care to achieve safer and more effective care. This means that the patient's needs and preferences are known ahead of time and communicated at the right time to the right people, and that this information is used to provide safe, appropriate, and effective care to the patient" *(AHRQCC)*.

Within the Montana Cleft Clinics specifically, the responsibilities of care coordination fall primarily to the Clinic Coordinators, but are ultimately shared across all providers and the patient's pediatrician. Once patients are connected with the Clinic Coordinator of their respective Cleft Clinic, they are contacted at least annually and invited to participate in a Clinic. Clinic Coordinators use their professional clinical judgment to identify those patients with more severe diagnoses or who are infants to be seen more often, up to 2-3 times each year in the Cleft Clinic setting. They also identify those who have reached stability in their care and are contacted every other year. The Clinic Coordinator provides written summaries of each provider's recommendations after each Cleft Clinic to the patient/family and the family is generally responsible for following up on the recommendations and making the necessary follow-up appointments. Clinic Coordinators and the Clinic's social worker are available to patients on an ongoing basis to assist with securing appointments with hard-to-reach providers or to identify other resources outside of the Clinic setting for which the patient may express a need. There is no structured, ongoing care coordination for patients after participating in the Clinic. Sometimes, providers who attend the ICT meetings at the end of the day will volunteer to make the necessary referrals or connections with other providers with whom they have a professional relationship or see a benefit in directly communicating. In some instances when the social worker or Clinic Coordinator identifies a family that has barriers to care that may significantly affect the long-term health or outcomes of a child, additional assistance is provided based on those specific patient/family needs throughout the year and between Clinics. Ultimately, the pediatricians of the patients are responsible for coordinating care and providing any necessary referrals to specialists. Patients pediatricians are provided with a summary review of

recommendations from the ICT. Benefis and St. Vincent's have a pediatrician on their ICT. Patients' pediatricians do not take part in the Clinics at this time.

**Clinic Day Care and Flow**

On the day of a Cleft Clinic, the designated providers present to the centralized location of the Clinic. In Billings and Missoula, these Clinics occur in the hospital system's pediatric specialty clinic space. In Great Falls, the Clinic is held at the office of the plastic surgeon to allow for the use of surgical and dental equipment, if needed, for evaluation.

Currently, at the Missoula and Billings Clinics, patients arrive in two separate cohorts. For example, the first cohort of 5-10 patients will present at 8:30a and see providers until 10:30a, when a second cohort of 5-10 patients will present to see the providers. At these two sites, patients are placed in one room, where they stay for the duration of their time at the Clinic, and the providers rotate to each patient room. This specific flow (keeping patients in one room and having providers rotate through rooms) commenced during the COVID-19 pandemic and may help to explain why patient numbers are lower on average at the CMC/Missoula Clinic. Though it has decreased the number of patients who are able to participate in a day, it has received positive feedback by families who like being in one spot throughout the appointment and providers who are able to mingle with other providers more easily throughout the Clinic.

At the Great Falls Clinic site, patient arrival times are staggered, and they present at 15-minute arrival times throughout the morning. At this site, the providers each stay in one room and the patients rotate from room to room to see each provider. Patients have recently been provided with a sheet of paper that contains each provider name, specialty, and contact information on it and space for the patient to keep their own notes, which has received positive feedback from patients who used to have trouble remembering the names of the specific providers they had seen at the Clinic that day. Since patients are generally expected to follow-up with providers after their visits, this assists them in being able to do so.

***Finally, it is important to note that only basic assessment and evaluation are conducted by the providers during the Cleft Clinics. In-depth procedures or treatments are not performed at these visits.*** Specific treatment needs occur outside of the Cleft Clinic at the individual offices of healthcare providers. Sometimes treatment is carried out by the same providers who attend the Clinics (such as surgeons and orthodontists), but it is also common for treatment to be carried out by other providers (such as SLPs in schools or closer to home). To this point, the purpose and goal of teams is to ensure that care is provided in a coordinated and consistent manner with the proper sequencing of evaluations and treatments. The Clinic does not generally decrease the number of provider visits a patient will need to attend in the year, but it may in some cases. For example, seeing a dietitian at the Clinic for basic Medical Nutrition Therapy might be adequate care to prevent a follow-up visit, but it may uncover the need for ongoing Medical Nutrition Therapy sessions outside of the Clinic if significant nutrition deficiencies are uncovered as a result of inadequate or inappropriate food intake as a result of the patient's CL/P. Still, there is no requirement or expectation that specific screenings are conducted consistently across patients and Clinics by each different discipline.

**Interdisciplinary Care Team (ICT) Meetings**

Once patients are seen in the Cleft Clinic, the providers are expected to remain together at the site and review each patient that was seen that day. The Clinic Coordinator often leads the meeting and facilitates discussion among the providers to assist with a team-based understanding of the patient and any further needs to be coordinated between providers. The ICT meeting is imperative, as the best patient outcomes could potentially involve surgical or procedural recommendations that would ideally take place in a specific order. There may also be social barriers to consider. For example, basic transportation or childcare barriers may necessitate coordination of appointments on the same day. Finally, making all providers aware of the patient's recommendations supports a more comprehensive patient care plan and holistic approach. Following the ICT meetings, the Clinic Coordinator summarizes recommendations and finalizes prioritized recommendations for patients, providing copies of these recommendations to the patient's pediatrician and each of the providers present for the Clinic. If the recommendations include a referral to providers who are not at the Cleft Clinic or require a pediatrician's referral, those recommendations are mailed to the patient and the patient's pediatrician within the next several weeks.

**Charting**

At each clinic site, providers are asked to document their encounter with the patient on a specific, state-provided paper template to maintain consistency across the Clinics and ensure documentation is complete for billing purposes. At the end of the clinic day, the Clinic Coordinator collects each provider's paper notes and compiles a brief summary of these into the CHRIS system. Of note, patient summary information that is entered into CHRIS is not "signed" by providers and therefore does not constitute an official medical record. Official patient records are maintained at each of the individual healthcare systems. In some health systems, an electronic record is created for the patient in the health system's electronic health record (EHR). The CHRIS system, purchased and ultimately maintained by CSHS, acts as the centralized data system and statewide patient registry that houses summaries of patient encounters for patients of the Cleft Clinics. Individual providers of the Cleft Clinics do not have access to the CHRIS system. If they need access to a patient's chart from a Cleft Clinic, they must request this from the Clinic Coordinator.

**Billing**

Patient encounters in the Cleft Clinic setting are billed by CSHS using the Healthcare Common Procedure Coding System (HCPCS) Codes T1024 or T1025. Montana Medicaid's Healthy Montana Kids *Plus* (HMK *Plus*) (administered by Montana Medicaid) and Healthy Montana Kids (HMK) (administered by Blue Cross Blue Shield (BCBS)) reimburse the HCPCS T1024 code at $100 / unit with a unit being each provider seen at a Cleft Clinic when the patient sees seven or fewer providers at the Cleft Clinic that day. The HCPCS T1025 code is reimbursed at $1,000 / unit when care is provided by eight or more providers at the Cleft Clinic that day. Other private insurance carriers reimburse the HCPCS T1024 and T1025 at other lower rates that vary by carrier and plan. More information about various health insurance reimbursement of the HCPCS can be found in the section Cleft Clinic Revenue and Reimbursement.

The use of HCPCS Codes in the Cleft Clinic setting with reimbursement by MT Medicaid is allowable at the negotiated rates described above through a Medicaid SPA originally approved in 2007, and rates have not been updated since that time. See MT Medicaid July 2019 CSHS Fee Schedule. In 2020, conversations with MT Medicaid were initiated regarding improved reimbursement for the HCPCS T1025 and T1024, but only minimal progress was made to this end. Specifically, T1024 has been a problematic HCPC because it is supposed to be billed only once per day per patient, but is actually billed for every provider seen at a "partial" Cleft Clinic when T1025 cannot be billed for a full Cleft Clinic day. In 2020, MT Medicaid suggested the possibility of simply determining a cost for a partial clinic that would be billed only once per patient per clinic day and not billed once for each provider the patient sees that day.

Clinic Coordinators enter each patient's encounter, visit summary, and basic health insurance information into CHRIS. Copies of health insurance cards and information about secondary health insurance is sent through mail, secure electronic file transfer, or fax to CSHS staff. Aspen Billing can then access patient encounter information and basic health insurance information directly through the CHRIS system and more specific health insurance information from CSHS staff or through the Medicaid Provider Portal. Aspen Billing then bills both public and private health insurance on behalf of CSHS. Aspen Billing is compensated with 10% of the revenue received from this process. Remaining revenue received by CSHS is applied to the contracts that support the health systems and providers who staff the Cleft Clinics.

### Cleft Clinic Attendance Data

The three Cleft Clinic sites function similarly, but see differing volumes of patients and involve different provider types at their Cleft Clinics based on provider availability and willingness to participate at each site.

Across the 23 Cleft Clinics at the three contracted sites between Q1 of 2019 and Q1 of 2021, 100% were staffed by at least eight different specialists, which represents a full team according to the state requirements for billing a full team as a HCPCS T1025 *(CCPRGF)*. Despite this, only 74% of the Cleft Clinics had the three core ACPA specialties in attendance (Speech-Language Pathology, Surgery, and Orthodontia) *(APCATM)*. The speciality not present in all of these cases was orthodontia.

Between 2011-2020, 815 unique patients attended at least one Cleft Clinic in the state of Montana. This includes all Cleft Clinics in operation during those years, such as the Helena Cleft Clinic and outlying Cleft Clinics in Wolf Point, Blackfeet, Kalispell, and Bozeman. This time range also coincided with COVID-19 for three clinic quarters of 2020. Despite these limitations, almost half of all patients seen during this time period attended four or more Cleft Clinics.

**Figure 3. Percent of Patients Attending by Number of Cleft Clinics Visits between January 1, 2011 and December 31, 2020.**

| Visits | Unique Patients | Percent of Patients |
|---|---|---|
| 1 | 265 | 32.52% |
| 2 | 98 | 12.02% |
| 3 | 65 | 7.98% |
| 4 | 62 | 7.61% |
| 5 | 54 | 6.63% |
| 6 | 47 | 5.77% |
| 7 | 28 | 3.44% |
| 8 | 31 | 3.80% |
| 9 | 24 | 2.94% |
| 10+ | 141 | 17.30% |
| **Total** | **815** | **100.00%** |

*Age of the patient was not considered in this dataset. For example, a 1-year-old patient may have only attended 1 Clinic, but this is appropriate based on the child's age. This means that it was appropriate that a portion of the clients only attended a Clinic a few times.
*Includes Helena and outlying Clinics in Wolf Point, Blackfeet, Kalispell, and Bozeman

*DCCTVS*

In the 10 years between January 1, 2011 and December 31, 2020, 815 patients participated at least 1 time in a Cleft Clinic. Almost half (47.5%) participated in at least 4 Clinics. When considering certain factors—that a large number of patients likely could not have participated in all 10 years due to age limitations based on the way the data was considered; the closure of outlying Cleft Clinics in Wolf Point, Blackfeet, and Kalispell; and the start of the COVID-19 pandemic during this time—**the data support the assertion that patients are returning consistently to use the Cleft Clinics**.

**St. Vincent's Healthcare - Billings, Montana**

- Number of Clinics (2019-2021): *8*
    - * Percent of Clinics with Full Team/8+ Specialties: *100%*
    - Percent of Clinics with ACPA recommended (Orthodontia, SLP, Surgery): *75%*
- Average Number of Patients at each Quarterly Clinic: *14*

**CMC - Missoula, Montana**

- Number of Clinics (2019-2021): *7*
    - *Percent of Clinics with Full Team/8+ Specialties: *100%*
    - Percent of Clinics with ACPA recommended (Orthodontia, SLP, Surgery): *43%*
- Average Number of Patients at each Quarterly Clinic: *10*

**Benefis Health System - Great Falls, Montana**

- Number of Clinics (2019-2021): *8*
    - *Percent of Clinics with Full Team/8+ Specialties: *100%*
    - Percent of Clinics with ACPA recommended (Orthodontia, SLP, Surgery): *100%*
- Average Number of Patients at each Quarterly Clinic: *13*

**Overall**

- Number of Clinics (2019-2021): 23
    - Percent of Clinics with Full Team/8+ Specialties: *100%*
    - Percent of Clinics with ACPA recommended (Orthodontia, SLP, Surgery): *74%*

In all cases where the full ACPA team was incomplete, orthodontia was the missing specialty. Orthodontia was also the one speciality that did not participate in the Provider Survey for this needs assessment. Additional work may be needed to further understand their lack or participation in the Cleft Clinics *(CCPTGF).*

[1] *The "Full Team/8+" category utilizes the HCPC code definition of a "Full Team" in which at least 8 different providers were present at the Clinic. The current contracts between DPHHS and the healthcare facilities defines a full team as the presence of all of the following provider types at a Clinic: BSN RN Clinic Coordinator, SLP, Surgery, Orthodontics, Psychology, Social Work, Audiology, Genetrics, General and Pediatric Dentistry, Otolaryngology, and Pediatrics primary care *(CSCCMS)*.

## ACPA Standards Overview

The ACPA is a non-profit organization that works to support the interdisciplinary care of individuals with cleft and craniofacial conditions. Their team-based care standards identify the following main areas of care: care team composition requirements, team management and responsibilities, patient and family/caregiver communication, cultural competence, psychological and social service, and an outcomes assessment *(ACPATM)*.

Of note, ACPA recommends “team-based” care, which does not have to take the exact form of a “Clinic” as Montana has been supporting, though “Clinics" are likely still a good option in a predominantly rural state with a relatively small number of providers. There is opportunity to learn from how other models are implemented and where new best practices can be adopted to create financially sustainable and convenient options for patients and providers. Even if continuing with “Clinic” formats, there are ways to streamline, simplify, and improve the Clinics to ensure that each patient receives the care they need and each provider has the time and resources to adequately provide the care.

The Montana Cleft Clinics were historically ACPA accredited. Due to changes to the accreditation process, the state is no longer able to apply on behalf of the Cleft Clinics supported by CSHS, since doing so would require a single Clinic Coordinator and central/shared records across all of the Clinics. If current clinic sites would like to receive ACPA accreditation, they would need to apply individually. While accreditation is not required for state-funded Cleft Clinics at this time, the ACPA accreditation standards for team-based care were used to compare the current Cleft Clinic structures at each of the three individual sites from the perspective of each Clinic Coordinator.

**Figure 4** shows a general compilation of how each of the three Cleft Clinic sites provides care in alignment with the ACPA standards. Green indicates that the Clinic Coordinators believe they are fully meeting a standard; yellow indicates that the standard is being partially met; and red indicates that the standard is not being met. ***Please note that these are generalizations across all 3 sites. Some sites may or may not meet ACPA standards in the way indicated in the table.***

Overall, the following sections are well met across all of the Clinics: Patient & Family/Caregiver Communication, Cultural Competence, and Patient & Family/Caregiver Communication. Areas of improvement include: Team Composition, Psychological & Social Service, and Outcomes Assessment.

**Figure 4.** Shows how each of the state-funded Cleft Clinic sites is providing services compared to the ACPA accreditation standards.

| ACPA Standard | 3 Clinic Sites Combined |
|---|---|
| **Team Composition** | |
| **Standard 1a.** The team includes a designated patient care coordinator to facilitate the function and efficiency of the team, ensure the provision of coordinated care for patients and families/caregivers and assist them in understanding, coordinating and implementing treatment plans. | |
| **Standard 1b.** The team includes speech-language pathology, surgery and orthodontic specialties who participate in team meetings as appropriate to specific patient needs. | |
| **Standard 1c.** The team demonstrates access to professionals in the disciplines of psychology, social work, audiology, genetics, general and pediatric dentistry, otolaryngology and pediatrics/primary care. Note: These services do not need to be provided directly by the team, itself. However, the team must maintain a list of reliable community resources for any of these services that are not provided by the team. Some record of assessment and/or treatment follow-up should exist in the centralized team record. | |
| **Standard 1d.** If applicable, the craniofacial team must include a surgeon trained in transcranial cranio-maxillofacial surgery. | |
| **Standard 1d.** If applicable, the craniofacial team must include access to a psychologist who does neurodevelopmental and cognitive assessment. Note: the results of the neurodevelopmental and cognitive assessment must be part of the CFT team assessment record. | |
| **Standard 1d.** The team also must demonstrate access to refer to a neurosurgeon, an ophthalmologist, a radiologist, and a geneticist. The participation of these individuals should be documented in each patient's team report. Note: these services do not need to be provided directly by the team, itself. | |
| **Team Management & Responsibilities** | |
| **Standard 2a.** The team has a mechanism for regular meetings among core team members to provide coordination and collaboration on patient care. Note: while face-to-face meetings are preferred, it is recognized that teams may use alternative means to interact. | |
| **Standard 2b.** The team has a mechanism for referral to and communication with other professionals. Examples include: referring patients to local care providers when necessary and appropriate; implementing a process for information exchange with schools, primary care professionals, outside agencies, and other professionals involved with the welfare of the patient; and having a process for obtaining informed consent consistent with federal, state, and institutional requirements. | |
| **Standard 2c.** The team re-evaluates patients based on team recommendations. Note: subsequent evaluations should be scheduled at regular intervals, the frequency and specific content of each of those evaluations being determined by the condition and needs of the individual patient and family/caregiver. | |
| **Standard 2d.** The team must have central and shared records such as comprehensive records on each patient must include histories, diagnoses, reports of evaluations, treatment plans, and reports of treatment. | |

| | |
|---|---|
| **Patient & Family/Caregiver Communication** | |
| **Standard 3a.** The team provides appropriate information to the patient and family/caregiver about evaluation and treatment procedures orally and in writing. Parents/caregivers must be given information about recommended treatment plans and any alternatives, benefits, and risk factors. Communication with the patient should follow after each team evaluation. | |
| **Standard 3b**. The team encourages patient and family/caregiver participation in the treatment process. Teams must have mechanisms that ensure the family/caregiver and patient have opportunities to play an active role in treatment decisions. When appropriate and the child is present, the child also may also have the opportunity to have input in treatment decisions. | |
| **Standard 3c.** The team will assist families/caregivers in locating resources for financial assistance necessary to meet the needs of each patient. Examples include: health insurance, state agencies, Public Law 94-142, 504s, and individual educational plans. | |
| **Cultural Competence** | |
| **Standard 4a.** The team demonstrates sensitivity to individual differences that affect the dynamic relationship between the team and the patient and family/caregiver. For example, accommodating linguistic, cultural, and ethnic diversity among patients and their families/caregivers and ensuring that appropriate interpreters are available to assist in both verbal and written communication. | |
| **Standard 4b.** The team treats patients and families/caregivers in a non-discriminatory manner. Services are provided without regard to race, color, religion, sex, national origin, disability, age, sexual orientation, or status as a parent/caregiver. | |
| **Psychological & Social Service** | |
| **Standard 5a.** The team has a mechanism to initially and periodically assess and treat, as appropriate, the psychological and social needs of patients and families/caregivers and to refer for further treatment as necessary. Note: Social workers and psychologists may either be part of the team or available by referral. | |
| **Standard 5b.** The team has a mechanism to assess cognitive development. Teams must ensure that assessments for cognitive development and learning disabilities have been conducted at appropriate time intervals so that each patient receives appropriate educational services from infancy throughout adolescence. Documentation of these assessments and recommendations should be part of the patient's team record. | |
| **Standard 5c.** The team conducts formal assessment of cognitive functioning of patients when deemed necessary. Specifically, cognitive psychometric testing must be performed, when necessary, on patients whose age is 4 or older and who have a craniofacial condition requiring transcranial surgery. | |
| **Outcomes Assessment** | |
| **Standard 6a.** The team uses a process to evaluate its own performance with regard to patient assessment, treatment, or satisfaction and to make improvements as a result of those evaluations. The team documents its treatment outcomes, including baseline performance and changes over time. Teams must conduct periodic retrospective or prospective studies to evaluate treatment outcomes. The team must also have a quality management system to evaluate patient/family satisfaction. | |

## Cleft Care in Communities without Cleft Clinics

In the past, the larger population centers of Helena and Kalispell had outreach Cleft Clinics, but these are no longer operating. Patients with CL/P in these communities have several options for obtaining care. Often, their care coordination is managed by their primary care pediatrician, and specialized care is provided by any specialists available in the area.

Kalispell's pediatric specialist landscape has changed significantly over the past several years as Logan Health has merged with many of the medical clinics including private pediatric and specialty care clinics in the Flathead area. The Logan Health system now includes most of the specialist providers necessary to maintain locally based care. According to providers who were interviewed for this project, much of the care for patients with CL/P is coordinated through referral systems of providers who personally know each other. There is significant interest in starting a Cleft Clinic through Logan Health that would be available to serve Kalispell and the surrounding area.

Since the dissolution of the Cleft Clinics in Helena, patients with CL/P are most commonly referred to the Cleft Clinics in Bozeman, Great Falls, or Missoula. Patients who do not wish to participate in those Cleft Clinics have their care coordinated through their pediatrician. Most patients would likely be referred directly to Dr. Santin in Great Falls for surgery. Other aspects of care are coordinated locally in the Helena area.

Those patients who formerly attended Cleft Clinics in Wolf Point and Browning are generally referred to the Cleft Clinic in Great Falls, or directly to a surgeon such as Dr. Santin in Great Falls or Dr. Spring in Kalispell for surgical procedures. Coordination of any other services they need happens through their pediatrician. This is similar to how patients from all rural areas are provided care—with referral to a Cleft Clinic or simply to a surgeon, with the rest of their care orchestrated through their primary pediatrician. If specialists are available in the rural community (for example, a SLP or dietitian) then that provider could provide care in the community, but patients generally need to travel to major medical centers for more specialized care.

## Healthcare Provider Survey Results

**Methods: Provider Surveys**

A 20-question survey was created by Yarrow staff using the Google Forms platform. Questions were informed by interviews with state staff and hospital-based Cleft Clinic Clinic Coordinators. The purpose of the survey was to explore the thoughts, needs, and feelings of the healthcare providers that participate in Cleft Clinics across the state. By filling out the survey, providers consented to sharing their information freely and without restriction. Survey responses were not anonymous.

