View from the Front Lines: Current Experiences in a Patient/Family-Centered Approach to Implementing and Evaluating Care for CMC, their Families, and Caregivers

Boston Children's Hospital

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Medical Director of Integrated Care, Co-Principal Investigator, HRSA-funded Enhancing Systems of Care for Children with Medical Complexity Coordinating Center

April 15, 2024

AMCHP 2024 Partnering with PURPOSE
APRIL 13-16 | OAKLAND, CA

Project Overview

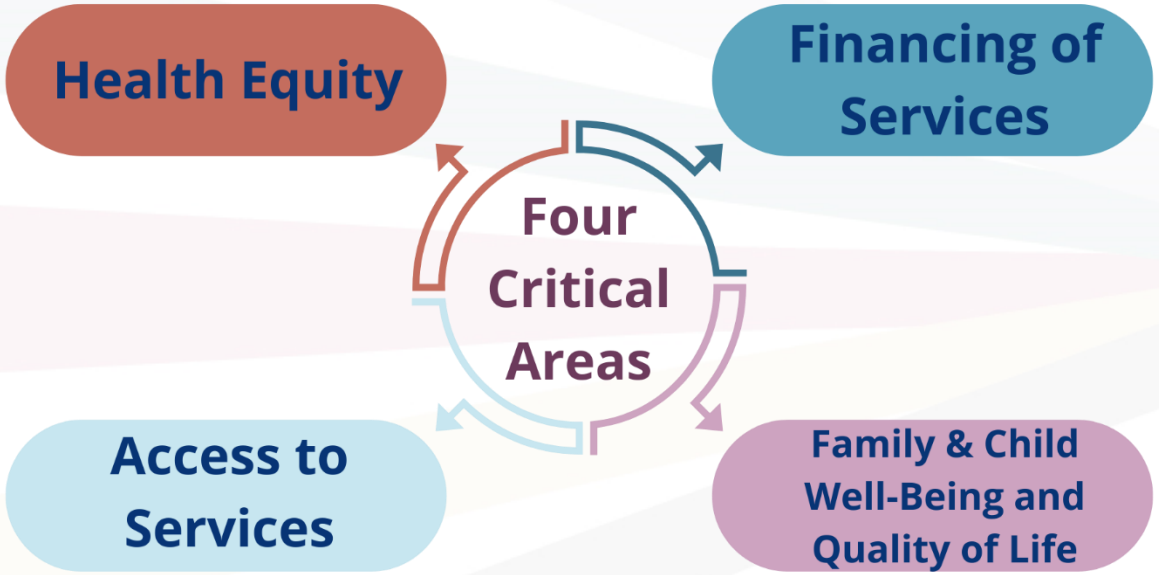
- **5-year project** funded by the Health Resources and Services Administration (HRSA)
- **Coordinating Center:** AcademyHealth, Family Voices, Boston Children's Hospital, University of California San Francisco, American Academy of Pediatrics, Patient Advocate Foundation
- The Coordinating Center supports **five demonstration sites** to improve equitable outcomes for children with medical complexity
  - Discover **effective models** that improve the quality, coordination, and experience of care
  - Offer **training & technical assistance** to build site capacity
  - Foster external **partnerships & collaboration**

Enhancing Systems of Care Sustainability Supplement

To improve care for children with medical complexity, we need to ensure that the Demonstration Sites' work can be sustained through improved policymaking and policy alignment.

- For the next two years with supplemental funding, we will explore the current state of policy for CMC, specifically regarding **Title V and Medicaid collaboration**.
- We hope to **create tools and resources** to address current gaps in the field.

