ROOTED IN HUMANITY: Urgent action framework for care that matters to CMC, families & clinicians

Boston University School of Social Work
Center for Innovation in Social Work & Health

Welcome! We're so glad you're here! This framework is designed to empower changemakers like you to reshape systems of care for children with medical complexity (CMC) in practical ways that truly matter to CMC, families, and clinicians. It focuses on humanistic care principles as essential in practice, policy, and education.

Distinctly, the ROOTED IN HUMANITY framework offers a refreshing alternative to standard solutions that haven't quite hit the mark for effective or quality care for CMC. Our framework emphasizes actionable changes that are urgently needed to create systems that:

- Celebrate the joy and wholeness of each child beyond just their medical diagnoses.

- Recognize the humanity of clinicians as a vital part of delivering quality care and achieving better outcomes.

- Encourage solutions that are rooted in reciprocity and mutuality among families and clinicians as true care partners and colleagues.

- Foster a culture that prioritizes relationships as the foundation of quality care.

- Focus on the well-being of CMC, their families, and clinicians alike.

- Spotlight small changes that can make a big difference for everyone involved.

Through this online guide, you will:

1. Discover how dehumanizing care affects CMC, families, and clinicians, and how it impacts healthcare outcomes.

2. Find actionable strategies for prioritizing humanistic care to change systems based on trust and mutual partnership.

3. Explore engaging tools, including a visual framework and real-world stories, to help build a shared understanding and inspire action in creating humanistic systems of care.

≡ **Connecting the Dots: Navigating the Guide**

START HERE: WHY USE THE URGENT ACTION FRAMEWORK FOR ESSENTIAL SYSTEMS CHANGE?

≡ **National Initiative Driven by Family & Clinician Experts Partnering as Colleagues**

? **How Humanistic Strategies Lead to Better Outcomes for All ("Sweeter Fruit")**

FOR YOU: HARNESSING THE URGENT ACTION FRAMEWORK FOR THE RIGHT KIND OF CHANGE

? **How to Drive Practical Collective Change Across Roles Through the Framework**

TO EXPLORE & SHARE: THE URGENT ACTION FRAMEWORK FOR HUMANISITIC CARE AS ESSENTIAL CARE

≡ **Intro to Framework: What Makes Humanistic Elements of Care Indispensable Here and Now?**

👆 **Interactive Tree Framework: ROOTED IN HUMANITY Urgent Actions for Systems Change in CMC Care**

TO EXPLORE & SHARE: REAL-LIFE STORIES TO BRING THE URGENT ACTION FRAMEWORK ALIVE

≡ **The Sweetest Fruit: Humanistic Care Celebrates Meaning & Joy Above All Else**

Trust is Paramount: Stories of the "Signs Everywhere" Phenomenon & Humanistic Care

The Syringe Story: A Real-World Illustration of the Humanistic Care Framework in Action

MORE HELPFUL INFORMATION

Who We Are

Resources & Examples for Humanistic Care

Dedication to Jordyn Valdez

Acknowledgements

Tell Us What You Think

Connecting the Dots: Navigating the Guide

About the framework and guide

Welcome to the 'ROOTED IN HUMANITY' framework! Imagine a "living tree" graphic that helps us think differently about how we need to improve care systems for children with medical complexity (CMC). This framework emphasizes the importance of designing care for real people in a trustworthy, human-centered way. In the urgent action guide, you'll find simple strategies, real-life examples, and helpful tips by role that encourage collaboration and small, practical changes that can truly make a big difference.

Tree graphic showing the ROOTED IN HUMANITY urgent action framework (click on image to enlarge)
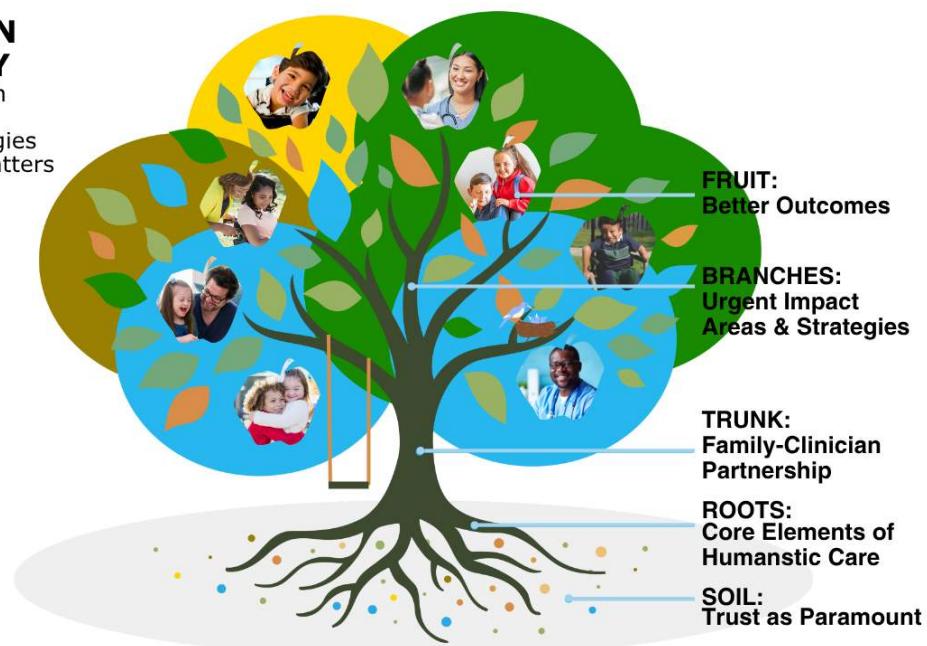
The five components of the framework: Soil, Roots, Trunk, Branches, & Fruit (click on image to enlarge)

Sections of the guide:

1 **"Start Here" explains why ROOTED IN HUMANITY is worthwhile and urgent.** It describes the framework's need arising through deep insights from family-clinician experts, and why humanistic strategies are practical and essential for better healthcare outcomes.

2 **"For You" offers role-specific guidance.** It provides actionable strategies, concrete examples, and key question prompts for different changemakers to implement the framework effectively and collectively.

3 **"To Explore & Share" presents the framework as a tool to inspire action.** It includes two parts: Part 1 is a rich interactive ROOTED IN HUMANITY tree framework and Part 2 offers real-world stories as a model of small change efforts with big impact. Both parts have quotes with AI-assisted audio to bring humanistic systems of care alive with anyone you engage.

ⓘ The framework is built upon the lived reality of CMC, families, and clinicians; you will find real-life quotes and stories throughout this guide and the framework from changemakers.

Putting the guide into action

Designing human-centered systems of care is all about our shared experiences and the connections we build with one another. When we come together, changemakers from all walks of life can make our systems work better in simple, everyday ways. By taking both small steps and bigger initiatives, we can create meaningful and lasting changes that truly make a difference.

- ☐ **Engage with the content together!** Use the guide as a fun and dynamic tool for immediate action and strategic planning. Remember, the framework is just words on a page; it's the people who bring it to life.

- ☐ **Start from family-clinician partnerships to understand top needs, barriers, and creative solutions**. Building trust and collaboration is so important for making real changes together! When we as changemakers work hand in hand, we can ensure that system improvements truly reflect what families need and want, while also addressing the frustrating challenges clinicians face each day.

- ☐ **Focus on actionable strategies (what we call "The Branches")**. This framework guides you through specific steps tailored for each role so you can easily implement meaningful change.

- ☐ **Recognize the urgency of humanistic care**. The framework helps us address healthcare pressures right now while prioritizing quality care.
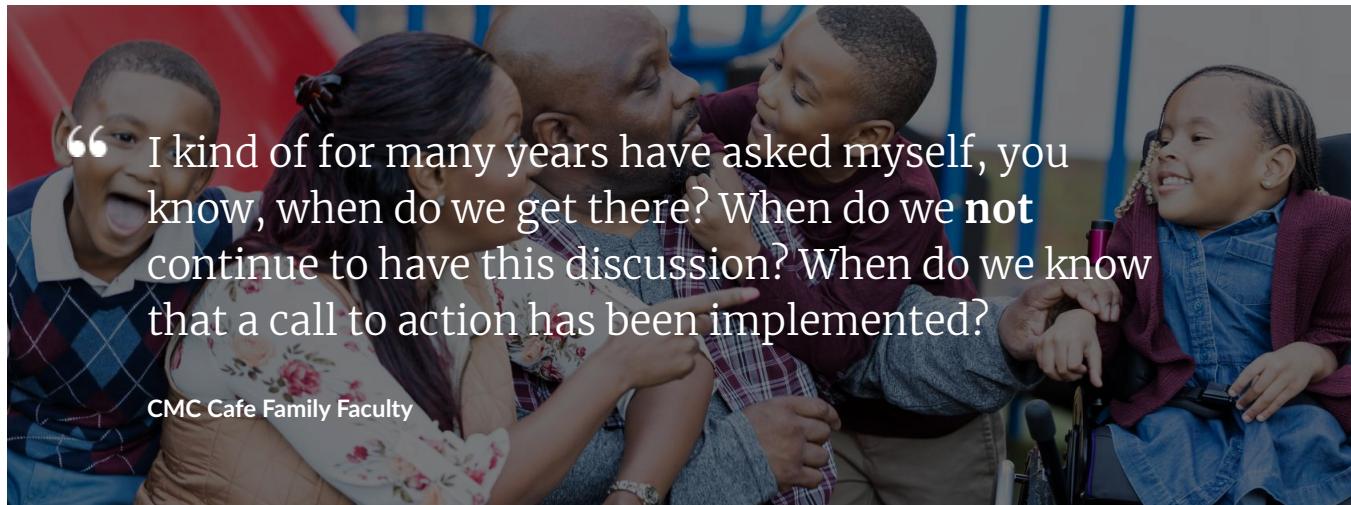
- ☐ **Celebrate small victories to spark further change**. Systems change can sometimes feel daunting and draining. We can lean on each other to celebrate and share the little wins along the way. Sharing our progress helps keep us going and can spark bigger changes together.

Thank you for joining us to put the humanistic care urgent action framework into action!

National Initiative Driven by Family & Clinician Experts Partnering as Colleagues

> " I kind of for many years have asked myself, you know, when do we get there? When do we **not** continue to have this discussion? When do we know that a call to action has been implemented?
>
> **CMC Cafe Family Faculty**

Collaborative Family-Clinician Insights Drive Urgency of Addressing Essential Challenges

We are an interdisciplinary group of diverse national system leaders in the care of children with medical complexity (CMC), primarily clinicians and family leaders - or both. Like many of you, we've experienced first-hand the human toll of broken systems of care. We believe that in working together, we can create change in healthcare and service systems that truly matters by:

1. Collaboratively designing more effective systems of care, by making urgent change first and foremost rooted in the full humanity of the people that comprise them

2. Actively working to understand and prevent real harm of system gaps and failings for everyone involved

We partnered as family and clinician faculty (some of us in dual roles) to guide The Future of Care for CMC Cafe Series (see below), and reflect upon learnings from the series. This partnership led to **a deep understanding of shared goals and priorities in the field for essential systems change – actions that truly humanize care for CMC, their families, and clinicians.**

Who We Are

See More Helpful Information to read our bios and learn more about who we are.

GO TO WHO WE ARE

> ⓘ **Throughout this guide and the framework itself, you will find real stories and quotes from changemakers like you who were: 1) CMC CoIIN project (see below) family focus group participants; 2) CMC Cafe (see below) participants or presenters; and/or 3) CMC Cafe core family or clinician faculty (or in dual role of family/clinician faculty where noted)**

About The Future of Care CMC Cafe Series

1 **Overview of Goals:** The series was a family-partnered, interdisciplinary initiative hosted by Boston University School of Social Work's Center for Innovation in Social Work and Health (CISWH) and funded by the Lucile Packard Foundation for Children's Health. The series aimed to advance actionable systems change in policy, clinical practice, research, and education to improve the quality of life and wellbeing for CMC and their families.

2 **Key Themes and Insights:** Six cafes (March to December 2024) highlighted critical topics such as humanism in care, family partnership to measure family well-being, and health equity and anti-ableism. The discussions built on learnings from the 2022 Future of Care for CMC National Convening and the **Collaborative Improvement and Innovation Network to Advance Care for CMC (CMC CoIIN) Pediatrics journal supplement.**

3 **Family/Clinician-Partnered Discussions:** Each cafe featured presentations by nationally-recognized experts, with family and clinician faculty co-facilitating breakout sessions. These sessions allowed participants to discuss topics that matter most to CMC and their families, ask questions, and share perspectives.

4 **National Interdisciplinary Participants:** The cafes brought together family partners, pediatric primary and specialty care providers, researchers, advocates, payers, maternal and child health professionals, state and federal agency staff, and others to share their insights and lived expertise.

5

Impact on Care Systems: The series provided <u>essential insights to shape meaningful improvements in policy, clinical practice, and education</u> by centering family and clinician expertise to promote sustainable, humanistic care elements and strategies.

framework of essential strategies for care that matters to CMC, their families, and clinicians.

The urgency for the right kind of solutions right now compelled the series' family and clinician faculty to develop the humanistic care framework and action guide.

FRUIT:
Better Outcomes

BRANCHES:
Urgent Impact
Areas & Strategies

TRUNK:
Family-Clinician
Partnership

ROOTS:

Check out the Urgent Action Framework

If you'd like, you can go right to the ROOTED IN HUMANITY tool to explore the framework more. Or, keep going through the guide as-is.
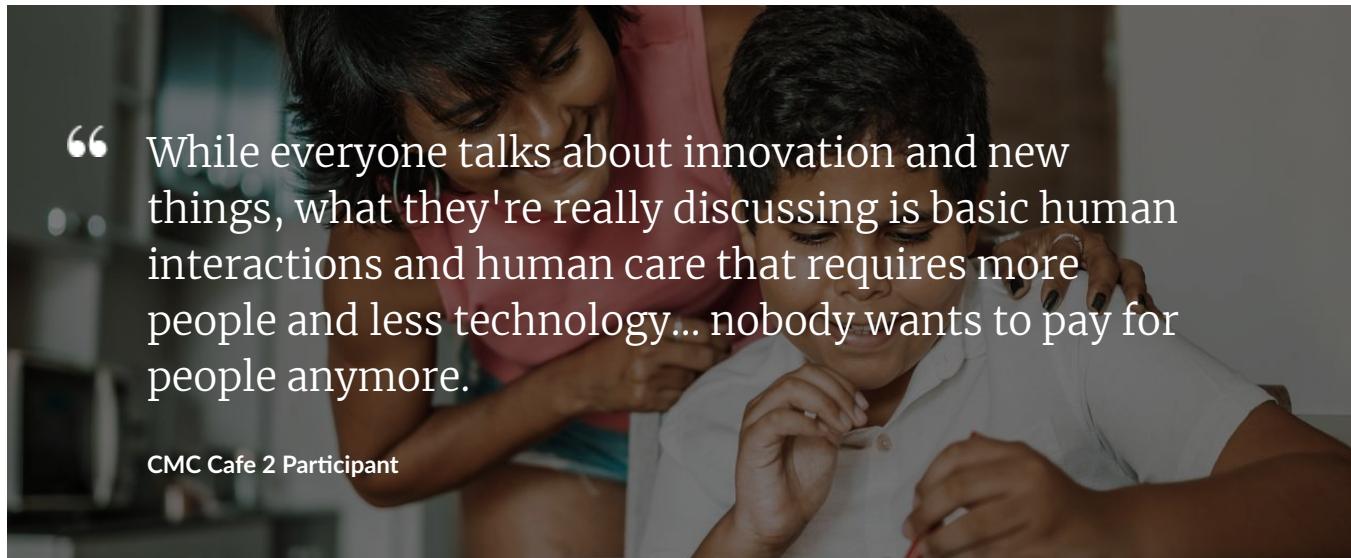
GO TO THE TREE FRAMEWORK

How Humanistic Strategies Lead to Better Outcomes for All ("Sweeter Fruit")

> " While everyone talks about innovation and new things, what they're really discussing is basic human interactions and human care that requires more people and less technology... nobody wants to pay for people anymore.
>
> **CMC Cafe 2 Participant**

How Humanistic Systems Change is What is Actually Needed for "Sweeter Fruit" (Better Outcomes)

Clinician Well-Being and Joy —

Humanistic systems of care bring a sense of purpose and fulfillment to clinicians by enabling clinicians to focus on meaningful connections with families. When clinicians and families work together, it becomes clear what truly matters in care. This approach not only enhances their professional satisfaction but also reduces burnout by aligning their work with impactful outcomes and removing barriers.

By listening to families and addressing their real needs, clinicians experience the joy of making a tangible difference. This mutual trust and collaboration create an environment where clinicians feel valued and empowered in their roles.

Child and Family Thriving*   —

Humanistic systems of care put the well-being of children and their families first by tackling everyday challenges and frustrations. For example, families having agency to choose the right supplies and services, or streamlining their paperwork burden through continous coverage or single applications. Both strategies help reduce time and stress so families can focus on their child's health and happiness and enjoying each other as a family.

By focusing on what matters most to families as experts in their child, these system changes create an environment where CMC and their families can truly thrive.

Sustainable Systems Change   —

Humanistic care inspires lasting change by finding smart, cost-effective solutions to real problems. For example, allowing families to order supplies directly reduces waste and ensures resources are used efficiently. This not only saves money but also makes care better by removing unnecessary barriers.

By trusting families and leveraging their expertise, systems can design changes that really stick. These improvements lay the groundwork for better care and smarter resource use for years to come.

Stronger Trust and Collaboration   —

Building trust between families and clinicians is key for effective care. Humanistic systems prioritize listening to families and acting on their insights, creating a foundation of mutual respect and collaboration. The "Signs Everywhere" Phenomenon in this guide shows how

important families' knowledge is and why it can't be overlooked. This trust becomes the heart of meaningful partnerships that lead to better outcomes.

When families feel heard and valued, they are more likely to engage actively in their child's care. This collaborative approach strengthens relationships, builds understanding to better advocate for needed change, and ensures everyone is working together toward the best possible results.

Safety and Preventing Harm ⸺

Humanistic care systems makes safety a top priority by giving families the right tools and resources. For example, providing supplies that actually work for their child's needs helps avoid risks from workarounds or incompatible equipment. And creating ways to integrate family's key clinical knowledge into inpatient care. This focus on safety reduces harm, however unintentional, and improves the quality of care for everyone.

By addressing these important issues, humanistic care not only protects CMC but also builds trust in the healthcare system. Families and clinicians can work together to create a safer, more reliable care experience.

Increased Efficiency and Reduced Waste ⸺

Humanistic care makes things run more smoothly by cutting out waste and unnecessary steps. As the syringe story included in this guide illustrates, allowing families to order the supplies directly they need avoids the hassle of extra paperwork and mismatched supplies.

This approach saves time and money while making sure resources are used where they are needed most. By focusing on what really matters, humanistic systems create a more equitable and efficient healthcare experience for everyone involved.

Connecting to the Branches and Fruit of our Tree

You can go directly to the interactive tree graphic to explore the full set of urgent action areas/strategies (the "branches") or the full set of better outcomes (the "fruit").

GO TO THE TREE FRAMEWORK

ⓘ **Important Note on Child Quality of Life and Well-Being:**

Throughout the [CMC Cafe series](#) and the [CMC ColIN project](#), family leaders emphasized the need for systems that address societal misconceptions and biases to create meaningful change. Family leaders repeatedly noted that CMC can and do live full, meaningful lives regardless of their disabilities. However, current measures of quality of life and well-being almost exclusively focus on physical functional status, healthcare utilization, and perceived burdens of a child's care on their families. The term "burden" implicitly undercuts the primary experience of families cherishing their child as a whole person. There may also be bias in which the gold standard currently is to compare CMC against children without special needs, effectively undervaluing CMC's unique expressions of a quality life.

*See these two articles for more, including the tie-in with family well-being:*

1. [What Families of Children With Medical Complexity Say They Need: Humanism in Care Delivery Change](#)

Also see: Perceived Disability-Based Discrimination in Health Care for Children With Medical Complexity

Next, we will dive deeper into real-life experiences from families and clinicians of barriers to Humanistic Care. This will help us better understand the urgent action areas (the "Branches") for systems-level change in our tree framework...

CONTINUE
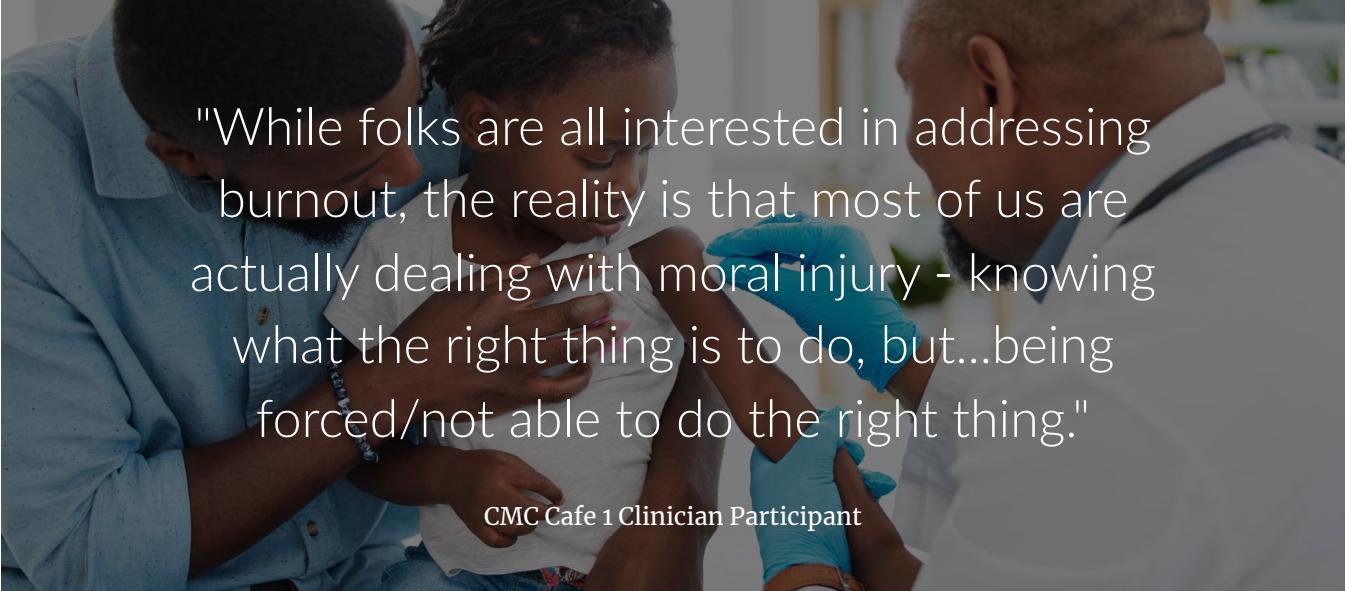
"While folks are all interested in addressing burnout, the reality is that most of us are actually dealing with moral injury - knowing what the right thing is to do, but...being forced/not able to do the right thing."

CMC Cafe 1 Clinician Participant

Removing Barriers to Humanistic Care

In our healthcare systems, there are often barriers that make it tough for clinicians to provide the humanistic care we all see as essential to standard practice. It's important to reform policies to make things easier, like simplifying prior authorizations and cutting down on paperwork. This way, clinicians can spend more time building meaningful relationships with families. We also need payment models that encourage

care focused on trust and collaboration, ensuring that clinicians have the time and resources to truly connect with CMC and their families.