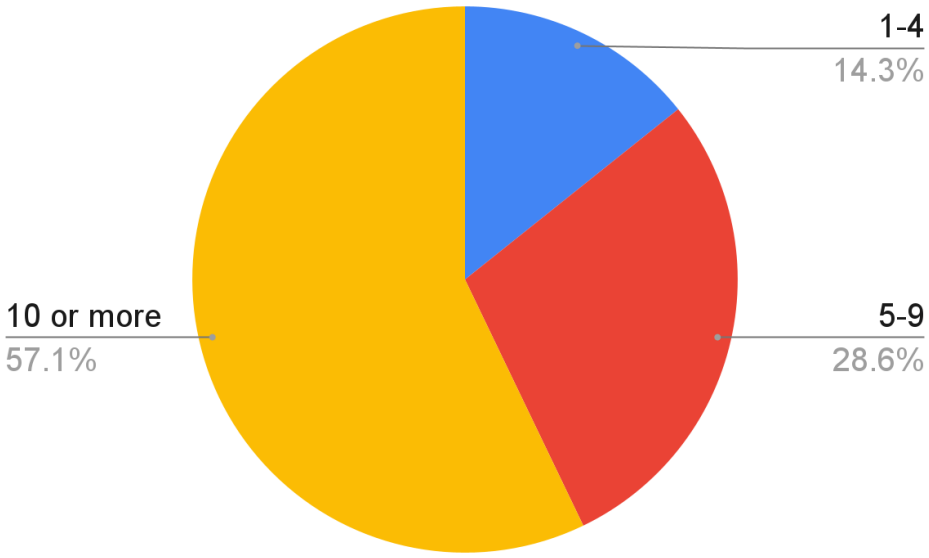
Surveys were distributed to 40 providers who have participated in at least one Cleft Clinic at any of the main or satellite sites in the past two years. Email addresses of all providers were collected either from the Clinic Coordinators' contacts lists or by calling each individual provider's office directly. An email with a link to the survey was sent to each provider up to three separate times. If there was no response, additional phone calls were made to the provider's office to encourage participation. Survey results were collected from early August 2022 through late September 2022. These data were compiled and analyzed on Google Sheets. The survey form can be found in Appendix 2.

**Results: Provider Surveys**

The overall response rate was 21 of 40 providers (53%). One of the 21 participants elected to call a Yarrow staff member to provide their answers verbally instead of through the online form.

- Demographics of participants:
    - Among the three clinic sites, 33.3% of the participants participate in the Benefis Clinics, 28.6% participate in the St. Vincent's Clinics, 23.8% participate in the CMC Clinics, and 14.3% participate in more than one clinic site.
    - Responses by provider type are as follows: speech/language therapist (4), dentist (3), social work / licensed clinical social worker (3), audiologist (2), dietician (2), genetic counselor (2), pediatrician (2), plastic surgeon (2), and counselor / licenced clinical professional counselor (1).
    - One respondent practices both as a plastic surgeon and as an ear, nose, and throat (ENT) specialist.
    - No responses were received from an orthodontist.
    - Of the participants, 42.9% are employed by the hospital/facility in which their Cleft Clinic is held, and 57.14% are in private practice or are employed in an independent clinic.

**Figure 5. Distribution of Experience (in Years) at the Clinics among the Provider Survey Participants.**




As noted in the Figure above, a majority of the providers (57%) that responded to the survey have 10+ years of experience participating in the Cleft Clinics, allowing for robust clinical insight into the Cleft Clinics in Montana.

**Thematic Analysis: Provider Surveys**

After survey results were collected, a basic thematic analysis of the results was conducted. The following themes emerged within the categories of 1) strengths, 2) weaknesses, 3) motivation to attend Clinics, and 4) quality of the current Clinics.

**1. Strengths** identified by providers (in response to the survey question *Describe the strengths of the current Cleft Clinics*):

**Convenient for families**

- Clinics allow for access to a wide range of specialists at one time and in one location
- Patients are not billed separately for each specialist they encounter at the Cleft Clinic

**Collaboration**

- Collaboration among the interdisciplinary team allows each provider to consider care from multiple perspectives
- This ability to collaborate and coordinate care provides more comprehensive care for patients
- Providers appreciate the consistency of the Clinics from year to year

**Care coordination**

- Clinic Coordinators are able to consolidate and summarize recommendations to patients, as well as ensure that primary care providers and others on the care team have documentation of recommendations

**2. Weaknesses** identified by providers (in response to the survey question *Describe the weaknesses of the Cleft Clinics or specific areas that need improvement*):

**Poor provider attendance**

- Respondents mentioned difficulties when specific providers are not in attendance (specific providers mentioned were plastic surgeon, orthodontist, ENT, pediatrician, dentist)
- Inconsistent provider attendance is a challenge not only for the patients but also the other providers attending the Clinics. For example, if a certain specialty such as dentistry is represented by a different dentist each time, they felt the quality of care is impacted

**Poor patient attendance**

- Many respondents mentioned frustration with late cancellations/no-shows on Clinic days but acknowledged this might not be a solvable problem

**Clinic days**

- Clinics can result in a very long day for patients, especially for younger patients or for those who might also need to travel long distances to reach the Clinic

**Outdated tools / lack of ability to perform specific procedures/tests**

- Outdated assessment forms, specifically those used by social work
- The use of paper charting is not efficient for provider-to-provider communication and providers overwhelmingly prefer an EHR.

**3. Motivation of providers to attend the Clinics** (in response to the survey question *What motivates you to provide your services and expertise at the Cleft Clinics?*):

**Important service**

- Caring for those in need, especially those that are facing challenging situations
- Respondents agree that interdisciplinary care is best for these patients with CL/P

**ICT**

- Providers appreciate their collaboration and being able to learn from other each other and their areas of expertise
- Professional relationships with other providers

**Patient population**

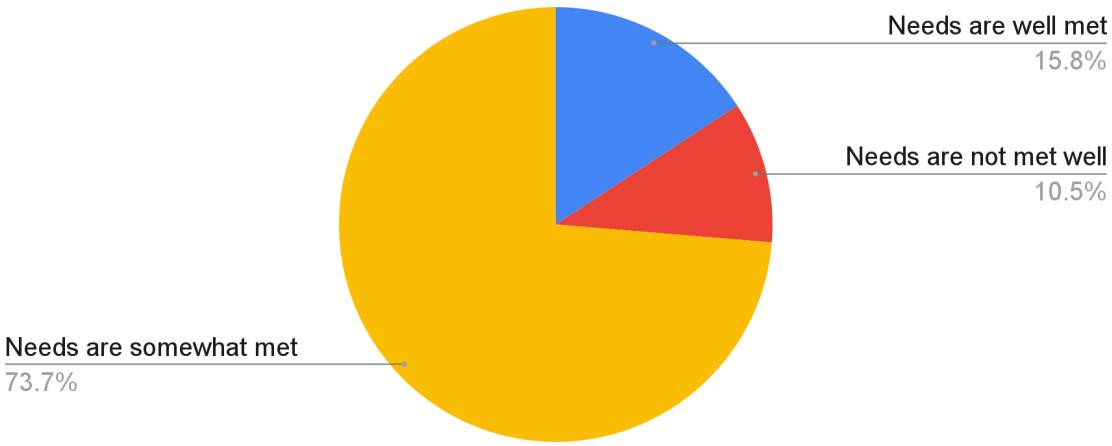
- Many respondents enjoy the unique care given to these children
- Given the comprehensive and long-term care for children with CL/P, providers enjoy building relationships with patients and their families

**Professional fulfillment**

- Respondents enjoy providing care that is challenging and rewarding

**4. Quality of care for Children with CL/P in Montana** (in response to the survey question: *In general, for children receiving care for cleft lip/palate, how well do you feel their medical and psychosocial needs are being met in Montana? This could mean at the Cleft Clinic or outside of the Cleft Clinic. It refers to both care for cleft and other care in general.*)

**Figure 6. Providers Opinion on Quality of CL/P & Healthcare to Meet Patient Needs in Montana.**




The chart above indicates that the majority of providers fall within the “Needs are somewhat met” and “Needs are not met well” categories, making up around 84% of responses. General reasons why they do not feel “Needs are met well" include geographic barriers and a lack of follow-through on recommendations.

Because much of Montana is rural, patients lack access to many specialists or have to drive long distances to receive care. As one respondent said, “That's not always easy, given how geographically widespread the population is. Many children come from very small communities and are isolated from both psychosocial and medical services they could benefit from.” While this is a major theme in the survey, it is a general rural health issue and not specific to CL/P care.

Providers also highlighted that Cleft Clinics can be successful only if patients follow-through on recommendations.

**Provider statements supporting childrens’ needs being met:**

- “I think medical needs are being met well, particularly when families are able to follow up on clinical recommendations. That's not always easy, given how geographically widespread the population is.”
- “I think the overall care and services are very good and mostly complete.”

- “Under the current Cleft Clinic organization, I feel the opportunity is there for good, coordinated care if the patient/guardian followed up with the recommendations of the clinic.”
- “Very well…so long as parents utilize the services available.”
- “I also feel like there are parents who are on top of it and that those kids’ needs are being met.”

**Provider statements supporting children’s needs not being met:**

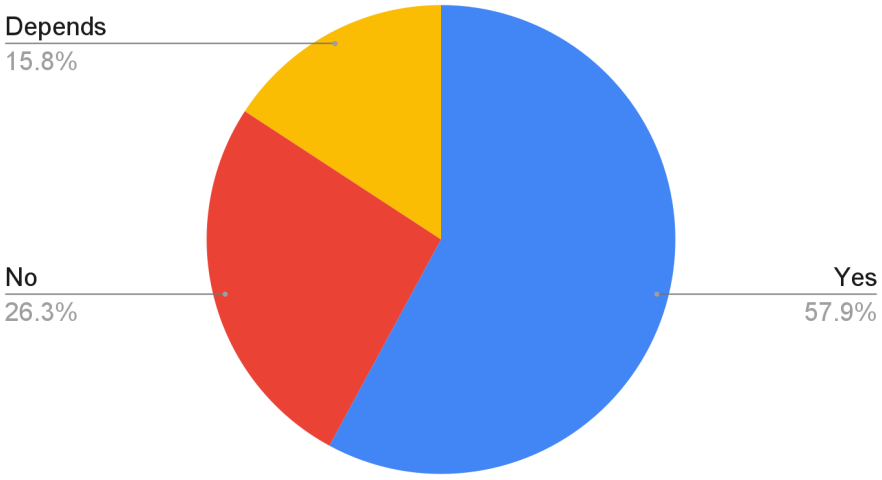
- “Montana has difficulty meeting needs due to travel times from the rural communities and access to pediatric specialists and therapists etc in rural areas but that is a problem not caused by the cleft clinic itself.”
- “Not well, we are short on knowledgeable providers across the state.”
- “I feel like some kids fall through the cracks- but I feel that is it typically due to parents inability to see the importance of medical visits beyond the cleft- ie: nutritional, ENT, hearing, speech etc.”
- “I feel that there are additional evaluating procedures that could be provided that would help give the providers a better understanding of the velopharyngeal function (Nasometry, Pressure flow rates).”

**Provider statements supporting childrens’ needs being somewhat met:**

- “I think that social workers that specialize in quarterbacking this care may be more effective than the clinics.”
- “They are somewhat met. I feel there are gaps in service in some surrounding communities that we serve at the GF clinic due to a lack of providers/services.”
- “Varies in region. Rural areas lack services.”
- “Based on what we're doing there, we're doing a decent job. But again, when you get outside Great Falls or easy driving distance to Great Falls the family has to be motivated and have a car with four working tires on it to access services. Some are more successful at this than others.”

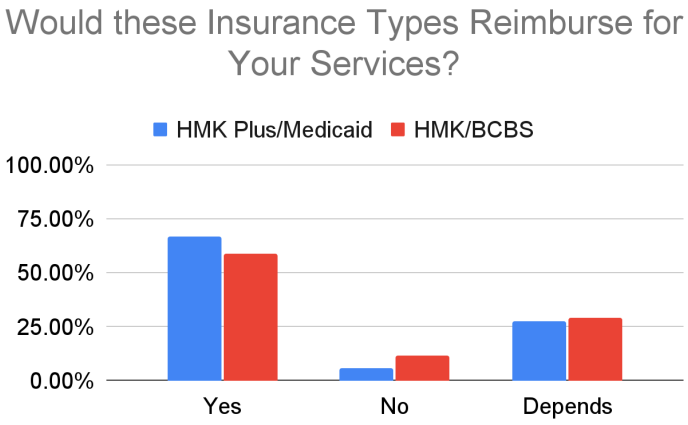
**Ability to Bill for Services Offered in the Cleft Clinic Visits** (in response to the survey question: *If you were to provide the same service in your office or hospital that you provide at the Cleft Clinic, would you be able to bill insurance for the encounter?*)

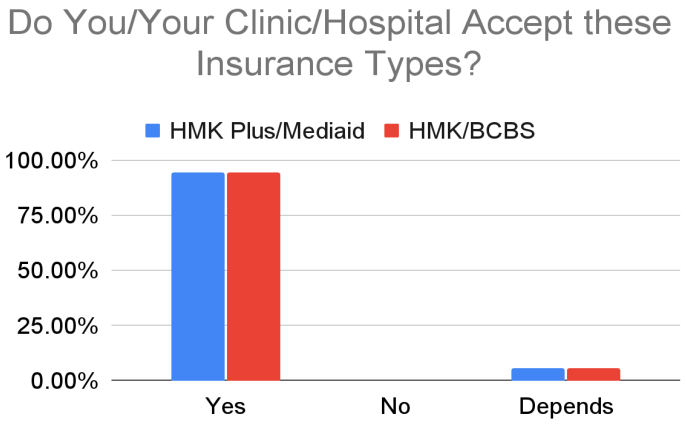
**Figure 7. Ability for Provider to Bill for Services Offered in the Cleft Clinic Visits.**




As noted in the pie chart above, around 58% of providers said “Yes,” they would be able to bill for their services offered in the Cleft Clinic visit, around 26% responded “No,” and around 16% of providers responded that it would depend on the encounter. Of those that responded “No,” providers included SLP and social work. One SLP noted that in order for an SLP to bill for their services, the evaluation needed to be more in-depth. Currently, the service provided by SLPs is more of a speech screening than a full evaluation. Based on the social workers’ experience, only the counseling provided at these Clinics would be billable, and not the case management.

**Figures 8 and 9. Insurance Acceptance for Services Provided at Cleft Clinics.**

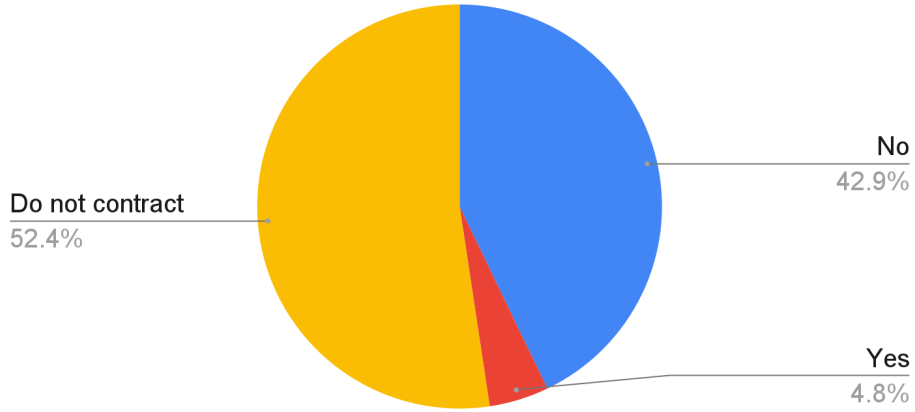



MT Medicaid, administered by the state Medicaid office and HMK, administered by BCBS, are accepted by providers who see children through the Cleft Clinics, and most would reimburse for the services as currently provided or as modified.

**Remuneration of Providers as Motivation** (in response to the survey question: *Are you motivated by the current provider rates under the CSHS state contracts?*)

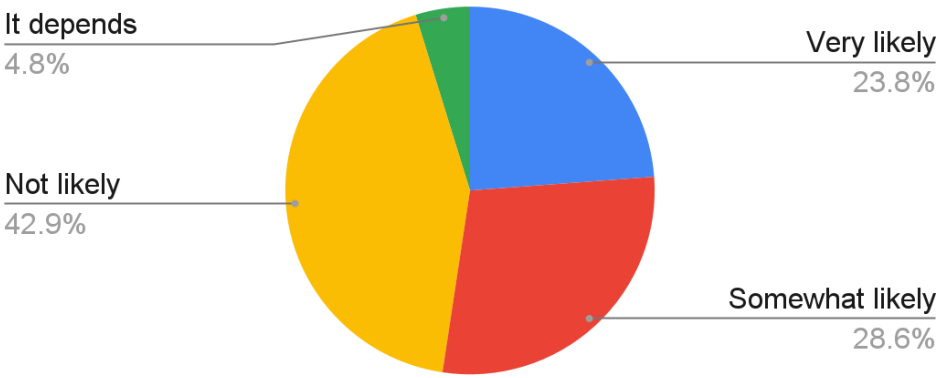
**Figure 10. Whether Providers Are Motivated by the Current CSHS Provider Rates.**




Providers currently receive reimbursements totalling between $300-$400 per day spent in the Cleft Clinic. Providers are paid $300 for the first 7 patients they see and then $25 for every additional patient they see, a rate that is not based on fair market value for these services. A majority of the providers participating in the Cleft Clinics fall in the “Do not contract” category, meaning they are not personally involved in the reimbursement process. Because many of these providers work under contract for a medical system, such as a hospital, they do not receive the reimbursements and are not affected by their rates. Instead, management staff may be making rate-related decisions. Of those providers affected by these rates, an overwhelming majority answered “No” to the survey question asking if they were motivated by the current provider rates.

**Willingness of Provider to Volunteer at Cleft Clinics Without Reimbursement** (in response to the survey question: *If you were not reimbursed for your time/services (either through CSHS or by billing), how likely would you be to volunteer your time at these clinics?*)

**Figure 11. Willingness of Providers to Volunteer at Cleft Clinics Without Reimbursement.**




As noted in the graphic above, around 24% of providers responded that they would be “Very likely” to volunteer, without reimbursement, at the Cleft Clinics, around 29% responded “Somewhat likely,” around 5% responded “It depends,” and around 43% responded “Not likely.” While the reimbursement rate for providers is low, it still seems to play a role in many providers' willingness to participate. Several providers reported that while money was not a motivating factor in their participation, they would still like to be paid “something” for their services. Among the subset of those providers who are more closely tied to the contracting rate for their services (all those did **not** indicate that they “Do not contract” and are likely unaware of contracting rates associated with their services), up to 50% indicated that they would “not likely” be willing to volunteer their time at the Clinics, while 40% indicated that they would be “likely” or “somewhat likely” to volunteer. *(Note: Figure 11 represents **all providers** surveyed, as opposed to the subset referred to in the previous sentence.)*

A number of providers stated that the reimbursements should be higher and that “compensation needs to be fair in order to compensate providers for their services.”

Reimbursement for providers’ time and expertise is one of many factors that play a role in why providers participate in the Cleft Clinics. Other motivating factors that arose in the surveys include:

- Participating in services that are important to the patient population
- Collaboration and relationship-building with the ICT team and patients
- Professional fulfillment

Providers were then asked “**If these Clinics were to run exactly the same as they do now, but you were to bill for each encounter with each patient as you would in your regular practice, what would be the benefits? Drawbacks? (To you, other specialists, patients, other stakeholders),”** with responses as follows.

The only **strength** listed was a possible increase in revenue, although there were nuances to this concept in each response. Several providers who brought this up indicated that it might not

be worth the billing increase, as it would also increase examination time, administrative paperwork, and billed time overall. One provider stated that the current setup was nice because of the convenience of not billing.

Provider responses mentioned the following **weaknesses**:

- Additional costs for families would likely result in a decrease in the number of patients and services provided.
- Additional administrative work and documentation requirements would result in increased costs for providers' practices.
- For some disciplines, examinations at the Cleft Clinics are not thorough enough to bill. As one dentist stated, "I wouldn't have the ability to bill like I would in my practice because I cannot take radiographs, or complete a cleaning. Drawbacks are that I can not see as many patients or do as thorough of an exam in these clinics so I don't feel like I am doing [the] patient as good of a service in these clinics."
- Several providers indicated they are not able to provide services that would be considered billable at the Cleft Clinic.