The Blueprint for Change



MCHB's Blueprint for Change

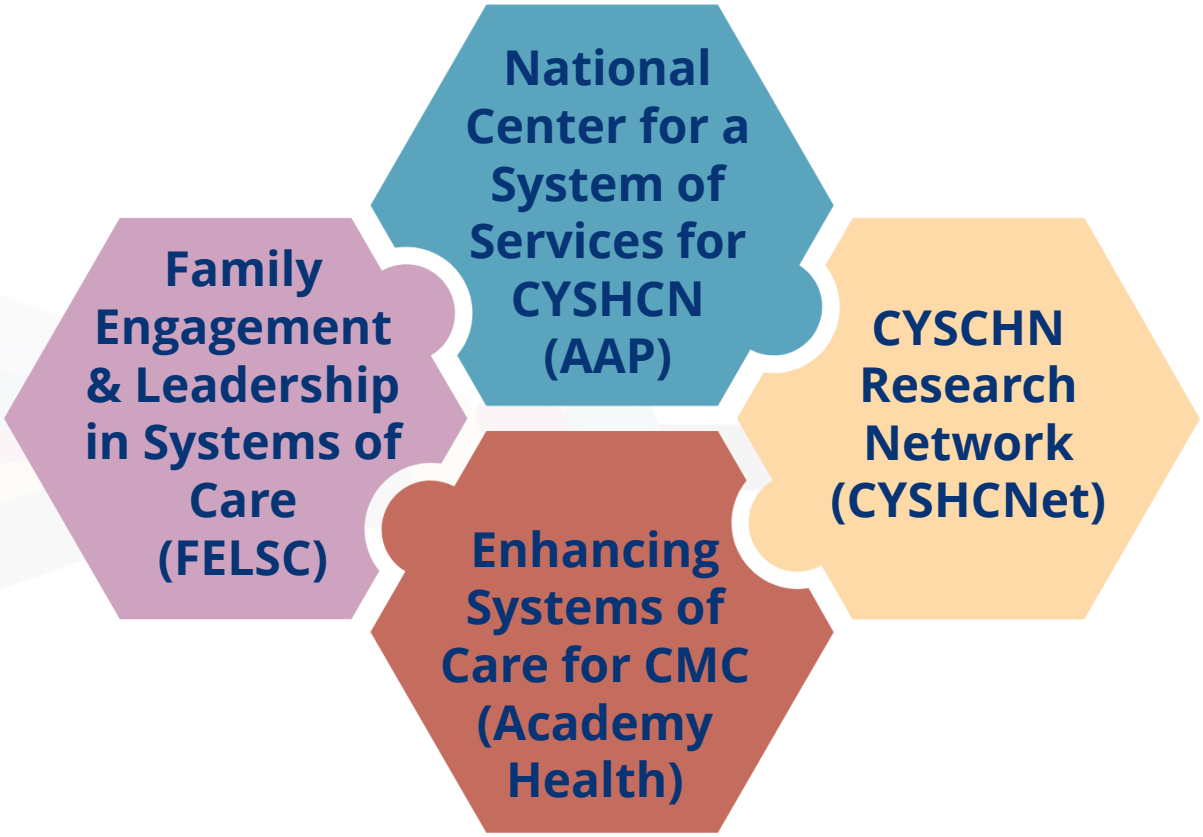
To make broader systemic changes, our project aims to advance the Maternal and Child Health Bureau's (MCHB) Blueprint for Change.

McClellan, S., Mann, M., Scoot., J., Brown, T., "A Blueprint for Change: Guiding Principles for a System of Services for Children and Youth With Special Health Care Needs and Their Families. "PEDIATRICS 2022 Jun 1;149(Suppl 7):e2021056150C. doi: 10.1542/peds.2021-056150C.

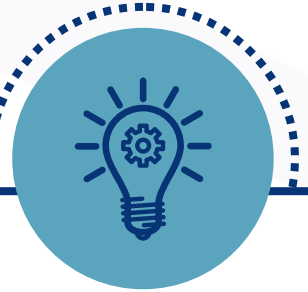
Our Role in the Blueprint

We represent one of **four projects and coordinating centers** working to advance the key areas of the Blueprint.

Our work focuses on implementing and sustaining models of care and **improving service delivery**.



Strategy



Develop a Blueprint Roadmap & support states in implementation

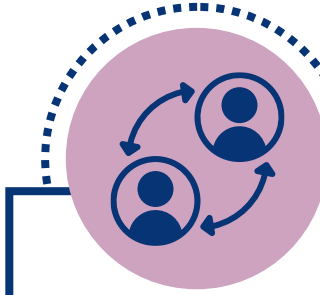
AAP

Research

Conduct and disseminate health systems research in partnership with families

CYSHCNet

Engagement



Lead family engagement including through a strong Family-to-Family (F2F) Network

FELSC

Service Delivery

Support implementation & evaluation of equitable, family-centered care models for CMC

AcademyHealth

The Blueprint in Practice

Resources

[Enhancing Systems of Care for Children with Medical Complexity (CMC) Coordinating Center | AcademyHealth]

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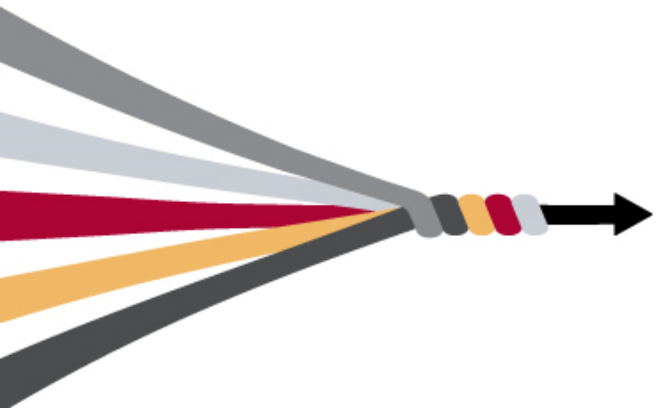
Improving the Systems of Care for Children with Medical Complexities