Let's also think about how education and training programs can better prepare healthcare professionals to practice humanistic care. Skills like active listening, narrative medicine, and addressing implicit biases are key! Research should aim to develop measures that highlight the value of relational care and how it positively impacts outcomes for CMC, their families, and clinicians. By aligning our policies, research, training, and payment systems with the principles of humanistic care, we can create a healthcare environment where clinicians feel empowered to provide care that truly matters to children and their families as partners in this journey.

Barriers to Humanistic Care: Stories and Experiences

Clinical Barriers:

Barrier – Role	Story Summary	Quote
Technology Over Connection – Family/Clinician	Medical procedure performed without consent or communication.	"I have so many examples of things that have gone badly... as putting a halter [for an EKG] where the technician just puts his hand in my daughter's shirt without even talking

		to her, without even asking her if that's okay."
Technology Over Connection – Clinician	Need for human interactions over technology.	"While everyone talks about innovation and new things, what they're really discussing is basic human interactions and human care that requires more people and less technology... nobody wants to pay for people anymore."
Transactional Care – Family	Critique of impersonal screening practices.	"We get asked that...through a doggone screener. And now the screeners on a tablet, so there's no interaction... This transactional approach erodes trust in so many other ways."
Transactional Care – Clinician	Personal experience with transactional primary care visit.	"I went to my primary care physician for a regular annual visit yesterday... I could feel that I could not stray from the question that much. I could not even go out of order... no wonder

		physicians are burning out."
Repetitive Information – Family	Frustration with repeatedly providing same information and being labeled "difficult."	"I've literally answered the same question 7 different times... That's why you have notes. Why take them if you're not going to pay attention to them?"
Repetitive Information – Clinician	Supporting a friend whose daughter was hospitalized – burden of repeating medical history.	"I was supporting a family... It would be nice to even say, 'you know, I read the notes, and I learned this. Did I get it right? Did I miss something?'"
Dismissive Attitudes – Family	Hospital staff dismissing her son's first-ever seizure as "a freebie."	"I'm freaking out because I'm like this has never happened... He's never experienced this before."
Dismissive Attitudes – Family	Pediatrician dismissing request for private duty nursing.	"I had gone to my son's PCP... She was like, 'Oh, no way will he be qualified for it!'"

Policy Barriers:

Barrier - Role	Story Summary	Quote
Time Constraints - Clinician	Limited time availability impacts the ability to provide next-level care.	"To me, time is the biggest barrier to providing that sort of next level care. Being able to call somebody at 5 o'clock at night when they're on their way home and it's their only 12 min of peace that they have. And you're like 'I will try to call you at 5 but I've got 3 other things I have to finish before the end of day and I myself have to get out at 5:15.' How can I make all of this happen? You know, it's time, it's time that really impacts how to make it all happen."
Access to Specialists - Family	Difficulty in accessing specialized care due to geographic and systemic limitations.	"Families often have to travel long distances to see specialists, and even then, appointments are months away due to limited availability."
Transportation Barriers - Family	Medicaid medical transportation unreliability and	"Medicaid medical transportation, and making sure that they show up - not only that they pick up the

	family restrictions.	family and the family qualifies for that ride, but that they show back up to the clinic and pick them up afterwards."
Transportation Barriers - Family	Single parent unable to bring siblings due to transportation restrictions.	"Additional barrier is not being able to bring siblings when they are single parent home and do not need the resource available to them for childcare."
Prior Authorization Burdens - Family	Systemic assumption that services will be denied.	"It's almost as if the assumption is that services will get denied, services, durable medical equipment will be denied... hoops that have to be jumped in order to get the things that are needed."
Prior Authorization Burdens - Clinician	Repeated authorizations for permanent conditions.	"It is almost as if they don't believe the doctor... rewriting scripts, redoing authorizations, and forms within a short amount of time for children who have permanent, long-lasting life-threatening conditions."
Emergency Preparedness	Medicaid policies prevent	"Emergency preparedness. They tell you to have a

Contradictions - Family	emergency preparedness despite guidelines.	week's worth of medicine except that Medicaid will only allow you to get medicine 3 days before... It takes 10 months to sandbag a month's worth of medicine."
Cross-State Coverage Gaps - Family	Out-of-state authorization doesn't include pharmacy coverage.	"Out of State authorization does not include pharmacy for Medicaid. So your child could be in ICU, and if that medication is not in the formulary in the hospital, they'll say, can you go to the CVS?"
Healthcare Transition Barriers - Family	Abrupt transition from pediatric to adult care systems.	"Once the child turns 21, there's a whole myriad of other complexities that start happening... the pediatric world they take care of you, and then the adult world is sort of like 'Here you go. Fly, do it on your own.'"
Healthcare Transition Barriers - Family	Reduced reimbursement and support for complex adult patients.	"As soon as our patients turn 21, the reimbursement [drops] from 140 down to 100. But oftentimes our patients are much more complex. So the reimbursement rates go

|		
		down, the complexity goes up."
Dental Coverage Inadequacy – Family	Limited adult dental coverage leading to family debt.	"When they become adults, and they haven't already had this work done... I have seen parents go into debt literally to stop their children from having dental pain... that is inhumane."
Early & Periodic, Screening, Diagnostic, and Treatment (EPSDT) Benefit Implementation Gaps - Family	State agencies lack knowledge of federal requirements.	"State governments usually... don't know that they are required under these federal laws to cover certain things. They don't know that they're required, or they're not allowed to have caps on things."
System Design Philosophy – Family	Current system prioritizes fraud prevention over optimal care.	"Clearly, our system is designed to prevent fraud and abuse... it just assumes that everybody is going to cheat... if it was designed to just get the most optimal quality of life... it would be a whole different system."
Multi-Insurance Coordination – Family	Complex coordination between public	"Coordination of benefits. When you have public and private. And in the case of my daughter, also Medicare for a

	and private insurance.	kidney transplant... So it's a mess in terms of both medical and pharmacy benefits."
DME Authorization Delays - Family	Extended wait times for essential equipment.	"It takes a year to get a new wheelchair in Wisconsin... Basic parts for wheelchairs especially a joystick adjustment" as problematic.
Clinician Shortage Impact - Family	Authorization doesn't guarantee access to services.	"We have such a lack of available clinicians that even if you can get the authorization, you have to wait 6, 12 months to see a PT sometimes."
Telehealth Reimbursement Gaps - Healthcare Clinician	Inconsistent billing rates limit telehealth access.	"Telehealth has proven very useful for busy families with complex children..." However, billing for telehealth is 'not one to one' compared to in-person visits."

How to Drive Practical Collective Change Across Roles Through the Framework

Why the ROOTED IN HUMANITY Tree Framework Matters Now More Than Ever

The framework offers practical clarity and focus to address a fundamental need that has persisted for decades - transforming healthcare systems to truly meet the needs of CMC, their families, and clinicians.
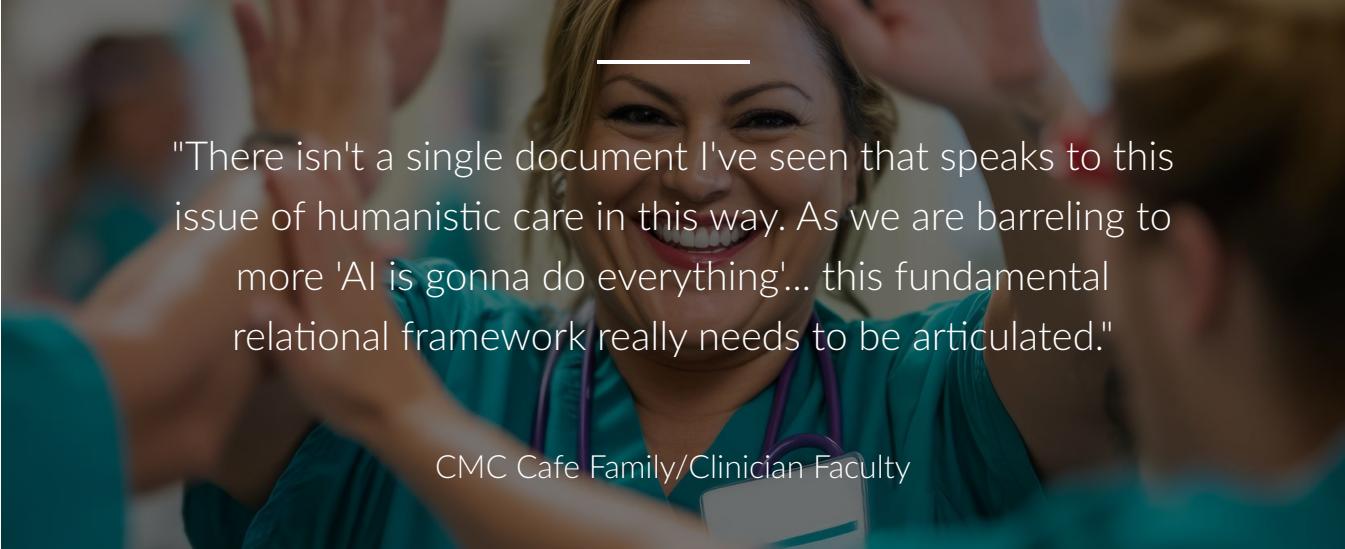
> "There isn't a single document I've seen that speaks to this issue of humanistic care in this way. As we are barreling to more 'AI is gonna do everything'... this fundamental relational framework really needs to be articulated."
>
> CMC Cafe Family/Clinician Faculty

Key Strategic Value Across All Roles for Systems Change:

The framework is designed to help every changemaker understand both the "why" and the "how" in your unique roles, while linking your efforts to a bigger movement aimed at transforming our healthcare systems. By bringing together policy, research, training, and payment systems with the principles of humanistic care, we can create a

human-centered, supportive healthcare environment. In turn, clinicians feel empowered to provide care that truly matters to children, working hand-in-hand with their families as colleagues and valued partners.
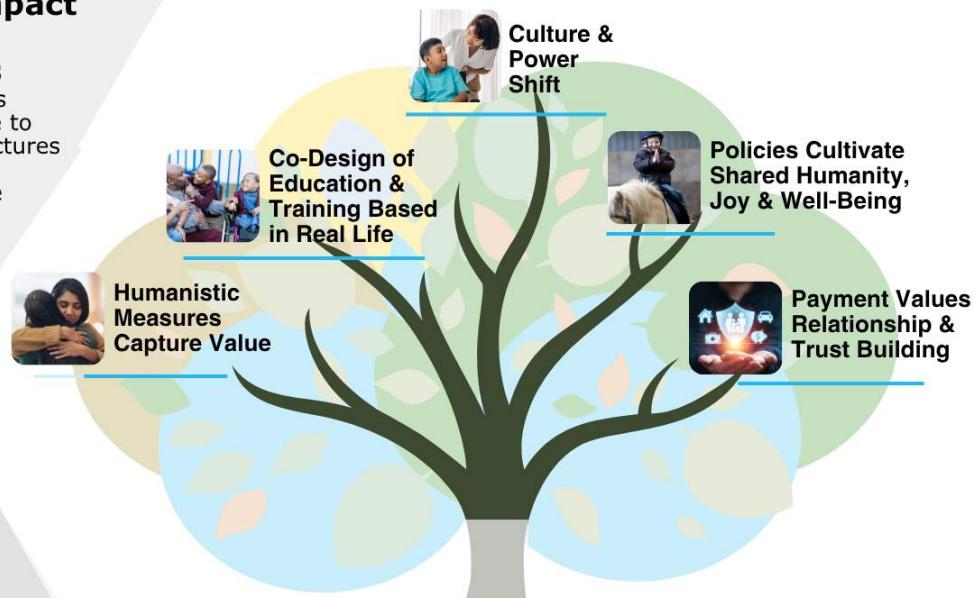

1 **Unified Approach:** Instead of fragmented efforts, this framework creates a common language and shared priorities across all unique roles.

2 **Implementation Focus:** Moves beyond identifying problems to providing specific, actionable strategies each role can take.

3 **Experience-Based:** Built on authentic family and provider input, not theoretical concepts, recognizing the reality of care delivery across multiple settings.

4 **Recognition of Urgency:** Acknowledges current healthcare pressures while maintaining focus on what's truly indispensable for quality care across all environments where children receive support.

5 **Partnership as the Foundation:** Recognizes that meaningful change requires all these roles working together across settings, not in isolation, with families as true colleagues and care partners.

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Next, we will describe how the humanistic care framework helps different changemakers...

CONTINUE

BRANCHES: Urgent Impact Areas & Strategies
Reaching across systems of care to center the structures essential for humanistic care to thrive.

Culture & Power Shift

Co-Design of Education & Training Based in Real Life

Humanistic Measures Capture Value

Policies Cultivate Shared Humanity, Joy & Well-Being

Payment Values Relationship & Trust Building

Click on image to enlarge

TIP: This framework identifies five urgent action areas (the Branches). Use the strategies below to advance these priorities in your role.

If you want to review the branches now, just click the button. Or scroll down here for our guide by role to using the framework...

GO TO THE INTERACTIVE TREE FRAMEWORK

Guide to the ROOTED IN HUMANITY urgent action framework by unique role in system change:

> ⓘ **Any specific resources, tools, or frameworks mentioned here are listed under More Helpful Information -> "Resources & Examples of Humanistic Care"**

GO TO "RESOURCES & EXAMPLES"

For Policy/Decision Makers   —

What you get:

- **Clear policy priorities** directly from family and clinician system leaders

- **Steps for system improvements** to make care more efficient and effective in the clinic and at home

- **Economic implications** showing how humanistic care reduces costs through better coordination and fewer unnecessary services

- **Actionable strategies** with measurable results, including tools like care mapping, that can support CMC in other service settings, such as schools

Your role:

Use this framework to guide decisions that improve care quality and efficiency in healthcare and home care systems.

Concrete Action Strategies:

1. **Test new payment models:** Adjust payments to streamline administrative processes, such as simplifying prior authorizations and reducing documentation burdens, and reward clinicians for spending time building relationships with families, coordinating care, and

making shared decisions. For example, Michigan's targeted case management model could be a guide.

2. **Pay family leaders for their expertise:** Include families as equal partners in systems change from the start. Use tools like the Family Engagement in Systems Assessment Tool (FESAT) to establish baseline measures and develop action plans for meaningful family partnership as colleagues in systems improvement efforts.

3. **Integrate community-based resources:** Fund family-led organizations and networks that help families navigate care, access services, and reduce paperwork. Build referral systems between clinical care and community organizations to address key unmet needs and provide psychosocial support.

4. **Support clinician well-being:** Invest in team-based care models inclusive of family colleagues that reduce burnout by distributing responsibilities and creating psychological safety for vulnerability and authentic relationship-building.

Key Questions:

- How can we better fund the five urgent action areas (the "Branches" of the tree framework)?

- What policies need to change to recognize families as clinical care partners and colleagues?

- How can we adjust payment models to give clinicians more relational time with families?

- What evidence is needed to support investments in humanistic care approaches?

- How can we measure the value of humanistic care in both clinical and economic terms?

- What current barriers stop clinicians from providing personalized, relationship-focused care?

For Family/Clinician Advocates*   —

What you get:

- **Advocacy tools** to show decision makers why families are primary care partners as well as colleagues

- **Real-world stories and data** that highlight the human and financial impact of current systems as well as examples of humanistic care and real partnerships for systems change

- **Clear communication** of what families and clinicians truly need

- **Unified messaging** to strengthen advocacy efforts, emphasizing that families are care partners, not patients

Your role:

Use this framework to advocate for humanistic policies, funding, and systems that recognize and support family expertise in all care settings.

Concrete Action Strategies:

1. **Use care maps to hold systems accountable:** Show gaps between promised and actual care. Use these maps to demand better standards for medical necessity (as opposed to "family preferences") and highlight system failures.

2. **Build cross-state affinity groups and peer support networks:** Connect family leaders and clinicians across states around shared priorities (home care, transition planning, payment reform, administrative reform). Convene regularly to share ideas, solve problems, and push for change together, including co-training curricula.

3. **Share evidence of system failures:** Document family need to repeatedly share the same information to protect their child from harm (e.g., the Signs Phenomenon elsewhere in this guide) and advocate constantly for basic needs, and other system inefficiencies. Use this objective data to show the need for mutual partnership as colleagues in care.

Key Questions:

- How can we use the framework to push for policies that value family expertise?

- What stories best show the need for change?

- How can we work together to make our advocacy stronger?

- What parts of humanistic care matter most to the communities we serve?

- How can we ensure our messages show families as clinical providers of care in the home?

- What policy changes should we focus on to address the five urgent action areas (i.e., the branches of the tree framework)?

For Research & Measurement Communities —

What you get:

- **Outcome targets** based on what families and clinicians actually need

- **Measurement frameworks and tools** that focus on experience (not just satisfaction) and meaningful outcomes

- **Accountability metrics** tied to trust, relationships, and family-defined quality of life

- **Research priorities** that tackle real-world challenges, like improving home and community care

Your role:

Create and test tools that measure the aspects of humanistic care that matter most to families and clinicians across child-serving settings.

Concrete Action Strategies:

1. **Work with family colleagues to evaluate care iteratively:** Partner to create tools that measure trust, feeling heard, and alignment with family-defined quality of life goals. Move beyond satisfaction surveys to focus on real experience (such as Patient Reported Experience Measures, or PREMs) and partnership (e.g., "provider usually or always asks me to share my knowledge or expertise as caregiver").

2. **Measure partnership both as a process and outcome:** Develop tools to assess how well clinicians and families work together for shared decision-making, authenticity, and recognition of family expertise. Track metrics like family involvement in care team meetings, co-documentation in electronic health records, and family advisory committee influence on policy decisions—measuring not just whether partnership exists but whether it drives meaningful change.

3. **Study barriers to humanistic care:** Research why best practices aren't being implemented despite decades of calls to action. Look at structural issues (like physical accessibility, health record limits, productivity metrics), cultural barriers (implicit bias, hierarchy of expertise), and resource constraints that prevent humanistic care—then test specific interventions to address these root causes.

Key Questions:

- How can we measure family-defined quality of life and other meaningful outcomes?

- What research is needed to solve real-world challenges to humanistic care?

- How can we measure trust, relationship-building, and partnership in ways that matter to families and clinicians?

- What goals reflect what families and clinicians truly need?

- How can we capture to then ameliorate the complexity of care coordination?

- What evidence shows the value of recognizing families as care partners and colleagues?

For Healthcare Organizations & Clinicians*   —

What you get:

- **Practical strategies** to improve systems of care within current constraints

- **Quality improvement tools** tested through collaborative learning approaches that span both clinical and home settings

- **Staff wellness approaches** to reduce burnout and support teamwork with family colleagues as well as better outcomes

- **Partnership models** that integrate family colleagues as key members of the care team given their role as primary medical providers in the home

Your role:

Make changes at your organization to improve care and advocate for system-wide support for family-partnered humanistic approaches.

Concrete Action Strategies:

1. **Deploy specific tools to improve care:** Integrate proven humanistic approaches like motivational interviewing, shared decision-making, and active listening to better understand family needs. Use pre-visit questionnaires and tools like the LifeCourse framework or "Creating Goals for Children" app to set goals beyond medical outcomes. Incorporate palliative care principles that prioritize quality of life, communication, and dignity alongside medical intervention.

2. **Redesign workflows:** Adjust schedules, productivity metrics, and team roles to allow protected time for building relationships with families. Try out group visits, home visits, or telehealth options to understand families' lived context. Track time spent on relationship-building as a key metric.

3. **Integrate family partnership with real decision-making power:** Embed family liaisons on care teams, as co-trainers, set up councils with diverse members, and integrate other robust roles, all with administrative support and real decision-making power in policy and practice. Partner with family organizations for training and mentoring. Use tools like the Family Engagement in Systems Assessment Tool (FESAT) to assess and improve meaningful family engagement at the organizational level.

Key Questions:

- How can we use quality improvement tools to improve care following the framework?

- What changes are needed to integrate families as a key part of the care team?

- How can we reduce staff burnout while building strong family relationships?

- What training do teams need to use humanistic approaches, including narrative medicine and disability studies?

- How can workflows be redesigned to focus on relationships and shared decisions?

- What tools can help us understand family goals and needs?

- How can we create a safe space for families and clinicians to work together?

For CMC Families & Care Partners   —

What you get:

- **Tools and language** to explain your needs to healthcare systems

- **Connection to a broader movement** who share in your experiences

- **Advocacy framework** to push for changes that matter to your family and honor your expertise in systems of care

- **Real-life stories and data** that show your lived expertise is valuable and essential across all care settings

Your role:

Share your experiences, advocate for change, and hold systems accountable to outcomes that matter to your family driven by your expertise as the primary medical provider for your child.

Concrete Action Strategies:

1. **Join leadership opportunities:** Participate in advisory councils and workgroups to share your experiences and influence policy and practice decisions. Participate in training simulations for clinicians. Seek training, mentorship and advocacy support from family-led organizations like Family Voices chapters and Family-to-Family Health Information Centers. When serving in partnership roles with equal responsibilities, request equal compensation for your expertise and time.

2. **Be clear about your needs:** Use care plans and maps to document your expectations and hold systems accountable. Frame your knowledge as essential medical information, not preferences.

3. **Share your story strategically:** Keep records of repeated information requests, gaps in coordination, and system failures and their impacts. Share them through focus groups, advisory committees and advocacy channels to show where changes are most needed. Connect your experiences to broader patterns that show the urgent need to partner with families for better solutions.

Key Questions:

- How can we use the framework to better explain our needs to healthcare, home care, and educational systems?

- What parts of the framework best reflect our experiences of providing and coordinating care?

- How can we use the framework's evidence to push for meaningful changes?

- What stories can we share to help others understand our expert role?

- How can we hold systems accountable to family-defined outcomes?

- What parts of humanistic care should we focus on in our advocacy?

NOTE: Clinicians include: medical doctors, clinical team (e.g., nurses, physician assistants, nurse-practitioners), allied health (e.g., occupational therapists, physical therapists), behavioral health (e.g., social workers), and other key practitioners

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ⓘ **TIP: Lean into Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit for Medicaid recipients under 21 years-old**

> *"I think EPSDT is really so robust that it solves most of our problems, not all of them, but it can solve most of our problems...What I'm hearing is it's actually written to cover a lot of things. It's actually written to serve families. There's a whole lot of things that are covered under [it], but implementation is where the problem is, and what is it about State Medicaid agencies that create rules and processes and procedures that make it so rigid or difficult or overwhelming."*
> ~Cafe 4 Participant

See: Distilling the EPSDT Guidance by Innovations Institute, UConn School of Social Work

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For All Changemakers

Cross-Cutting Reflection Questions

- How does our current work align with the vision of humanistic care outlined in the tree framework?

- THE SOIL: How can we ensure our efforts elevate and cultivate trust?

- THE ROOTS: What narrative roadblocks do we encounter that prevent progress toward more humanistic approaches?

- THE TRUNK: Are we partnering alongside family leaders as colleagues and clinicians to drive practical change with tangible impact on life lived?