The following feedback was provided in response to the survey question "**Any other thoughts/comments? In your opinion, how do you think these clinics might be structured to best meet the needs of patients, providers, and the systems that host these clinics?"**

- Increased care coordination between Clinics
- A modern and accessible EHR
- Shorter days for patients
- Current collaborative and interdisciplinary structure should be retained regardless of any other changes, as it provides quality care to its patients.
- Increase in provider reimbursement
- Continuity of care
    - One provider stated, "It may be a lot more effective if the patients saw the same providers outside of the clinic and when they came to the clinic it was always scheduled with the same team. If there are multiple providers for one specialty then the specialty teams and patients still should stay together. It also develops a better relationship and I feel would support better care and follow through."
- Increase attendance rates for ICT team
- Updated registry with all present and future patients to ensure patients are followed up on until they reach adulthood

**Summary of Needs**

Finally, many of the 21 participants indicated specific needs that they, as healthcare providers, feel would improve the Cleft Clinics. Many of these needs seem to have been influenced by the survey's line of questioning around billing and coding for procedures conducted at Cleft Clinics. Of note, whether the providers need to have a comprehensive understanding of billings and coding will depend on the future structure of the Cleft Clinics. Within the current model, it is not necessary for providers to designate a specific Current Procedural Terminology (CPT) code(s) to their encounter. A summary of providers' needs from the survey is as follows:

- More time with each patient to conduct a better, more thorough evaluation
- A consistent team of providers that attend each and every Clinic
- Better knowledge of CPT codes that would be appropriate to use for billing (several providers indicated they were unsure of CPT codes that could be used)
- Better knowledge and understanding of reimbursement rates for services (including HMK *Plus*, HMK, and private insurances)
- For those who are aware of typical reimbursement rates, several providers indicated needing a higher reimbursement and overall being more fairly compensated for their time at the Cleft Clinics.
- Hospitals/clinics to continue to support their participation in Cleft Clinics and pay their salaries if they cannot bill independently
- Genetic counselors are currently licensed in the state of Montana but they cannot currently bill health insurance directly for their services.
- A modern, electronic EHR needs to be implemented
- For pediatricians and primary care providers around the state, more awareness of the Cleft Clinics so that they would be more involved with referrals and follow-up
- Better information to new parents about the existence of Clinics, as well as more information and support
- Specifically for SLP and ENT collaboration, a more detailed assessment of the overall velopharyngeal function (nasometry and pressure-flow studies) as well as video fluoroscopy and nasopharyngoscopy tests to get a complete picture of the velopharyngeal function

## Parent/Guardian Interviews

**Methods: Parent/Guardian Interviews**

The objective of the parent/guardian interviews was to understand the needs of patients/families who attend the Cleft Clinics and how those needs are or are not being met by the Cleft Clinics. Prior to receiving patient contact information or commencing interviews with parents/guardians of the patients who attend the Cleft Clinics, the University of Montana Institutional Review Board (IRB) approved this project on August 26, 2022 (IRB #122-22).

Participation in these interviews was completely voluntary, and participants could withdraw from the interview at any time. All interviews were conducted over the phone by a Yarrow staff member and lasted between 30-60 minutes each.

To ensure that a wide array of participant types were included in the interviews (including from each Cleft Clinic site, those who had to travel 60+ miles to attend a Clinic, various patient ages and attendance frequency, etc.), the DPHHS epidemiology team provided patient contact information from CHRIS for approximately three times the number of each demographic of patient identified below. Patients who attended a Clinic more than 59 months previously were not included. Patient information shared included child/patient name, date of birth, sex, relevant cleft diagnosis, parent/guardian name and relationship to child, phone number, and mailing address.

Specific demographics included in the parent/guardian interviews were:

- Families that live in **Helena** and attended the Helena Clinics (when they were available)
- Families that live in **Billings** and attend the St. Vincent's Clinic
- Families that live 60+ miles from **Billings** and attend the St. Vincent's Clinic
- Families that live in **Missoula** and attend the CMC Clinic
- Families that live 60+ miles from **Missoula** and attend the CMC Clinic
- Families that live in **Great Falls** and attend the Benefis Clinic
- Families that live 60+ miles from **Great Falls** and attend the Benefis Clinic
- Families with a child aged 10+ years of age and attended a Clinic at least 5 times
- Families with a child between 7-10 years of age and attended a Clinic at least 5 times
- Families with a child between 5-7 years of age and attended a Clinic at least 5 times
- Families with a child less than 5 years of age and attended a Clinic less than 5 times

Although Cleft Clinics were historically held at additional locations (including in Browning and Wolf Point up through 2016 and Kalispell up through 2018), contact information for those patients/families was not easily accessible from DPHHS because the families that attended Clinics at those locations did so more than 59 months prior to this analysis. Emphasis was placed on interviewing families that had attended Clinics multiple times. Almost one-third of Cleft Clinic participants have only participated one time and may not have the specific familiarity with the Clinics necessary to adequately inform the interviews. Those patients under five years of age may have attended the Clinics less than five times since attendance generally occurs annually and these children are not old enough to warrant so many Clinic visits.

Based on research predicting that saturation in qualitative interviews can be reached after 9-17 interviews, the Yarrow staff initially estimated that 12-15 different family interviews of diverse representation could be conducted before reaching saturation *(SSSQR)*.

An introduction letter and consent form were mailed to each of the 69 families identified by CSHS to let them know they might receive a call from a Yarrow staff member to complete an interview. One week after the letters were mailed to parents/guardians, Yarrow attempted to call each of the families to either conduct the interview at that time or schedule the interview for later, until the interview quota for each patient type was met. At the start of each interview, Yarrow verified that the parent/guardian had received and read the letter and consent forms, and the parent/guardian's verbal consent was obtained and recorded before beginning the interview. Calls were recorded via Recordator and transcribed and de-identified via Rev. All recordings and transcripts were housed by Yarrow on a password-protected HIPAA-compliant Google Drive. If a parent/guardian preferred not to be recorded, the option was provided to send consent via Docusign, and the Principal Investigator or co- Principal Investigator would take notes during the interview. No parents/guardians opted for a non-recorded interview. All participating parents/caregivers were mailed a $50 gift card after completion of the interview. Transcriptions were coded by Yarrow staff members, who also performed thematic analysis and wrote up the findings.

Interviews took place over a period of approximately three weeks.

**Results: Parent/Guardian Interviews**
Saturation was achieved after completion of 12 parent/guardian interviews.

The geographical breakdown of participants is as follows:

- 2 families that live in **Helena** and attended the Helena Clinics (when they were available)
- 1 family that lives in **Billings** and attends the St. Vincent's Clinic
- 1 family that lives 60+ miles from **Billings** and attends the St. Vincent's Clinic
- 3 families that live in **Missoula** and attend the CMC Clinic
- 1 family that lives 60+ miles from **Missoula** and attends the CMC Clinic
- 2 families that live in **Great Falls** and attend the Benefis Clinic
- 2 families that live 60+ miles from **Great Falls** and attend the Benefis Clinic

The breakdown of clinic frequency and age of the child is as follows:

- 5 families with a child aged 10+ years and attended the Clinic at least 5 times
- 2 families with a child between 7-10 years of age and attended the Clinic at least 5 times
- 1 family with a child between 5-7 years of age and attended the Clinic at least 5 times
- 4 families with a child less than 5 years of age and attended the Clinic less than 5 times

**Results of the interviews are organized into the following categories:**

1. Ratings of Clinics and Strengths/Weaknesses
2. Insurance Coverage
3. Care In Between Cleft Clinics / Outside Providers
4. Travel to/from Cleft Clinics
5. School-Based Services*
6. What Matters Most
7. Ideas for Improvement

## 1. Ratings of Clinics and Strengths/Weaknesses

Participants were asked the following question prompt: “On a scale of 1-10, how would you rate the usefulness of these clinics?” The scale was 1-10, 1 being “not useful/waste of time” and 10 being “very useful/always attend.”

**Figure 12: Parent/Guardian Ratings of the Usefulness of Cleft Clinics on a Scale of 1-10 (1 = Not Useful/Waste of Time and 10 = Very Useful/Always Attend).**

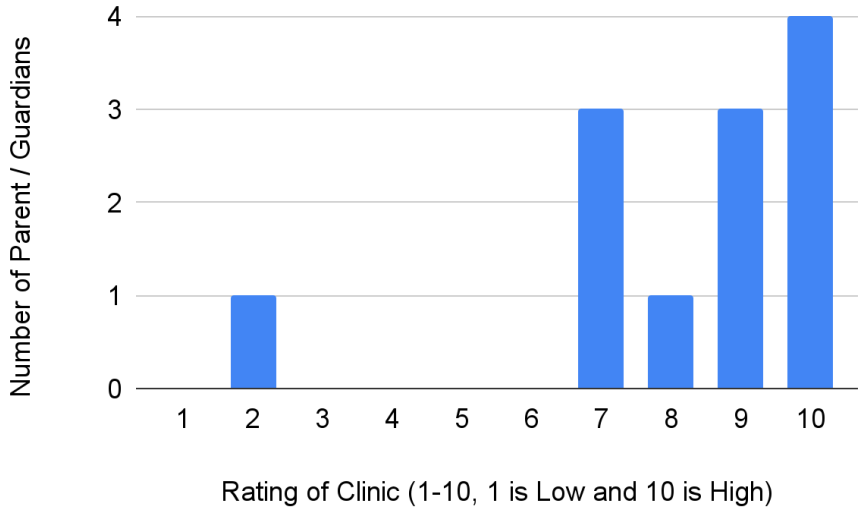



Figure 12 represents the overall parent/guardian ratings for the Cleft Clinics in response to the question above. As indicated by the Figure and the **average rating of 8.2 out of 10**, most parents/guardians reported these Clinics to be very useful.

To further understand reasons why participants awarded the numerical rating they did, follow-up questions were asked to identify particular strengths of the Clinics, as well as weaknesses and gaps.

### Strengths of Cleft Clinics

The three major themes that emerged as strengths of the Cleft Clinics were: convenience, being a good resource, and clinical expertise/trust in the providers.

**Convenience.** Many participants agreed that the multidisciplinary clinic setup was helpful, for reasons including decreased visits overall outside of the Clinic, fewer offices to visit across town, and less travel to appointments that are spread out across various days and weeks. Even if they identified that their child didn't need to see a certain specialist, they were generally happy that a basic evaluation was conducted and the need to see that provider outside of the Clinic space was spared until it was truly necessary for their child's care.

- "They're great. I have all these appointments in one day. We're [a long distance] from Great Falls. I don't have to go every week for six weeks just to see all those different doctors. I don't have to call anybody and make all those appointments. I don't have to make unnecessary appointments like the orthodontist, he can't do anything for now. But if I wouldn't have been at those clinics, I would think maybe I should go see him."
- "I just like how she can see so many people and they can evaluate her progress and let me know what steps I need to take for future care, or if she needs anything. Or if I need to set up appointments with people, then they can let me know. It's nice to just be able to see all those people in one day and kind of get a plan for what needs to be done in the future."
- "I definitely think they're kind of cool. In Montana, it's really hard to get quality healthcare sometimes because we are such a rural area. It was very helpful to just have a one stop shop and be able to touch base with different professionals."
- "It's also less traumatic for the child to go to one place instead of having 11 doctor's appointments or multiple doctor's appointments a year."

**Good resource.** Participants shared many reasons why they felt the Cleft Clinics were a good resource, including facilitating better-informed decision-making by the parent/guardian, understanding the plan of care, receiving education/anticipatory guidance, and connecting to non-medical resources for things like social and financial services. Parents expressed that the CL/P diagnosis is difficult because of how little they know about what is needed when their baby is born. They have a lot to learn about the conditions in addition to learning about the vast medical system that they will need to interact with in order to get the care that their child needs. The Clinic is a place where they are able to get a lot of resources at once and feel like there is comprehensive and competent support.

- "They've been very helpful just making those initial connections with people that we needed at the time when she first was born with it. That was really helpful to me, just because you don't really expect something like this to necessarily happen to your child, but just having that asset there to take advantage of and to get the help that you need and make a plan for what needs to be done in the future, that was very helpful."
- "I liked that the cleft team or the care nurse was in touch with me before [my child] was born, to tell me about the clinic and to say, 'this is what's available. We're going to get you in touch with these doctors. This is what you're going to need.' I didn't feel like I was

thrown in the deep end without any help. There were people available to answer any question that I had."

- "I like that there's a social worker usually too, to talk with so that, cause they got me help with insurance and food stamps and things like that when he was real young."
- "I think it's good because they get to that kind of evaluation of all the different things, and then you can kind of come up with a plan. Because not knowing really necessarily what to do that first time, it made it a lot easier. Because then you get connected with all the people that you're going to need in the future."
- "Those are all recommendations that I've gotten through the clinic itself. So like I said, it's nice because then I kind of know what to do for her outside of the clinic."
- "When she was little there wasn't a whole lot that they could do except for until she got older, just telling me what was coming, what I could expect."

**Clinical Expertise.** Participants indicated that they found the ICT members to be well-informed providers—so much so that a few families sought care from those providers outside of the Cleft Clinics. There is a lot of fear in the unknown nature of the CL/P diagnosis. Parents are worried that they will miss a piece of the care that they should be seeking out for their child. The Clinics offer experts and help build parents' confidence in the system, the providers, and help them feel like they're getting the best care available for their child. Several of them expressed some reservation about their primary pediatrician being able to provide the expert care that their child needed and especially appreciated the second opinion, and often validation, of the providers they saw as the experts at the Clinics.

- "I really like that everyone was very well informed. Everyone really knew what they were talking about and that inspires confidence when they're helping you. They weren't just taking a stab at things, they knew what they were talking about. And that was really nice."
- "I've heard from my doctors here in town like his primary doctor [that] he's underweight, you know .. you're not doing something right, he's not hitting these milestones and I go to these clinics for people who see these types of children with … this disability or deformation and they understand that kids like this … those milestones aren't realistic for these kids because of, like, the barriers that stand in their way."
- "We actually ended up switching speech therapists and we're working with the speech therapist from the clinic now."
- "I usually see … I had a different pediatrician when [my child] was born and then I met [a different pediatrician] at the clinic and I really fell for her, so now she's [my child's] pediatrician because I met her at the clinic."

Other minor themes that parents/guardians identified regarding strengths include the multidisciplinary team approach, good communication between the ICT providers, and the positive atmosphere at the Cleft Clinics.

### Weaknesses of Cleft Clinics

Alternatively, the three major themes that emerged on this topic were: lack of communication, lack of trust in providers / lackluster evaluation, and poor attendance by certain specialists.

**Lack of communication between ICT members.** Participants shared frustration with records not being sent, lack of communication between ICT members, and lack of outreach regarding upcoming Cleft Clinics. Patients expect a certain level of communication and teamwork from the providers who they see through the Cleft Clinics and while they seem to understand that the system is complex they are also often experiencing lack of coordination. Sometimes this is between the providers and the coordination of care outside of the Clinics, but often it seems like the Clinics can become a source of confusion when care has been happening outside of the Clinic, but not communicated back to the Clinic Coordinator or to other members of the ICT.

- "I'm not sure if just the stuff is being sent from the Cleft Clinic to the [other medical facility] and it's just not getting where it needs to go, or if it's just not getting sent from the Cleft Clinic. I'm not sure, but I know that I always like to have her audiology stuff sent to her ENT doctor, and he's mentioned that he doesn't always get it."
- "I asked him to do that. And then he says, 'Oh, well, the speech person will take care of that.' But the speech person did a whole different type of test, which was through her nose to see if her nose leaked air when she spoke, not actually her palate. So that was kind of annoying. He kind of pushed it off. And basically someone else will take care of it."
- [Regarding the ending of Cleft Clinics in Helena]: "I actually never heard anything. If I remember correctly, like I said, I think we were scheduled in 2020 in that spring to do one, I think, and then got canceled, of course. And then I just never heard anything until possibly an invite to one couple years ago. Yeah. And there was no explanation other than the explanation of COVID for the original Helena one."
- "I called [the Clinic Coordinator] … and she's all like, 'I don't know what's going on. Let's just have you pop in for Cleft Clinic here in September.' That's when we went in and [the plastic surgeon] was like, 'I recommend these three things.' And I'm like, 'dude, we already did a scope. We brought you the information. We've already done a sleep study. We have the information and you're skipping over [things].'"

**Lack of trust in providers / lackluster evaluation.** Participants also expressed discontent with some of the providers. Specifically, many did not feel confident in the provider's experience or proposed plan of care. Several also mentioned feeling that the provider did not conduct a thorough assessment or take their concerns into account. While patients like having the access to providers who can verify that treatment from their specialty isn't necessary, it is also frustrating to patients when enough of an evaluation can not be or is not completed at the Clinic to rule out or recommend additional treatment. When a patient is told they need to make an additional appointment outside of the Clinic for a more in-depth evaluation to determine whether ongoing care with that speciality is warranted, it makes the patient feel like the Clinic simply creates more appointments for their family. When the evaluations are too simplistic, patients have less confidence in the results of the evaluation and the provider specifically. In some cases, parents are just unsure whether the evaluation or care they received was adequate. It is clear that in some cases caregivers are left without a satisfactory explanation from their provider about what was evaluated and why they reached whatever conclusion they came to.

- “You want to go home confident or feel like you've been overseen but when you're kind of like, ‘Okay, well I guess I'll just go with this, and I'm not too confident,’ then it's like, ‘Okay.’ And then you don't really trust it either.”
- “And then seeing the orthodontist as a newborn, at the time, I didn't understand this, but now that I'm part of a huge cleft group on Facebook I understand that some babies get NAM, which is an appliance put in the mouth to cover the palate so they can eat properly. That's normally done by an orthodontist, but that was not recommended to us when he was little. At the time, I didn't understand why we would be evaluated by an orthodontist. But now that I know what other people's journeys have been, I'm like, oh, that might be why as a newborn, they were all like, let's have you pop in with orthodontist.”
- “Personally, the three years I've been there, I've never felt like … [the ENT] … they just kind of peek in her mouth for a second … Sometimes it was from a distance. Sometimes it was a little bit closer. But it's just kind of like, ‘Oh, I peeked. Okay.’ And I don't feel like they really do any kind of testing, little basic tests and things like that just to see how everything's doing.”
- “But like I said, [the ENT] was just like, ‘Oh, the speech therapist will see if she's got any air.’ But I was like, ‘She only did the nose air and not the mouth air.’ So it just seemed like he just brushed off my concern. And so he wasn't spiritually there and he just didn't have that pediatric care feeling so I would definitely not trust him to do anything. Even if he's an experienced person, I didn't get that feeling of trust.”
- “I also feel like … that little machine that they have for the hearing. Maybe it's good, but I've just seen a lot more specialty type of hearing tests done so I don't know if they're equivalent. But it just seems the kind of test you do in school for hearing versus a real professional.”

**Poor attendance by certain specialists.** Participants mentioned specific instances of arriving at a Cleft Clinic only to find the ICT was not fully present. Multiple participants commented on the lack of an orthodontist in attendance; the absence of other specialists such as pediatrics or audiology was also mentioned. For specialties that are particularly difficult to access outside of the Clinics, it becomes a primary reason that they attend the Clinic. When those specialists are also missing from the Clinic, then the primary need of that patient for that day cannot be met through the Clinic. Orthodontia is particularly difficult for those patients with Medicaid to access and there is a sense that if they can establish a relationship with an orthodontist in the Clinic setting, then they are more likely to be able to access that care outside of the Clinic.

- “This year, there was a spot for an orthodontist. They didn't list the name or if anybody was supposed to be there, but there wasn't anybody there. There was the dentist there, but there wasn't an orthodontist there.”
- “I know it's really hard to find an orthodontist to be able to be there at every single clinic, but for some reason every clinic we're at, we never see one.”
- “So that's been kind of disappointing I guess for us, because that's a huge thing with his cleft palate. He's going to be probably missing that tooth and needing the bone grafts and needing all that. And although, like I said, I love having the dentist there, I feel like a specialty person that is involved in moving the teeth is what should be there.”

- “They don't have a pediatrician with our cleft team. Our cleft team doesn't have a designated pediatrician.”
- “The last time audiology wasn't there, so we didn't get to see them. The audiology is one of the main people that I like her to see, because sometimes she has had ear problems in the past. Of course, I always take her to her regular ENT doctor, but it's always nice to have that evaluation there as well. Just sometimes not everybody there is on the list that you are supposed to see.”

Other minor themes that emerged from parents/guardians regarding weaknesses of the Cleft Clinics include excessively long clinic days and questioning why they needed to see all of the providers, even those who were not relevant to their child’s age/needs.

### 2. Insurance Coverage

As noted previously, insurance coverage varies widely among those accessing the Cleft Clinics. Of the participants interviewed, coverage was provided by Healthy Montana Kids *Plus*, Healthy Montana Kids, and through various private insurance plans. Although families do not receive a bill for their attendance at Cleft Clinics, it was deemed important to understand affordability of care and services related to their CL/P that is received outside the Cleft Clinics (within their own communities).

**Figure 13: Insurance Coverage from Parent/Guardian Perspective.**

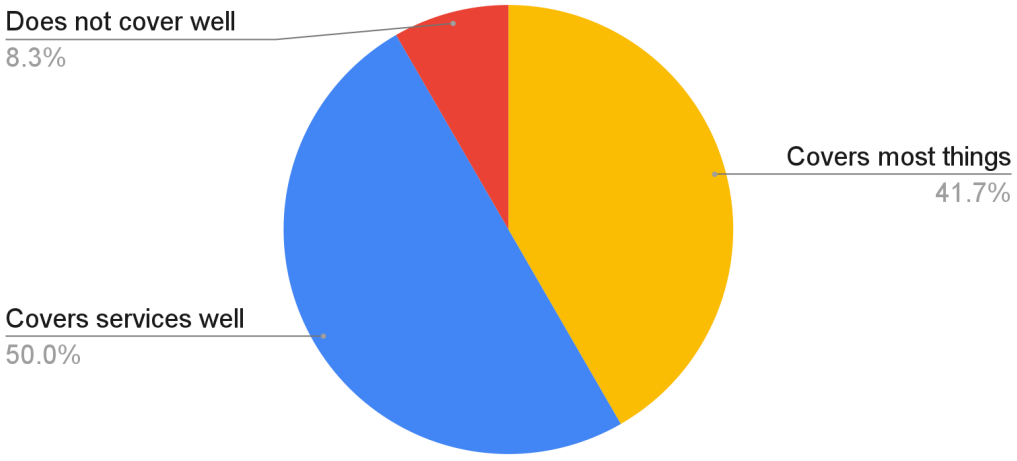



Figure 13 breaks down the responses by parents/guardians to the following question about their family’s insurance coverage: “What has been your experience with receiving bills and affording care for those 1:1 visits that happen outside of the clinics?”

Of the participants who believe that **their insurance covers their child’s medical needs well**, the following details were provided:

- “All of it goes through Healthy Montana Kids, so we haven't had any problems so far.”
- “We've actually been fortunate we have been able to afford all of her care. Her main bill, of course, was the cleft repair itself. But insurance did cover some of that. Then there's

been the two sets of ear tubes that she's had. And portions of that have been picked up by the insurance as well. Then we've been able to make payment plans through the clinic, through the Billings Clinic to pay the rest of the bill. So it wasn't like we had to pay a huge chunk at once. We could just make payments and make arrangements for payments through them. So that's actually not been difficult."