Montana Pediatrics

Melissa Eastlick, MSW

CMC Manager &

Patient & Family Experience Advocate



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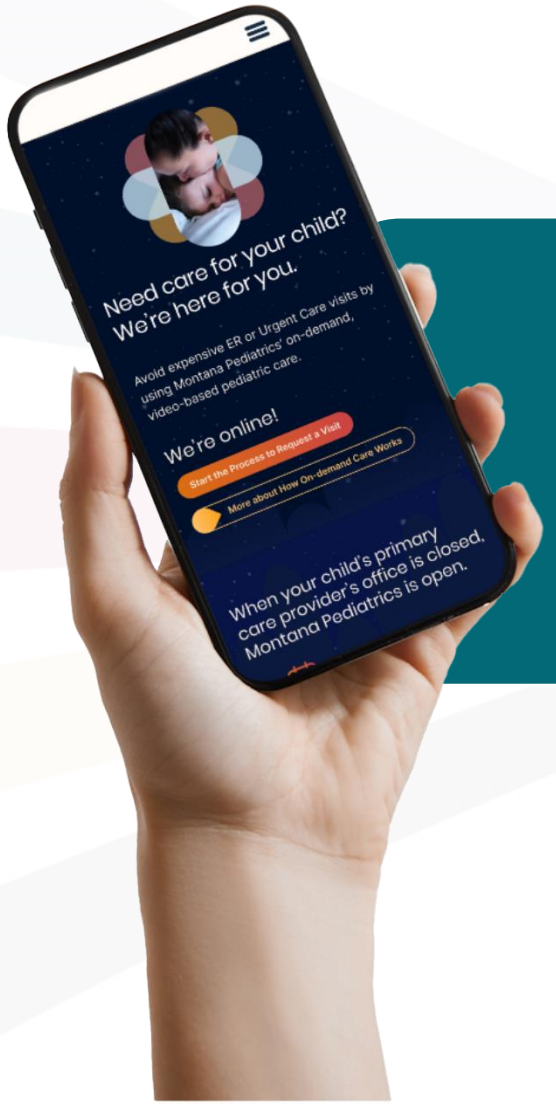
Montana Pediatrics & Our Mission



Montana Pediatrics is a **technology-enabled collaborative** network of **Montana-based pediatric providers** who **work together** virtually to **extend care to Montana's children** in **support of one another** and each child's own **medical home**.

2018 — Began building provider network

2019 — Launched first on-demand model

2020 — Formalized partnership with Logan Health

2022 — Added complex care program

2024 — Growing 5 unique programs

Montana Pediatrics' Programs

- **On Demand Program**: A tele-health program that serves as a pediatric-specific alternative to urgent care. This program was designed to support families in the times and spaces with their primary care is unavailable.
- **Indigenous Partnerships:** Working hand in hand with four tribal health programs to provide culturally informed, quality, and accessible medical care.
- **Type 1 Diabetes:** Partnering with MT DPHHS more efficient and effective communication between providers and other care teams (schools, families). Provide monthly training for school nurses to increase education and ability to care for students with Type 1.
- **Pediatric Mental Health:** Piloting a program that offers interventions while prioritizing existing relationships families and their usual place of care.
- **Rural Complex Care Coordination:** A pilot program, launching June of 2024 to support CMC in aligning care and communication across the child's care team with a cloud-based Shared Plan of Care.

Rural Complex Care Coordination

Project Goal

To improve health equity for children with medical complexity in Montana by implementing a care coordination model that utilizes technology to overcome barriers of rurality and non-integrated care from CMC (who have multiple providers within Montana and surrounding states), to enhance the family voice as drivers for change in Montana, and to improve the access to high quality care after-hours care and in rural communities, and Native American communities.

Project Aims & The Blueprint

Our project aims work toward addressing the four critical areas identified in the HRSA's **Blueprint for Change** for CYSCHN:

- **Health Equity**
- **Access to Services**
- **Family and Child Well-Being Quality of Life**
- **Financing of Services**