- THE BRANCHES: Which urgent action area & strategy of the framework should we prioritize first in our context?

- THE FRUIT: How can we measure progress toward the framework's vision of care that truly meets the needs of CMC, their families, and clinicians?

- What partnerships do we need to build to advance humanistic care across all settings where children receive support?

- What systemic barriers must we address to create sustainable change?

**Want to see a real-world illustration of the framework in action?**

The Syringe Story lays out a systems change effort from a Texas complex care clinic led by Dr. Rahel Berhane with Lisa Kirsch. It illustrates beautifully that humanistic care isn't abstract - it arises out of deeply practical needs with

commonsense solutions that lead to better outcomes for everyone involved.

GO TO "THE SYRINGE STORY"

Intro to Framework: What Makes Humanistic Elements of Care Indispensable Here and Now?
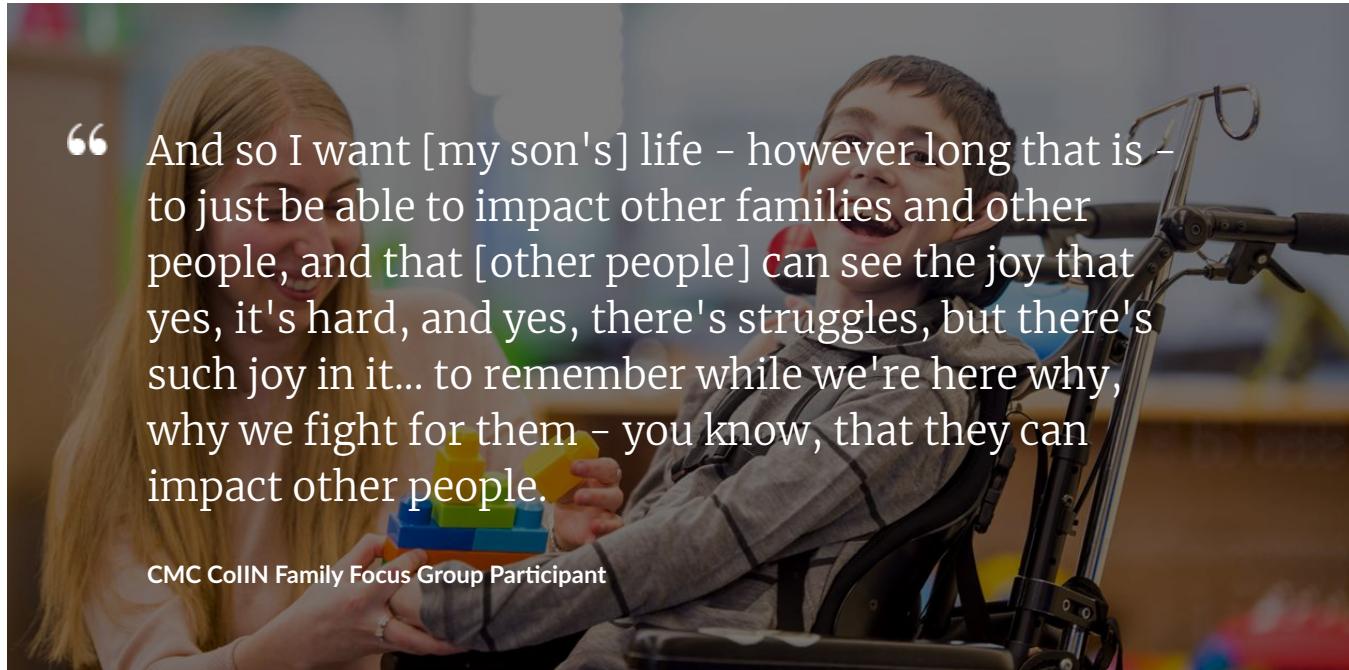
> " And so I want [my son's] life – however long that is – to just be able to impact other families and other people, and that [other people] can see the joy that yes, it's hard, and yes, there's struggles, but there's such joy in it… to remember while we're here why, why we fight for them – you know, that they can impact other people.
>
> **CMC CoIIN Family Focus Group Participant**

0:26   1x

Ai-generated audio of real quote

A note on the urgency of this work at this moment

The urgency for humanistic care predates recent political crises, which makes it even more important. Humanistic care is a foundational need for CMC, their families,

and clinicians. It's not a reaction to challenges; it's a proactive approach. When systems are under threat, the framework highlights with clarity elements of care that we cannot do without.

"Without the humanistic framework, everything falls apart... someone is going to be taking care of people in some mechanism. And what is it? What is the indispensable thing that needs to stay as everything falls apart is this."

CMC Cafe Family/Clinician Faculty

CONTINUE

Three reasons Humanistic Care is essential to the right kind of systems change

1   Families of CMC are in fact experts in their child's care, including as the primary medical provider where most of the care takes place in the home.

2   Children with medical complexity are full human beings who are children first and foremost. Their families hold this truth with

joy.

3   Clinicians' well-being and joy in the work are essential to effective and sustainable systems of care.

"I'm actually a valued member of the workforce, and I'm performing a valuable service. I'm not asking you to pay me for that service necessarily, but I am asking you to treat me as a human being in that context, and my mental and physical well-being and health are important to that in the context of optimal, efficient, effective care of this child, because otherwise my kiddo is going to end up in the hospital if I can't do my job."

CMC Cafe Family Faculty

"I just want them to be a kid."

"Ask more questions, like spend more time ... getting to know ... you wanna feel like ... they are seeing you and your kid as an individual and unique in that moment."

CMC CoIIN Family Focus Group Participants

"If you're crying because the kid passed away in your emergency room, you can't cry more than the family, because your job is to support the family... The idea that somehow you're a technician - and that's what we've moved to with physicians and it drives me freaking nuts... We need to push back that boundary in a way that says that the compassion, the relationship, is the product that creates the care."

CMC Cafe Clinician Faculty

The urgent need to humanize care is not new...

FAMILIES LEAD THE CALL TO HUMANIZE CARE FOR DECADES

THE IMPACT OF MEDICAL ADVANCES

CLINICIANS ALSO NEED HUMANISTIC SYSTEMS

Families of children with medical complexity (CMC) have long advocated for a more humanized approach to care because, practically speaking, it leads to better outcomes for CMC. Their voices have highlighted the need to address the shared humanity of children, families, and clinicians. This call is especially urgent in today's healthcare environment, where the system often dehumanizes all involved.

By focusing on the human experience, family leaders remind us of the importance of compassion and connection. Their advocacy underscores the need for systemic change to prioritize humanity alongside medical outcomes for effective, efficient, quality care.

FAMILIES LEAD THE CALL TO HUMANIZE CARE FOR DECADES	THE IMPACT OF MEDICAL ADVANCES	CLINICIANS ALSO NEED HUMANISTIC SYSTEMS

Advances in healthcare have shifted the focus from caring for the whole person to prioritizing biology and cures. While these innovations have enabled children with medical complexity to survive and live into adulthood, they come with challenges.

The systems that once saved these children are now ill-equipped to support their long-term well-being. This paradox highlights the need for healthcare structures that balance medical advancements with humanistic care.

FAMILIES LEAD THE CALL TO HUMANIZE CARE FOR DECADES	THE IMPACT OF MEDICAL ADVANCES	CLINICIANS ALSO NEED HUMANISTIC SYSTEMS

The current healthcare system often fails to prioritize essential humanistic structures, leading to barriers with unintended consequences that prevent clinicians from being able to provide the care necessary for CMC to stay well and thrive.

As a CMC Cafe Clinical Faculty member noted, *"People are leaving the profession avoiding CMC. Those in the workforce would rather see 60 kids a day with ear infections. This framework could answer the call of 'I don't have joy in my work anymore. And now you're asking me to do even more.' No, in fact, here's the approach for fixing the system. It's called team-based, humanistic care of*

clincians and families working together as colleagues. Here's the approach for you to feel more joy in your work."

To truly support these individuals, healthcare must evolve to integrate compassion, empathy, and holistic care. Building systems that value humanity is essential for fostering meaningful connections, thriving lives. and practical solutions in navigating complex conditions with no easy answers.

## ...but the framework of humanistic care as essential is new:

"I don't think there has ever really been a real focus on humanistic care. And I think that's what's different in what we're talking about here. I don't know that the concepts and terminology around humanistic care ever really were a part of the framework of family-centered care. It may have been sort of an underlying theme, but never really fully articulated."

CMC Cafe Family Faculty

Interactive Tree Framework: ROOTED IN HUMANITY Urgent Actions for Systems Change in CMC Care
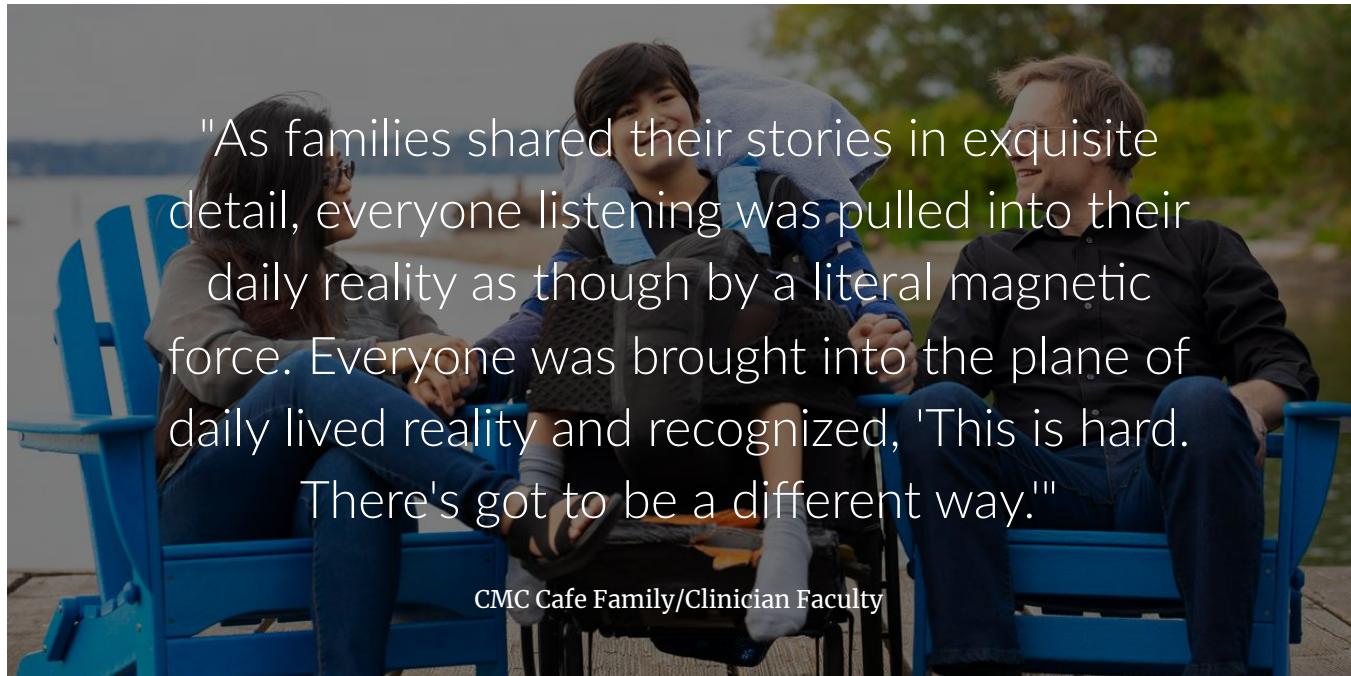
"As families shared their stories in exquisite detail, everyone listening was pulled into their daily reality as though by a literal magnetic force. Everyone was brought into the plane of daily lived reality and recognized, 'This is hard. There's got to be a different way.'"

CMC Cafe Family/Clinician Faculty

A living tree graphic: Interactive tool brings the framework alive for collective action

This interactive tool visually maps the humanistic care framework onto a tree to help changemakers like you fully understand each component and how they work together holistically. Together, these components support a healthy ecosystem of care, similar to the ecosystem of a tree, where each part needs to work together for the tree to grow and thrive. **Share this tool with others to inspire collective action.**

The first graphic lays out each component holistically:

1. **The soil (trust)**

2. **The roots (elements of humanistic care)**

3. **The trunk (family-clinician partnership)**

4. **The branches (urgent action areas & strategies)**

5. **The fruit (better outcomes)**

The following graphics below zoom in on one part at a time and how it helps the whole "tree" stay healthy – like systems of care. It starts with the soil of trust as foundational and climbs up the tree from there.

Want to see a real-world illustration of the framework in action?
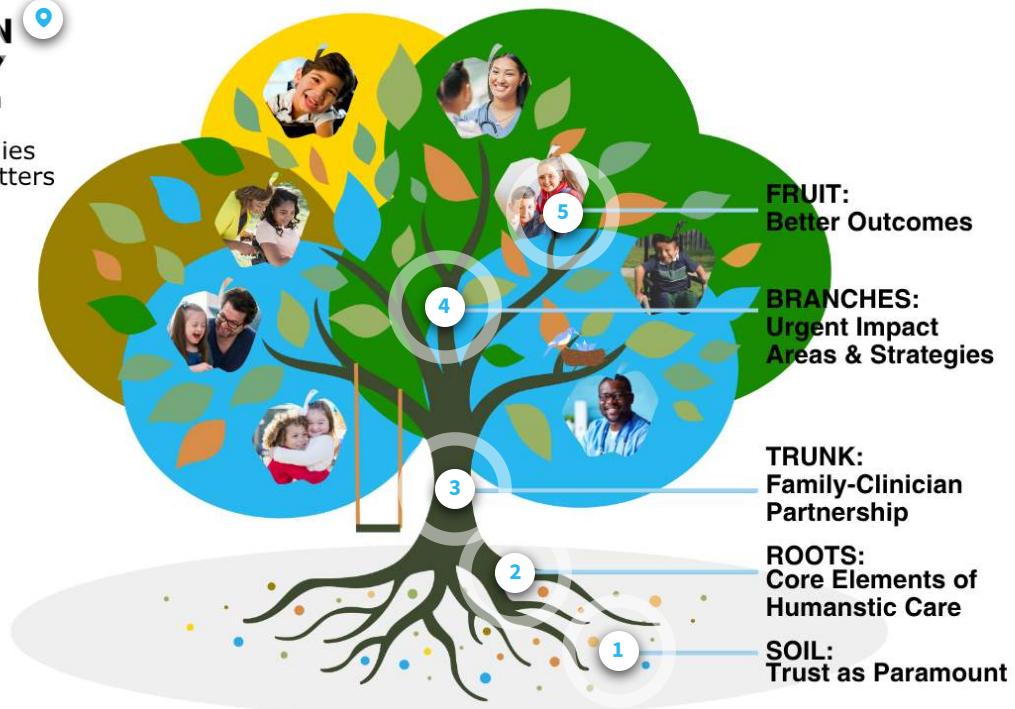
The Syringe Story lays out a systems change effort from a Texas complex care clinic led by Dr. Rahel Berhane with Lisa Kirsch. It illustrates beautifully that humanistic care isn't abstract - it arises out of deeply practical needs with commonsense solutions that lead to better outcomes for everyone involved.

GO TO "THE SYRINGE STORY"

ROOTED IN HUMANITY

An urgent action framework of essential strategies for care that matters to CMC, their families, and clinicians.

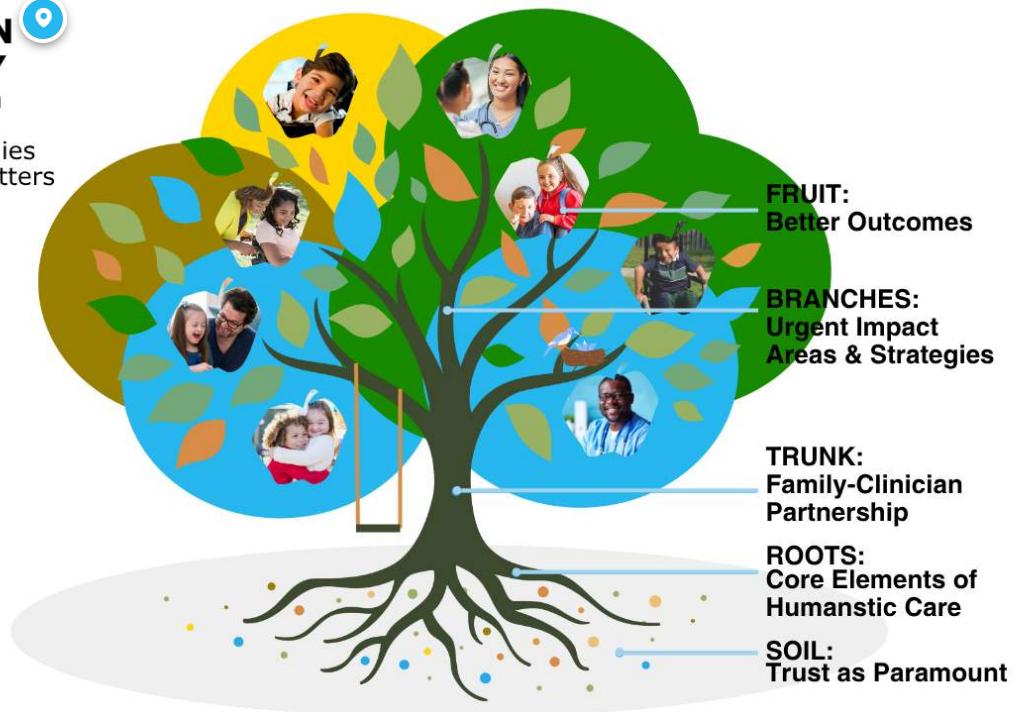## Why This Framework? Why Now?

FRUIT:
Better Outcomes

BRANCHES:
Urgent Impact
Areas & Strategies

TRUNK:
Family-Clinician
Partnership

ROOTS:
Core Elements of
Humanstic Care

SOIL:
Trust as Paramount

ROOTED IN HUMANITY
An urgent action framework of essential strategies for care that matters to CMC, their families, and clinicians.

Why This Framework? Why Now?

FRUIT:
Better Outcomes

BRANCHES:
Urgent Impact Areas & Strategies

TRUNK:
Family-Clinician Partnership

ROOTS:
Core Elements of Humanstic Care

SOIL:
Trust as Paramount

Rooted in Humanity: An Urgent Action Framework

0:19   1x

The humanistic tree framework captures the elements that matter most to center in systems change for essential care and high-value outcomes. These elements interconnect like the ecosystem of a tree: soil, roots, trunk, branches, and fruit.
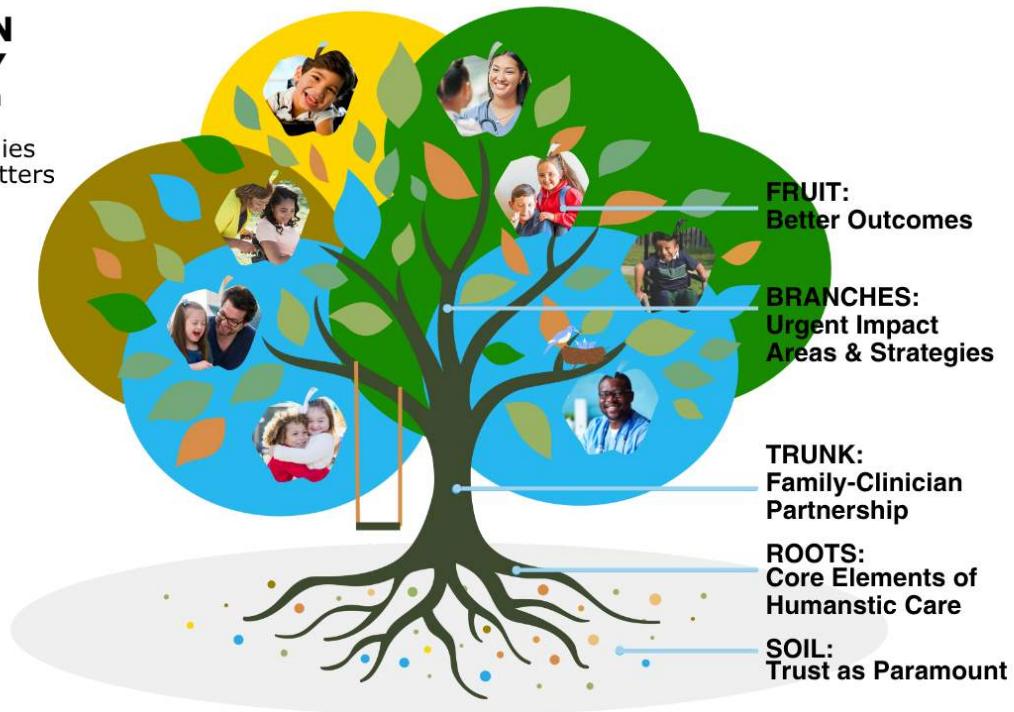
"I want [my son's] life – however long that is – to just be able to impact other families and other people, and that [other people] can see the joy that yes, it's hard, and yes, there's struggles, but there's such joy in it… to remember while we're here why, why we fight for them – you know, that they can impact other people."
~CMC CoIIN Family Focus Group Participant

ROOTED IN HUMANITY
An urgent action framework of essential strategies for care that matters to CMC, their families, and clinicians.

Why This Framework? Why Now?

FRUIT:
Better Outcomes

BRANCHES:
Urgent Impact Areas & Strategies

TRUNK:
Family-Clinician Partnership

ROOTS:
Core Elements of Humanstic Care

SOIL:
Trust as Paramount

Why This Framework? Why Now?

The humanistic care framework for children with medical complexity (CMC), their families, and clinicians arose out of a family-clinician partnered cafe series on improving systems of care.
(Learn more at "National Initiative Driven by Family & Clinician Experts Partnering as Colleagues")

We are a group of national system leaders in the care of CMC, primarily clinicians and family leaders – or both – who have experienced first-hand the human toll of broken systems of care.