- "We're pretty low income. So we're lucky that everything does get covered. So I don't really have any complaints there."
- "We make sure and the nurses at the different facilities that we've taken him to always make sure to contact us to make sure there's a referral sent from his primary care provider so that insurance would be billed and we wouldn't have to worry about it."

For the participants who believe that **their insurance covers most needs well (though with exceptions)**, the following specific examples were noted:

- Orthodontia/Dentistry:
    - "It's just the teeth part of that. Whenever our insurance or most insurances see anything to do with orthodontists, they're like, 'What?' so they just don't want to pay for any of it."
    - "I think really we don't pay for anything except for fluoride. I don't know why, but that's just a normal thing I guess. Everybody wants to do fluoride every six months, but nobody wants to pay for it."
    - "I think the insurance only covers if we go to Helena to get our kids cavities filled when they have to be under anesthesia. I know the insurance hasn't covered some of the kids that did them in Great Falls, but it does cover the ones in Helena, and we're very far from Helena. If I could do it in Great Falls, I don't want to travel all the way to Helena."
    - "When we submitted to our insurance for [their] braces and all of that stuff, they denied it. And they said that it was a cosmetic procedure for him to have braces. And [the orthodontist] wrote a scathing letter to the insurance about how that's ridiculous, and it's an absolutely necessary part of his treatment to have braces due to his cleft. We still ended up paying for all of it. So, it wasn't necessarily a hardship because we did put on a payment plan, but that's ridiculous."
- Speech/Language Therapy
    - "As far as speech, we're very blessed with the person we worked with, because our insurance would only cover so many visits before she would have to resubmit. As far as speech therapy and if it's recommended even by a pediatrician or a surgeon or the cleft clinic to be seen twice a week or once a week, and we still have to continually resubmit it to our insurance and resubmit it to our insurance. And I'm just kind of like, 'Dude, this kid's going to be in speech for seven years. You might as well just submit it for seven years.'"

### 3. Care In Between Cleft Clinics / Outside Providers

Given the multidisciplinary nature of comprehensive care for children with CL/P, most patients also receive evaluations, treatments, and other related services outside of the Cleft Clinics.

Several questions were posed to participants to help understand which providers their children typically see outside of Cleft Clinics, how they know to make those appointments (and how they are coordinated), whether or not those providers are easy to access, and who they typically call with questions/concerns in between Cleft Clinics.

The two major themes that emerged from participants regarding care between Cleft Clinics / outside providers are **ease of access** and **quality of communication**.

### Ease of Access

Participants explained that while there are some barriers to accessing care in between and outside of the Cleft Clinics, a majority noted that the recommended care was easy to access.

Some of the barriers to outside providers included long waiting lists. Specific specialists noted as being difficult to access were mental health providers (including psychiatry), genetics, and pediatric dentistry.

- "It's been very difficult to get her into psychiatrists. We used to drive to Helena, but then he doesn't take her insurance anymore, so now we're on a waiting list here in Great Falls. We've got a lot of the bugs ironed out now, but mental health providers are just so few and far between, it's difficult."

Those that spoke to ease of access to providers outside the Cleft Clinic provided examples including easy set up of appointments, accommodating staff, and locally available providers.

- **Outside providers are easy to access.**
    - "In the past when we actually scheduled surgeries, when we were part of cleft clinic with [the plastic surgeon], he would schedule it right then and there. Or he would say, 'I'm going to have my assistant or front office or whoever call you to set up an appointment.' And so then she would call and set up an appointment. So it was, everything's pretty, in my opinion, self-explanatory once you're in there. So they do a really good job about communicating about what you need."
    - "If I had a question, I would just call [the plastic surgeon] and just call the front office and just say, 'Hey, we're part of cleft clinic, and during cleft clinic he was requesting this. Can I just maybe have his nurse call me or something like that?' So the doctors that are all a part of cleft clinic take it serious, and they kind of like, 'Okay.'"
    - "I'm not saying we're first priority, but I think it's pretty valid that I can call if I need anybody to schedule something or ask a question. Even right now, if I felt that his speech was going downhill and I felt like the school, we wanted something more than what the schools are providing, I would call [the SLP] and just talk to her. But that's because we've been a part of the cleft clinic for so many years that I feel like I know everybody."

## Quality of Communication

Participants were also asked to identify whom they would call if they had questions or needed a referral for their child. Generally speaking, parents/guardians called their PCP or directly contacted the specialty provider their child needed to see. For many participants, their child's PCP was very helpful and easy to communicate with.

- **Patient's PCP is helpful.**
    - "Usually I just would contact her primary care, her pediatrician that I have through the clinic. Most of it I can just go through a regular pediatrician."
    - "I've had a pretty good experience with Benefis Health Clinic Pediatrics. They've always been very helpful with getting us referred and in on that."
    - "Yeah, I think [her pediatrician is] very good. I think she can see it with her eyes closed."
    - "She just sends out whatever we need. If we need a referral, I just call her and she sends it out. I just call her and be like, 'we're going to pop in to see the ENT, his referral is expired' and they're like, 'great, here you go.'"

Although very few participants said they would initially reach out to the Clinic Coordinators for information, questions, or referrals, several spoke highly about the Clinic Coordinators and appreciated the intermittent follow-up from them.

- **Good communication with the Clinic Coordinators:**
    - "She calls periodically just to check in and see how things are going. She understood about us not wanting to come in during COVID, but she would just call every few months just to check in and see if we needed to come in again or any of that. And she's really friendly and really nice."
    - "[She] has made herself very readily available if I had any questions, and I do feel like she's very knowledgeable too."
    - "The nurse coordinator always called with a follow-up just to make sure any questions I have were answered. And sometimes to make sure that any appointments that were suggested to be made, were made. She would check and make sure that had been done."
    - "If we get a recommendation for somebody from someone at the clinic, they will follow up. I've had them follow-up and that's because I forget things like that. So, that's been something that's nice."

When interviewed, Clinic Coordinators indicated that, due to time constraints, they were unable to follow up with a majority of patients on a regular basis. However, they did recognize the importance of prioritizing certain patient needs ahead of others. For example, if they were aware that a certain specialty was more difficult to access than others, they would prioritize that care coordination effort.

The current ICT structure allows for quality collaboration and timely communication between various specialists, and if this set-up no longer existed then parents/guardians would rely heavily on multiple different providers communicating between each other. Mixed viewpoints

emerged from participants when asked about communication between providers in between and outside of the Cleft Clinics. Many of these specific viewpoints can be found under the "Weaknesses" section above.

### 4. Travel to/from Cleft Clinics

Because Montana is a geographically large state, one of the major considerations for participation in these Cleft Clinics is travel/transportation. Interestingly, the vast majority of participants indicated that travel was **not** a barrier in being able to attend the Clinics, even among those living 60+ miles away from their Cleft Clinic. Many stated that they were able to get mileage reimbursed by their insurance and that they regularly traveled to the city where the Clinics were held for other needs:

- "I've been helped a lot with the mileage reimbursement for her travels."
- "We're used to driving to Missoula for food or for specialty appointments or if it's like orthodontia care, they don't have a lot of children's stuff out here. It's a cost you pay for living in the country."
- "No, nothing is hard about that because we're used to that. We usually go to Great Falls when we have to see a doctor … we actually go to Great Falls for pretty much everything, so we're used to traveling."
- "At the time, when I was going back and forth, yeah, gas money would have been helpful, because we were not doing well at that time. So, it would have been nice. If they make that more obvious, more upfront on anything from Healthy Montana Kids, it would just be extremely helpful. That would have been a good thing."

### 5. School-Based Services

Recognizing that many participants had school-aged children, questions about available school-based services were explored. If applicable, the following question was asked: "Does your child have an IEP or 504 plan at school? Can you tell me about the process of getting that in place? Did you need to involve any of the healthcare providers? How could this process be improved?"

Based on these conversations with participants who have school-age children, speech-language therapy is the most commonly used school-based service. Several families were informed of school-based services through the Cleft Clinic, whereas other families were either already aware of the services (by having older children in the school system) or through other means such as school nurses.

- "I'm trying to remember exactly how we [got an IEP]. I think what is hard is we knew that once he was in school the service would be provided. There may be some parents who don't know that. We called [the school] and told them that he needs speech and that he needs to be evaluated. And they did it. So I felt like it was us communicating. We obviously knew that he needed speech, so we just did it."
- "I had [my child] tested for stuff in school, like reading abilities, to see if she needed any extra help. And I knew she did, but there was no way to help her without the 504 or the

IEP. Well, they couldn't have those without the diagnosis, and I couldn't find anybody to diagnose her. [We] finally got in with Shodair . . that made a huge difference in the IEP to have more help, more clarification."

- "She's a little developmentally disabled, so they kind of have to alter her curriculum a little bit for her. I really just worked with the school to make sure she's getting some additional small group time, one-on-one help, to try to make sure that she can try to be as successful as possible. I was able to get the IEP done no problem. [The school nurses are] pretty good at making sure kids are taken care of in that way."
- "We did private speech for years with the lady that's always at cleft clinic, and then now he's doing speech through school. So we've graduated from private speech just to school now."
- "The speech gal at the cleft clinic this year said to have her have a speech evaluation through the school, just because she noticed some of her sounds weren't quite there yet."
- "When we went to clinic when they were younger, [the SLP] said in order to get into speech for free through the school system, that we needed to make an appointment through whatever school he would go to. It was super easy. We went in, made an appointment, and then they did that for us."

## 6. What Matters Most

Participants were asked to share an overall picture of the most important pieces of their child's CL/P journey with the question: "What matters most to you when thinking about your child's cleft lip/palate healthcare? Even outside of the clinics - what kinds of things do you find the hardest about getting the right care for your child?" The three themes that emerged from this question were: ensuring mental health care, high quality of care, and safety.

**Ensuring mental health care**

- "For me, the hardest part has been getting the mental health support when you're dealing with children with conditions like this."
- "It doesn't bother [him] the way he looks, but eventually it's going to. It's going to put him in a position of either he's suffering from bullying or isolation, that kind of thing."

**Quality of care**

- "I feel like just having a team of people to be able to come together and make it personable for that child. Every kid in every situation and every palate is so different. To have everybody come together and actually talk about our kid and it not just be a case . . . and then bounce ideas off each other."
- "I hope it never goes away. I can't imagine not having this service and especially for maybe a family who is really struggling financially."

**Safety**

- "His safety always. My biggest fear just from stories and stuff I've heard is I don't want any specialist putting him through any unnecessary surgeries."

## 7. Ideas for Improvement

In summary, parents/guardians were asked to share their ideas about what could be improved with the Cleft Clinics. Prompts were offered on what could be included or changed, where the gaps might be, ideas on changes to the clinic flow, etc. The following four themes emerged from these conversations: improve the flow/efficiency of the clinic days, expand resources and assistance with mental health / social skills / behavioral needs, consistently provide more specific materials to families, and increase involvement by specific providers and allow more time with specific providers.

### Improve the flow/efficiency of the clinic days

- **Running a more efficient Cleft Clinic with less waiting time.** Ideas presented included arranging for more difficult/intensive exams to happen earlier in the day (specifically for younger children) and reversing the setup so that each family stays in one room and the provider goes room to room. Both of these examples would allow for the child to settle in and be more comfortable during the visit.
    - “Under the age of seven at least … I feel like they should do the more harder … specialists to view them first because it seems like they don't really get like a more accurate feel and test on the child that they should. Because every time we went, the audiologist was last, and that seems to be the more difficult one for most of the kids; they always will come out screaming and it definitely didn't work on my son.”
    - “I know we're there for two and a half hours, but there's a whole lot of waiting instead of seeing an actual specialist the entire time.”
    - “I do like it the last couple times that they have done it. We have gone to our own room, and the doctors have rotated to come and see us. Rather than going in and then going back out to the waiting room and juggling back and forth. And if you see so many people, it's a lot of back and forth. Whereas this way, you can just stay and just wait for the doctors to come to you.”

- **Having the option to only see the providers they want/need to at a Cleft Clinic to decrease overall time spent at the Clinic.** Some of the participants mentioned that their children see a different specialist than who is present at the Cleft Clinics. For example, the ICT may include a SLP who attends each Cleft Clinic but the family chooses to see a different SLP for therapy in between the Cleft Clinics. Thus, some participants expressed interest in only seeing those they felt were needed.
    - “There would be some clinics we'd go to where they'd be like, you have to see these people and I'd be like yeah, no, we actually see these people privately outside of clinic, so I don't necessarily need to revisit them in clinic. [A SLP] did his hearing tests privately at her office once a year on schedule, and then did his speech therapy and his evaluations. I didn't really need those to be taking up my time when I'm trying to fight a toddler for five hours.”

    - “When it could be like, I need to see the surgeon, I need to have his hearing checked. I need to have the ENT give him a check, and then I'm out. These are what I should be able to tell the team.”
    - “I guess if a physician isn't going to be at the cleft clinic, it might be nice to know that as well. Not that she wouldn't go just because of that, but it would be nice to know if, say, audiology isn't going to be there or if there's going to be somebody missing from the clinic that you're taking her to that day.”

### Expand resources and assistance with mental health / social skills / behavioral needs

Many participants recounted the lack of resources available for mental health / social skills / behavioral needs at the Cleft Clinics. There can be social implications that can arise with CL/P and other craniofacial conditions that can be difficult for a child to navigate. Additionally, as stated below by one of the participants, frustration can build in a child if they have trouble communicating physically (or emotionally) which could potentially lead to behavioral issues. Several participants specifically identified that gap in care:

- “It'd be cool if they can go more into the behavior and things like that. They don't really go into that. And I think that being born that way and having more frustrations communicating, I think leads to behavioral issues and emotional issues and stuff like that. So that's something I feel like should be brought up.”
- “The social piece, that's an interesting sideline, because there is not enough, within the school system either. There is no social skills class to get her into to help with that social piece.”
- “We are going to have to go to Helena to see the geneticist there because they want to do a full evaluation to check for behavioral issues and things like that. So they want him to see their psychologist there and just a bunch of things that they don't typically come here to the cleft palate for.”

### Consistently provide more specific materials to families

Of note, there is very little information available online for Montana residents wanting to attend or learn more about the Cleft Clinics. Some families who participated in the past were unaware they could still attend the Clinics after they had fallen through the cracks. This lack of online information could also potentially pose a barrier to out-of-state residents to Montana and trying to set up care.

Participants described notable gaps in communication between the Clinic Coordinators and parents/guardians regarding the Clinics and available resources. Specific materials that might help to improve this communication include: lists of providers who participate in Clinics, confirmation prior to a Clinic about which providers plan to attend, educational handouts to families about important screenings, information on financial aid / Medicaid reimbursements, and information about school-based services.

- “There needs to be a list of providers. I realize that they will be out months because I had to wait months to get into Shodair, but I was more than willing to do that just because I

could get an appointment for both of them. If you can get an appointment, then you wait. But if you can't even find the person to get an appointment with, then it's a problem."

- "So all I know is the cleft clinic, they don't give you their personal information if you want to schedule an appointment with them separately to do more thorough evaluation. They tell you their name and stuff, but I don't feel like I even get anything back with the different doctors that I saw and their name and last name. But yeah, that's something that is not shared with the parent, at least not with me."

### Increase involvement by specific providers and allow more time with specific providers

Several participants appeared to value seeing specific providers over others. If that specific provider was not present on a Clinic day, many felt that Cleft Clinics were less valuable. If that provider was not present, parents/guardians would often set up a separate appointment to see that specific provider outside of the Cleft Clinic, which overall decreases the value of the ICT structure. Consistent participation by providers would be ideal for this reason. Additionally, some parents/guardians spoke to wanting to have more one-on-one time with providers to engage in a more thorough evaluation.

- "It's really hard to find an orthodontist to be able to be there at every single clinic, but for some reason every clinic we're at, we never see one. And we only see a dentist. And although I respect that some dentists can get the certain hours in and education of moving teeth, that's not what their specialty is. We've actually thought about moving to a different rotation, because it seems like every year that we go, that same month or whatever it is, we never see an orthodontist."
- "I would say if anything, when you have kids that have these cleft palates and these abnormalities, I would think that they would maybe need to step up their genetics game to get the people referred to Shodair to screen for genetic issues. That's been the hardest thing."
- "I think that's something that it lacks is just the one on one time. They all have their own offices and they can't coordinate it all in a day, but I wouldn't mind making a few appointments and then another day making a couple other appointments or even spreading it out if I had to. But just more time and more care, more evaluation and stuff like that."
- "And don't get me wrong, everyone there is good. And I know that they're just all on a timeframe and the way it's set up to kind of go go go. But yeah, just more hands on, more tools, a little more time with the specialists that you really want to have more time with."

Overall, these qualitative interviews revealed that parents/guardians are satisfied with the care they receive at the Cleft Clinics. The Clinics are beneficial not only for the children's health but also for the parents/guardians in learning how to support their child's development and care. In general, it was found that most families are able to afford their care with their available insurance plans, are able to travel to the Clinics, and can access their care outside of the Clinics relatively well. Orthodontia, dentistry, and mental health / behavioral services are exceptions to this easy access and are important specialty areas to note for future CL/P Clinic planning. The

biggest area for improvement is communication. Specifically, communication from Clinic Coordinators to families, communication between providers, and communication from the providers to families all need to be improved.

Finally, the value of parent/guardian perspectives should not be overlooked when considering and planning care for children with CL/P in the state of Montana. This feedback and their ideas for improvement can be emphasized when considering new mechanisms and processes into the Clinics, which may ultimately improve both the quality of care and the patient outcomes.

## Clinic Coordinator Time Study Results

**Methods: Clinic Coordinator Time Study**

In an effort to understand more about the role of the current Clinic Coordinators and their time dedicated specifically to Cleft Clinics and its patients/families, a small time study was attempted. A spreadsheet was created for each of the three Clinic Coordinators to document the number of hours spent on certain tasks involved in pre-clinic duties, clinic day duties, and post-clinic duties. Clinic Coordinators were asked to prospectively keep track of their time starting from their last Cleft Clinic and moving forward to their next Cleft Clinic. Clinic Coordinators were also encouraged to have a Yarrow staff member help them fill out the spreadsheet over the phone if that was desired.

**Results: Clinic Coordinator Time Study**

Currently, CSHS contracts three Clinic Coordinators to carry out the roles/responsibilities associated with the Cleft Clinics housed under each of their respective facilities (Benefis, CMC, and St. Vincent's). In total, the payments by CSHS for all three Clinic Coordinators' contracts between SFY 2020 through SFY 2022 have ranged from approximately $122,000-$138,000 annually. The average cost of care coordination services at each site annually in SFY22 was $46,071.

Per the contracts sent to hospital systems that employ these Clinic Coordinators, the following roles are to be fulfilled by one FTE bachelor's-prepared registered nurse patient care coordinator:

1. Attend orientation, training, or clinic preparation meetings; participate in nurse coordinator teleconferences as scheduled. The contractor is to pay salary, registration and per diem for attendance of orientation, ongoing education, training, clinic preparation meetings, and nurse coordinator teleconferences.
2. Participate actively in the interdisciplinary team process to assess each clinic attendee using the nursing process; facilitate communication between service providers to create a comprehensive care plan; identify responsibilities of the individuals involved to assure optimal evaluation and outcomes for each clinic attendee. Coordinator will compile a post-clinic report for each CCTC attendee that includes an interdisciplinary team summary and a letter to the participant's family outlining the care plan.
3. Review (at least semi-annually) prior clinic reports and follow-up on previous clinic recommendations and referrals.
4. Promote the visibility of the CCTC services.
5. Maintain and manage staffing for interdisciplinary teams, in accordance with Department standards.
6. Conduct post-clinic care coordination including follow-up of referrals to additional services, either through direct contact with each family and/or in close collaboration with public health services, or the patient's primary care provider in the family's county of residence.
7. The contractor must fund continuing education for the RN.
8. With the administrative assistant, provide post-clinic documentation and reporting. Client reports are to be completed within three weeks of the date of service.

Contracts also stipulate an FTE Administrative Assistant to carry out additional duties listed here:

1. Track and follow-up of client referrals received from providers and facilities.
2. Pre-clinic coordination including scheduling interdisciplinary team providers, client scheduling, client assessment, and client record management.
3. Clinic day coordination including clinic staffing, client, family, and provider assessments, and documentation.
4. With the nurse patient-care coordinator, provider post-clinic documentation and reporting. Client reports are to be completed within three weeks of the date of service.

One of the three Clinic Coordinators completed the time study. Though it is difficult to apply the results as a representative sample across all clinic sites, the results of that documentation are as follows:

**Clinic #1 Time Study:**

**Time spent on pre-clinic duties:** Over the span of nine weeks immediately preceding the September 2022 Clinic, a total of 85.75 hours was reported as spent on pre-clinic duties such as mailing invitation letters, printing documents, prepping charts, calling families, confirming providers' availability/attendance, verifying insurance, packing all needed supplies and papers, etc.

- For the first two weeks of this nine-week period, 38.75 hours were reported on sending invites and ordering lunch. The Clinic Coordinator indicated those hours represented a typical amount of time spent on those tasks.
- For the remaining seven weeks of this nine-week period, the Clinic Coordinator indicated these 47 hours were **not** representative of the typical amount of time spent on those tasks. It was indicated that, on three separate occasions, the Clinic Coordinator was pulled to cover other nurses in other areas of the pediatric clinic and thus was not able to dedicate as much time to Cleft Clinic duties.

**Time spent on clinic day duties:** It was reported that 8.75 hours were spent on Cleft Clinic day between setting up, running the Clinic, completing tear-town, and returning all the supplies to the main pediatric office where they are stored.

**Time spent on post-clinic duties:** During the six-week period immediately following the prior Clinic in May 2022, 95.5 hours were reported as spent on post-clinic duties such as finalizing letters with provider recommendations and mailing them to families.