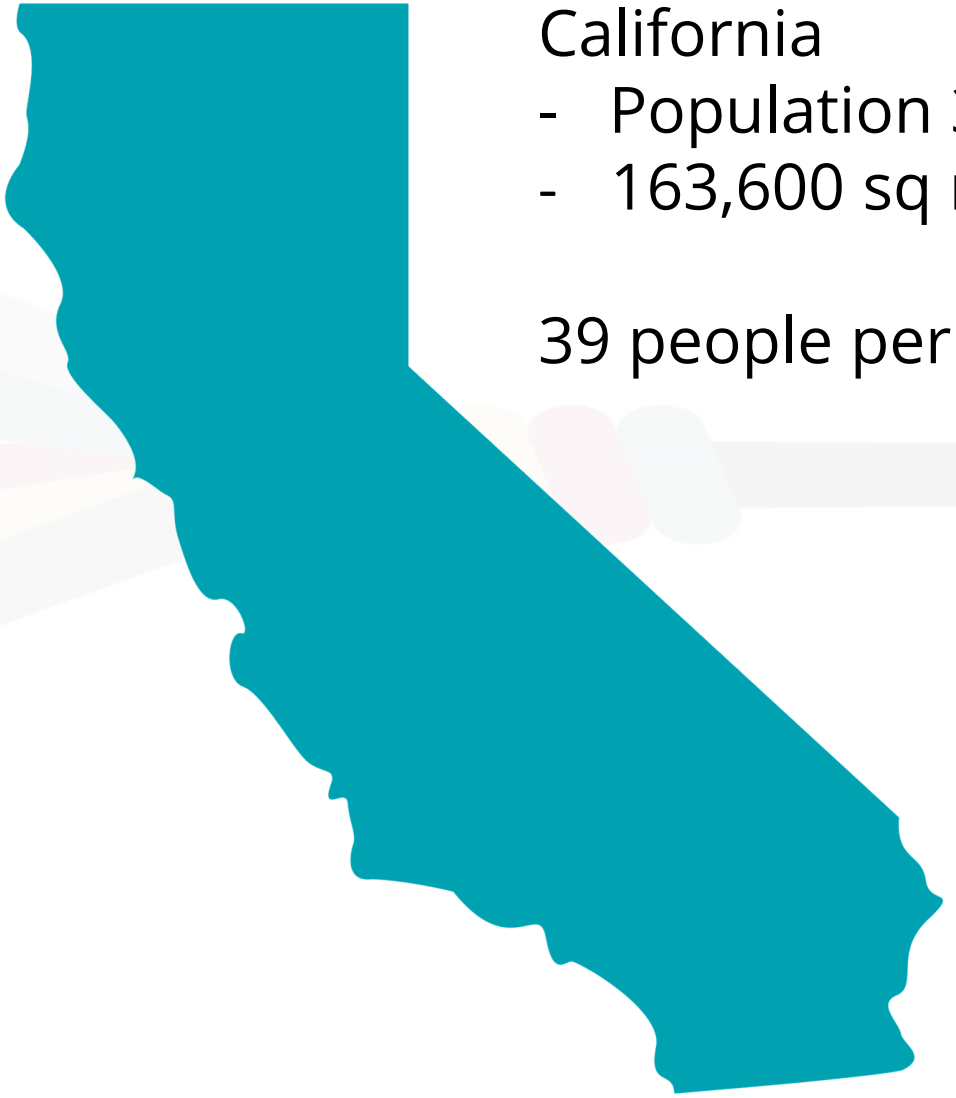
Project Aims

1. Create a community advisory board to ensure adequate representation of family-voice in the development of our care model, and to empower patients/parents in advocating for the needs of CMC in Montana, and to reduce the disparities of parents/caregivers.
2. Create a sustainable, telemedicine-based, virtual care coordination program for children with medical complexity (CMC) that overcomes the challenges of geography and disjointed care from providers within Montana, and out of state.
3. Increase equitable access to pediatric primary and specialty care.
4. Demonstrate to payors, including Montana Medicaid, the value of our model as a needed, sustainable, and permanent program in Montana.