We believe that in working together, we can create change in healthcare and service systems that truly matters by:
1. Collaboratively designing more effective systems of care, by making urgent change first and foremost rooted in the full humanity of the people that comprise them
2. Actively working to understand and prevent real harm of system gaps and failings for everyone involved

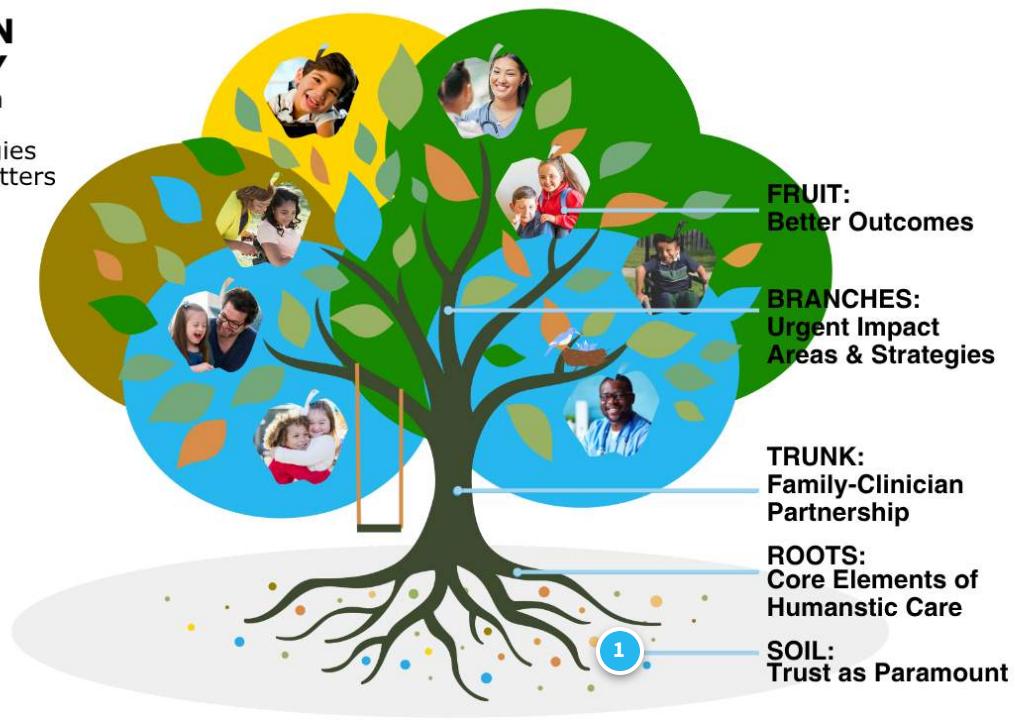We partnered as family and clinician faculty (some of us in dual roles) to guide The Future of Care for CMC Cafe Series, and reflect upon learnings from the series. This partnership led to a deep understanding of shared goals and priorities in the field for essential systems change – actions that truly humanize care for CMC, their families, and clinicians.
(See "Who We Are" to learn more about us)

ROOTED IN HUMANITY
An urgent action framework of essential strategies for care that matters to CMC, their families, and clinicians.

Why This Framework? Why Now?

FRUIT:
Better Outcomes

BRANCHES:
Urgent Impact Areas & Strategies

TRUNK:
Family-Clinician Partnership

ROOTS:
Core Elements of Humanstic Care

SOIL:
Trust as Paramount

Soil: Trust for Transformation

▶ ● ——————————— 0:08 1x 🔊 🗎

Mutual trust between families and clinicians as partners is the soil for transformation nourishing all elements of humanistic systems of care. For effective CMC policy, an assumption of trust is critical by all system leaders.
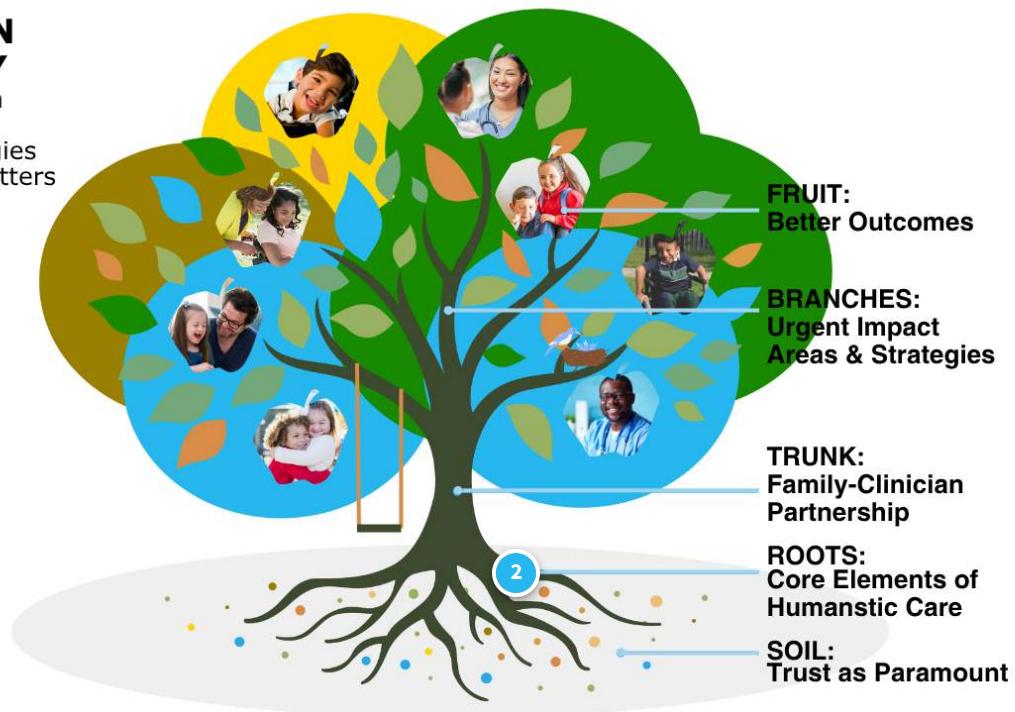
"Families have as much stake in having a sustainable system that is not abused. Maybe they have more stake in that than anyone else."
~CMC Cafe Family/Clinican Faculty

ROOTED IN HUMANITY
An urgent action framework of essential strategies for care that matters to CMC, their families, and clinicians.

Why This Framework? Why Now?

FRUIT:
Better Outcomes

BRANCHES:
Urgent Impact Areas & Strategies

TRUNK:
Family-Clinician Partnership

ROOTS:
Core Elements of Humanstic Care

SOIL:
Trust as Paramount

Roots: Foundational Elements for Humanistic Care

The core, indispensable principles that nourish and sustain systems transformation through the humanstic care framework to benefit CMC, families and clinicians.
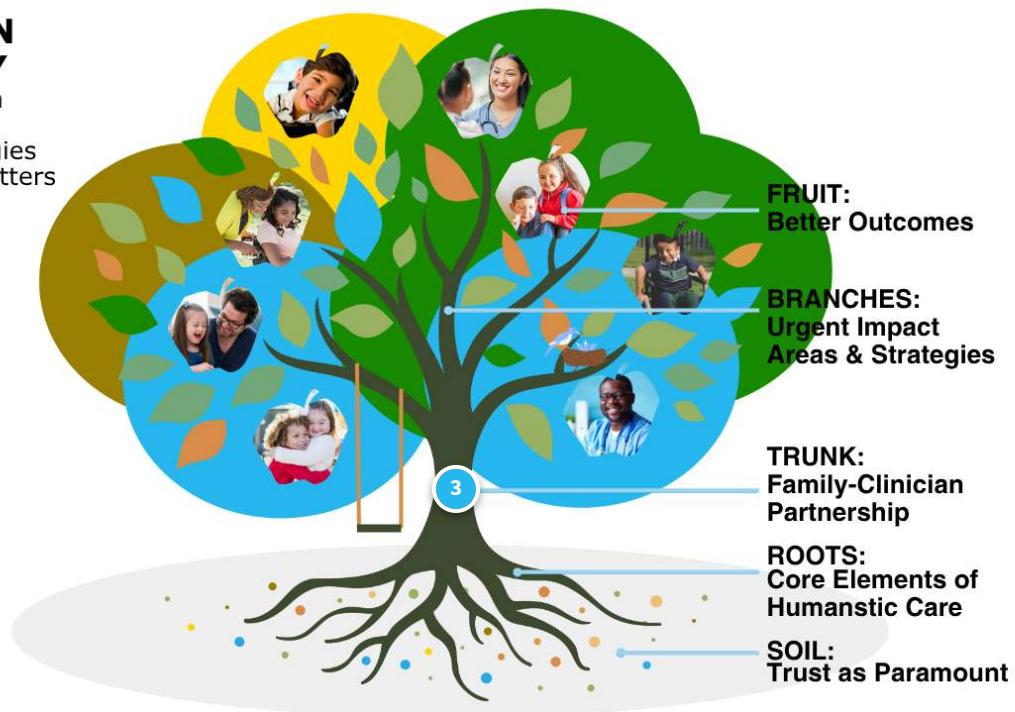
"We sort of have to somehow find ways to move beyond this deadened transactional thing to valuing relationship, longitudinal relationship."
~CMC Cafe Family Faculty

ROOTED IN HUMANITY
An urgent action framework of essential strategies for care that matters to CMC, their families, and clinicians.

Why This Framework? Why Now?

FRUIT:
Better Outcomes

BRANCHES:
Urgent Impact Areas & Strategies

TRUNK:
Family-Clinician Partnership

ROOTS:
Core Elements of Humanstic Care

SOIL:
Trust as Paramount

Trunk: Mutual Partnership as Driving Conduit

▶ ●──────────────────────────── 0:31 1x 🔊 📄

No single entity can affect meaningful change alone—it requires families, clinicians, policymakers, and payers working together.

"We lose our way when we try to design for multiple stakeholders simultaneously...design for the highest needholder, and the primary intended beneficiary, which in this case is children and families... and then look at trade offs for other stakeholders. When we try to do everything for all people, we diminish families [and] patient[s]... **Targeted Universalism***...argues that when you focus on the highest needholder group and design for them, it actually ultimately benefits all stakeholder groups."*
~CMC Cafe 3 Participant

ROOTED IN HUMANITY
An urgent action framework of essential strategies for care that matters to CMC, their families, and clinicians.

Why This Framework? Why Now?

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Better Outcomes

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SOIL:
Trust as Paramount
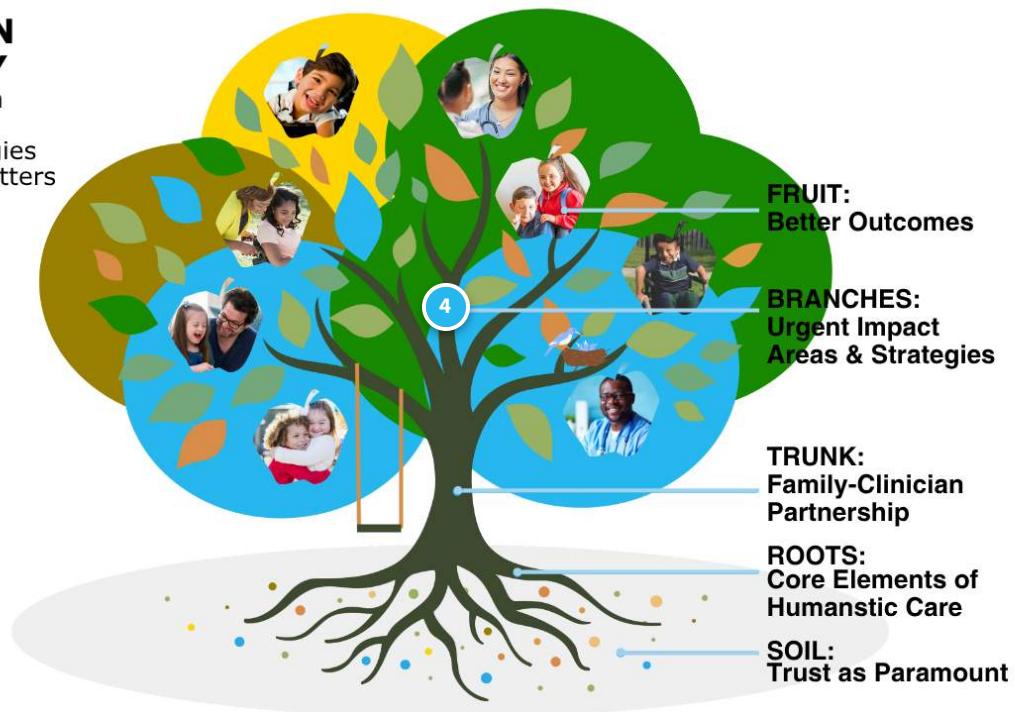
Branches: Network of Urgent Actions

0:21   1x

Reaching across systems to center the structures essential for humanistic care to thrive.
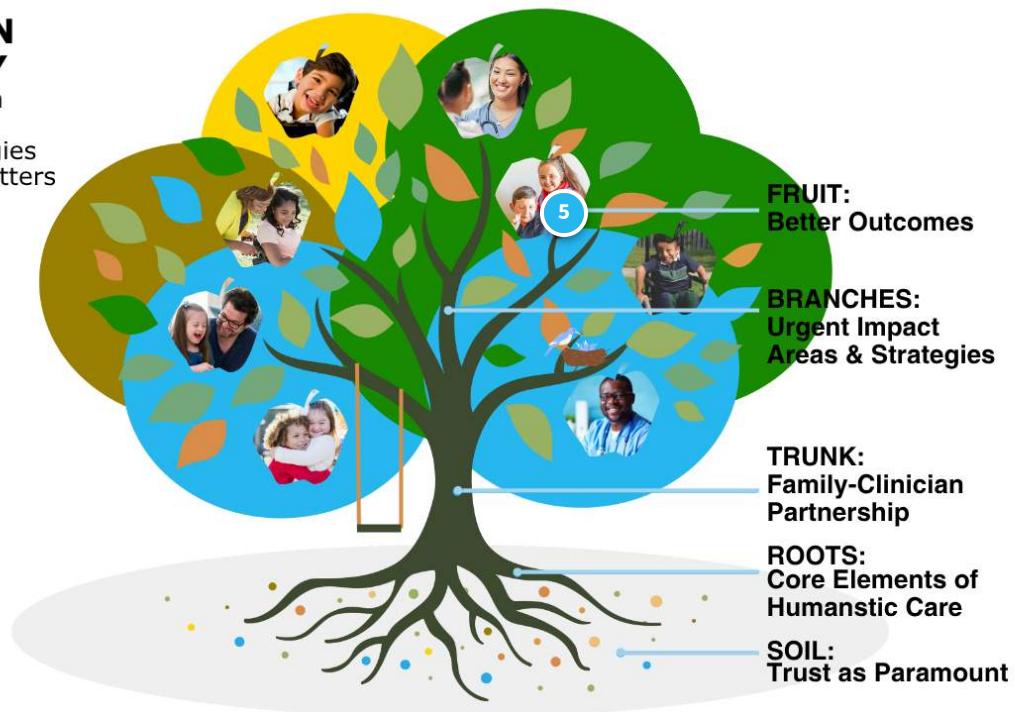
"While everyone talks about innovation and new things, what they're really discussing is basic human interactions and human care that requires more people and less technology... the innovation would be giving everybody more time to spend with families and actually do the care that is necessary."
~CMC Cafe 1 Participant

ROOTED IN HUMANITY
An urgent action framework of essential strategies for care that matters to CMC, their families, and clinicians.

Why This Framework? Why Now?

FRUIT:
Better Outcomes

BRANCHES:
Urgent Impact Areas & Strategies

TRUNK:
Family-Clinician Partnership

ROOTS:
Core Elements of Humanstic Care

SOIL:
Trust as Paramount

Fruit: Crucial Outcomes of Humanistic Care

▶ ──●────────────────────── 0:10 1x 🔊 📄

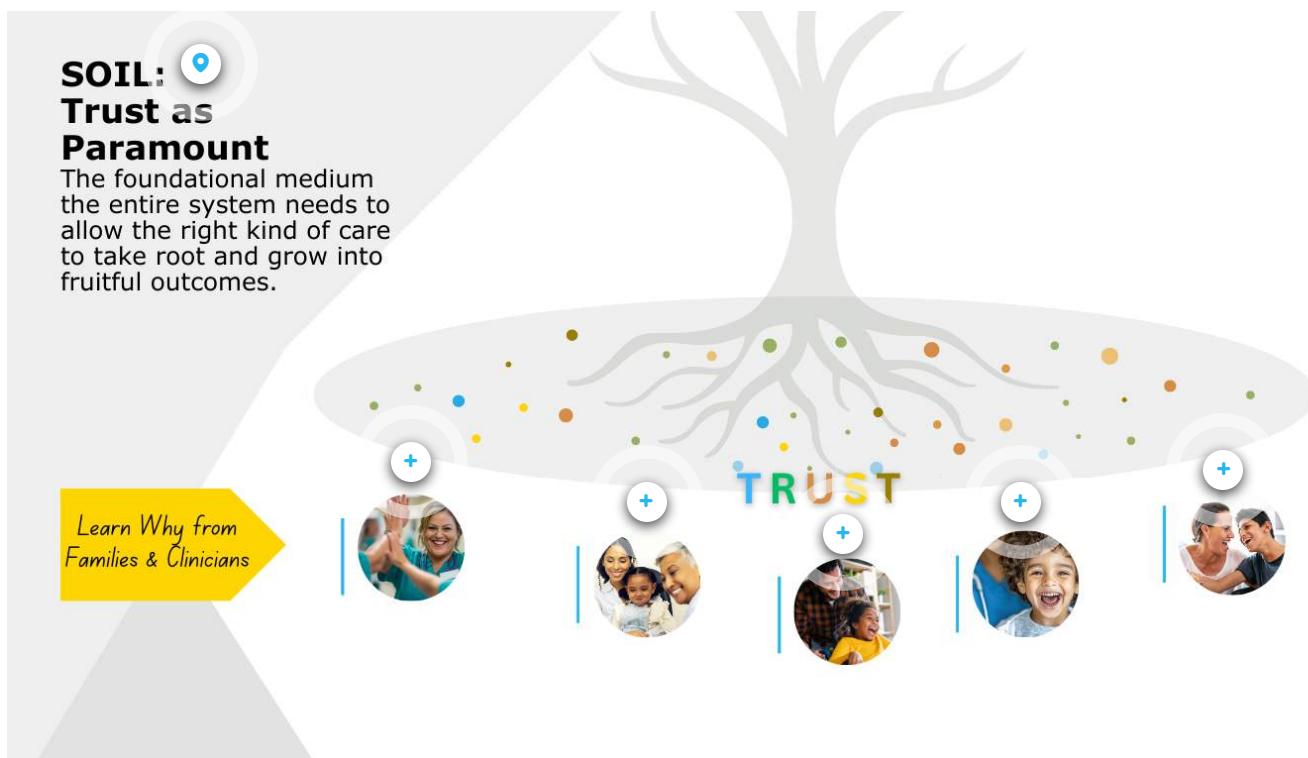Focusing concrete action in urgent impact areas for humanistic care drives the kind of change we all value, benefiting not only CMC, their families, and clinicians but also systems of care overall.

"My little clinic here. The type 2 diabetes program has some of the best outcomes in a free clinic, because the person who's doing it cares, and the parents and the families know that."
~CMC Cafe Clinician Faculty

ⓘ **Throughout this guide and the framework itself, you will find real stories and quotes from changemakers like you who were: 1) CMC CoIIN project family focus group participants; 2) CMC Cafe participants or presenters; and/or 3) CMC Cafe core family or clinician faculty (or in dual role of family/clinician faculty where noted)**

SOIL: 📍
Trust as Paramount
The foundational medium the entire system needs to allow the right kind of care to take root and grow into fruitful outcomes.

Learn Why from Families & Clinicians

TRUST

SOIL: Trust as Paramount
The foundational medium the entire system needs to allow the right kind of care to take root and grow into fruitful outcomes.
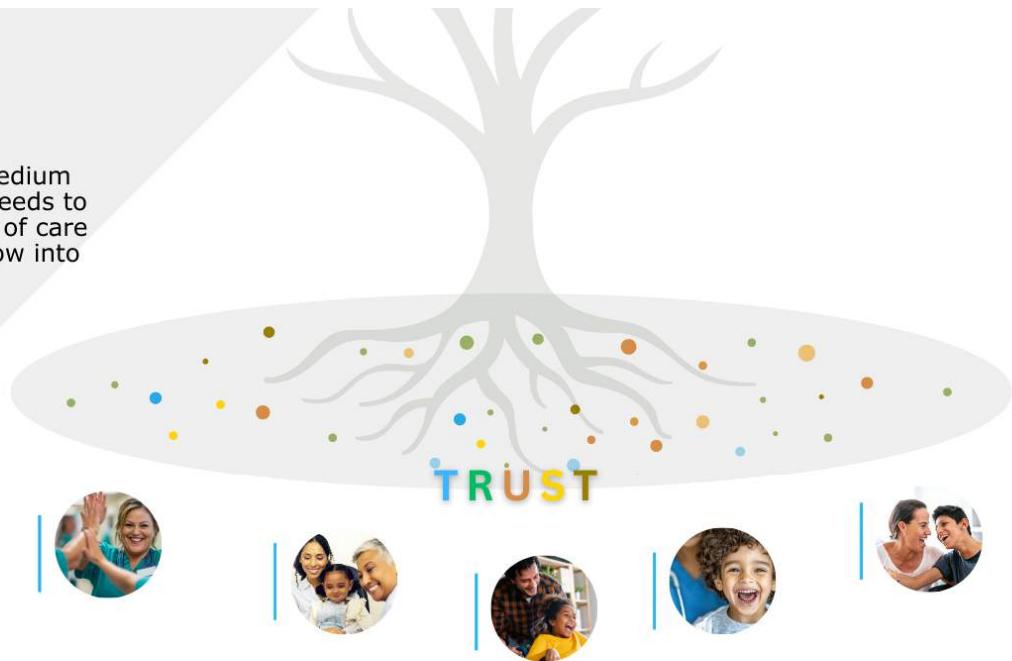
Learn Why from Families & Clinicians

TRUST

Why trust is the soil

0:11   1x

Humanistic systems of care are fundamentally about facilitating genuine, caring working relationships between clinicians and families. Trust is the foundation of these relationships, an antidote to dehumanizaing experiences. Given families' expertise in their child's care, trust must reshape policy.

"We're creating cultural transformation in trust. You know, trusting families as colleagues... coordination and collaboration is done with a sense of trust, which is in that soil."
~CMC Cafe Family Faculty

SOIL:
Trust as
Paramount
The foundational medium
the entire system needs to
allow the right kind of care
to take root and grow into
fruitful outcomes.

Learn Why from
Families & Clinicians

TRUST

Back to the basics

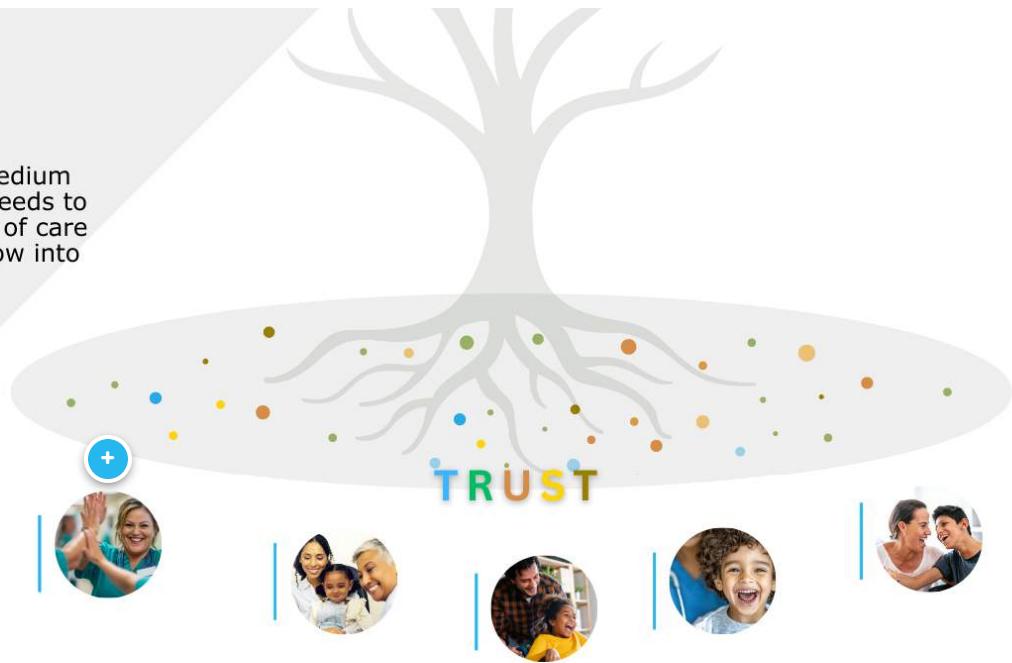▶ ━━●━━━━━━━━━━━━━━━ 0:18 1x 🔊 📄

"I think sometimes in the beginning we overcomplicate and we don't need to. It's back to some of the basics... relationship–building foundational skills: active listening, empathy... If we take that approach to how we're doing this, it becomes an authentic relationship or partnership instead of that power dynamic relationship"
~CMC Cafe Family Participant

SOIL:
Trust as
Paramount
The foundational medium
the entire system needs to
allow the right kind of care
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fruitful outcomes.