- For the first two-week period following the last Cleft Clinic, 32.5 hours were documented for Cleft Clinic duties, as 0.5 of the Clinic Coordinator's time was spent in the main pediatric clinic and not on Cleft Clinic duties. This was **not** representative of a normal amount of time spent on those tasks. The Clinic Coordinator felt that she usually spends more time on these tasks.
- Over the next four-week period, 63 hours were documented as Cleft Clinic duties, and it was indicated those hours represented a typical amount of time spent on those tasks.

**Clinic #1: Total Time in a Clinic Quarter:** Between pre-clinic preparation, actual clinic day facilitation, and post-clinic follow-up, the Clinic Coordinator spent a total of 190 hours on Cleft Clinic operations. Generally, a Cleft Clinic is held each quarter (520 hours of work based on 1.0 FTE). This would suggest that Cleft Clinic work consumes approximately 37% of an FTE. This site does not have an Administrative Assistant position for the Cleft Clinics.

## Financial Assessment

**Methods: Internal Finance Data from ECFSD and Aspen Billing**

Cleft Clinic **revenue** information was provided by the CSHS contracted biller, Aspen Billing. This included revenue data for all patients with health insurance who were seen at any of the Cleft Clinics from SFY 2017 to SFY 2022. Patient insurance profiles and insurance billing and reimbursement rates were compiled internally within the Aspen Billing system and provided to Yarrow, LLC for analysis. When data from SFY 2017 and 2018 were used, outreach clinic sites data, including Bozeman and Kalispell, were included in their primary clinic location's analysis. When using SFY 2019, 2020, and 2021, the one Helena Clinic that took place in this time period was excluded from this analysis. Data sets that relied on participation data (e.g., average revenue per patient) were calculated using participation information provided by CSHS data analysts. These modification explanations can also be seen in the revenue analysis Figure.

Cleft Clinic **cost** information included in this report was provided by CSHS staff via invoices they had received from the three health systems hosting Cleft Clinics in SFY 2019, 2020, and 2021. Two of the sites (Benefis and CMC) bill CSHS at an hourly rate for the time the Clinic Coordinator spends on Cleft Clinic organization, facilitation, follow-up, and coordination between Clinics. One site (St. Vincent's) bills a flat rate each quarter without tracking hours. The flat rate was negotiated based on estimated time spent by the Clinic Coordinator as well as centralized management functions and other facility cost considerations. In order to best estimate costs per Clinic and per patient, costs associated with Clinics that were canceled due to COVID or other atypical events were not used in these analyses. These canceled Clinics included:

- No Clinics at any sites in Q4 SFY20
- No Clinic at CMC in Q2 of SFY21
- No Clinic at Benefis in Q3 SFY22

CSHS administrative costs of administering and managing the various contracts were not included in the total cost estimates of the Cleft Clinics.

### Descriptions of Current Sources of Funding

Currently, Cleft Clinic funding is sourced from three pools of money: the State Special Revenue, Genetic Revenue Surplus, and revenue generated from the services rendered and billed through the Cleft Clinics.

**State Special Revenue Fund.** These are funds that have been legislatively earmarked to support Cleft Clinics in Montana.

**Genetic Revenue Surplus Funding.** These are funds generated as a portion of each health insurance plan sold in the state of Montana and obligated to genetic testing, treatment, and support. Throughout 2020 and 2021, funding from this revenue stream was approved for use in supporting the Cleft Clinics' financial sustainability during those years and for SFY 2024, 2025, 2026. This funding will not be available in SFY 2027 or beyond.

**Revenue Generated from Cleft Clinic Services Rendered.** In 2007, MT Medicaid and the Montana Title V CYSHCN Program established codes for reimbursement for multidisciplinary Cleft Clinics managed by the CYSHCN Program. A patient attending a Cleft Clinic and seeing 8+ providers is considered to have seen the "full team," and the visit is billed using HCPC T-1025 and reimbursed at a rate of $1,000. Recognizing that every patient does not need to see a full team at every annual or bi-annual visit, T-1024 was established at a rate of $100 per unit, to be billed in multiple units with a maximum of 7. For example, if a patient came to Cleft Clinic and saw the Clinic Coordinator, Orthodontist, Genetic Counselor, Speech Pathologist, and Otolaryngology, 5 units of T-1024 would be billed. This reimbursement methodology makes it possible to account for patients not seeing a full team. In late 2018, CSHS contracted with a third-party biller, who has been able to bill for reimbursement using HCPC codes T1024 & T1025.

Below is a breakdown of each of the current funding streams and their stability moving forward. Each Cleft Clinic must be able to financially sustain its own programming in the future and should not rely on the availability of Genetic Revenue Surplus after SFY 2026.

**Figure 14. Sources and Descriptions of Current Cleft Clinic Funding in Montana.**

| Source | Type | Amount | How many years? | Stability | Contingencies/ Requirements |
|---|---|---|---|---|---|
| **State Special Revenue** | State Tobacco Settlement | $25,000 / year | Indefinitely | Based on MT State Legislature | -Could be endangered if no stable process for Cleft Clinics exists |
| **Genetic Revenue Surplus** | State Genetic Fund | $100,000 / year | 3 years (SFY 2024, 2025, 2026) | Available for 3 years | -Based on number of health insurance plans sold in MT<br>-Should not expect its availability into the future |
| **Clinic Revenue at Cleft Clinic Sites through CSHS** | Revenue from services rendered and billed at Cleft Clinics | Variable based on number of patients seen in Cleft Clinics | Indefinitely, at CSHS -sponsored Cleft Clinic Sites | Variable based on number of patients seen in Cleft Clinics | Aspen receives 10% of reimbursements as fee for their billing services |

*(INCSJF)*

The cost of the Clinics and contracts have consistently exceeded the available funding in the past five years, creating a state of continual deficit. Additionally, the source funding has become increasingly unpredictable.

For more information about how Cleft Clinic contracts and funding is administered, see Contracting and Administration.

## Cleft Clinic Revenue and Reimbursement

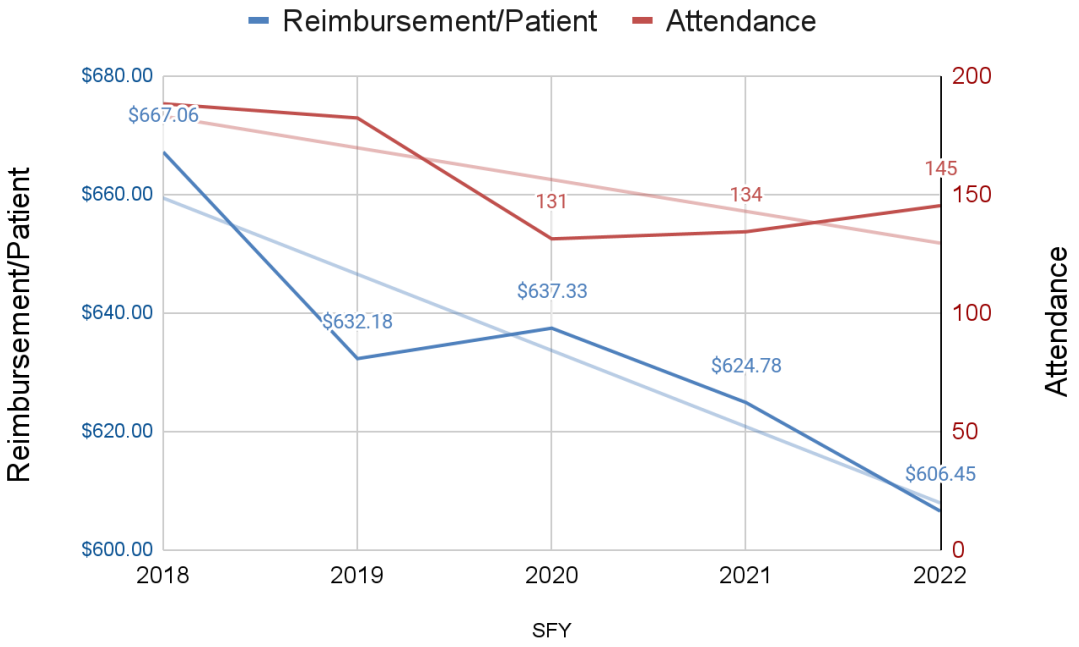
Between SFYs 2018-2022, not including the data from the Helena Clinic, the Cleft Clinics across the state have generated almost half a million dollars, with an average of $99,122 per year over those five years. Though attendance at the Cleft Clinics—and thus revenue—began to fall between SFY 2018 and SFY 2019, COVID-19 devastated the Cleft Clinics' ability to operate consistently and forced every Clinic to reduce the number of patients seen. Not only has patient attendance decreased over this time, the amount reimbursed per patient has also steadily declined.

**Figure 15. Revenue, Attendance, and Reimbursement among Montana Cleft Clinics from SFY 2018 - SFY 2022.** *(Does not include the Helena Clinic data.)*

| SFY | Revenue | Attendance | Reimbursement / Patient |
|---|---|---|---|
| 2018 | $125,407.15 | 188 | $667.06 |
| 2019 | $115,057.51 | 182 | $632.18 |
| 2020 | $83,490.00 | 131 | $637.33 |
| 2021 | $83,720.00 | 134 | $624.78 |
| 2022 | $87,935.01 | 145 | $606.45 |
| **AVG / SFY** | **$99,121.93** | **156** | **$633.56** |
| Total | $495,609.67 | | |

*(CCDAA, CSHBH, CSHPI )*

**Figure 16. Average Reimbursement per Patient and Attendance among Montana Cleft Clinics from SFY 2018 - SFY 2022, with Trend Lines.** *(Does not include the Helena Clinic data.)*




*(CCDAA, CSHBH, CSHPI)*

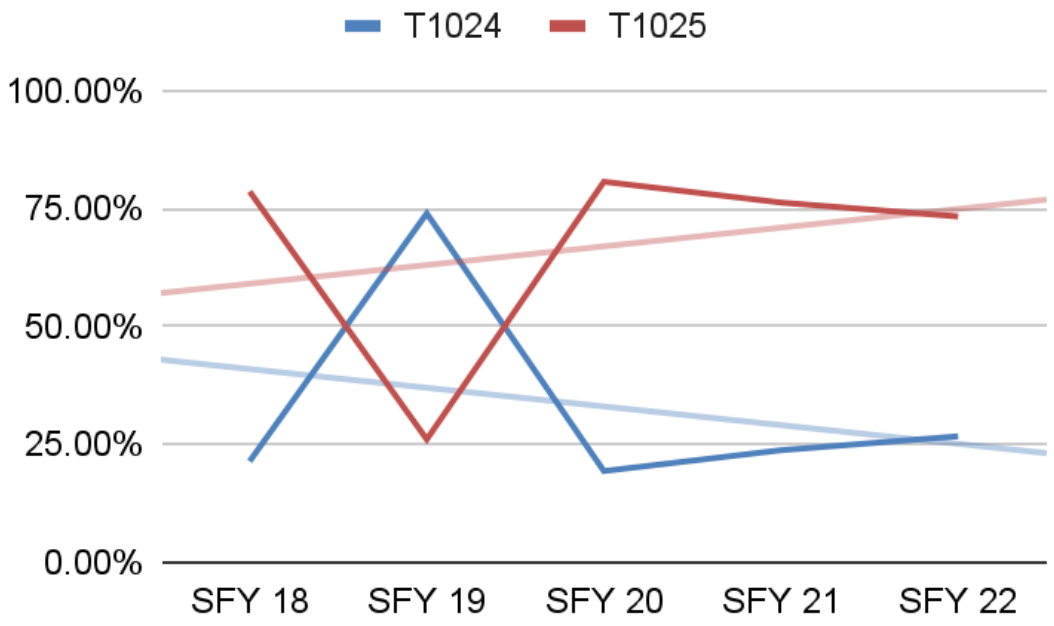
As noted above, the number of patients attending the Clinics across the state and the reimbursement rate per patient have both trended downwards since SFY 2018. Although the patient attendance numbers show a decline over the years, the varied methods used by each Cleft Clinic site regarding how invited patients are tracked and how they each define appointment types resulted in the inability to calculate no-show rates or the number of cancellations and/or families opting not to attend.

It is likely that a confluence of multiple factors have caused the declining rates of reimbursement. Patients who do not have health insurance are still considered in the calculations of average reimbursement per patient, lowering the average rate of reimbursement per patient. Some private payers do not cover Cleft Clinic services or cover less than MT Medicaid. People are not individually billed for services rendered in the Cleft Clinics, including co-pays or out-of-pocket payments of any kind. Reasons that Medicaid may not reimburse for an encounter even if the patient has Medicaid coverage include: if the patient is 18 or older, has out-of-state Medicaid, or the encounter is for a patient with a craniofacial diagnosis (opposed to only a CL/P diagnosis).

Another possibility that could impact the amount of revenue generated by the Cleft Clinics involves whether a full team is present on the day of the Cleft Clinic and whether each patient

actually sees the full team. If a patient sees a full team, this would be billed using HCPCS T1025 at $1,000 / patient. If a full team is not present or a patient opts to see only a partial team, then HCPCS T1024 is billed at $100 / provider seen / patient, which will result in a lower billed amount and lower reimbursement per patient amount. Between SFY 2018 - SFY 2022, the use of the HCPCS T1025 has been steady, with a slight upward trend in use.

**Figure 17. Percent of Patient Encounters Billed as T1024 or T1025 among Montana Cleft Clinics from SFY 2018 - SFY 2022, with Trend Lines.** *(Does not include the Helena Clinic data.)*




*(CCDAA, CSHBH)*

**Figure 18. Revenue, Attendance, and Average Per-Patient Reimbursement among Montana Cleft Clinics from SFY 2018 - SFY 2022, by Clinic Site.** *(Does not include the Helena Clinic data.)*

| | Billings | Missoula | Great Falls |
|---|---|---|---|
| **Revenue Total** | $200,207.06 | $159,521.28 | $135,881.33 |
| **Attendance Total** | 338 | 222 | 220 |
| **Revenue / Patient** | $592.33 | $718.56 | $617.64 |

*(CCDAA, CSHBH, CSHPI)*

The Billings-based Cleft Clinic site sees 50%+ more patients than do the Missoula and Great Falls sites, which is consistent with their larger population base. Missoula sees the highest revenue per patient amount among the three Cleft Clinic sites and is reimbursed $100+ more per patient than the Great Falls and Billings sites.

**Figure 19. Average Revenue Per Clinic among Montana Cleft Clinics from SFY 2020 - SFY 2022, by Clinic Site.** *(Does not include data from the single Helena Clinic in this time period.)*

| | |
|---|---|
| Benefis | $ 7,324.50 |
| CMC | $ 7,458.00 |
| St. Vincent | $ 9,592.73 |
| Combined Avg (No Aspen) | $ 8,172.42 |
| **Combined Avg Include Aspen (-10% of revenue)** | **$ 7,355.18** |

Avg Revenue / Clinic accounts for all revenue paid to CSHS to determine the average revenue generated by each Clinic. 10% was subtracted when accounting for Aspen's fees for billing.

*(CCDAA, CSHBH, CSHPI)*

**Figure 20. Average Revenue Per Patient among Montana Cleft Clinics from SFY 2020 - SFY 2022, by Clinic Site.** *(Does not include data from the single Helena Clinic in this time period.)*

| | |
|---|---|
| Benefis | $ 555.08 |
| CMC | $ 755.77 |
| St. Vincent | $ 596.18 |
| Combined Avg (No Aspen) | $ 634.40 |
| **Combined Avg Include Aspen (-10% of revenue)** | **$ 570.96** |

Avg Revenue / Patient accounts for all revenue paid to CSHS to determine the average revenue generated by each patient. The denominator includes all patients, even those without health insurance or full coverage. 10% was subtracted to account for Aspen's fees for billing.

*(CCDAA, CSHBH, CSHPI)*

## Cleft Clinic Costs

The average cost per Cleft Clinic was calculated utilizing data from SFYs 2020, 2021, and 2022. Costs were derived from (1) quarterly payments to the three Cleft Clinic sites, and (2) reimbursements paid to providers for their services. During this time, 84% of the contracted funds went to the hospital-based Cleft Clinic site contracts and 16% went to provider contracts. When calculating the costs of the Clinics, outreach clinics were included. Since SFY 2020, there were 2 outreach clinics to Bozeman from the Billings-based Clinic and 0 outreach clinics to Kalispell by the Missoula-based Clinic. In SFY 2022, CSHS paid $175,490.26 to contract with the 3 healthcare systems and all of the supporting providers to run the Clinics *(including Aspen's costs)*.

**Figure 21. Average Cost Per Cleft Clinic from SFY 2020 - SFY 2022, by Clinic Site.**

| | |
|---|---|
| Benefis | $ 11,458.53 |
| CMC | $ 11,607.80 |
| St. Vincent | $ 20,297.71 |
| **Combined Avg** | **$ 14,622.14** |

Avg Cost / Clinic accounts for the contracts paid by CSHS to Hospitals for care coordination, and contracts paid to providers to determine the average cost / clinic.

*(CCIT)*

St. Vincent's Healthcare in Billings has the highest cost at $20,297 per Clinic, but also has the highest volume of patients of the three clinic sites. Benefis in Great Falls and CMC in Missoula have a similar number of patients attending their Clinics and have similar costs at around $11,500 per Clinic.

**Figure 22. Average Cost Per Patient from SFY 2020 - SFY 2022, by Clinic Site.**

| | |
|---|---|
| Benefis | $ 911.41 |
| CMC | $ 1,215.55 |
| St. Vincent | $ 1,289.49 |
| **Combined Avg** | **$ 1,143.68** |

*This does not include Q4 SFY2020 expenditures from any Clinic or Benefis expenditures from Q3 SFY23. These were Clinics that were canceled due to COVID-19 in which CSHS was billed for the cost of the Clinic, but no patients presented and no revenue was collected.

Avg Cost / Patient accounts for the contracts paid by CSHS to Hospitals for care coordination, and contracts paid to providers to determine the average cost / patient.

*(CCIT, CSHBH)*

St. Vincent's Healthcare in Billings saw the highest cost per patient when administering the Cleft Clinics at $1,289 per patient and Benefis in Great Falls had the lowest cost per patient at $911 per patient.

## Cost to Revenue Comparison

Between SFY 2020-2022, the average cost to run the Cleft Clinics was **double** the revenue that was reimbursed to CSHS. The average amount reimbursed per patient in this time period was $571 / patient and the cost as calculated by CSHS contract payments was $1,144 / patient. In SFY 2022, CSHS paid $175,490.26 to contract with the three healthcare systems and all of the supporting providers to run the Clinics. In the same time period, $87,935.01 was received through reimbursement for those services.

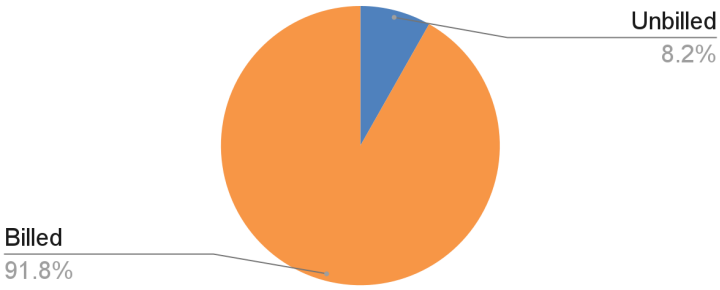
**Figure 23. Ratio of Cost to Reimbursement Amount at Cleft Clinics from SFY 2020 - SFY 2022, Overall and by Clinic Site.**

| | SFY 20 | SFY 21 | SFY 22 |
|---|---|---|---|
| Benefis | 2.56 | 1.24 | 1.71 |
| CMC | 1.48 | 1.79 | 1.47 |
| St. Vincent | 2.46 | 2.07 | 2.46 |
| **Combined Avg** | **2.30** | **1.84** | **2.04** |

## Health Insurance Coverage of Cleft Clinic Services

Between SFY 2018-2022, 91.8% of all Cleft Clinic encounters were billed to private or public health insurers. Reasons that an encounter might not be billed include: lack of any health insurance, incomplete health insurance information, health insurance that doesn't cover the Cleft Clinic (such as Wyoming Medicaid), a person 18 years of age or older on MT Medicaid, and patients with a craniofacial diagnosis rather than CL/P.

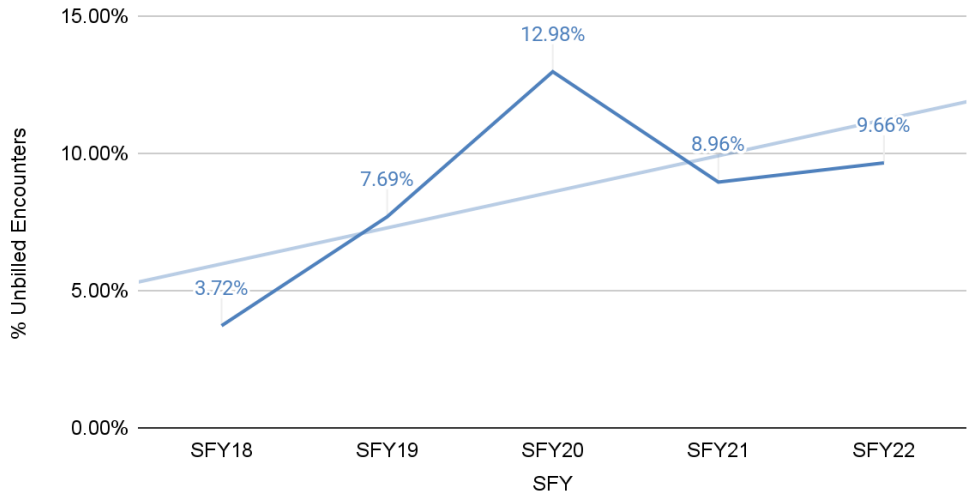
**Figure 24. Cleft Clinics Billed vs. Unbilled Encounters (SFY 2018 - 2022).**




*(CCDAA, CSHBH, CSHPI)*

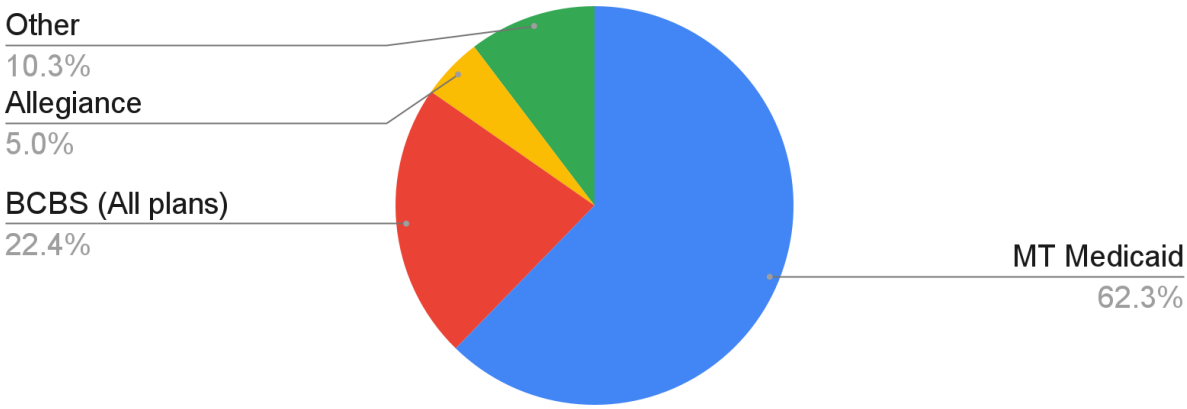
As can be seen in Figure 25, the percent of unbilled encounters from SFY 2018-2022 has increased over time. Efforts have been made to obtain accurate health insurance information from patients, and the exchange of health insurance information between hospitals, CSHS, and Aspen Billing has been streamlined and improved. Nonetheless, unbilled encounters have continued to rise over the past five years.