Background of Montana

Montana
- Population is 1.08 million
- 147,000 sq miles

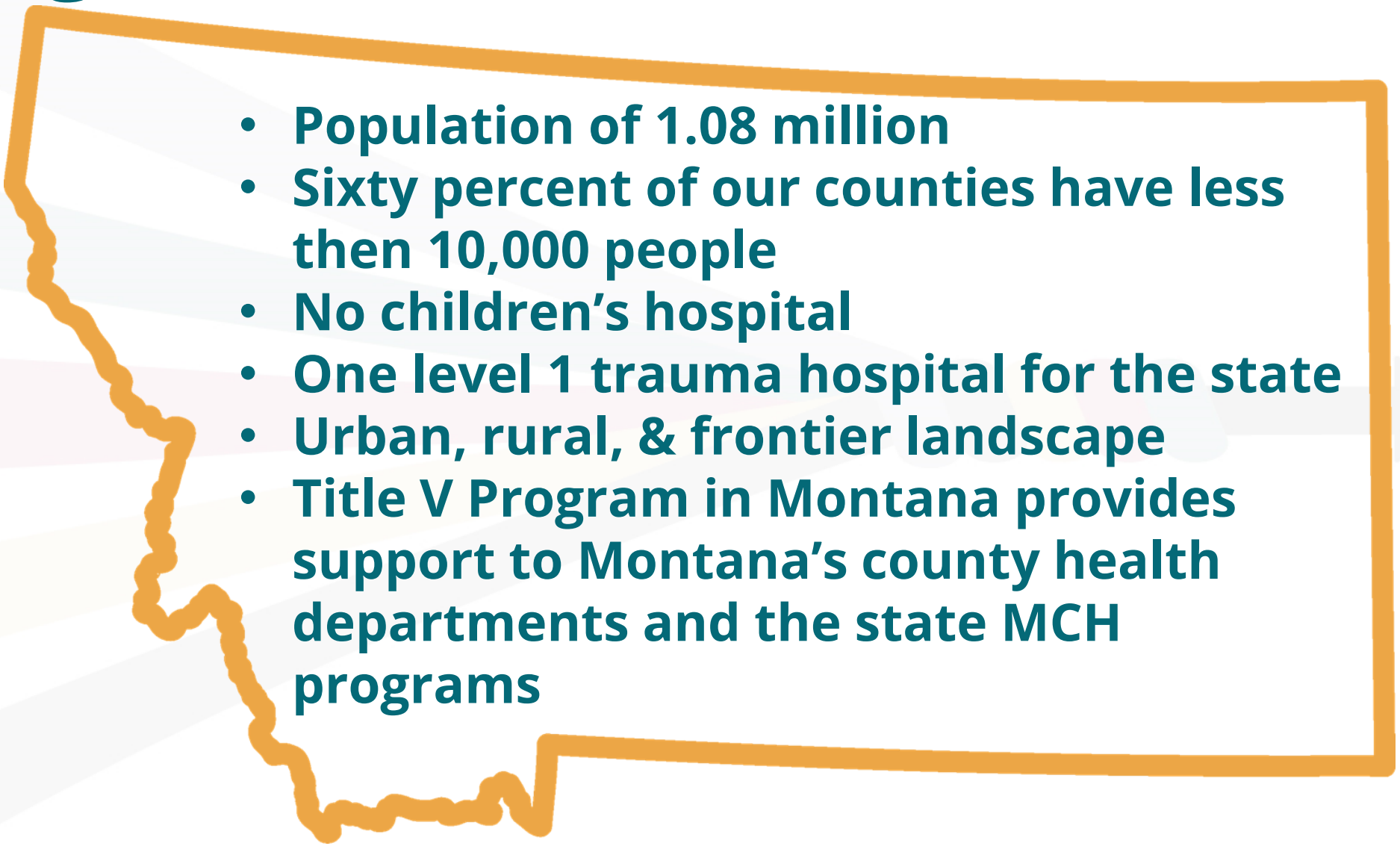
7 people pers sq mile



California
- Population 39,540,000
- 163,600 sq miles

39 people per square mile

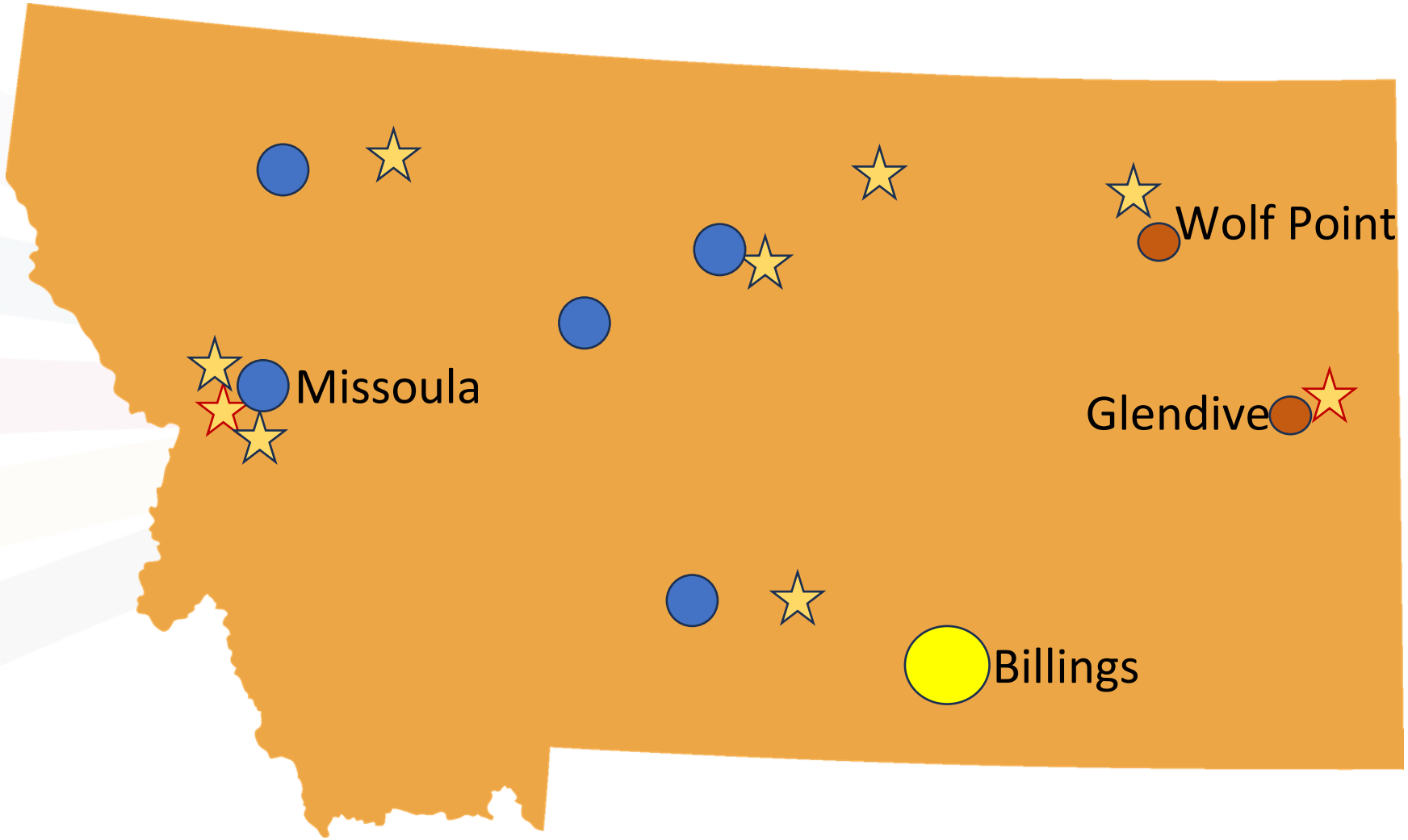
Background of Montana



- Population of 1.08 million
- Sixty percent of our counties have less then 10,000 people
- No children's hospital
- One level 1 trauma hospital for the state
- Urban, rural, & frontier landscape
- Title V Program in Montana provides support to Montana's county health departments and the state MCH programs