Learn Why from
Families & Clinicians

TRUST

Rebuilding of trust

0:14 1x
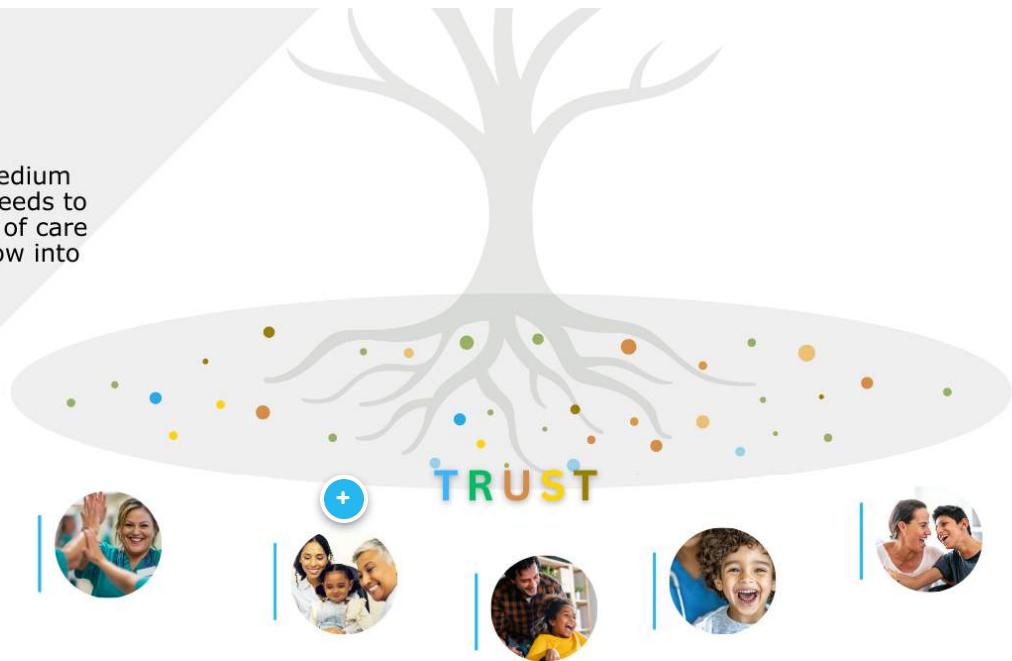
"We can no longer rely on...the model 'Let me tell you what you need to know'. Everybody needs to be mindful of how do we earn the trust of the people that we're trying to serve and disavow the notion of hierarchy, of tradition, and in many cases recognize that trauma has occurred, and it really is a rebuilding of trust."
~CMC Cafe Family/Clinician Faculty

**SOIL:
Trust as
Paramount**
The foundational medium
the entire system needs to
allow the right kind of care
to take root and grow into
fruitful outcomes.

Learn Why from
Families & Clinicians

TRUST

Trust permeates

0:04   1x
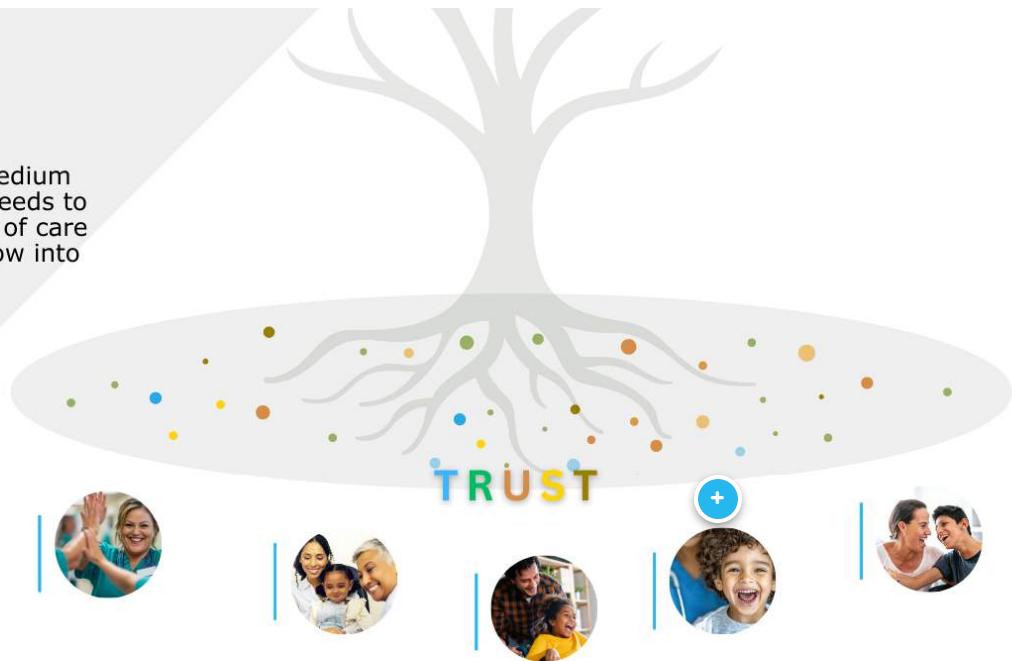
"Trust kind of permeates through the soil...it's part of it all."
~CMC Cafe Family Faculty

SOIL: Trust as Paramount
The foundational medium the entire system needs to allow the right kind of care to take root and grow into fruitful outcomes.

Learn Why from Families & Clinicians

TRUST

Relationships grounded in trust

▶ ───●────────────────────── 0:14 1x 🔊 📄

"Developing authentic relationships grounded in trust and respect and earning that trust through humility, honesty and being present, providing individualized whole person care aligned with family goals and priorities."
~CMC Cafe 2 Participant & Family Navigator

SOIL:
Trust as
Paramount
The foundational medium the entire system needs to allow the right kind of care to take root and grow into fruitful outcomes.
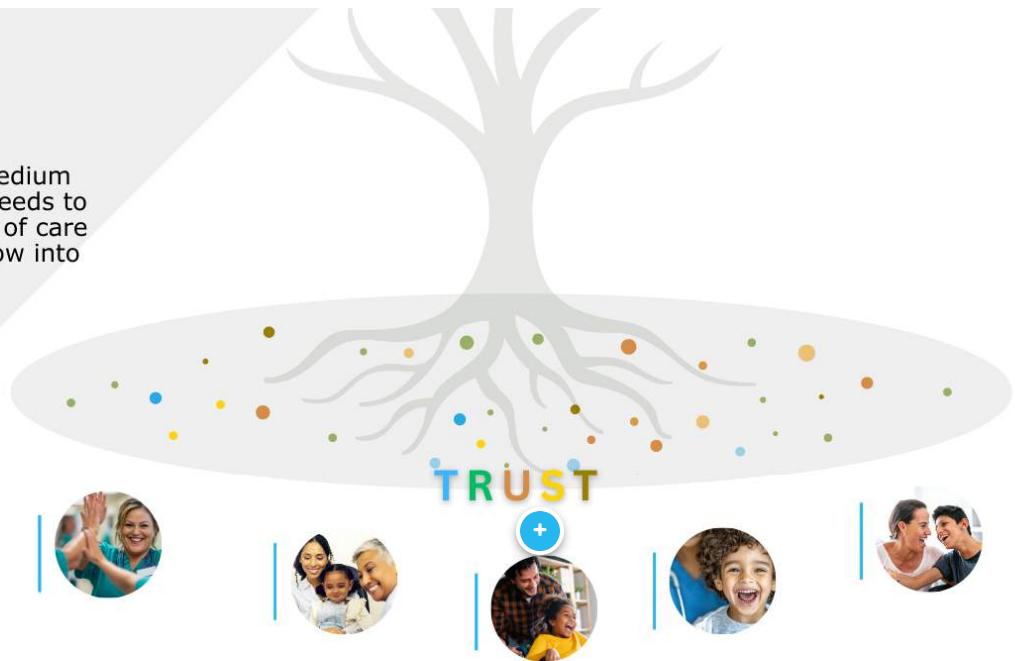
Learn Why from Families & Clinicians
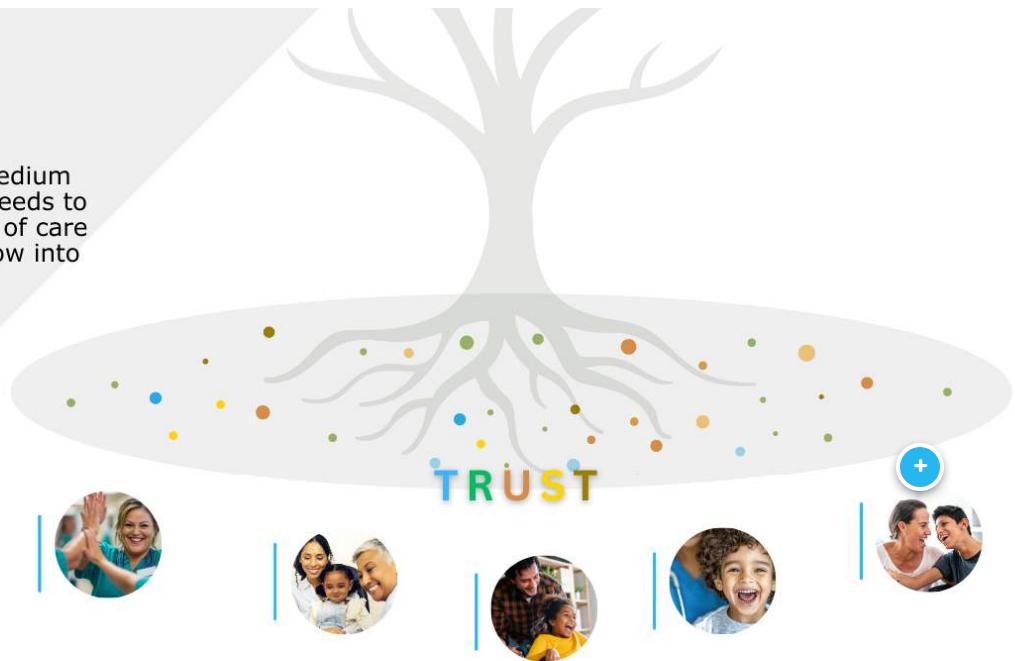
TRUST

Trust is part of mutuality

▶ ──────●────────────────── 0:14 1x 🔊 📄

"...trusting families. That's a somewhat radical thing to say. It shouldn't be. But, you know, it's part of the mutuality of patient and family centered care... You have to trust us ...we really have to trust families as the experts."
~CMC Cafe Family Faculty

ROOTS:
Core Elements of Humanistic Care
The core, indispensable principles that nourish and sustain systems transformation through the humanistic care framework to benefit CMC, families and clinicians.

Families & Clinicians Describe Each Element in Their Own Words

Prioritize Well-Being & Quality of Life

Mutuality of Expertise

Center Joy & Meaning

Embrace Clinician's Humanity

Relationship-Driven

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Families & Clinicians Describe Each Element in Their Own Words

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Embrace Clinician's Humanity

Relationship-Driven

Humanistic Care as the Roots of Change

▶ ━━●━━━━━━━━━━━━━ 0:11 1x 🔊 📄

Humanistic systems of care at the core enable clinicians to focus on the human side of care as the path to better outcomes: building genuine relationships with families, sharing in the richness of their everyday realities, and partnering with them to provide individualized, whole-person care based on what is most important to that family and child.

"We're starting from the premise that everyone's a human, and we all need to be able to feel like the care is actually within a system of care that honors our shared humanity."
~CMC Cafe Clinician Faculty

ROOTS: Core Elements of Humanistic Care

The core, indispensable principles that nourish and sustain systems transformation through the humanistic care framework to benefit CMC, families and clinicians.

Families & Clinicians Describe Each Element in Their Own Words

Prioritize Well-Being & Quality of Life

Mutuality of Expertise

Center Joy & Meaning

Embrace Clinician's Humanity

Relationship-Driven

Family: Value each individual

0:11   1x

"Value each individual and recognize their life and the value of that life to them and their loved ones. Do not try to estimate the quality of life for another person."
~CMC CoIIN Focus Group Participant

ROOTS:
Core Elements of Humanistic Care
The core, indispensable principles that nourish and sustain systems transformation through the humanistic care framework to benefit CMC, families and clinicians.

Families & Clinicians Describe Each Element in Their Own Words

Prioritize Well-Being & Quality of Life

Mutuality of Expertise

Center Joy & Meaning

Embrace Clinician's Humanity

Relationship-Driven

Clinician: Retrain to show up in the room differently

▶ ●───────────────────────── 0:24   1x 🔊 ▯

"We had to literally retrain ourselves about how to be in the room... We even say, we put the computer away for the second part of the conversation... It is an evaluation of 'How are you doing? What supports do you have? Who helps you? Do you have someone you would call in the event of an emergency? How are the other children? Is there something else outside of this that is hard and heavy for you?'"
~CMC Cafe Family & Clinician Faculty

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Relationship-Driven

Family: We are clinicians

▶ ●───────────────── 0:16 1x 🔊 📄

"That is one of the biggest things I think that we're lacking as parents of medically complex kids is that understanding that we are clinicians... providing clinical care in the home where most care is taking place, and that is where again, I've experienced that kind of partnership."
~CMC Cafe Family Faculty

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Relationship-Driven

Clinician: Need each other's expertise

▶ ●───────────────────────────── 0:21 1x 🔊 📄

"We come from an acute care world... which is a paradigm that does not work when all of the diagnosis has more or less been made, and you are going there to sort of figure out "how do I make the best life possible?". There the expertise distance is much smaller. So it's a different kind of relationship that needs to happen."
~CMC Cafe Family/Clinician Faculty

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Relationship-Driven

Family: Find out what's important

0:10 1x

"'Tell me what's important to you. Tell me what's important to your family and your child.' Then that just opens it all up to work on all of these other pieces."
~CMC Cafe Family/Clinician Faculty

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Embrace Clinician's Humanity

Relationship-Driven

Clinician: Joy in sharing power

▶ ●—————————————————— 0:13   1x   🔊   📄

"Joy in sharing power with families – it actually is mutually beneficial. It brings joy into the work where it can, and helps to humanize care when you're able to connect in that way."
~CMC Cafe Family/Clinician Faculty

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Embrace Clinician's Humanity

Relationship-Driven

Family: Doctor relating as a human being matters

▶ ●————————————————————— 0:14 1x 🔊 📄

"One doctor ... spoke to us as a doctor but also a human being. They're different perspectives. [Clinicians] are so knowledgeable about medical stuff but there's more to life ... someone who 'gets it' makes a difference."
~CMC CoIIN Family Focus Group Participant

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Mutuality of Expertise

Center Joy & Meaning

Embrace Clinician's Humanity

Relationship-Driven

Clinician: Take your humanity into account

0:20   1x

"My own vulnerabilities, and how I feel about myself. How my own biases get in my own way of taking care of my patient… How can I be…trustworthy… How can I be a high quality partner in all my relationships where I trust and I'm trusted."
~CMC Cafe Family/Clinician Faculty

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- Prioritize Well-Being & Quality of Life
- Mutuality of Expertise
- Center Joy & Meaning
- Embrace Clinician's Humanity
- Relationship-Driven

Family: Matters for both families & clinicians

▶ ——●———————————————— 0:12 1x 🔊 📄

"We're all trying to be engaged as humans. First and foremost in a fundamentally human pursuit which is taking care of kids. And I think valuing both sides of that relational contract is critically important."
~CMC Cafe Family/Clinician Faculty

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Mutuality of Expertise

Center Joy & Meaning

Embrace Clinician's Humanity

Relationship-Driven

Clinician: We also want relational care

▶ ━━●━━━━━━━━━━━━━━━ 0:15   1x   🔊   📄

"We really want relational health and not transactional health. And I think the clinicians really want that, too... if I'm just like an AI bot telling you that you should get an immunization, it's a little different than me talking about... just the trust."
~CMC Cafe Clinician Faculty

Learn from real-life stories about the soil & roots
Don't miss the powerful experiences of family and clinician participants and faculty from the CMC Cafe series about why trust is the soil and what the five core principles of humanistic care (the roots) look like.

GO TO "TRUST IS PARAMOUNT" STORIES

TRUNK: Family-Clinician Partnership

No single entity can affect meaningful change alone—it requires families & clinicians, alongside policymakers, and payers working together.

Learn Why from Families & Clinicians

FAMILY-CLINICIAN PARTNERSHIP
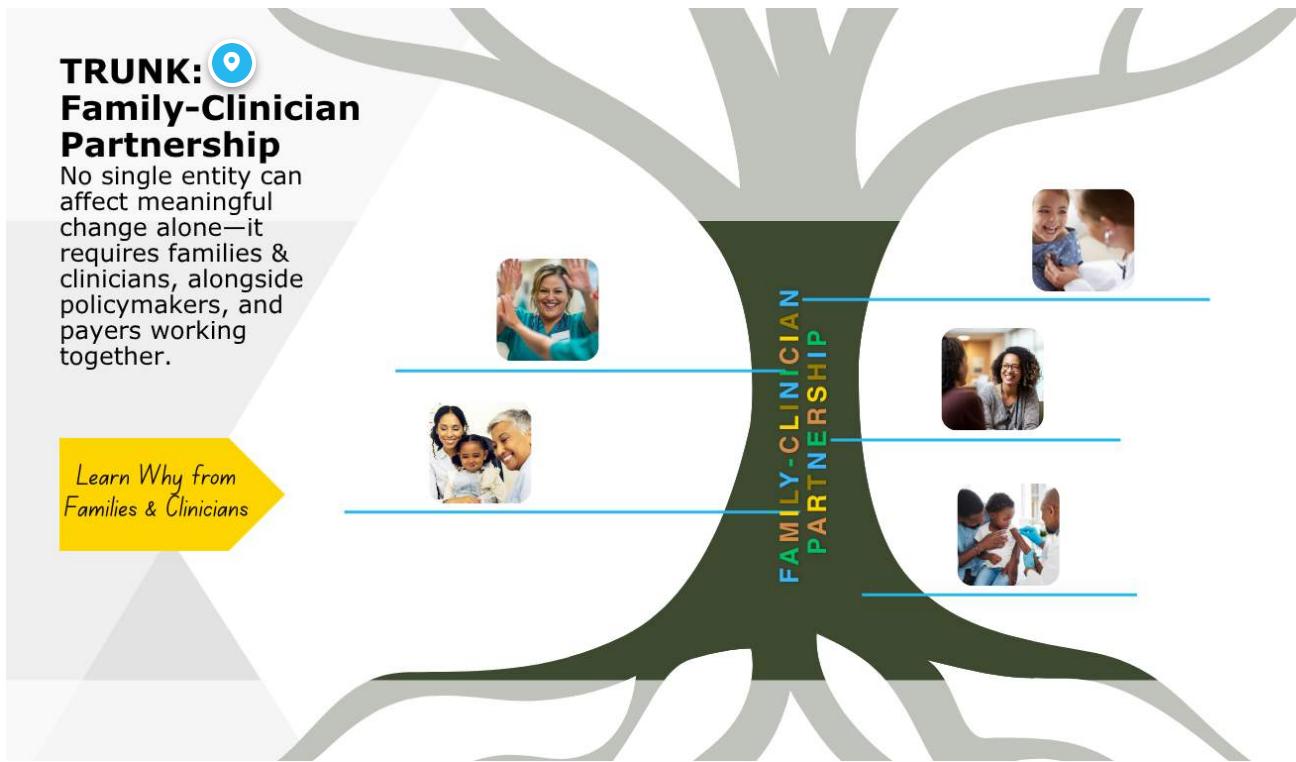
Why Family-Clinician Partnership is the Trunk

▶ ━━●━━━━━━━━━━━━━━━━━━━━ 0:17   1x 🔊 📄

Family colleagues and clinicians need each other's complementary perspective, expertise, and camaraderie to humanize systems design at every level as the two groups most engaged in the care of CMC. This partnership is integral to identifying, advocating for, and building key collaborations to address the core policy challenges facing CMC.

"As we're working together as a team, we all bring expertise and experience that's unique… [that has] equal value."
~CMC Cafe Family Faculty

"Families need to be involved in the process, co-creators and drivers of what the needs truly are."
~CMC Cafe Family Presenter

TRUNK:
Family-Clinician Partnership
No single entity can affect meaningful change alone—it requires families & clinicians, alongside policymakers, and payers working together.

Learn Why from Families & Clinicians

FAMILY-CLINICIAN PARTNERSHIP

Practical solutions

0:11   1x

"You're not going to find solutions without involving the people who are experiencing the problem... families typically have practical solutions rather than wanting to change entire systems."
~CMC Cafe Family Faculty

TRUNK:
Family-Clinician Partnership

No single entity can affect meaningful change alone—it requires families & clinicians, alongside policymakers, and payers working together.

Learn Why from Families & Clinicians

FAMILY-CLINICIAN PARTNERSHIP

Co-design & technical solutions

0:17   1x

"The approach gets away from a checklist idea and what can feel to people with lived expertise as token participation versus really a deep and what we're calling radical family partnership, and what that needs to look like, and how that drives technical solutions and drives co-design."

~CMC Cafe Clinician Faculty

TRUNK: Family-Clinician Partnership

No single entity can affect meaningful change alone—it requires families & clinicians, alongside policymakers, and payers working together.

Learn Why from Families & Clinicians

FAMILY-CLINICIAN PARTNERSHIP

Other partners are also needed

▶ ●————————————————————— 0:30 1x 🔊 📄

"We have been able to solve a lot of these kinds of issues through educating state policy officials somewhat, even at pretty high levels into the State Medicaid program. And I have used ... a medical legal partnership to assist me with this...I'm a family member. I'm an advocate, but I don't have a law degree. But when I partner with someone who has a law degree, who says 'You know, she's right about this, you need to be doing these things. And so you need to figure out a way to do this, or we're gonna have to file something.' suddenly things get done."

~CMC Cafe 3 Family Participant

TRUNK: Family-Clinician Partnership
No single entity can affect meaningful change alone—it requires families & clinicians, alongside policymakers, and payers working together.

Learn Why from Families & Clinicians

FAMILY-CLINICIAN PARTNERSHIP

Builds coalitions

▶ ●────────────────── 0:13 1x 🔊 📄

"This approach [of family-clinician partnership in systems change] has two advantages: it addresses immediate problems for families and builds coalitions through successful action that can support future steps."
~CMC Cafe Clinician Faculty

TRUNK: Family-Clinician Partnership
No single entity can affect meaningful change alone—it requires families & clinicians, alongside policymakers, and payers working together.