**Figure 25. Percent of Unbilled Encounters at Cleft Clinics from SFY 2018 - SFY 2022, Overall, Annually.** *(Includes trendline.)*




*(CCDAA, CSHBH, CSHPI)*

**Figure 26. Percent of Cleft Clinic Patient Encounters Billed to Each Health Insurer at All Cleft Clinics from SFY 2017 - SFY 2022.**



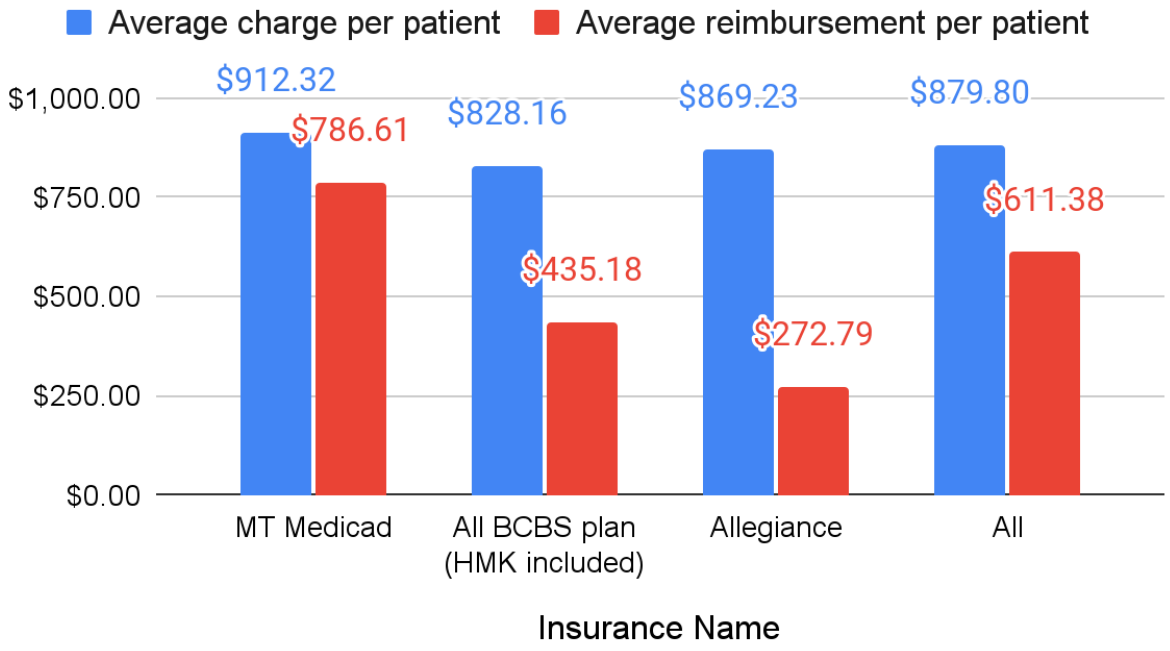

*(CSHSIC)*

Of all the care provided through the Cleft Clinics between SFY 2017-2022, 62.3% was billed to MT Medicaid. MT Medicaid (HMK *Plus*) and HMK (BCBS) health insurance plans fully cover the HCPCS Codes T1024 and T1025 for Cleft Clinic care. In this chart, all BCBS plans including HMK are lumped together. MT Medicaid is charged an average of $912.32 per patient, and reimbursement is on average $786.61 per patient. “Other” insurance companies billed for services include a wide variety of health insurance plans. Not all of those insurers who are billed

for Cleft Clinic care actually reimburse for the care. Major insurers that reimburse nothing (or less than 10%) for Cleft Clinic care when billed HCPCS over the past five years include:

- Aetna
- BCBS - Idaho
- BCBS - Federal Employee Program
- Cigna
- Mountain Health Co-op
- Idaho Medicaid
- Tricare
- United Healthcare
- Wyoming Medicaid

**Figure 27. Amount Billed vs. Amount Reimbursed by Insurance Type for Cleft Clinic Care, SFY 2017 - SFY 2022.**




*(CSHSIR)*

Among each insurance carrier there is a discrepancy between what is being billed for Cleft Clinic care and what is being reimbursed. There is supposed to be parity in reimbursement rates of HCPCS codes between MT Medicaid/HMK *Plus* and BCCS/HMK. Due to the way that insurance reimbursement details were maintained it isn't possible to tell if that parity exists. It is clear that there is a disparity, seen in the chart above, between reimbursement of MT Medicaid and the combination of all BCBS plans utilized by patients. This includes HMK, independent plans, and out-of-state BSBC, the latter of which reimburses nothing for the Cleft Clinics. Of note, although Allegiance reimburses well below the amount submitted for reimbursement, their provider fee schedule actually indicates that they reimburse $2,000 for HCPC T1025.

## Alternative Financial & Clinic Models from Other States and Cystic Fibrosis

**North Dakota.** In North Dakota, Cleft Clinics run similarly to Montana's current state-supported model. The North Dakota Department of Health Special Health Services (SHS) supports CL/P clinics in Fargo, Bismark, Grand Forks, and Minot. In Fargo and Bismark, the clinics are held at churches. In Grand Forks and Minot, the clinics are held in university buildings. In total, the clinics serve roughly 120 families per year with an overall budget of $600,000 per biennium.

The clinics are facilitated by a Clinic Coordinator who is an employee of the ND Department of Health. At certain sites, the North Dakota University System partners with the North Dakota Department of Health to host the clinics, allowing students to assist with coordination. Providers who attend the clinics are considered volunteers; they enroll as vendors with the state and are paid an honorarium per clinic. Reports generated from the clinic visit include recommendations to help direct care for the coming year.

All children who might benefit are eligible to attend with no direct cost to the family. The clinics are financially supported through the MCHBG and by billing Medicaid (Medicaid is the only insurance that is billed if the patient is covered by Medicaid). No cost is passed on to the family regardless of their health insurance coverage.

**Vermont.** In Vermont, the UVM Cleft and Craniofacial Program assumed control of the cleft clinics in January 2019. Prior to this time, the Vermont Department of Health oversaw the Cleft Clinics in Vermont. A full-time (1.0 FTE) nurse coordinator was employed by the state to coordinate these clinics. Based on those that were interviewed about this transition, historical knowledge of the motivation for UVM to assume control of the clinics is unknown.

The Craniofacial Clinic meets the fourth Wednesday of each month at the UVM Plastic, Reconstructive, and Cosmetic Surgery office in Colchester, VT. At each monthly clinic, the following providers are always present: plastic surgeon, two SLPs, ENT, genetics, social work and child life. At every other clinic (six out of the 12 clinics), a local orthodontist is present. The clinic coordinator organizes the clinic invitations so that those patients that need to see the orthodontist are able to be there when the orthodontist is present. For those patients that need more extensive SLP evaluation, they typically come in months when the orthodontist is not present (to allow for more time with the SLP and to keep the clinic flowing). Clinics are organized by the clinic coordinator and involve a morning wave of patients (followed directly by a team meeting) and an afternoon wave of patients (followed directly by another team meeting). Not every provider will see every patient. In preparation for the clinic, the clinic coordinator will look at recommendations from the previous visit and determine who sees which provider. The program is accredited by ACPA and uses an EHR for charting. The Clinic Coordinator at UVM spends less than 50% of their time on Cleft Clinic duties.

Financially, the clinics generate revenue based on individual billing by each provider. No team codes are used for billing. All ICT members are employees of the UVM Health Network except for the orthodontist who is in private practice. It is unknown at this time if the orthodontist

volunteers their time or bills separately from UVM Health Network for their services at Cleft Clinic. Of note, the UVM Cleft and Craniofacial Program received a grant from the Foundation for Faces of Children to assist families with travel expenses.

**Seattle Children's Craniofacial Center.** As the pediatric and adolescent academic medical center for Washington, Alaska, Montana, and Idaho, Seattle Children's Craniofacial Center is a regional option for some Montana families with certain needs. The Craniofacial Center runs four different types of clinics. The first type is one large, interdisciplinary clinic held every Monday at the Seattle Children's campus. It lasts all day, and all disciplines (including pediatric specialists) are available on that day. The clinic routinely sees 70 patients / day and sometimes up to 100 patients / day. The second type of clinic is the "triage clinic," which is set up to see new patients being referred to decide whether they need to be referred into the program. The third type of clinic specifically cares for children with 22q syndrome and provides services 3.5 days per month. The fourth type of clinic is specific for children with plagiocephaly and is run by a nurse practitioner. If appropriate, most providers are able to conduct telemedicine visits, especially with families living in other states.

Follow-up / case management is conducted primarily between the nurses and pediatricians, but it depends on the issue. Three social workers on the team follow up on issues related to finances or psych / mental health. All of the care coordinators are RNs and are employees of Seattle Children's.

Financially, the Craniofacial Center receives reimbursement for their services from all major insurance plans. All providers that see a patient at the clinic will bill independently, effectively as if they were the only ones seeing the patient. The providers will indicate the level of care, and coders will do all the billing. They do not use any team billing codes. They also do not receive any funding from the state of Washington to run their program. Seattle Children's also has a large Uncompensated Care Program at Seattle Children's to help families with financial needs, although it is not specific to craniofacial patients.

**Wyoming.** Wyoming's state Children's Special Health (CSH) Program used to coordinate CL/P clinics in Casper using an interdisciplinary team of providers. Just before the onset of the COVID-19 pandemic (early 2020), many of the providers had already opted to try to run these clinics on their own from start to finish without the support of CSH. Their rationale stemmed from concerns with state budget cuts, decreased financial support, and decreased staff. Once the pandemic was in full swing, **the clinics stopped, and they have not restarted** in the state of Wyoming as of this writing.

For Wyoming children in need of CL/P care, there are currently no state-supported cleft clinics and no state or federal funding dedicated to serving this population. For the past two years, most families have had to transfer their care to either Children's Hospital of Colorado or Intermountain Primary Children's Hospital in Salt Lake City. A few children have been attending the Cleft Clinics in Billings, MT.

**Cystic Fibrosis Clinic Conversion.** The Cystic Fibrosis Clinics (CFC) in Montana were presented with a similar financial scenario in approximately 2015, in which the Team rates reimbursed for CFC in Montana became unsustainable. At this crossroads, Billing Clinic decided to take on the responsibility of providing comprehensive cystic fibrosis care throughout the state and **not** rely on CSHS for billing and funding of services. When Billings Clinic assumed this responsibility, they conducted financial assessments and determined that their funding was higher and more sustainable when they began billing each provider individually for each service provided at the CFC. Additionally, they found that "downstream" services such as lab, radiology, etc. that were generated from providing the CFC care created an important source of revenue for their institution. Now, Billings Clinic CFC providers travel at least one week each month to provide CFC services in communities across Montana. In these communities, they generally rent space from another healthcare institution, but bring their Billings-based providers to the community to provide care and bill for this care through Billings Clinic. They have not found that patients have issues with receiving multiple bills or copays when seeing multiple providers throughout the day. Major differences between the CFC and the Cleft Clinics that would impede implementing this exact same model for Cleft Clinics lies in the makeup of the providers involved in the different clinics. The CFC are staffed with providers who are generally employees of the health system, and the teams are much smaller. In Cleft Clinics, there are not only more disciplines involved, but many of these providers such as orthodontia and dentistry are not employed by hospital systems, and those such as pediatric audiologists, SLPs, ENTs, and CL/P surgeons are not always employed by hospital systems. Patients are also seen far more frequently in the CFC, usually quarterly, but often monthly. Cleft Clinic patients are generally only seen annually through the Cleft Clinic setting.

Despite a higher revenue from billing individual providers than was previously provided through the HCPCS codes, the CFC team still seeks grant funding to cover some costs associated with the CFC and they have a hospital-sponsored "Piggy Bank" fund available to patients so that a family's travel, hotel, or other associated costs can be covered if needed.

The CFC Clinic Coordinator also noted that prior to converting to administering CFC statewide solely through Billings Clinic, considerable communication breakdown resulted from the use of paper records and teams with high provider turnover. Now that patients can access their patient portal through the Billings Clinic EMR and providers are always consistent, there is better communication and perceived higher quality of care with dedicated providers.

## Current Cleft Clinic Structure Strengths and Weaknesses

The current Cleft Clinic model has strengths, weaknesses, and a variety of stakeholders who all have different motivations, needs, resources, and limitations. The following describes many of the strengths and weaknesses from those various perspectives.

### Strengths of Current Cleft Clinic Structure

**Site/Clinic Perspective**

- Cleft Clinics are able to provide a wide array of services to patients in a condensed and streamlined time frame.
- Clinics are held in three separate population centers across Montana, meaning patients and providers may experience less travel compared to only one Clinic in one location.
- Patients are referred to the Clinic from a wide variety of community providers.
- Clinics are well-known by the medical community at large.
- The structure of the Clinic allows for roundtable / group conversation within the ICT to coordinate care and understand the patient and family needs in greater depth.
- Several providers donate their time and show exceptional devotion to the patients and the Clinics.
- Clinic Coordinators are familiar with local, state, and national resources, and they can help to connect patients to those resources.
- Clinic Coordinators can serve as a known contact person for providers to refer new patients to.
- Hospital/clinic sites do not carry the burden of contracting with the individual providers that are not employed by the hospital.
- Hospital/clinic sites are not responsible for any overhead around billing for the appointments.

**Provider Perspective**

- Collaboration among the ICT allows for patient care considerations from multiple perspectives.
- For certain providers and Clinic Coordinators, they have been involved in the Cleft Clinics for many years and find professional fulfillment in seeing these patients year after year.
- For patients that don't have a medical home or primary care provider, the Clinic Coordinator can help identify and refer to other related medical services.
- It is helpful for the ICT members to hear recommendations and to learn from one another's expertise.
- Clinic Coordinators are able to summarize the multiple recommendations for the patients and follow-up with families on those recommendations if needed.
- For families that are able to follow up on clinical recommendations, providers feel their medical needs are met well and that their care is mostly complete.
- Based on the provider survey, around 24% of providers responded that they would be "Very likely" to volunteer, without reimbursement, at the Cleft Clinics.

**Patient/Family Perspective**

- The multidisciplinary approach is more convenient for families, leading to decreased Cleft Clinic visits (overall) and potentially less trauma to the child.
- The availability of a surgical craniofacial specialist in Montana provides in-state surgical options as opposed to needing to travel to other cities such as Seattle or Salt Lake City for pre-op consults, surgeries, and post-op care.
- Families find the ICT members to be well-informed providers.
- There is no balance billing or additional cost to the family when seen at the Cleft Clinic.
- Many families find the Clinics to be an excellent resource. Parents/guardians feel better informed when making decisions, have a better understanding of the plan of care, receive education and anticipatory guidance at the Clinics, and can connect with non-medical resources for things like social and financial services.
- Families enjoy the positive atmosphere at the Clinics.

**Other**

- Reimbursement is a simple process without separate billing from each rendering provider.
- The patient doesn't get billed separately if their deductible hasn't been met.
- MT Medicaid provides the best reimbursement of the HCPCS codes of any insurer. MT Medicaid is also the most common insurer among Cleft Clinic patients.
- Clinic Coordinators are experts in the resources and relationships within their own communities.
- Clinics are geographically well positioned to provide relatively convenient access to services across Montana.

## Weaknesses of Current Clinic Structure

**Site/Clinic Perspective**

- CSHS's role in Cleft Clinics has changed in recent years, leading Clinic Coordinators to shoulder most of the responsibility of identifying local providers to join the ICT.
- Though the Clinic Coordinator communicates with local providers, it is ultimately the state paying the reimbursement. Thus it is difficult to hold either party accountable for ensuring that the providers attend scheduled Clinics.
- The small reimbursements make it increasingly difficult to staff a full team of 8+ providers.
- The patient care plans (follow-up reports) compiled by the Clinic Coordinators require a considerable amount of time and effort.
- Paper charting is still used at the Clinics. It is often difficult and time-consuming for Clinic Coordinators to decipher the handwriting of each provider and then transcribe and document the encounters into the CHRIS system.
- CHRIS is an outdated system for documenting patient encounters and is not actually accessible to the Cleft Clinics' providers.
- CHRIS does not have the necessary fields to easily document secondary health insurance and/or update new primary health insurance information.

- Patient's health insurance information has to be separately transmitted through a different secure portal from Clinic Coordinators to CSHS for billing by the third party.
- Considerable physical space is required to run the Cleft Clinics. This same space could otherwise be used for other billable services that would generate more revenue for the day.

**Provider Perspective**

- For providers who are aware of typical reimbursement rates, many indicate a need for higher reimbursement and overall being more fairly compensated for their time at the Cleft Clinics.
- For providers who are still paying for their own clinic's overhead on a day when they provide care at Cleft Clinics for little or no compensation, those days result in financial loss for their entire practice.
- Because contracting with CSHS is time-consuming and involved, some providers volunteer their time at Cleft Clinic to simply avoid the contracting process.
- Patients are able to receive basic assessments and coordination at Cleft Clinics, but certain evaluation tools and equipment for procedures may not be practical or available. Many providers prefer more time with each patient in order to conduct a more thorough evaluation.
- Scheduling the Clinics on a day when all/most providers can attend can be challenging.
- There is no electronic health record (EHR) to share information between ICT and other providers. Providers overwhelmingly prefer an EHR.
- The specific paper templates from CSHS for charting are sometimes outdated and only remain in the possession of the Clinic Coordinator.
- Inconsistencies in provider attendance at the Clinics lead to difficulties with incomplete patient evaluation and gaps in care coordination.
- Alternatively, the clinic day may become inefficient and repetitive for patients who see providers at the Clinic that are different from the providers they see outside of the Clinic.
- It is difficult to engage orthodontia providers in many communities, even though the ACPA recommendations identify them as one of the three core team members.
- Overall, some providers feel there are not enough knowledgeable or specialty providers available across the state to meet the needs of children with CL/P.
- Among providers who are more closely tied to the contracting rate for their services, up to 50% indicated that they would "not likely" be willing to volunteer their time at the Clinics.

**Patient/Family Perspective**

- Frequent lack of communication between ICT members and from Clinic Coordinators (e.g., records not being sent, ICT members not aware of updates, lack of outreach regarding Cleft Clinic dates).
- Lack of communication between ICT members and outside (community) providers.
- Long clinic days are difficult for families especially with infants and small children.
- The Clinics do not always flow well, resulting in a lot of waiting either in the exam room or in the waiting room.

- Lack of trust in providers at the Clinics, specifically feelings that the providers don't conduct a thorough assessment or listen to their concerns.
- Poor attendance by certain providers and coming to a Clinic that is not fully staffed. Orthodontia is frequently absent and, for older children, that may be a specialist the family is needing to see.
- Alternatively, some families are required to see specialists that they don't need to or want to see.
- Lack of attention to and resources for mental health / social / behavioral concerns.

**Other**

CSHS

- There is an exorbitant amount of back-end administrative work to maintain the Clinics, including 25+ contracts between hospitals and individual providers.
- Improvements are needed inFacilitate the transfer of patient insurance information from each patient across every clinic site to Aspen Billing.
- It is difficult to maintain consistency between the three clinic sites.
- There is no incentive among clinic sites to improve Clinics and attendance.

**Financial**

- Costs of offering the Clinics are currently double that of the revenue received in reimbursement.
- The HCPCS codes reimbursement amount has not been updated since 2007.
- Invoicing for the Clinic Coordinator role at each of the sites is different (for instance, a flat rate every quarter vs. hourly charges for the quarter).
- Providers are not reimbursed or paid fair market value for their services.
- Declining attendance at the Clinics has led to a decline in overall reimbursement.
- In recent years, multiple Clinics were canceled, but CSHS still paid for the work conducted to organize the Clinics.

## Alternative Cleft Care & Clinic Structures for Montana

Current Cleft Clinic contracts that cover care coordination and provider reimbursements exceed the revenue that they generate. This is an unsustainable model that requires modification. This section presents several ideas suggested by hospital systems, state employees, or parents/guardians.

For selected scenarios, illustrative budgets and extended considerations have been outlined. Hospital administrators and Clinic Coordinators were convened (or attempts were made to engage them for feedback) to discuss the potential benefits and drawbacks of each scenario. Each system who was engaged agreed that there was no clear best scenario and requested additional time to consider each.