Community Advisory Board (CAB)

- CAB Members
- Critical Access Hospitals
- Acute Care Hospitals
- Trauma One Hospital



The Journey of our Community Advisory Board (CAB)

- September to December 2022: Planning for the CAB and submitting the IRB
- January to February 2023: Recruitment for the CAB
- February 22, 2023: 1st CAB meeting!
- March to May 2023: Evaluating the next steps of the CAB
- May 24, 2023: 2nd CAB meeting- reset
- June to November 2023: The formulation of our mission statement and discussing the experience and expertise of the CAB members.
- December 2023 to February 2024: Readdressing the governance, workflow, and role descriptions of the CAB.

The CAB's Mission Statement

"Sharing knowledge to ensure competent, equitable, and accessible healthcare to support children with medical complexities and their families."

Our CAB Today

- We currently have nine people serving as a Community Advisory Board member. Each member has lived experience in raising a child with medical complexity.
- The 9 CAB members represent different regions of our very large state.
- We have two Indigenous members participating on the board.
- There is one dad serving on the board and we hope to recruit another male caregiver soon.
- Due to our long distances from one another we meet virtually on a quarterly basis and then provide weekly email updates to support further collaboration and communication.

Performance Measurements

Patients & Families

- Provide care coordination and optimize resources to improve health equity and reduce parent/caregiver burden driven by a program rooted in parent voice.

Success in year five:

- Have a diverse network of empowered families and community members to advocate for the needs of CMC across all levels/disciplines within Montana.
- Provide a care coordination program optimizing continuity of care through the utilization of Share Plan of Care (SPOC) and strategic implementation of technology to improve health equity via access to care and care integration (including remote patient monitoring), reduce caregiver burden, with data showing improvements in these areas through our family evaluation surveys.
- Have 75+ patients in our program from diverse background and ensure specific representation from our Native American and foster-care populations.

Ensuring A Strong Voice From Our Most Important Partners- Patients & Families

- Having roles identified at the start of the work. This helps members show up and have clear expectations in how they will participate.
- Ensure there is a shared language and understanding around the mission and provide learning opportunities to build upon this shared work.
- Regular check-ins to ensure both the professionals and CAB members are on the same page.
- Utilizing the **Family Engagement Survey Assessment Tool** from **Family Voices** to assess the level of family Engagement, Transparency, Representation, & Impact,
- Ensuring constant feedback loops about the work being done and how the CAB's input is impacting workflows and change.

Next Steps

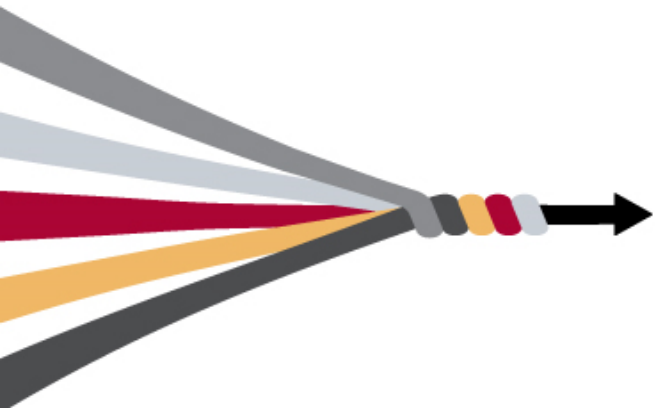
- Launching our Rural Complex Care Coordination program on June 1, 2024.
- From June 2024 to May 2025, we plan to enroll 100 patients into the Rural Complex Care Coordination program.
- Continue to collaborate with and provide support to the primary care providers across the state of Montana.
- Plan to keep a strong patient and family voice guiding every step of this work. With the launch of the pilot program, we will then have two sets of patients and family voices to help provide feedback in how to better support families raising a child with medical complexities.

A Family-Centered Health Home for Complex Care in Austin, Texas

Dell Children's Comprehensive Care Clinic (CCC)

Rahel Berhane, MD, Medical Director

Sherry Santa, Family Liaison



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Dell Children's Comprehensive Care Clinic (CCC)

- CCC is a primary care clinic dedicated to the care of 840+ children in Central Texas with the most complex medical issues (CMC).
  - Patients must have chronic medical conditions expected to be lifelong and potentially life-limiting; conditions requiring 3 or more specialists, high medical technology use; and/or high emergency department and inpatient hospital services utilization.
- CCC provides team-based, timely, comprehensive care and empowers families by providing tools, knowledge, and support to live the best life possible.
- CCC's journey and ongoing quality improvement (QI) activities address the 4 critical areas identified in HRSA's *Blueprint for Change* for CYSHCN:
  - **Access to Services**
  - **Family and Child Well-Being and Quality of Life**
  - **Health Equity**
  - **Financing of Services**

Key Milestones in the CCC's Care Redesign Journey

2012 – CCC created to evaluate the value of a comprehensive pediatric medical home for CMC.