Learn Why from Families & Clinicians

FAMILY-CLINICIAN PARTNERSHIP
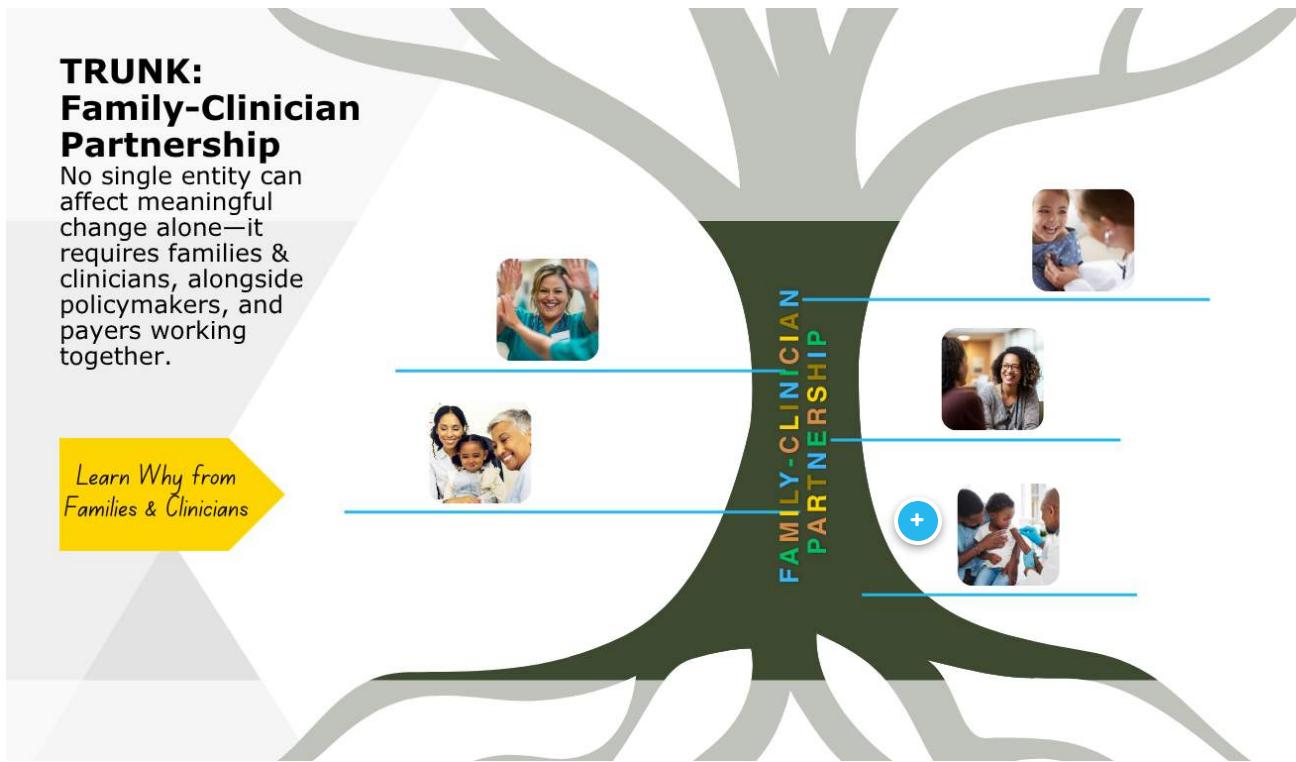
Design for highest needholder

0:16   1x

"I think we lose our way when we try to design for multiple stakeholders simultaneously. I think we have to design for the highest needholder, and the primary intended beneficiary, which in this case is children and families...it actually ultimately benefits all stakeholder groups."
~CMC Cafe 3 Participant

BRANCHES:
Urgent Impact
Areas &
Strategies
Reaching across
systems of care to
center the structures
essential for
humanistic care
to thrive.

Click the i icon for
strategies
Click the + icon for
illustrative quotes

Culture &
Power
Shift

Co-Design of
Education &
Training Based
in Real Life

Policies Cultivate
Shared Humanity,
Joy & Well-Being

Humanistic
Measures
Capture Value

Payment Values
Relationship &
Trust Building

BRANCHES:
Urgent Impact Areas & Strategies
Reaching across systems of care to center the structures essential for humanistic care to thrive.

Click the i icon for strategies
Click the + icon for illustrative quotes

Culture & Power Shift

Policies Cultivate Shared Humanity, Joy & Well-Being

Co-Design of Education & Training Based in Real Life

Payment Values Relationship & Trust Building
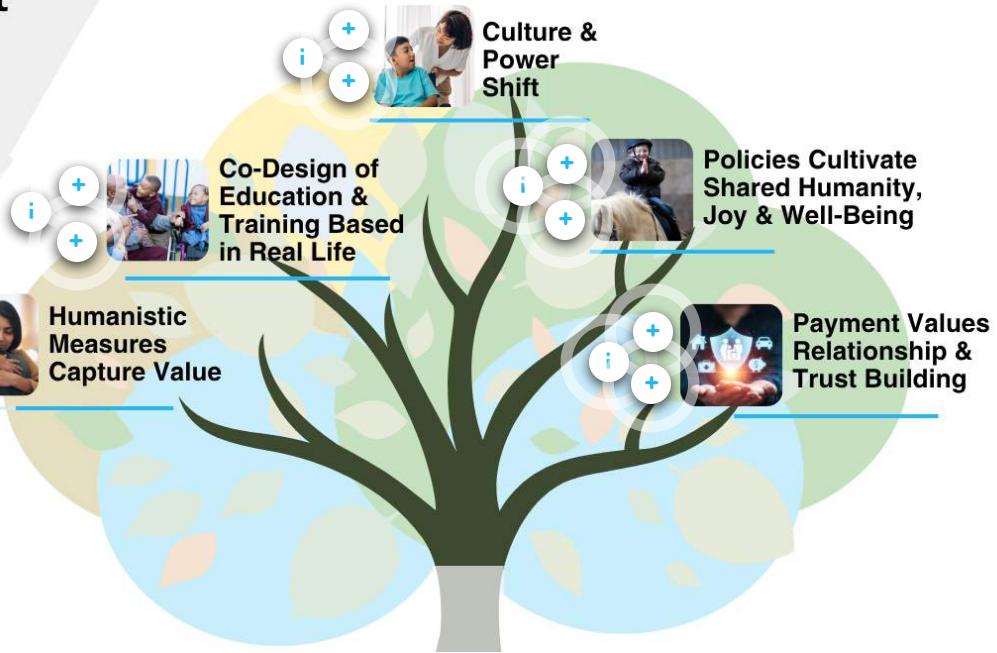
Humanistic Measures Capture Value

How Did Faculty Identify the Branches?

Key Characteristics of Strategies:

1. Important to CMC and their families
2. Supports clinician well-being
3. Urgency
4. Concrete and actionable
5. Increased efficiency/decreased waste
6. Simplification – removing barriers, not adding them
7. Innovative/testing novel ways to interact/work together – new approaches

Additional Criteria:

1. Evidence-based/evidence-informed
2. Feasible/implementable – whether families and clinicians both feel bought into it (gutcheck – is it realistic) - what can we do now with the resources we've got?
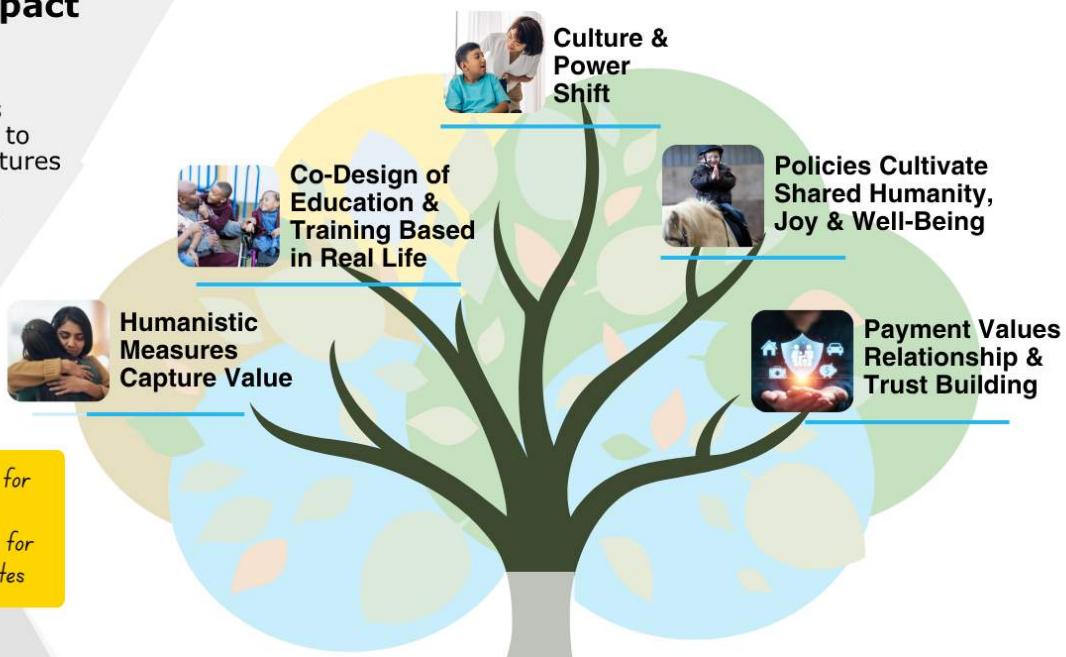3. Quick win
4. Measurable
5. Political will/feasibility

BRANCHES: Urgent Impact Areas & Strategies

Reaching across systems of care to center the structures essential for humanistic care to thrive.

Click the i icon for strategies
Click the + icon for illustrative quotes

Culture & Power Shift

Co-Design of Education & Training Based in Real Life

Policies Cultivate Shared Humanity, Joy & Well-Being

Humanistic Measures Capture Value

Payment Values Relationship & Trust Building
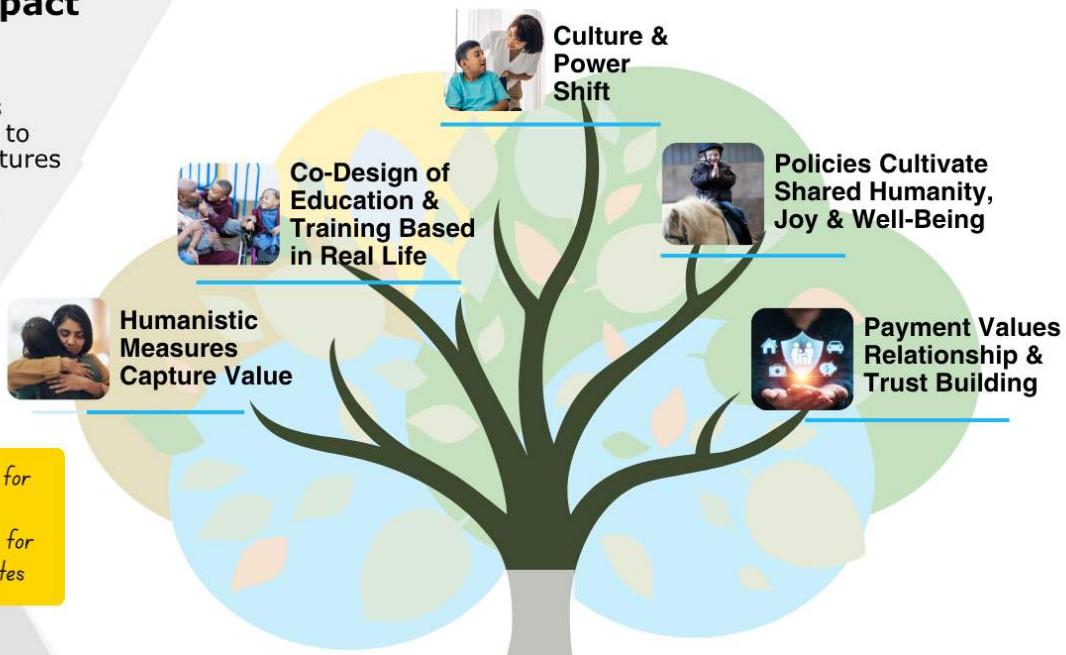
Humanistic Measures Capture Value

- **Measure experience, not just satisfaction**: Track what children, families, and clinicians actually experience in care, using tools like care maps to identify gaps and hold systems accountable

- **Center family-defined and clinician-supportive outcomes**: Measure quality of life, well-being, and what familiies and clinicians say matters most, including relationships and joy

- **Start research from family priorities**: Design studies based on what families identify as important to avoid bias and capture real value from lived expertise, alongside clinicians

- **Question existing measures**: Review current metrics for unintended bias (like comparing to typically developing children) and assess how deeply family expertise shaped the research

BRANCHES: Urgent Impact Areas & Strategies
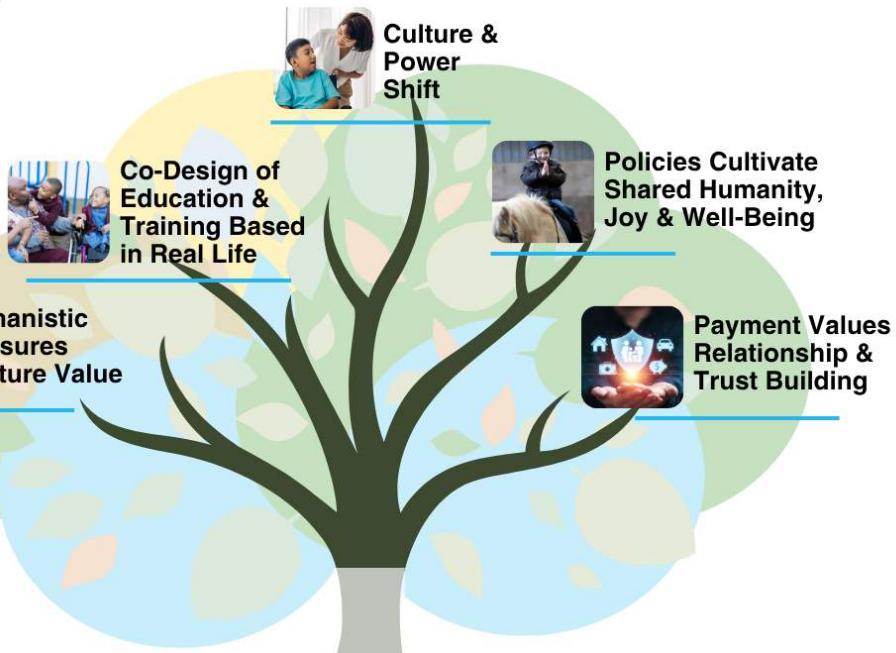Reaching across systems of care to center the structures essential for humanistic care to thrive.

Culture & Power Shift

Co-Design of Education & Training Based in Real Life

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Humanistic Measures Capture Value

Payment Values Relationship & Trust Building

Click the i icon for strategies
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"Common ground" measures

0:22   1x

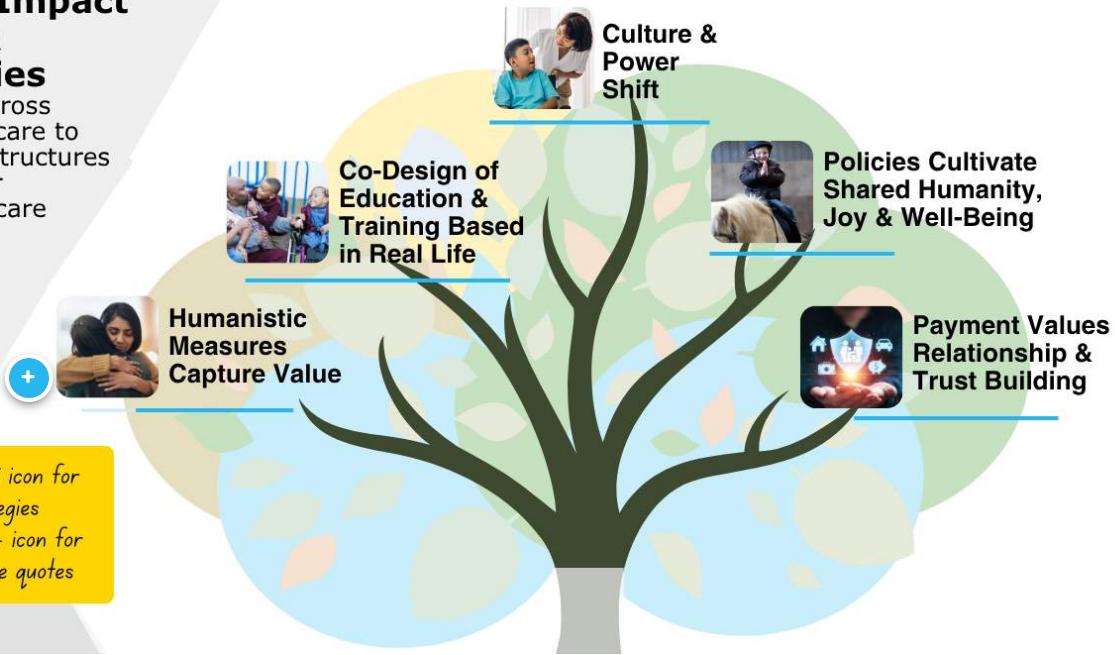*"Identifying "common ground" measures that permit a shared approach to designing policies that benefit multiple stakeholders...the need to find overlap between what families need and what payers are incentivized to provide: would empowering a family to have access to a co-produced plan of care that describes who's responsible for what – 'Would that make your life better?'"*
~CMC Cafe Clinician Faculty

BRANCHES: Urgent Impact Areas & Strategies
Reaching across systems of care to center the structures essential for humanistic care to thrive.

Culture & Power Shift

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Humanistic Measures Capture Value

Payment Values Relationship & Trust Building

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Quality of life is central
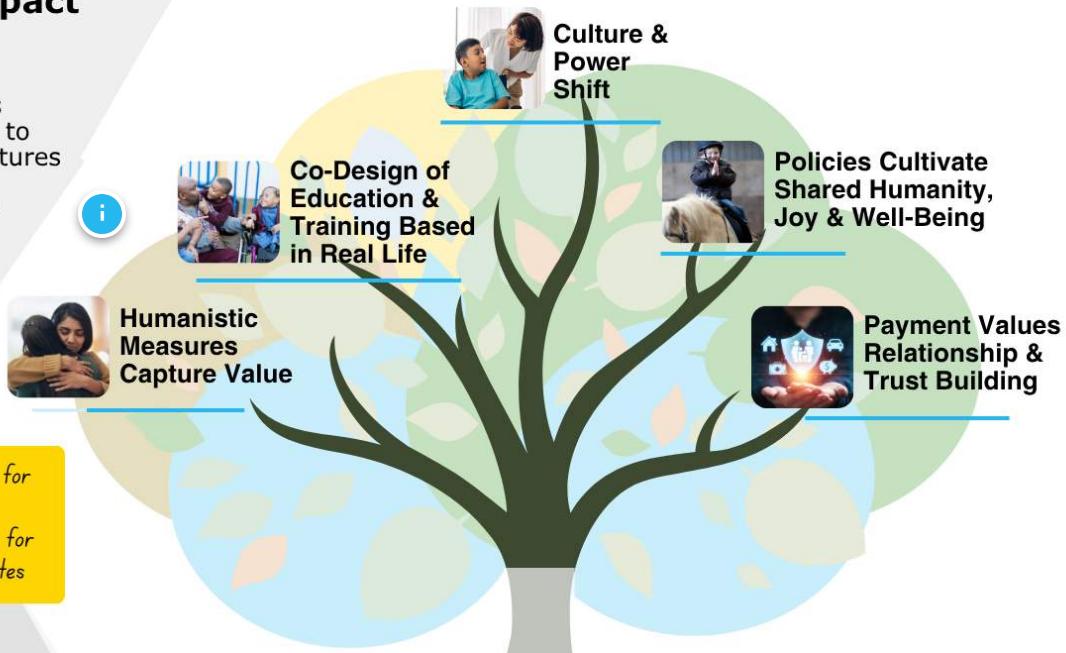
▶ ●━━━━━━━━━━━━━━━━━━━━ 0:09 1x 🔊 📄

"If quality of life is a central design outcome that we're designing to for CMC, then we would design a completely different system."
~CMC Cafe Family/Clinician Faculty

BRANCHES: Urgent Impact Areas & Strategies
Reaching across systems of care to center the structures essential for humanistic care to thrive.

Culture & Power Shift

Co-Design of Education & Training Based in Real Life

Policies Cultivate Shared Humanity, Joy & Well-Being

Humanistic Measures Capture Value

Payment Values Relationship & Trust Building

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Co-Design of Education & Training Based in Real Life

- **Integrate lived experience into training**: Include narrative medicine, disability studies, and family stories in healthcare education with experiential learning like home visits and simulations

- **Establish family and youth faculty roles**: Position families and youth as co-educators in staff training, using their real-life experiences to drive reflective practice

- **Restore humanity in medical training**: Train clinicians in humanistic approaches from the start, creating psychological safety for vulnerability and authentic relationships

- **Break down silos between disciplines**: Create interdisciplinary co-education focused on relationships and shared humanity while maintaining professional boundaries

BRANCHES: Urgent Impact Areas & Strategies
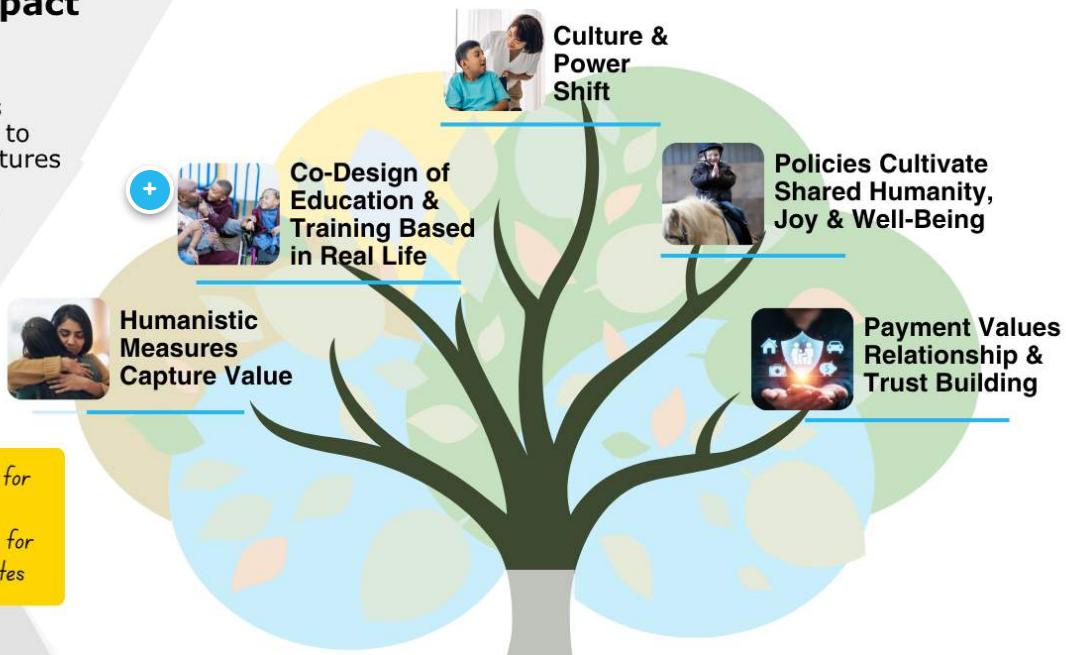Reaching across systems of care to center the structures essential for humanistic care to thrive.