These include the following scenarios:

1. **Healthcare System Assumption of Cleft Clinics - Individual CPT**
2. **State-Sponsored Statewide Cleft Coordinator**
3. **State-Sponsored Cleft Clinics (current model with modifications)**
4. **Healthcare System Assumption of Cleft Clinics - HCPCS**

The following general budget assumptions were made throughout this section:

- SFY 2024, 2025, 2026 there is annual availability of $100,000 (total $300,000) that will not be available after those three years
- State Special Revenue / Tobacco Settlement funding of $25,000 annually will be available indefinitely as long as there are Cleft Clinics to support
- HCPCS average reimbursement amount: $634.40
- Average number of patients seen at each Cleft Clinic site annually: 50
- Number of Cleft Clinic Sites in SFY 2024, 2025, 2026: 4 sites (**note:** this an increase of 1 site)
- Average cost of care coordination services at each site annually (SFY22): $46,071
- Average cost of provider contracts associated with hospitals at each site annually (SFY22): $3,433
- Average cost of provider contracts **not** associated with hospitals at each site annually (SFY22): $6,117
- Providers will continue to volunteer their services at the Clinics or take a small $300 / day reimbursement

Other assumptions are noted throughout the section as they apply to the specific scenario being explored.

No single scenario is a perfect solution. In each scenario, there will be stakeholders who take on additional roles or receive less compensation. Ensuring that patients continue to receive access to ICT Cleft Clinics in Montana remained the top priority when considering various options.

## Healthcare System Assumption of Cleft Clinics - Individual CPT

In this scenario, sites would maintain ICT Cleft Clinic structure so that pediatric clinics or specialty clinics through the hospital systems provide care coordination, and **each provider bills separately for their service at the Cleft Clinic**. Hospital sites would directly bill patient health insurance for each encounter with one of their employed providers. Providers not employed by the hospital participating in the Clinics would be responsible for billing their own encounters with patients at Cleft Clinics. CSHS would not be involved with patient billing.

In SFY 2024, 2025, 2026, hospitals would be provided a base funding amount of $100k / # of participating clinic sites as a way of supporting the Clinics' financial stability while hospital sites determine best practices around 1) organizing clinic flow to optimize the time patients and providers spend in the Clinic and 2) the best procedures to complete with each provider type for maximum reimbursement and high-quality patient care.

The ***Illustrative Example*** in this section shows a scenario in which Hospital A's Cleft Clinic provides services to 50 people over the course of a year and employs the following providers whose service is billed at the rate billed to Medicaid: Surgeon ($112.41); SLP ($139.05); Pediatrician ($206.97); Social Work Family Therapy ($124.25); Dietitian ($21.40).

- Hospital A would receive:
    - Reimbursement from providers = $30,204
    - $100,000 / 4 = $25,000
    - **Annual Total = $55,204**
- Providers would receive (varies by provider and service):
    - **Dentist** = 1 patient ($92.26); 50 patients **($4,613)**
    - **Orthodontist** = 1 patient ($95.80); 50 patients **($4,790)**
    - **Audiology** = 1 patient ($77.81); 50 patients **($3,890.50)**

**Comparison:** In SFY 2022, Cleft Clinic sites received an annual average of $46,071 / site for care coordination duties and $3,433 in provider contracts to the hospital. This scenario would provide approximately $55,204 / hospital site annually. In SFY 2022, providers contracting directly with CSHS were compensated $0-$1,850 per year, so this model has the potential to increase their reimbursement as well.

**Considerations:**

- At this time, base funding is only available for the next three SFYs.
- During these three SFYs, work can be done to streamline and identify how to provide billable services within the Cleft Clinic setting.
- If providers chose not to participate, they would not jeopardize the "full team" billing option under HCPC T1025.
- Hospitals may consider limiting the number of contracts with outside providers to only those that are required under the ACPA recommendations (surgery, orthodontia, SLP) and not already employed by the hospital.

**Pros:**

**Patients**: Maintains the ICT system that is familiar to patients, allowing them to see multiple providers in a day. Patients could more easily opt out of seeing certain providers since billing would no longer be contingent upon seeing a “full team.”

**Clinic Coordination:** If coordinated through a primary pediatric office, care coordination for all patient needs could be streamlined.

**Providers:** Negates the need for contracting with CSHS. Providers will receive revenue based on their services, and less of their time will be volunteer or limited in pay. Providers would no longer need to use CHRIS for charting.

**CSHS Overhead:** Significantly decreases CSHS overhead to execute and maintain contracts with hospital sites and private providers, and eliminates billing tasks.

**EHR:** The sponsoring health system EHR can be used to maintain patient records.

**Cons:**

**Patient Billing:** Patients may be responsible for copays for each provider seen that day, and those with private insurance may receive multiple bills for the balance due after insurance coverage.

**Clinic Coordination:** Limited funds to support the Clinic Coordinator’s coordination tasks would be available to offset this for 3 SFY. This cost would need to be absorbed by the hospital and/or through a fee to ICT providers.

**Hospital Administration:** Some hospitals may require credentialing or contracting or space rental for providers who provide care in their facilities.

**Providers:** Providers who do not offer billable services would not be compensated when they participate.

## Cleft Clinic Case Study: Billing Separately for Each Provider - CPT

The entirety of the following information is ***for illustrative purposes only***. Each health system, provider, and private practice will need to critically review the CPT codes and other procedures outlined here to determine whether they are appropriate for Cleft Clinic purposes and for each individual patient served. In the Figure below, each provider type is listed along with the procedure codes they may use in the Cleft Clinic and how much Medicaid reimburses for that procedure according to the July 2022 Provider Fee Schedules for Outpatient Provider Visits, Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Nutrition, and the Dental Providers. In the columns under the "Case Study" heading are **theoretical procedures that might occur by various providers**. Those providers who are commonly employed by the hospital system that organizes the Cleft Clinics have their procedures listed under the "Hospital" column. Dentists, orthodontists, and audiologists each have their own, individual columns to suggest that they might bill separately as a private practice /provider.

| | | | Case Study | | | | |
|---|---|---|---|---|---|---|---|
| **Provider Type** | **Procedure Code** | **Medicaid Fee Schedule (Non-facility Fee)** | **Hospital** | **Dentist** | **Orthodontist** | **Audiology** | **Code Description** |
| *Surgery | 99213 | $112.41 | $112.41 | | | | Established patient office or other outpatient visit, 20-29 minutes |
| *Surgery | 99214 | $158.46 | | | | | Established patient office or other outpatient visit, 30-39 minutes |
| *Speech Pathology | 92522 | $139.05 | $139.05 | | | | Evaluation of speech sound production (e.g., articulation, phonological process, apraxia, dysarthria) |
| *Speech Pathology | 92524 | $136.94 | | | | | Behavioral and qualitative analysis of voice and resonance |
| *Speech Pathology | 92507 | $95.53 | | | | | Treatment of speech, language, voice, communication, and/or auditory processing disorder; individual |
| *Orthodontist | D8670 -- | $95.80 | | | $95.80 | | PERIODIC ORTHODONTIC TX VISIT |
| Pediatrician | 99381/91, 99382/92, **99383**/93 | $147.04 | | | | | New/Established well child check |
| Pediatrician | 99204 | $206.97 | $206.97 | | | | New patient office or other outpatient visit, 45-59 minutes |
| Pediatrician | 99214 | $158.46 | | | | | Established patient office or other outpatient visit, 30-39 minutes. |
| Pediatrician | 99205 | $273.74 | | | | | New patient office or other outpatient visit for the evaluation and management which requires a medically appropriate history and/or examination and high medical decision making |
| Pediatrician | 99215 | $223.50 | | | | | Evaluation and management of an established patient in an office or outpatient location for 40 minutes |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Audiologist | 92550 -- | $27.91 | | | | $27.91 | Tympanometry and reflex threshold measurements |
| Audiologist | 92556 -- | $49.90 | | | | $49.90 | Speech audiometry threshold; with speech recognition |
| Social Worker or Psychologist / Psychotherapy | 90832 | $95.07 | | | | | Psychotherapy for 16-37 minutes |
| Social Worker or Psychologist / Psychotherapy | 90847 | $124.25 | $124.25 | | | | Family psychotherapy session WITH patient present, for 50 minutes |
| Dentist | D0190 -- | $24.84 | | $24.84 | | | Screening of a patient |
| Dentist | D0191 -- | $17.74 | | | | | Assessment of a patient |
| Dentist | D0145 -- | $35.48 | | | | | Oral evaluation, pt < 3yrs |
| Dentist | D1310 -- | $42.58 | | $42.58 | | | Nutri counsel-control caries S |
| Dentist | D1330 -- | $24.84 | | $24.84 | | | Oral hygiene instruction |
| Dietitian | 97802 | $45.67 | | | | | Initial assessment and intervention, individual, face-to-face with the patient, each 15 minutes |
| Dietitian | 97803 | $21.40 | $21.40 | | | | Re-assessment and intervention, individual, face-to-face with the patient, each 15 minutes |
| Genetic Counselor | 99205 | $273.74 | | | | | |
| ENT | -- | | | | | | |
| | | Total - 1 Patient | $604.08 | $92.26 | $95.80 | $77.81 | |
| * Required ACPA Cleft Clinic | | **Total - 50 Patients** | **$30,204.00** | **$4,613.00** | **$4,790.00** | **$3,890.50** | |

-- Procedure not recommended through Provider Survey

July 2022 Dental Fee Schedule. https://medicaidprovider.mt.gov/18
July 2022 OPPS Fee Schedule. https://medicaidprovider.mt.gov/02
July 2022 Nutrition (EPSDT) Services Fee Schedule. https://medicaidprovider.mt.gov/04

## State-Sponsored Statewide Cleft Coordinator

In this scenario, a part-time statewide RN Care Coordinator and a full-time Clinic Coordinator would organize Cleft Clinics across Montana and provide care coordination services for all children in MT with CL/P. The statewide Care Coordinators would facilitate Cleft Clinics in major population centers and provide limited care coordination to those patients in rural areas. This model may be appropriate to pilot potential telehealth Cleft Clinic options.

At the Cleft Clinics, CSHS would bill HCPCS, and providers would be asked to volunteer their services as in-kind or receive minimal reimbursements similar to current reimbursement amounts. The illustrative budget below budgets $48,000 / year in provider contracts, whereas in SFY22 only about $28,650 was paid out in provider contracts to both hospital and non-hospital provider contracts.

Below is an ***illustrative budget*** of both expenditures and revenue sources.

| **Budget Assumptions** | |
|---|---|
| Base Funding Available for SFY 2024, 2025, 2026 | $125,000.00 |
| Number of Clinics / Year in State | 12 |
| Average Reimbursement per Patient via HCPCS | $634.40 |
| Average Number of Patients / Site / Year | 15 |
| Statewide RN/SW Care Coordinator Salary / Contract | $100,000.00 |
| Statewide Clinic Coordinator Salary / Contract | $70,000.00 |
| Travel for Statewide RN Care Coordinator / Clinic Avg | $400.00 |
| Provider reimbursements / Provider / Year | $1,600.00 |
| Providers at All Sites / Year | 30 |
| Space Rental | $500.00 |
| Third Party Billing % of Total Revenue | 10 |

Below provides a basic budget of expenditures and revenue over the next 3 years.

| **SFY 2024, 2025, 2026** | | | |
|---|---|---|---|
| **Expenditures** | | | |
| **Description** | **# Units** | **Cost / Unit** | **Total Cost** |
| Statewide RN/SW Care Coordinator Salary / Contract | 0.5 | $100,000.00 | $50,000.00 |
| Statewide Clinic Coordinator Salary / Contract | 1 | $70,000.00 | $70,000.00 |
| Travel for Statewide RN Care Coordinator / Clinic Avg | 12 | $400.00 | $4,800.00 |
| Provider reimbursements / Provider | 30 | $1,600.00 | $48,000.00 |
| Space Rental | 12 | $500.00 | $6,000.00 |
| Aspen Billing (10% of HCPCS Revenue) | | 10% | $11,419.20 |
| Overhead (10%) | | 10% | $17,880.00 |

| | | | |
|---|---|---|---|
| **Total Expenditures** | | | **$208,099.20** |
| | | | |
| **Revenue** | | | |
| **Description** | **# Units** | **Income / Unit** | **Total Cost** |
| Base Funding Available for SFY 2024, 2025, 2026 | 1 | $125,000.00 | $125,000.00 |
| HCPCS Codes Revenue | 180 | $634.40 | $114,192.00 |
| **Total Revenue** | | | **$239,192.00** |
| | | | |
| **Net Profit (Loss) / Year** | | | **$ 31,092.80** |
| **Net Profit (Loss) / in 3 Years** | | | **$ 93,278.40** |

The following three years of expenditure and revenue show that the Clinics will become unsustainable in this model starting in SFY 2027.

| **SFY 2027, 2028, 2029 (5% increase in costs & HCPCS)** | | | |
|---|---|---|---|
| **Expenditures** | | | |
| **Description** | **# Units** | **Cost / Unit** | **Total Cost** |
| Statewide RN/SW Care Coordinator Salary / Contract | 0.5 | $105,000.00 | $52,500.00 |
| Statewide Clinic Coordinator Salary / Contract | 1 | $73,500.00 | $73,500.00 |
| Travel for Statewide RN Care Coordinator / Clinic Avg | 12 | $420.00 | $5,040.00 |
| Provider reimbursements / Provider | 30 | $1,680.00 | $50,400.00 |
| Space Rental | 12 | $525.00 | $6,300.00 |
| Aspen Billing (10% of HCPCS Revenue) | | 10% | $11,990.16 |
| Overhead (10%) | | 10% | $18,774.00 |
| **Total Expenditures** | | | **$218,504.16** |
| | | | |
| **Revenue** | | | |
| **Description** | **# Units** | **Income / Unit** | **Total Cost** |
| Surplus Base Funding Available for SFY 27, 28, 29 | 1 | $31,092.80 | $31,092.80 |
| Special Cleft Funds $25k/yr | 1 | $25,000.00 | $25,000.00 |
| HCPCS Codes Revenue | 180 | $666.12 | $119,901.60 |
| **Total Revenue** | | | **$175,994.40** |
| | | | |
| **Net Profit (Loss) / Year** | | | **$ (42,509.76)** |
| **Net Profit (Loss) / in 3 Years** | | | **$ (127,529.28)** |

**Considerations:**

- At this time, base funding is only available for the next three SFYs.
- Revenue surplus can be rolled over into the SFY 2027, 2028, 2029 to create a “base” of funding for those three years. Preliminary budgets suggest this model would only work for about three years before expenditures outpace revenue in SFY 2027.
- Work could be undertaken to improve Medicaid reimbursement rate for HCPCS T1024 and T1025 during this time to better support revenue once base funding is no longer available.
- This model would work well to pilot telehealth options for Cleft Clinic work.
- This model may also improve outreach to rural areas in Montana as the Coordinators are tasked with management of all patients with CL/P throughout the state.
- Could contract a health system to do this work statewide rather than two individuals

**Pros:**

- **Patient Billing:** Maintaining the current HCPCS billing process should ensure that patients do not pay a copay or receive additional bills for Clinic services.
- **CSHS Involvement:** CSHS would retain stewardship of the Cleft Clinics and ensure that they continue in a high quality manner.
- **Dedicated Specialist:** This model would allow for two people to dedicate time fully to cleft care, which may improve communication and bring consistency to Clinics and coordination.

**Cons:**

- **Funding:** CSHS may need to tie the Coordinators’ contracts to the amount of revenue realized through the ICT Clinics that are conducted as a way of maintaining financial sustainability after the next 3-4 years.
- **CSHS Administration:** This model would still rely heavily on CSHS to manage contracts with the Coordinators, providers, and medical biller.
- **Loss of Local Knowledge:** There is a possibility that the Care Coordinator would not have the capacity to have in-depth knowledge of local resources around the state.
- **EHR:** CSHS will need to spend time and money investing in an EHR system or another patient record keeping system like CHRIS.
- **Significant Change:** This would likely involve a significant amount of change to the feel of the Clinics from all stakeholder perspectives and would require a considerable amount of communication of changes.

## State-Sponsored Cleft Clinics (current model with modifications)

This model is the closest to the current Cleft Clinic model. In this scenario, CSHS would maintain administration and billing of the Cleft Clinic structure as it is currently administered, with changes applied only to how hospitals are paid. Hospital sites would be paid 60-70% of revenue received through CSHS billing of third-party insurers. CSHS would retain 20-30% of revenue received by billing of third-party insurers to pay providers that provide services in the Cleft Clinics, but are not employed by the hospital. Aspen is provided 10% of all revenue received as payment for their billing services.

The percentage of revenue that is distributed to the hospital vs. retained to pay providers will be determined based on the number of providers who are not employed by the hospital providing care coordination services. This scenario assumes that non-hospital providers' reimbursements are capped at $300 / day at 4 days / year for a total of $1,200 / provider throughout the year. In the examples below, revenue is split according to the following scenarios:

- 70/20% (hospitals / private providers) when there are 5 or fewer private providers who are not hospital employees
- 60/30% (hospitals / private providers) when there are 6 or more private providers who are not hospital employees

In SFY 2024, 2025, 2026, hospitals would be provided a base funding amount of $100k / # of participating clinic sites plus 60-70% of revenue from Cleft Clinic services. 20-30% of reimbursed funds would be used to pay providers. 10% of reimbursed funds are provided to Aspen Billing for their services.

**Illustrative Financial Example**

| **Budget Assumptions** | |
|---|---|
| Base Funding Available for SFY 2024, 2025, 2026 | $100,000.00 |
| Number of Clinic Sites in State | 4 |
| Average Reimbursement per Patient via HCPCS | $634.40 |
| Average Number of Patients / Site / Year | 50 |
| 70/20% - Providers Not Employed by Hospital (5 or less) | 5 |
| 60/30% - Providers Not Employed by Hospital (6+ or less) | 7 |
| Aspen Billing % of Total Revenue | 10 |

***Illustrative Example:***
Base funding: Four sites in MT provide Cleft Clinic services, means base funding = $100k / 4 = $25,000 / site

Reimbursed funding: Hospital A Cleft Clinic provides services to 50 people over the course of the year and employs 5+ of the providers who participate in the Clinics.

Average reimbursement is $634.40 / patient for a total of $31,720.

- Hospital A would receive:
  - 70% of $31,720 = $22,204

    - $100,000 / 4 = $25,000
    - **Annual Total = $47,204**
- Providers would receive:
    - 20% of $31,720 = $6,344
    - $6,344 /5 providers not employed by Hospital A
    - **Annual Total / Provider = $1,222.76**

| Case Study- Hospital A | | |
|---|---|---|
| | **Revenue 70/20%** | **Revenue 60/30%** |
| Hospital Base | $25,000.00 | $25,000.00 |
| Reimbursement Revenue Total (Annual Pts * Avg Reimbursement) | $31,720.00 | $31,720.00 |
| Hospital Reimbursement Revenue (Percent of Total) | $22,204.00 | $19,032.00 |
| **Hospital Annual Total (Base + % of Reimbursement)** | **$47,204.00** | **$44,032.00** |
| Total Provider Annual | $6,344.00 | $9,516.00 |
| **Per Provider Annual** | **$1,268.80** | **$1,359.43** |
| Aspen Billing | $3,172.00 | $3,172.00 |

**Considerations:**

- At this time, base funding is only available for the next 3 SFYs.
- During these 3 SFYs, efforts can be made to increase HCPC reimbursement rates and increase the number of private insurers that reimburse for the services.
- The % going to the hospital will need to be adjusted based on the # of providers attending Clinic who are not employed by the hospital and thus need to be paid an reimbursement by CSHS

**Comparison:** In SFY 2022, Cleft Clinic sites received an annual average of $46,071 / site for care coordination duties and $3,433 in provider contracts to the hospital. This scenario would provide approximately $47,204 / hospital site annually.

**Pros:**

- **System**: Maintain a system that is familiar to all parties involved, including hospital, providers, and patients.
- **Funding Balance:** When linked directly to the number of patients seen, CSHS will not run a deficit of funding.
- **Providers:** CSHS will still provide a reimbursement for providing cleft services.
- **Patient Billing:** Maintain the current billing process through the CSHS to ensure that no patients receive a bill for any services at the Cleft Clinics.

**Cons:**

- **Inconsistent Hospital Income:** Hospitals may experience higher or lower revenue to support the Clinics depending on how many patients attend each Clinic.
- **Providers:** This scenario would still rely on providers taking very low reimbursements or volunteering their time.
- **EHR:** CSHS will need to spend time and money investing in an EHR system or another patient record keeping system like CHRIS.

## Healthcare System Assumption of Cleft Clinics - HCPCS

In this scenario, sites would maintain ICT Cleft Clinic structure so that pediatric clinics or specialty clinics within the hospital systems provide care coordination. **Hospital sites would directly bill patient health insurance using HCPCS Codes T1024 and T1025 for patient encounters at the Cleft Clinics**. Providers not employed by the hospital that participate in the Clinics would be contracted directly by the hospital to provide Cleft Clinic services. CSHS would not be involved with patient billing or paying providers for services in any capacity.

SFY 2024, 2025, 2026, hospitals would be provided a base funding amount of $100k / # of participating clinic sites plus however much revenue they are able to collect by directly billing HCPCS codes that their employed and contracted providers provided at each Clinic. Providers employed outside of the hospital system hosting the Clinic may need to be contracted with the hospital or pediatric clinic to receive compensation.

***Illustrative Example:***
Base funding: Four sites in MT provide Cleft Clinic services, base funding = $100k / 4 = $25,000 / site

Reimbursed funding: Hospital A Cleft Clinic provides services to 50 people over the course of the year. Hospital A employs or contracts any of the providers involved in the "full team" for a Cleft Clinic. The average reimbursement received billing HCPCS is $634.4/patient.

- Hospital A would receive:
    - 1 patient = $634.4
    - 50 patients = $31,720
    - **Annual Total (50 patients + base) = $56,720**
- Contracted providers **would be paid by Hospital A** at a rate negotiated between Hospital A and the provider.