2013 – CCC Family Advisory Group (later re-named the Family Workgroup) established to partner in designing, implementing, and evaluating the clinic's QI process.

2017-2021 – CCC was 1 of 10 sites in HRSA's Collaborative Improvement and Innovation Network (CoIIN) to Advance Care for CMC. Key partners: family leaders, TX Medicaid, Title V, and BCBS. **2019** – CCC Family Liaison position established (an outcome of the CoIIN).

2021 – Assisted by the Value Institute at UT Austin, CCC implemented a new Whole Child Visit approach to integrate care planning and test a Medicaid alternative payment model (APM).

2022 – CCC moved to a new clinic co-located with the Rosedale School.

2022-current – Partnering with the Dell Medical School at UT Austin, CCC is 1 of 5 demonstration sites for the HRSA-funded 5-year cooperative agreement Enhancing Systems of Care (ESC) for CMC project with the goal to improve the quality, coordination, and experience of care and services for CMC and their families/caregivers.

Access to care that is integrated, easy to navigate, and high quality

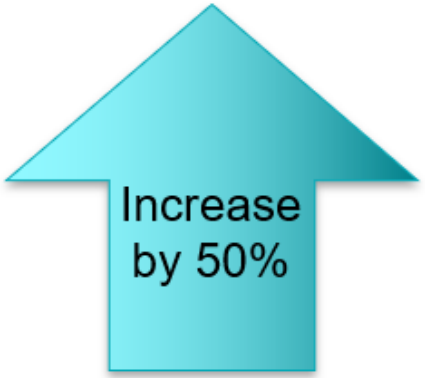
Within a complex health care system, CCC offers a relationship-based care model with a comprehensive primary care team.

- A primary nurse is assigned to provide service coordination for each patient and family.
- Providers who know the child and family are available 24/7.
- CCC holds daily team huddles and coordinates care transitions with inpatient providers.
- The full care team, including the family, has access to a shared data platform (MySTORY) with the child's care plan.
- Some specialty visits are integrated at the CCC.
- The Whole Child Visit brings together the child and caregivers with the full care team (e.g., specialists, home health) for meaningful, comprehensive care planning.

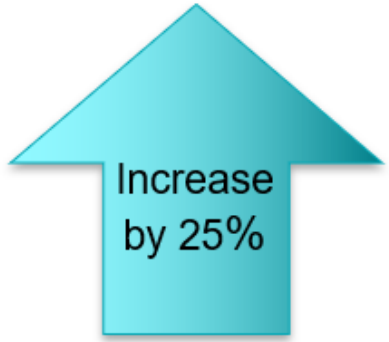
Family and child well-being and quality of life - what matters most

- The family voice is the CCC's North Star. Work to engage families centers on an innovative model that allows the care team to intimately know families' stories and journeys. This is foundational to providing high-value medical care based on what matters to families.
- At the core of the CCC are:
  1. the Family Liaison (a clinic parent) and
  2. the Family Workgroup, highly-engaged parents of CMC who meet monthly to monitor progress, inform model improvements, and ensure family priorities remain paramount.
- The Family Workgroup designed the survey for the Whole Child Visit pilot and provided essential input for the family survey for the current HRSA demonstration.

ESC demonstration targeted outcomes to support family and child well-being and quality of life



- # of families of CMS who report being actively engaged as shared decision makers in developing their child's shared plan of care
- # of families of CMC who report an improved patient/family experience of care (as measured by CAHPS)



# of families of CMC who report increased coordination of care and access to the services, supports and resources they need (as measured by the PICS)

- 3 additional family reported well-being measures re. stress, care team understanding of their child, and the Whole Child Visit helping their child achieve their full potential
- Advocacy to inform Texas policy change regarding how care for CMC in Medicaid is organized and compensated

Promoting health equity for CMC (1 of 2)

- Of CCC's 840+ patients, 30% are Hispanic, 23% are non-English speaking, and over 80% have Medicaid coverage.
- An ESC project priority is to understand current systemic barriers and challenges and assess CCC's capacity to reduce health disparities.
- Qualitative outcome measurement include:
  - Family surveys,
  - Family experience group feedback, and
  - Photovoice, which enables families to increase awareness, encourage dialogue, and create change using photos of their caregiving experience.

Promoting health equity for CMC (2 of 2)

- Through the ESC project, the CCC is:
  - Expanding its Family Workgroup to better represent the diversity of clinic families by race, ethnicity, and language. Experienced members will mentor new members.
  - Partnering with Texas Parent to Parent, the state's Health Information Center and Family Voices affiliate, to ensure meaningful family involvement at all stages of care model implementation and evaluation.
  - Developing a health equity assessment using the REaL (Race, Ethnicity, and Language) approach for stratifying data and the Intentional Equity in Quality Improvement questions recommended by the Institute for Healthcare Improvement.