Culture & Power Shift

Co-Design of Education & Training Based in Real Life

Policies Cultivate Shared Humanity, Joy & Well-Being

Humanistic Measures Capture Value

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Counteracting perfectionist culture

0:24   1x

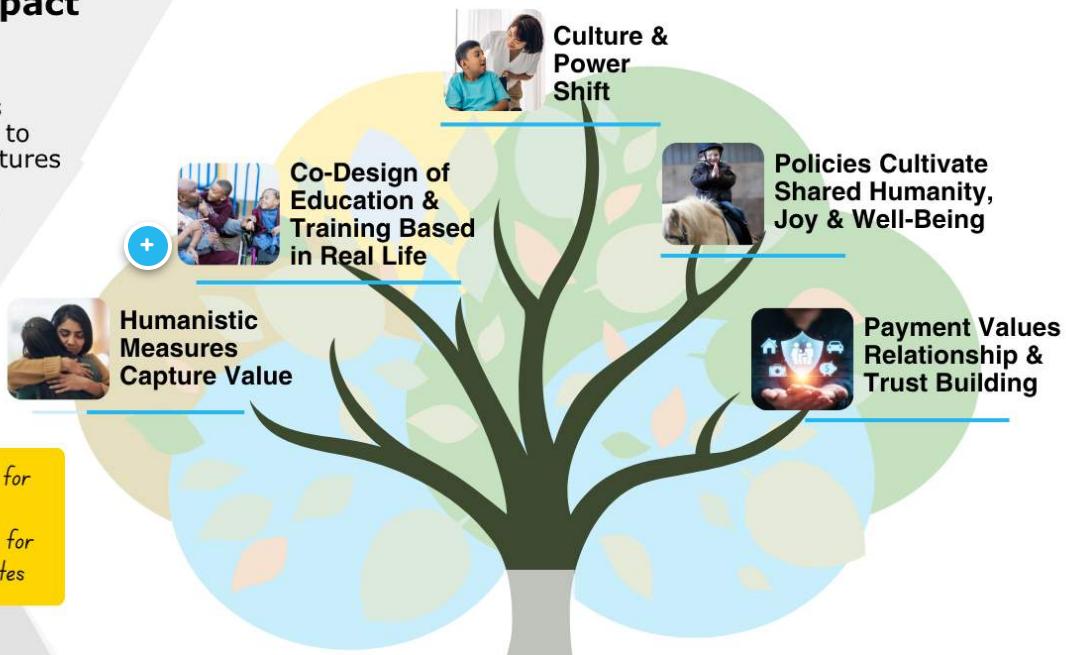*"Medical culture is creating [clinicians] that have to go after perfection...they don't know how to take care of themselves while also providing care...there is literature, of course, to call out the shame of feeling like they need to be perfect and to identify it...We have to talk about it [in medical training], right? Because shame thrives in secrecy and continues if we don't call it out."*
~CMC Cafe Family Faculty

BRANCHES: Urgent Impact Areas & Strategies

Reaching across systems of care to center the structures essential for humanistic care to thrive.

Click the i icon for strategies
Click the + icon for illustrative quotes

Culture & Power Shift

Co-Design of Education & Training Based in Real Life

Policies Cultivate Shared Humanity, Joy & Well-Being

Humanistic Measures Capture Value

Payment Values Relationship & Trust Building

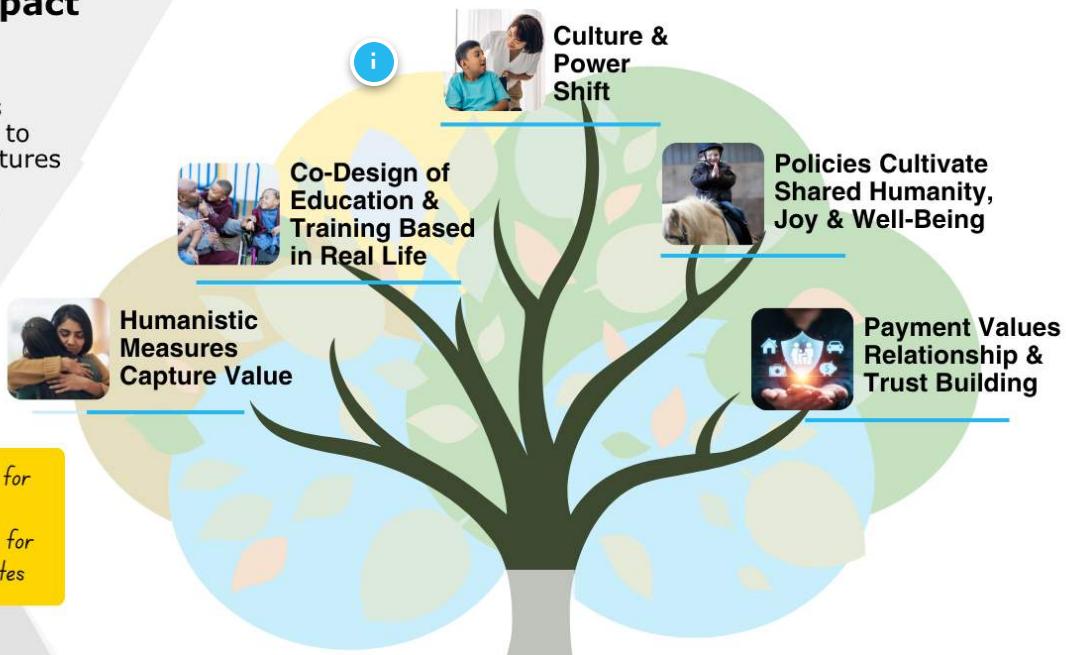**Understanding home life**

0:12   1x

"To be able to come into a home and see what our life is like, I think, was really valuable... to see the joy, because I think oftentimes that's missed where, you know, folks are rounding when kids are sleeping or when there's a crisis."
~CMC Cafe 2 Family Participant

BRANCHES: Urgent Impact Areas & Strategies
Reaching across systems of care to center the structures essential for humanistic care to thrive.

Culture & Power Shift

Co-Design of Education & Training Based in Real Life

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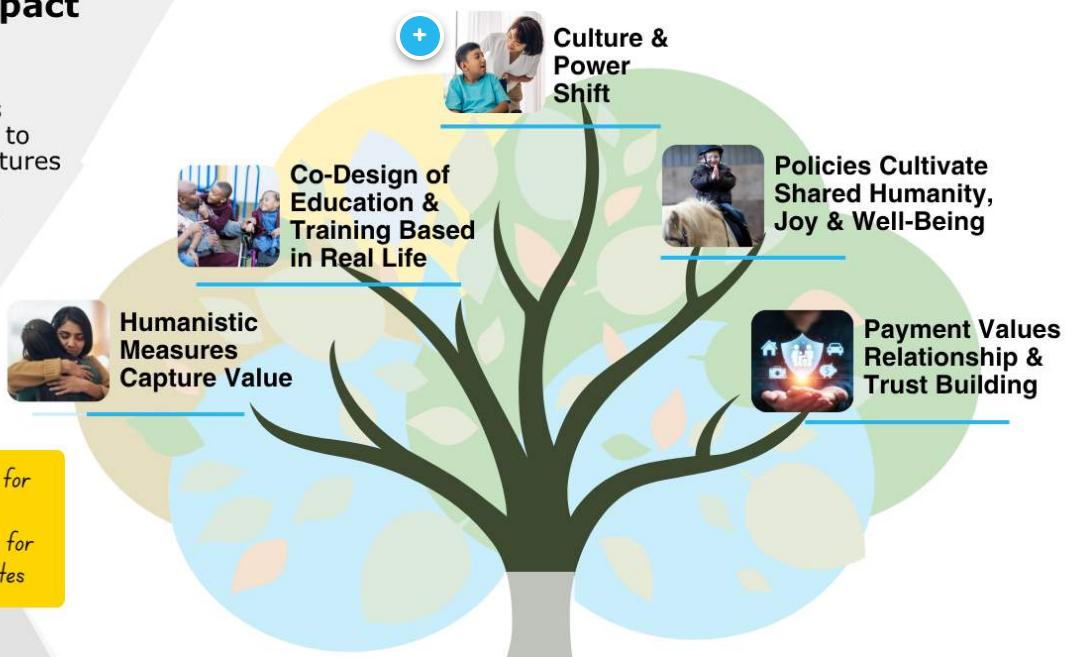Click the i icon for strategies
Click the + icon for illustrative quotes

Culture & Power Shift

- **Center well-being and challenge bias**: Transform culture through education and policies that actively address implicit bias, ableism, and trauma from healthcare experiences (see "Signs Everywhere Phenomenon")

- **Move to true partnership at all levels**: Create genuine partnership models beyond traditional advisory roles—families as colleagues in care teams and systems change (see "The Syringe Story")

- **Build trust and mutual respect**: Address power imbalances through training for all team members on effective partnership, transparent communication, feasible meeting options for family colleagues, and equal compensation

- **Use FESAT for systems assessment**: Implement the Family Engagement in Systems Assessment Tool to measure and improve meaningful family partnership

BRANCHES: Urgent Impact Areas & Strategies

Reaching across systems of care to center the structures essential for humanistic care to thrive.

Culture & Power Shift

Co-Design of Education & Training Based in Real Life

Policies Cultivate Shared Humanity, Joy & Well-Being

Humanistic Measures Capture Value

Payment Values Relationship & Trust Building

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Elevate humanism as a core value

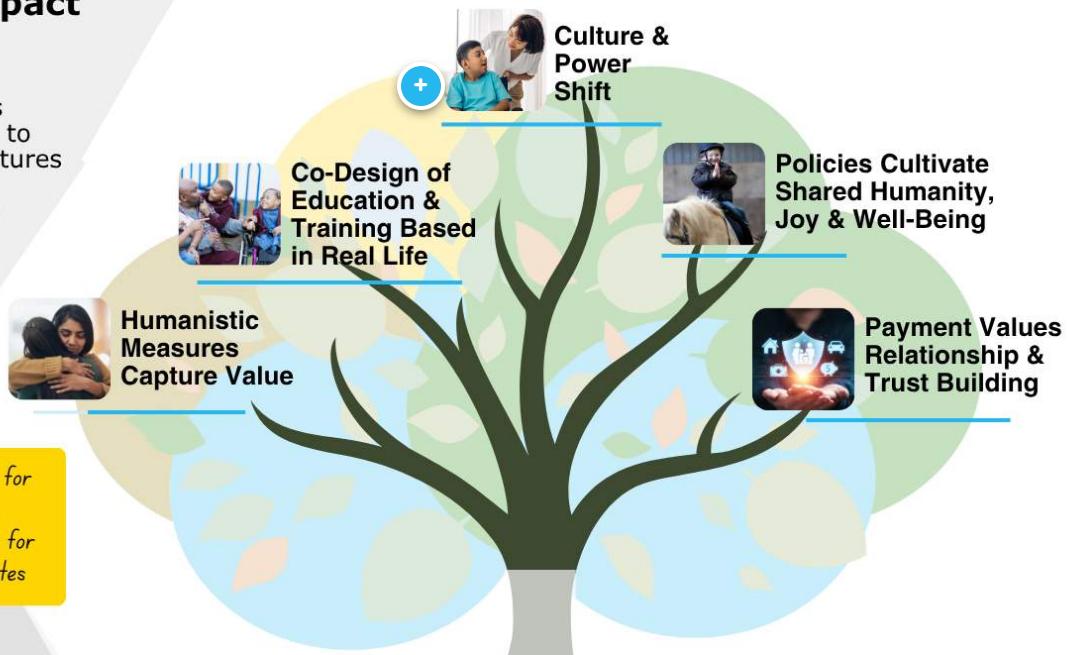
0:19   1x

"It also means embracing the discomfort that can come with slowing down, being vulnerable, and ceding some control in order to build authentic relationships. Leaders must create psychological safety for this type of growth for both families and clinicians and explicitly elevate humanism as a core value for everyone involved."
~CMC Cafe Family Faculty

BRANCHES: Urgent Impact Areas & Strategies

Reaching across systems of care to center the structures essential for humanistic care to thrive.

Culture & Power Shift

Co-Design of Education & Training Based in Real Life

Policies Cultivate Shared Humanity, Joy & Well-Being

Humanistic Measures Capture Value

Payment Values Relationship & Trust Building

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See the child as a full person
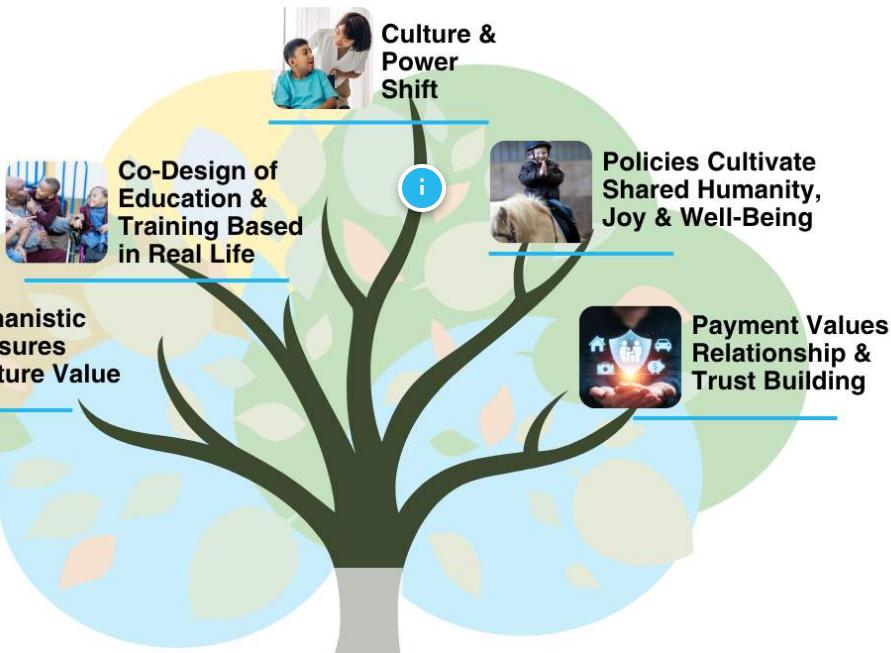
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"The mechanistic approach to the body...focuses so much on what is wrong with the body...to the complete exclusion of...who is the person who lives in that body...The humanism bit needs to completely change the culture and the paradigm."
~CMC Cafe Family/Clinician Faculty

BRANCHES: Urgent Impact Areas & Strategies
Reaching across systems of care to center the structures essential for humanistic care to thrive.

Click the i icon for strategies
Click the + icon for illustrative quotes

Culture & Power Shift

Co-Design of Education & Training Based in Real Life

Policies Cultivate Shared Humanity, Joy & Well-Being

Humanistic Measures Capture Value
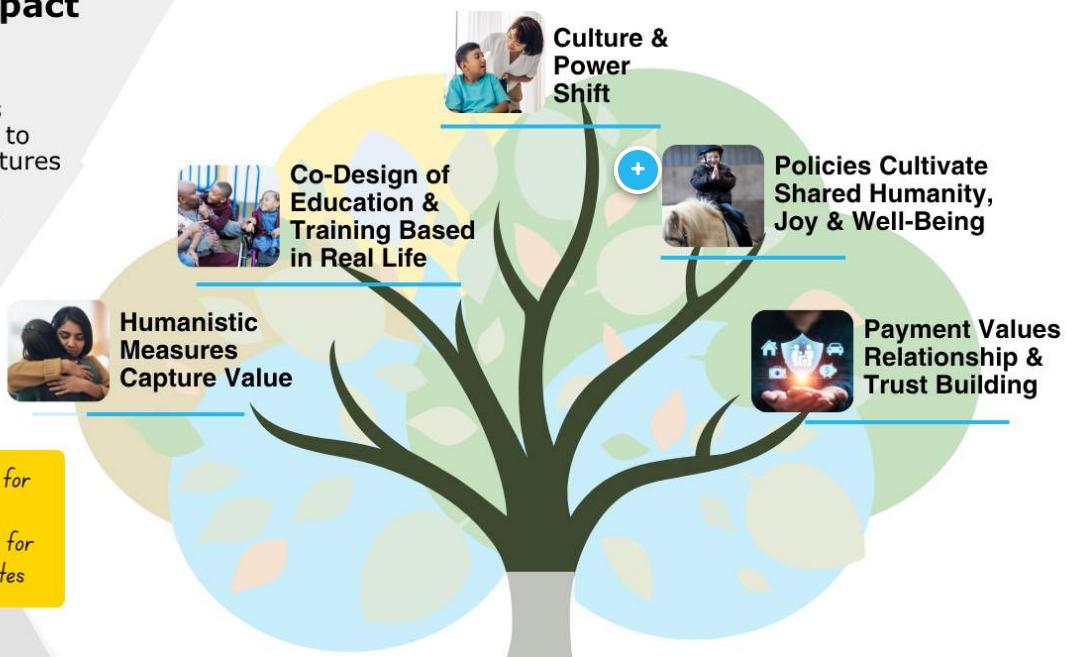
Payment Values Relationship & Trust Building

Policies Cultivate Humanity, Joy & Well-Being

- **Trust family expertise**: Create policies that enable family choice and control (e.g., medical supplies/equipment), reduce administrative burden, and actively support well-being. Leverage existing policies like EPSDT (Early & Periodic Screening, Diagnostic, & Treatement) benefits towards this end

- **Elevate joy as a clinical priority**: Center joy alongside medical intervention through palliative care principles and tested frameworks that prioritize quality of life, communication, and dignity

- **Partner with family-led organizations**: Develop referral pathways to family-led organizations and peer navigation at multiple touchpoints. Provide sustainable funding for ongoing collaboration

- **Support clinician well-being**: Codify team-based approaches with shared knowledge and collective support, including family leaders as colleagues. Build narrative medicine and reflective practice cultures

BRANCHES: Urgent Impact Areas & Strategies

Reaching across systems of care to center the structures essential for humanistic care to thrive.

Click the i icon for strategies
Click the + icon for illustrative quotes

Culture & Power Shift

Co-Design of Education & Training Based in Real Life

Policies Cultivate Shared Humanity, Joy & Well-Being

Humanistic Measures Capture Value

Payment Values Relationship & Trust Building

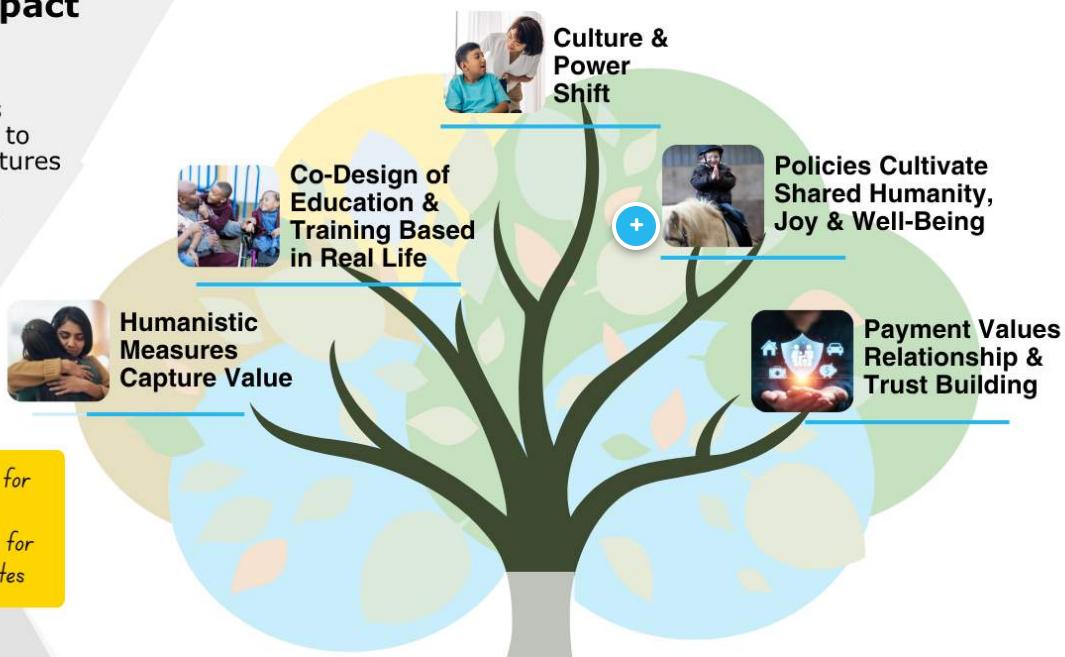**Time for reflective practice**

0:25   1x

"Once a week the team has a debrief session where we get together, and people just talk about the most compelling story they heard, and how it made them feel, but there is no room for reflective practice skill building in our current setup...I cannot justify to my administrator that we have to spend an hour debriefing on really compelling stories that we heard this week, just so we can process them."
~CMC Cafe Family/Clinician Faculty

BRANCHES: Urgent Impact Areas & Strategies
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Click the i icon for strategies
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Culture & Power Shift

Co-Design of Education & Training Based in Real Life

Policies Cultivate Shared Humanity, Joy & Well-Being

Humanistic Measures Capture Value

Payment Values Relationship & Trust Building

Team-based care with families

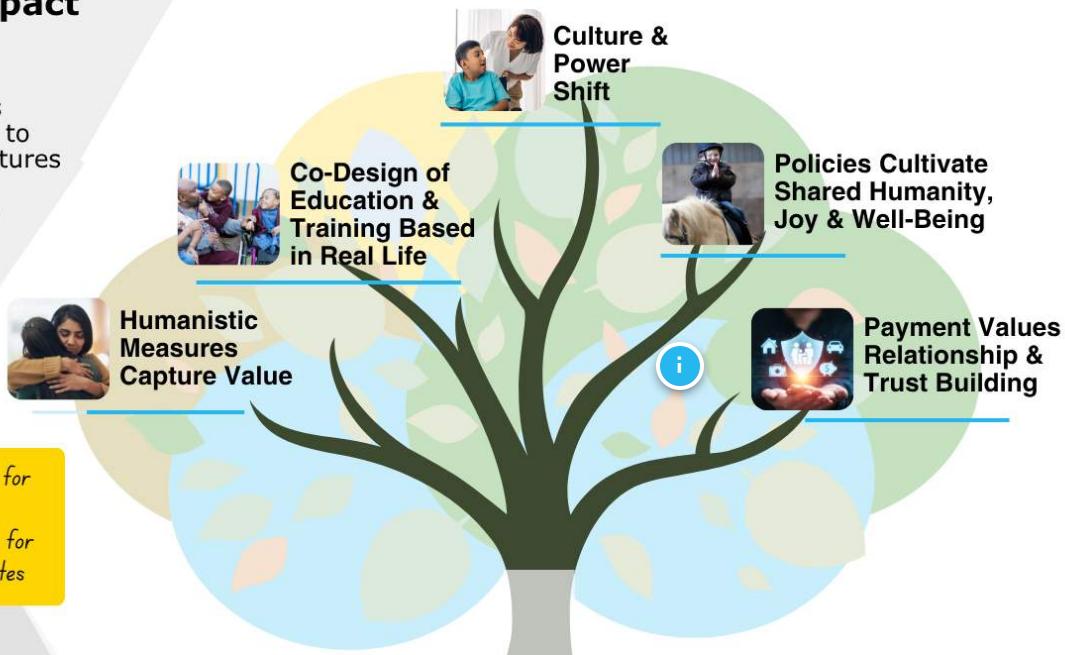▶ ●———————————————— 0:17 1x 🔊 📄

"I don't have joy in my work anymore. And now you're asking me to do even more. No, in fact, here's the approach for fixing the system. It's called team- based care with families on the team. Here's the approach for you to feel more joy in your work."
~CMC Cafe Clinician Faculty

BRANCHES: Urgent Impact Areas & Strategies

Reaching across systems of care to center the structures essential for humanistic care to thrive.