**Comparison:** In SFY 2022, Cleft Clinic sites received an annual average of $46,071/site for care coordination duties and $3,433 in provider contracts to the hospital. In SFY 2022, providers contracting directly with CSHS were compensated on average per site $6,117 per year. This scenario would provide approximately $56,720 / hospital site annually to cover those three types of costs.

**Considerations:**

- At this time, base funding is only available for the next 3 SFYs.
- During these 3 SFYs, work can be done with Medicaid to increase the HCPC T1024 & T1025 rates and to increase the number of private insurers who reimburse for these codes.
- Health systems may consider reducing the number of outside providers involved in the Clinics so that only contracts with ACPA-required disciplines are maintained.

**Pros:**
**System**: Maintain a system that is mostly familiar to all parties involved, including the hospital, providers, and patients.
**Billing:** May be simpler for hospitals than to bill for each service separately.
**Providers:** Providers not employed by the hospital would not need to bill separately for each

patient.
**Patient Billing:** Maintaining the current HCPCS billing process prevents patients from having multiple copays.
**EHR:** The sponsoring health system EHR can be used to maintain patient records.

**Cons:**
**Inconsistent Hospital or Clinic Income:** Hospitals or clinics may experience higher or lower revenue to support the Cleft Clinics, and this may be unpredictable from quarter to quarter.
**Limited CSHS Involvement:** The CSHS would have limited involvement with the Cleft Clinic. Could still maintain Technical Assistance as needed.
**Clinic Coordination:** CSHS would not provide Clinic Coordinator funding. Hospitals or clinics would be responsible for determining contracting amounts with partnering providers based on their costs associated with coordination.
**Provider Contracting:** Contracting with outside providers often requires that the providers are credentialed at the hospital and creates additional work for the hospital to create, manage, and pay these contracts. Using HCPCS T1025 would still require the presence of 8+ providers at each Clinic.

## Additional Options

| Additional Structures | Pros | Cons | Considerations & Questions |
|---|---|---|---|
| **Do Nothing - Continue Same Structure**<br>Continue to provide contracts to the same hospitals for Cleft Clinic coordination and providers at the same current rates.<br>● CSHS would continue to bill for encounters using the HCPCS code.<br>● CSHS would continue to pay contracts with the reimbursement revenue and base funding for the next three years. | See Strengths and Areas for Improvement for current Clinic structures. | **Funding:** The cost to run the Cleft Clinics is double that of the current revenue realized by HCPCS T1024 and T1025. The Cleft Clinics would likely be viable for the next 3 years, but not for much longer after that time. There is also a high likelihood that the Cleft Clinics would run a deficit, with no means of preventing this. | ● It may be possible that the Cleft Clinics could continue over the next 3 years with the base funding plus revenue available, and a new model could be negotiated during that time. |
| **Do Nothing - No State Clinics:**<br>CSHS could provide notice to current Cleft Clinic sites, providers, patients, and families that they cannot support the Clinics any longer and allow communities and private health systems across the state to fill this gap with systems that work well for their resources. | **CSHS**: Dramatically reduces the burden of administration on CSHS. | **Patient Access:** This will likely reduce patients' access to the necessary medical professionals that they have traditionally had access to through the Cleft Clinic model. | ● Most people in Montana receive CL/P care outside of the Cleft Clinics, and it is not known whether patients experience poorer outcomes because of it. |
| **Annual Clinics Statewide**<br>Hold ICT Cleft Clinics once each year. Clinic could be 2 | **Patient Billing:** Maintaining the current HCPCS billing process should ensure that patients do not pay a copay or | **Limited Care Coordination:** Emphasis would be on attending the Clinic and less emphasis placed on care coordination. | ● Would providers be more or less likely to engage in a longer but only annual Clinic?<br>● Would providers be more likely if |

| Additional Structures | Pros | Cons | Considerations & Questions |
|---|---|---|---|
| days long and see 30-40 patients in the 2 days.<br>● CSHS would bill HCPCS<br>● Facility managing Clinic Coordination would receive payment based on number of patients served **<u>or</u>** CSHS could contract one person to administer these Clinics statewide.<br>● Providers would be asked to volunteer. | receive additional bills for CC services.<br>**Engagement:** Coordinators and providers may be more engaged in a 2-day Clinic annually rather than quarterly, ongoing. | **Less Patient Follow-up:** There may be less work throughout the year for a local Care Coordinator.<br>**Less Access Overall:** If a patient isn't available to attend the annual Clinic, then they may not be able to be seen in a Clinic for another year. | they could bill independently for each patient? (rather than HCPCS)<br>● Would this allow for Clinics to occur in more locations around the state?<br>● What can we learn from St. Luke's in Idaho, which runs clinics similar to this? |
| **Out-of-State Satellites**<br>Out-of-state hospital/clinic (e.g., Seattle Children's, Shriners, Intermountain Healthcare) set up a satellite clinic in Montana, and everything is done through them. | **Experienced Providers:** Providers brought in to staff these Clinics and provide this care are likely national experts in CL/P<br>**Patient Expenses:** These institutions often cover expenses for patients and do not discriminate based on a patient's ability to pay<br>**CSHS Overhead:** This would drastically decrease the current overhead that CSHS faces managing contracts | **Lack of Local Coordination:** Institutions from out of state may not be able to provide the same support for accessing local, ongoing care.<br>**Access in Rural Areas:** It is likely that these Clinics would take place in population centers and could still pose hardship for people in rural communities.<br>**Diminish Local Services:** People may be less likely to use the services of the few CL/P surgeons available in Montana. | ● Would these institutions be interested / find value in providing periodic Clinics in MT?<br>● Would this allow for Clinics to occur in more locations around the state? |

## State Surplus / Tobacco Settlement Funding in 2027 and Beyond

Over the next three SFYs 2024, 2025, 2026, CSHS will use the State Surplus / Tobacco Settlement Funding to support the adoption of new Cleft Clinic models across the state. After this time, assuming stability in new models has been achieved, CSHS will still be able to support the Cleft Clinics with just $25,000 annually. These funds can be spent on anything that improves patient care for people with CL/P through the Cleft Clinics. Ideas for best utilizing these funds include, but are not limited to:

- Provide support services for families including transportation and CL/P-related healthcare payments.
- Incentivize quality improvement / quality assurance to the hospitals/health systems facilitating the ICT clinics and the private practice cleft clinic providers.
- Provide additional reimbursements to providers who are difficult to engage.
- Support the pilot of a telehealth Cleft Clinic model with the participating ICT clinic sites.
- Support continuing education to providers (both participating in the Clinics and those who work with patients with CL/P in any form).
- Provide more general education to the public about CL/P.
- Offer better promotion of the Cleft Clinics.
- Cover services not otherwise covered by Medicaid (ex. orthodontia).
- Purchase or maintain a shared EHR for increased communication between state-wide coordinator and all providers.

## General Opportunities for Improvement

Of the areas for exploration listed below, some will not be relevant based on the Cleft Clinic model identified for future implementation.

Increase Access

- Consider telehealth options for access to Clinics in rural areas.
- Investigate low-cost ways to establish Cleft Clinics in population centers that currently lack Clinics (Helena, Kalispell, Bozeman).
- Provide additional support to American Indian / Alaska Native communities to narrow racial disparities in CL/P access and specialized care.

Establish Strategic Partners

- Consider establishing a connection or partnership with Montana State University College of Nursing to support a Bozeman-based Clinic or statewide care coordination center.
- Determine whether Montana School for the Deaf and Blind (Great Falls) could provide the necessary screenings/evaluations at the Cleft Clinics at little or no charge.
- Intermountain Healthcare, based in Salt Lake City, has recently merged with St. Vincent's Healthcare in Billings, MT. They provide ACPA-standard CL/P care and may be able to make this CL/P care available to patients in the Billings area.
- Shriners Hospital for Children provides CL/P nationally and internationally. It may be possible to establish Montana-based access through a combination of telemedicine and financial support.
- Work with Office of Public Instruction and local school districts to ensure that they understand how to support patients in using the Cleft Clinics and that individualized education plans and legal implications of Section 504 of the Rehabilitation Act of 1973 are applied equitably to people with CL/P.

Ensure Stable Funding for SFY 2027 and Beyond

- Work with MT Medicaid to increase reimbursement rates billed for HCPCS T1025 and T1024.
- Increase the number of private insurers that cover the HCPCS T1025 and T1024.
- Understand all of the possible procedures that could be conducted at the Cleft Clinics by each participating provider type and provide education to providers.
- Improve/ensure adequacy of MT Medicaid reimbursement rates for those specific procedures that could be conducted and billed at Cleft Clinics (if billing by individual provider and procedure).
- Consider applying for grants that could contribute to "baseline" funding for Cleft Clinics starting in SFY 2027.
- Engage in continuous research and conversation with healthcare partners to identify indefinitely or consistently sustainable financial Cleft Clinic structures.

Improve Quality in Clinics

- Need an EHR.
- Research and replace the CHRIS system with one that will better suit the needs of the Cleft Clinics. Consider a system that will allow each provider to electronically chart in real time and access the charts between Cleft Clinics.

- Review provider note templates and work with providers to improve and modernize these.
- Further investigate the lack of participation from orthodontic specialists and support changes to incentivize their involvement.
- Advocate for the presence of mental health professionals on the Cleft Clinic team.
- Encourage the inclusion of pediatricians on the Cleft Clinic team.
- Promote CL/P continuing education opportunities for all providers who participate in Cleft Clinics.
- Consider creating a Community of Learning (COL) or other quality improvement collaborative to bring Cleft Clinic site Coordinators/teams together to collaborate on QI projects across all of the sites.
- Develop and use a robust patient registry that can follow patients from infancy to adulthood.

Increase Public Knowledge

- Update the DPHHS website with additional information about how the Cleft Clinics are administered, what is covered by insurance, providers that families will have access to through the Clinics, etc.
- Consider regular press releases or other media stories that promote CL/P general knowledge and Cleft Clinic awareness specifically.
- Provide suggested information and wording to participating Cleft Clinic sites for their websites and patient materials.

## Immediate Next Steps

The current contracts supporting the Montana Cleft Clinics through CSHS have been extended and are set to expire at the end of June 2023. New contracts need to be established and solid plans for the statewide Cleft Clinics need to be in effect on July 1, 2023. To ensure that this happens with minimal disruption to patients, families, providers, and coordination sites, the following timeline is important:

- **November 1, 2022:** CSHS submits a Decision Brief to DPHHS leadership with recommendations for updated Cleft Clinic models in Montana.
- **December 2022 - February 2023**: CSHS develops the RFP that will go out for bid to interested coordination sites.
- **March - April 2023:** Coordination sites are able to submit bids for the RFP for Cleft Clinics.
- **May 2023:** DPHHS/CSHS scores and determines awards of the RFPs.
- **June 2023:** Contracts are signed between awarded sites and DPHHS/CSHS.
- **July 2023:** Cleft Clinic coordination sites are under contract and able to provide Cleft Clinic services.

If it is expected that the Cleft Clinics will change in a way that affects patient access or differs from their current expectations, this needs to be communicated prior to the changes. Particularly if there will be less access (e.g., a clinic site decides to not coordinate Cleft Clinics), patients will need to be notified multiple times through multiple modalities. They also need to be provided with exceptional direction regarding how they can plan to access care going forward. This work should be done in coordination between the care coordination site and CSHS staff to ensure consistency of messaging. Examples of necessary communication include:

- Phone calls to every patient/family that has used the Cleft Clinic services in the past 3 years
- Letters to every patient/family that has used the Cleft Clinics in the past 5 years
- Direct and intentional communication with every pediatrician who is noted as the primary pediatrician of every patient/family that has used the Cleft Clinic services in the past 3 years
- Direct and intentional communication with every provider who has participated in the Cleft Clinics in the past 5 years with contact information of CL/P provider colleagues and best practices regarding how care coordination will take place without the Cleft Clinics going forward
- Broad communication to all pediatricians, OB-GYNs, general practice providers, health center administrators, etc. who proved care in the medical catchment area
- Create a clear plan to allow for patients to contact the Clinic Coordinator for records or connections to providers and resources after the discontinuation of the Cleft Clinic

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# Appendices

## Appendix 1: Interview Questions- Patients & Families

**Interview Questions for Participating Parent/Guardian:**

*Recording starts here.*

**Introduction/Consent/Background/Interview Opening ("getting to know you")**

(Introduction): We have been contracted to assess and identify gaps in specialty care and services for children attending cleft clinics. We will be using this information to create a plan in hopes to better support access to these clinics. As a parent/caregiver of a child attending these clinics, we are working to prioritize your comments and experiences into our recommendations. I have approximately 20 questions to ask, and I anticipate this interview may last 30-60 minutes. Would you have time to answer some questions?

You should have already received a copy of the Consent Form in the mail. Do you have any questions regarding this project? Based on that Consent Form, do I have your verbal consent to proceed? Do I have your permission to record this conversation? *Obtain verbal consent (recorded) from parent/guardian prior to starting on the list of questions.*

1. I understand you have a child who attends Cleft Clinic or has attended them in the past. What is your relationship to this child? Can you tell me a bit more about your child (age, gender, cleft lip, cleft palate or both)? Any other relevant medical diagnoses you'd like to share?

2. What clinics did/do you normally attend (CMC, Benefis, St Vincent's)?

3. How long has your child been attending these clinics (or has attended these clinics)?
    a. Follow-up question: If minimal attendance, why didn't you go back?

**Descriptions/Perceptions of the Clinics**

4. How would you describe the cleft clinics overall? For example, if a friend asked you what they were, what would you say?

5. On a scale of 1-10, how would you rate the usefulness of these clinics? (1 = They are an enormous waste of time and nothing about them is helpful; 10 = They are perfect. I get everything I need and would drop everything to make sure I attended.)
    a. (What could be improved?) What would need to be included or changed about the clinic for you to raise your rating by 1 point? For example, are there gaps? What about the flow? What would need to be improved to have you rate them as a 10?
    b. (What is going well?) Why didn't you rank this lower- why wasn't it a 1 or 2? What things do you like about the clinic that allowed you to give the score that you gave it?

6. Tell me about your travel to/from the clinics.
    a. About how far do you need to travel?

b. Are the care coordinators flexible with scheduling needs based on your travel distance?
c. Are there any other travel or scheduling barriers you have experienced?

7. After you attend a clinic, do you feel as though you and/or your child's needs have been met?
    a. If NO: what needs are not being met by attending these clinics?
    b. If YES: can you give me some examples of those needs and how they were met?

**Care Coordination/Care Between Clinics**

8. Outside of cleft clinics, what other providers does your child see for care related to their cleft lip/palate?
    a. Speech/language therapy - if not, why?
    b. Plastic surgeon - if not, why?
    c. Orthodontia - if not, why?

9. Specific to your child's cleft lip/palate care, tell me about how you know what appointments and different kinds of care you need to get in your community outside of the cleft clinic visits.
    a. Who usually follows up with you between cleft clinic visits? (Person from the cleft clinic? Pediatrician or other PCP? Individual providers you saw at the clinic?)
    b. How involved is your primary care provider in helping to coordinate visits with other specialists or services specific to your child's cleft lip/palate care? Do you feel that PCP is kept in the loop by other providers/specialists on your child's cleft lip/palate care?

10. If you are unsure what kind of specialists you are supposed to follow up with or have questions about your child's condition or health regarding their cleft lip/palate, who do you call?

11. How well do you feel like all of the providers you see outside of the clinic are familiar with the recommendations and care your child is receiving from other providers? In other words, do you feel like all of the different providers communicate with one another well or are there any gaps in communication?

12. Are there any providers that you have more trouble accessing than others for any reason? Which ones and why?
    a. Is it easy to get appointments and reschedule? Insurance is covered?
        i. What kind of insurance coverage do you have for your child?
    b. Does the clinic care coordinator ever help you when you run into problems accessing providers?

13. You have probably seen **providers outside of the clinics**, for example 1:1 with speech therapy or orthodontia visits. What has been your experience with receiving bills and affording care for those 1:1 visits that happen **outside of the clinics**?

14. Have you ever had to travel **outside of your community or hometown** to receive certain services <u>related to your child's cleft lip/palate care</u> (e.g., if you are referred to a specialist outside of your hometown)?
    a. If so, what was that process like?
    a. Are you typically able to get to those other appointments?
    b. If not, what are the barriers?

15. (If applicable) Does your child have an IEP or 504 plan at school? Can you tell me about the process of getting that in place? Did you need to involve any of the healthcare providers? How could this process be improved?
        a. Is your child receiving special services like speech/language at school?

**<u>Child's Needs/Wrap-Up</u>**

16. If these clinics changed and didn't look the same way in the future, how would that look for your child's care?

17. What matters most to you when thinking about your child's cleft lip/palate healthcare?
        a. Even outside of the clinics - what kinds of things do you find the hardest about getting the right care for your child?

18. Overall, do you feel like your child's needs are being met? These could be medical needs, emotional needs, or other social/financial needs for the child and/or family.

19. Is there a question you expected me to ask that I did not?

20. Is there anything else you would like me to know about these clinics? Any last thoughts?

Thank you for your time and for sharing this information. Your answers will remain anonymous and will be kept in a secure electronic database. As a thank-you for your time, we will soon send you a $50 gift card! Please contact me if you have any questions or think of anything else you'd like to add at a later time.

## Appendix 2: Survey Questions- Providers

### Cleft Clinic Provider Survey

Thank you for providing services to the children and families that attend the Cleft/Craniofacial Clinics at our sites across Montana. These clinics have been supported by Montana's Department of Public Health and Human Services (DPHHS) Children's Special Healthcare Services (CSHS) for decades. Due to changes in funding allocations and improvements in access to pediatric specialty care across the state since their inception, CSHS is currently conducting a comprehensive needs assessment of these clinics. Among other things, this needs assessment aims to examine current clinic structures, assess financial sustainability, and also understand the needs and feelings of you, our providers.

Your responses are being collected by Yarrow, LLC, a public health consulting organization that has been contracted by MT DPHHS CSHS for the purposes of conducting this assessment. While your answers to this survey will not be published in their entirety, please know that your responses are NOT intended to be anonymous. By filling out this survey, you consent to sharing your information freely and without restriction. You may also be contacted by someone from Yarrow, LLC to follow up on your responses via telephone.

Please contact Kirsten Krane, Managing Member, at kirsten@yarrowcommunity.org or Mackenzie Peterson, CSHS Director mackenzie.petersen@mt.gov with any questions or concerns.

Thank you for your time and willingness to share your perspectives on these clinics. Your insight is invaluable to future planning efforts of the Cleft/Craniofacial services for children in Montana.

1. Email:
2. What is your name and position?
3. To which Cleft Clinic site(s) do you provide services?
    - Benefis / Great Falls
    - Community Medical Center / Missoula
    - St. Vincent's / Billings
    - Other:
4. Where are you employed?
5. How long have you been involved with CSHS Cleft Clinics in Montana?
6. Describe the strengths of the current Cleft Clinics. (Consider the strengths that affect providers, patients, and any other stakeholders.)
7. Describe the weaknesses of the Cleft Clinics or specific areas that need improvement. (Consider perspectives of the providers, patients, and any other stakeholders.)
8. What motivates you to provide your services and expertise at the Cleft Clinics?
9. Are you motivated by the current provider rates under the CSHS state contracts? Why or why not?
10. If you were not reimbursed for your time/services (either through CSHS or by billing), how likely would you be to volunteer your time at these clinics?
    - Very likely
    - Somewhat likely
    - Note likely at all
    - It depends (please explain below)
    - Other
11. If you were to provide the same service in your office or hospital that you provide at the Cleft Clinic, would you be able to bill insurance for the encounter?

    - Yes
    - No
    - Maybe
    - Other
12. What are some CPT codes you would commonly use if you provided the same services that you provide in the Cleft Clinic in an outpatient setting? -- OR -- How would you code and bill a visit if you provided the service in your office as opposed to in the Cleft Clinic?
13. Would Healthy Montana Kids Plus (HMK Plus)/ Medicaid generally reimburse you for the service(s) you described above?
    - Yes
    - No
    - Maybe
    - Other
14. Do you / your clinic / hospital accept Healthy Montana Kids Plus (HMK Plus) Medicaid? If sometimes, please explain in the "Other" space.
    - Yes
    - No
    - Sometimes
    - Other
15. Would Healthy Montana Kids (HMK through BCBS) generally reimburse you for the service(s) you described above?
    - Yes
    - No
    - Maybe
    - Other
16. If you would typically be reimbursed for the same services you provided through Cleft Clinic, approximately how much money would you receive from Medicaid or other private insurances for those services?
17. Do you / your clinic / hospital accept Healthy Montana Kids (HMK through BCBS)? If sometimes, please explain in the "Other" space.
    - Yes
    - No
    - Other
18. If these Clinics were to run exactly the same as they do now, but you were to bill for each encounter with each patient as you would in your regular practice, what would be the benefits? Drawbacks? (To you, other specialists, patients, other stakeholders)
19. Outside of the CSHS Cleft Clinics, are you normally able to bill for case management, care coordination, and/or interdisciplinary team care in your practice?
    - Yes
    - No
    - I don’t know
    - Other
20. Can you bill for a procedure or visit that you conduct outside of your clinic (outside the four walls)?
    - Yes
    - No
    - I don’t know
    - Other

21. In general, for children receiving care for cleft lip/palate, how well do you feel their medical and psychosocial needs are being met in Montana? (This could mean at the Cleft Clinic or outside of the Cleft Clinic. It refers to both care for cleft and other care in general.)
22. Any other thoughts/comments?  In your opinion, how do you think these clinics might be structured to best meet the needs of patients, providers, and the systems that host these clinics?

Thank you!

Thank you for taking the time to share your thoughts and knowledge.
If you have any questions or concerns, please contact Kirsten Krane, Managing Member, at kirsten@yarrowcommunity.org or Mackenzie Peterson, CSHS Director at mackenzie.petersen@mt.gov with any questions or concerns.