Financing services

- CCC partners closely with Texas Medicaid and a Medicaid managed care organization, BCBS of Texas, to support and sustain its care model.
- This challenging work involves reducing administrative burden and paying differently for care. The current system does not incentivize care integration and progress has been incremental.
- Innovation includes 2 APM arrangements with BCBS to improve care for CMC:
  - BCBS delegates service coordination to CCC nurses for the most complex patients and provides CCC with a per member per month payment.
  - BCBS provides enhanced rates for certain evaluation and management codes to pay CCC for the significant time required to prepare and conduct Whole Child Visits.

Financing services

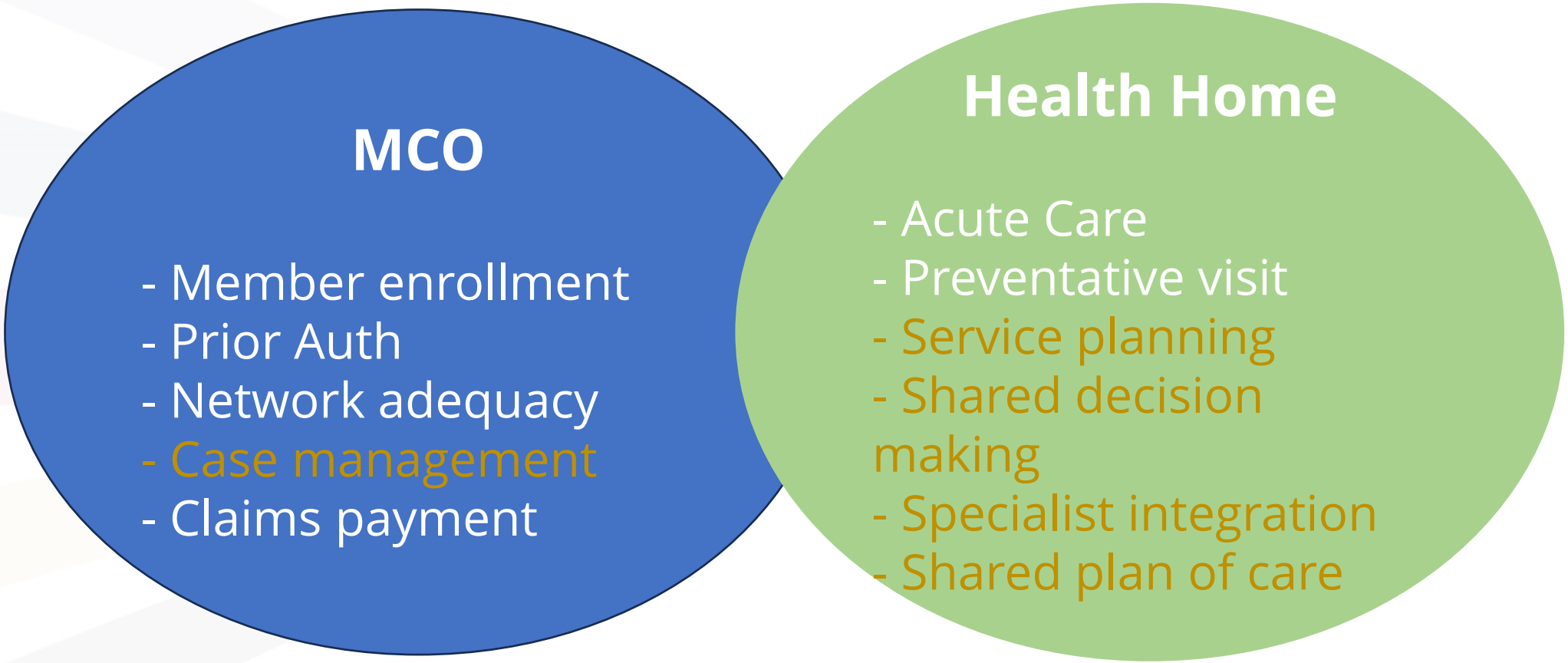
MCO

- Member enrollment
- Prior Auth
- Network adequacy
- Case management
- Claims payment

Health Home

- Acute Care
- Preventative visit
- Care coordination

Financing services



Want to Learn More?

Transforming Care for Children with Complex Medical Needs: Insights from HRSA-funded Demonstration Sites|
April 23, 12:00-1:30pm, ET

Children with medical complexity live with health conditions that often require care from different health providers. This system of care can be hard for families to navigate. AcademyHealth and other partners are working to change this system. Join us as we introduce the Enhancing Systems of Care for Children with Medical Complexity initiative and hear more about current work to make sure that care for CMC is easy to access. We will also hear a parent's and provider's perspectives on why this initiative is essential.

Link in the chat. (Please note, a free AcademyHealth account is required to register.)

Acknowledgements

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