Culture & Power Shift

Co-Design of Education & Training Based in Real Life

Policies Cultivate Shared Humanity, Joy & Well-Being

Humanistic Measures Capture Value

Payment Values Relationship & Trust Building

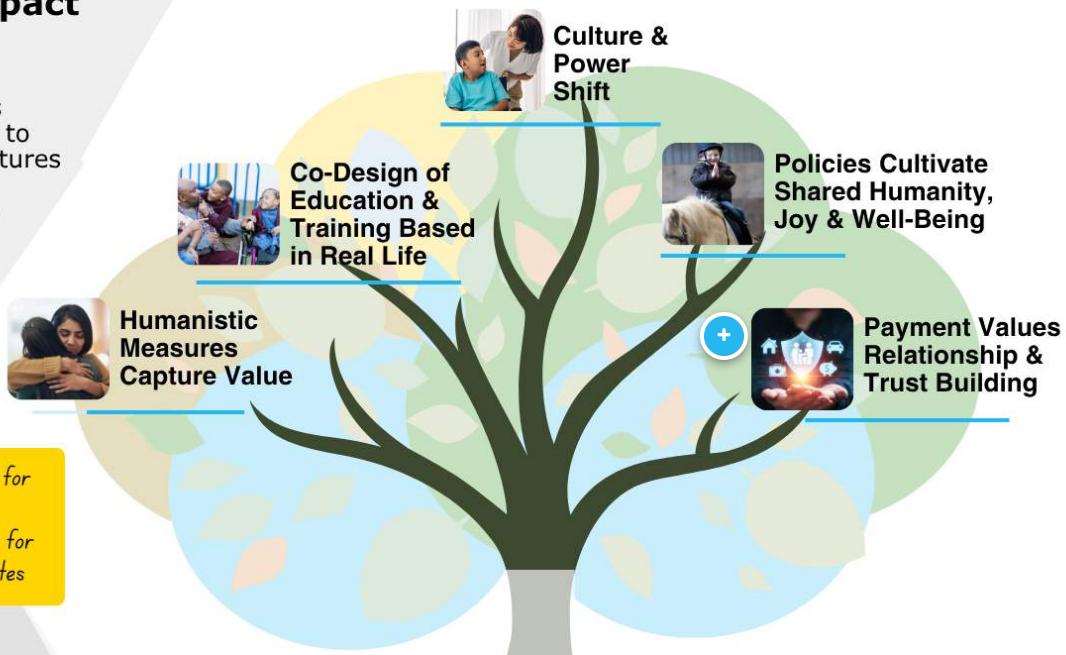Click the i icon for strategies
Click the + icon for illustrative quotes

Payment Values Relationship & Trust Building

- **Redesign payment to value relationships**: Realign payment systems and streamline administrative processes to enable clinicians to spend time building relationships with families as a core element of care

- **Rethink productivity metrics**: Move from efficiency measures toward models that reduce redundancies and support relational rather than transactional care

- **Engage managed care organizations early**: Include MCOs in transformation efforts and create "centers of excellence" to pilot relationship–based care models with flexible elements like transportation and telehealth

- **Fund partnership sustainably**: Provide payment for the time required to deliver humanistic care and sustainably resource family partnership roles in care teams and systems change

BRANCHES: Urgent Impact Areas & Strategies

Reaching across systems of care to center the structures essential for humanistic care to thrive.

Culture & Power Shift

Co-Design of Education & Training Based in Real Life

Policies Cultivate Shared Humanity, Joy & Well-Being

Humanistic Measures Capture Value

Payment Values Relationship & Trust Building

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Full biopsychosocial spiritual model

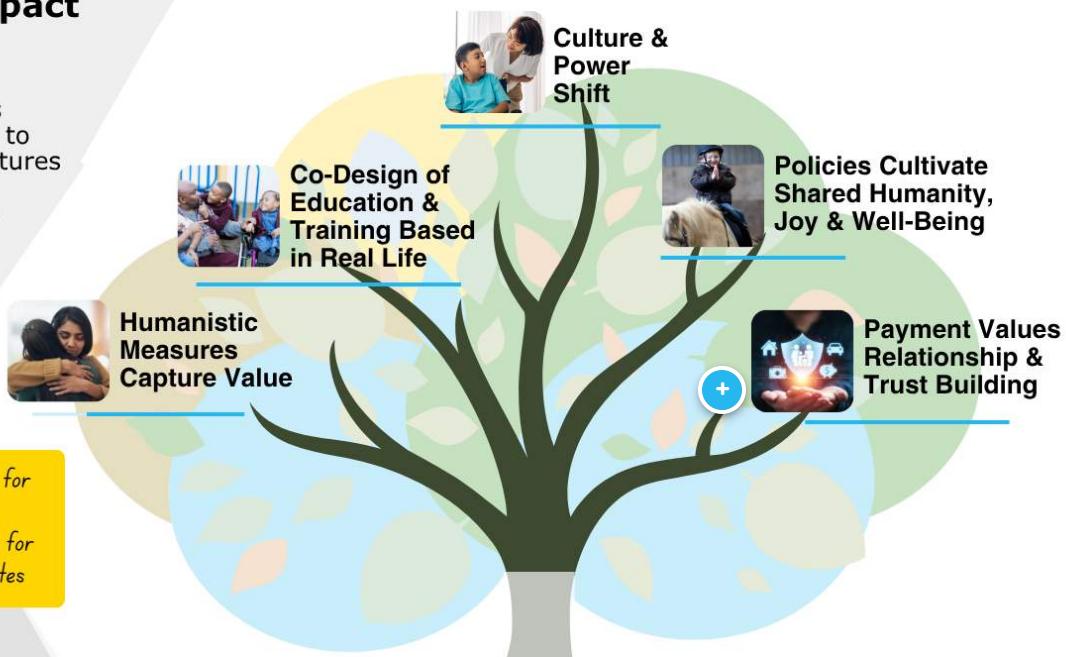▶ ──────●────────────────── 0:23 1x 🔊 📄

"We are also taking the family support approach... I offer 6 free [therapy] sessions ... Our nurse navigator does a great job of stacking appointments for families...we do virtual visits on a regular basis, so that our families don't actually have to come into a physical appointment. So we're really taking a full biopsychosocial spiritual model approach...we're only a year in ...our patient load is up to about 115"
~CMC Cafe 1 Clinician Participant

BRANCHES: Urgent Impact Areas & Strategies
Reaching across systems of care to center the structures essential for humanistic care to thrive.

Click the i icon for strategies
Click the + icon for illustrative quotes

Culture & Power Shift

Co-Design of Education & Training Based in Real Life

Policies Cultivate Shared Humanity, Joy & Well-Being

Humanistic Measures Capture Value

Payment Values Relationship & Trust Building

Time efficiencies are key

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"Time is the biggest limiter. So how do we work efficiencies into our workday to give us more time to have more humanistic interactions?"
~CMC Cafe Family/Clinician Faculty

How to Drive Practical Collective Change Across Roles Through the Framework

As named, this section of the guide describes how the humanistic care framework helps different changemakers.

GO TO SECTION ON CHANGE BY ROLE
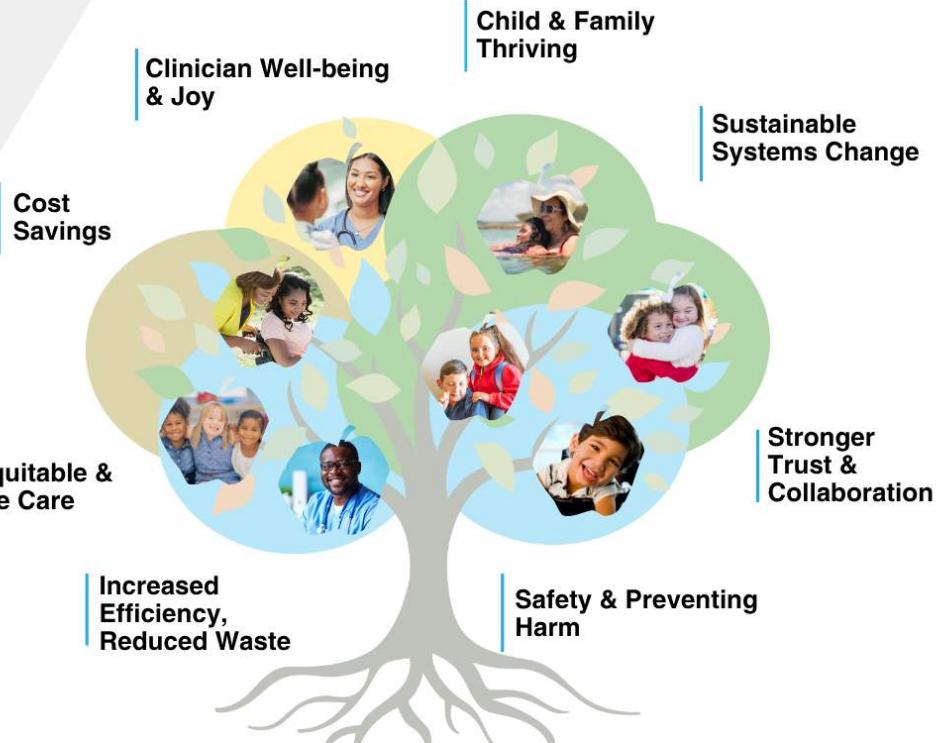
FRUIT: Better Outcomes

Focusing concrete action in urgent impact areas for humanistic care drives the kind of change we all value, benefiting not only CMC, their families, and clinicians but also systems of care overall.

Click the i icon for more info
Click the + icon for illustrative quotes

Child & Family Thriving

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Tying Humanistic Care to "Sweeter Fruit"
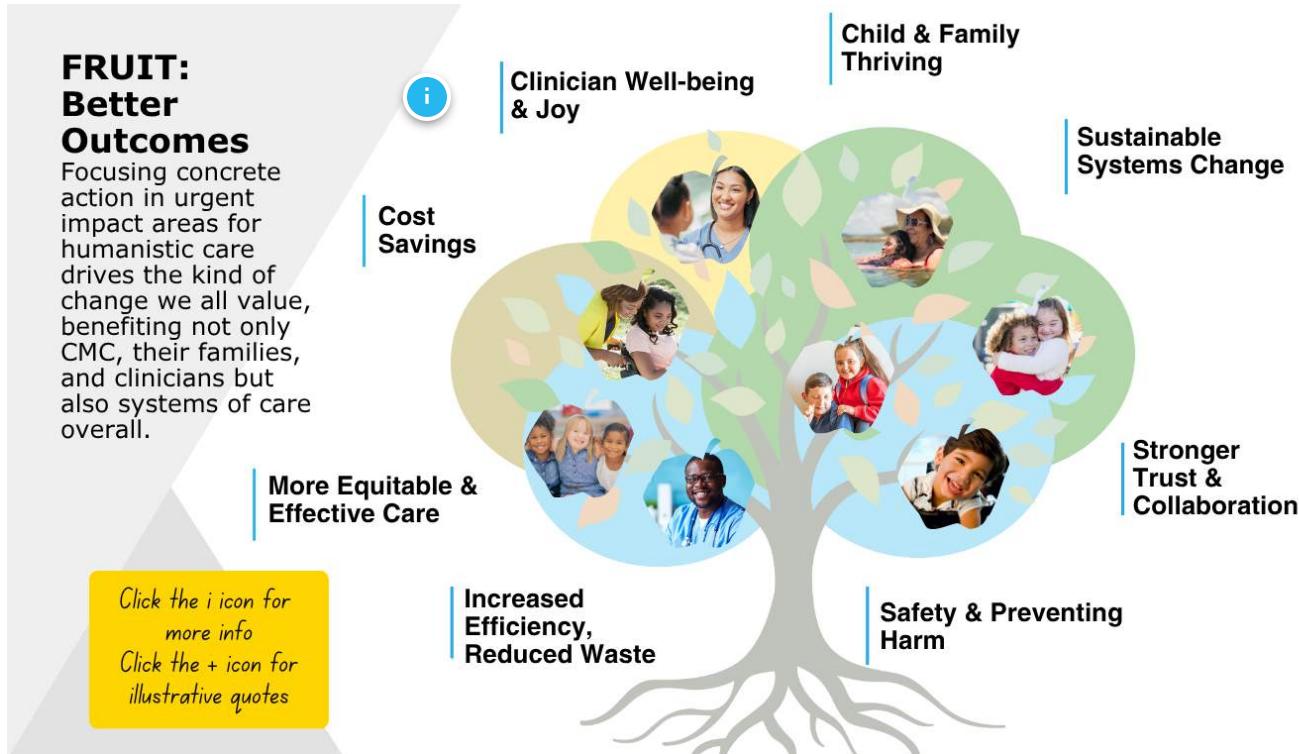
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Humanistic care isn't just a nice idea – it's practically essential for achieving the outcomes that matter most to children with medical complexity, their families, clinicians and the healthcare systems that support them.

"We're trying to find things that can be concrete and actionable that will create increased efficiency and decreased waste and simplification, removing barriers and not adding them."
~CMC Cafe Clinician Faculty

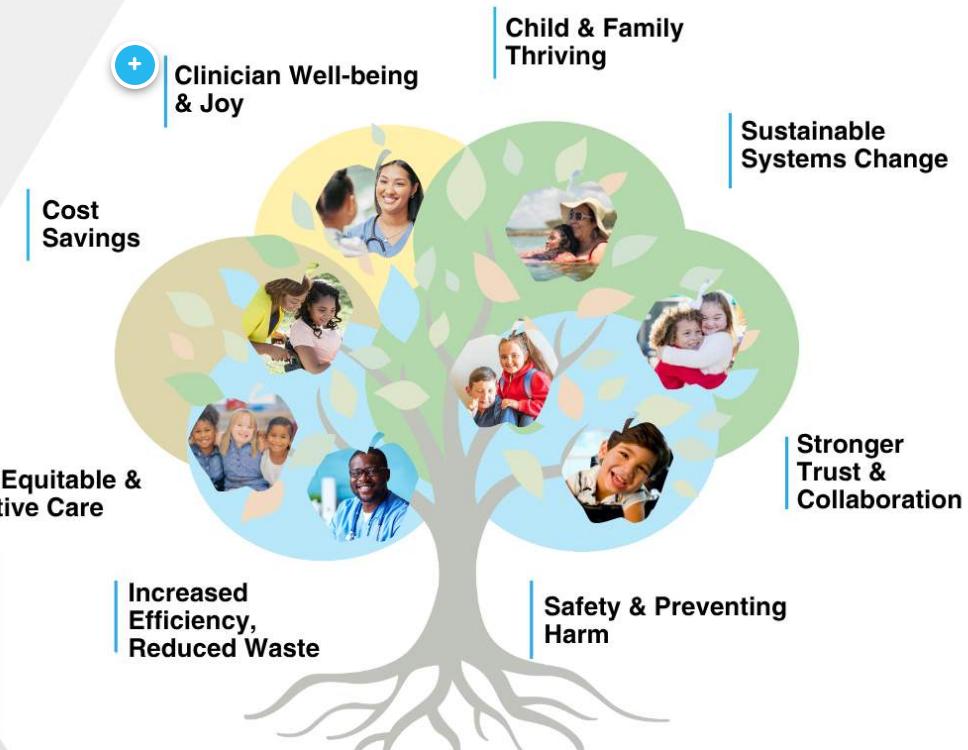*NOTE: Some quotes are repeated here from other sections for emphasis

FRUIT: Better Outcomes

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How it works:
When clinicians embrace authentic partnership and acknowledge families as experts, they discover more effective solutions and experience renewed purpose in their work.

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Joy in sharing power

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"By listening to families and truly sharing power. I mean, I'm a pediatrician...you have a lot of power over how the system works. If you think of it that way. But the reality is that there's this huge amount of joy in sharing the power and the authority with family members. And that's actually, I think, what all of us really want deep inside."
~CMC Cafe Clinician Faculty

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"More time to be human"

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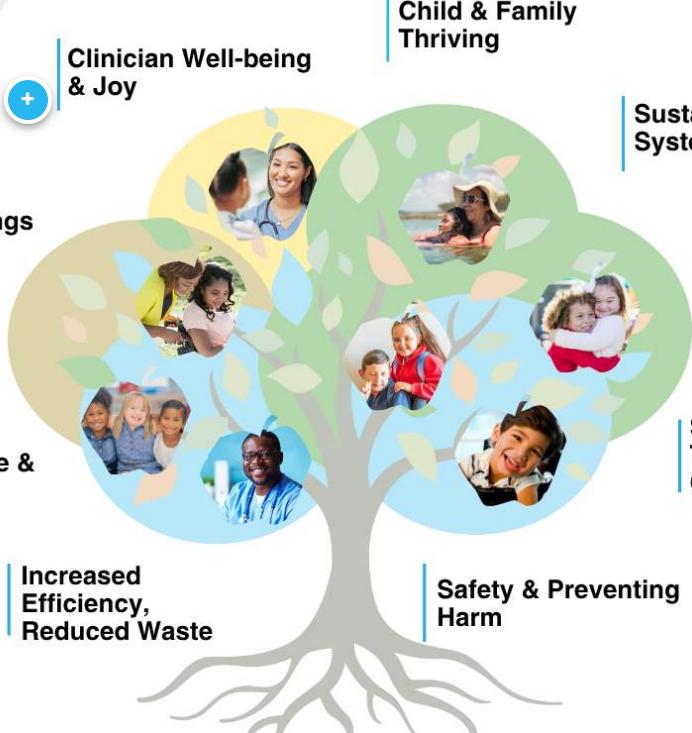
"And one of the outcomes that they actually measured was prevention of provider burnout. Because they actually had a [care] team there who could help [providers], you know, with being more human, give them more time to be human [with children and families]."
~CMC Cafe 2 Family Participant

FRUIT: Better Outcomes
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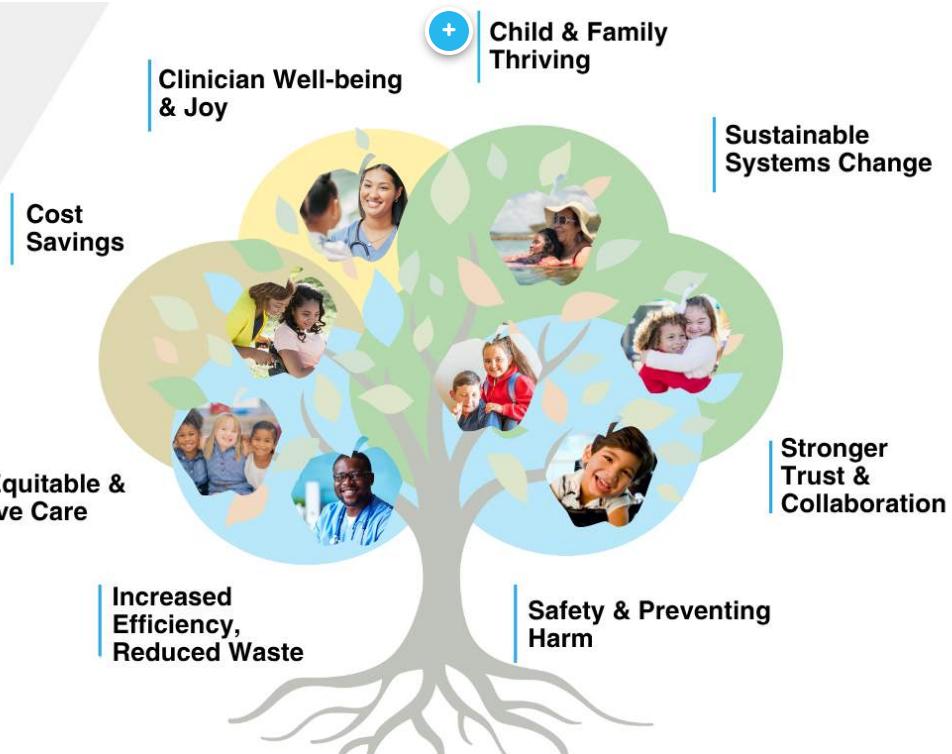
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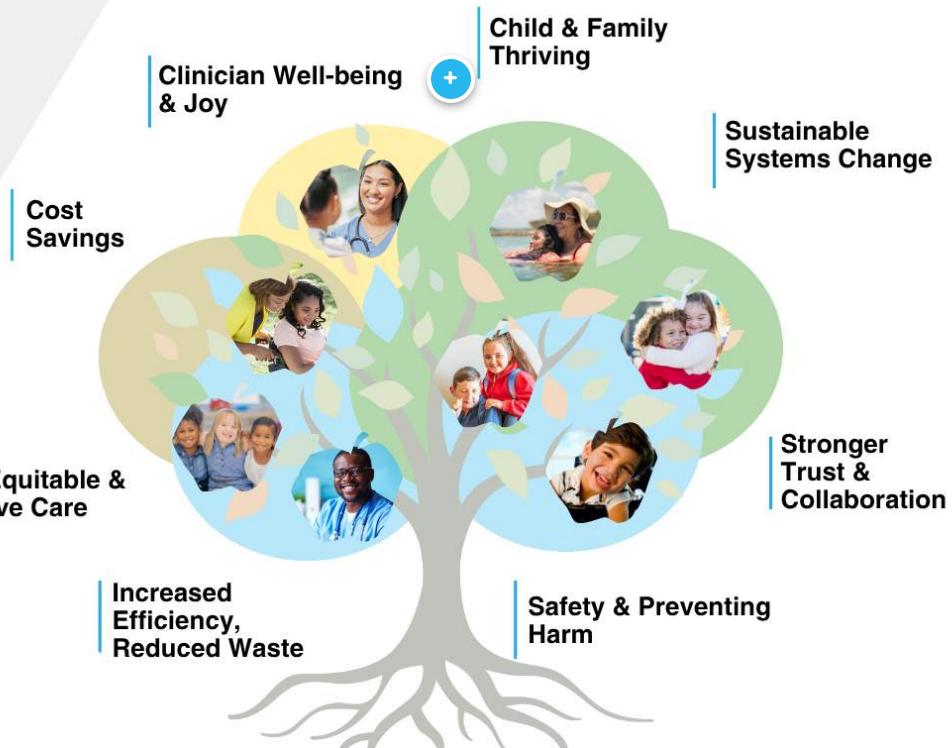Click the + icon for illustrative quotes

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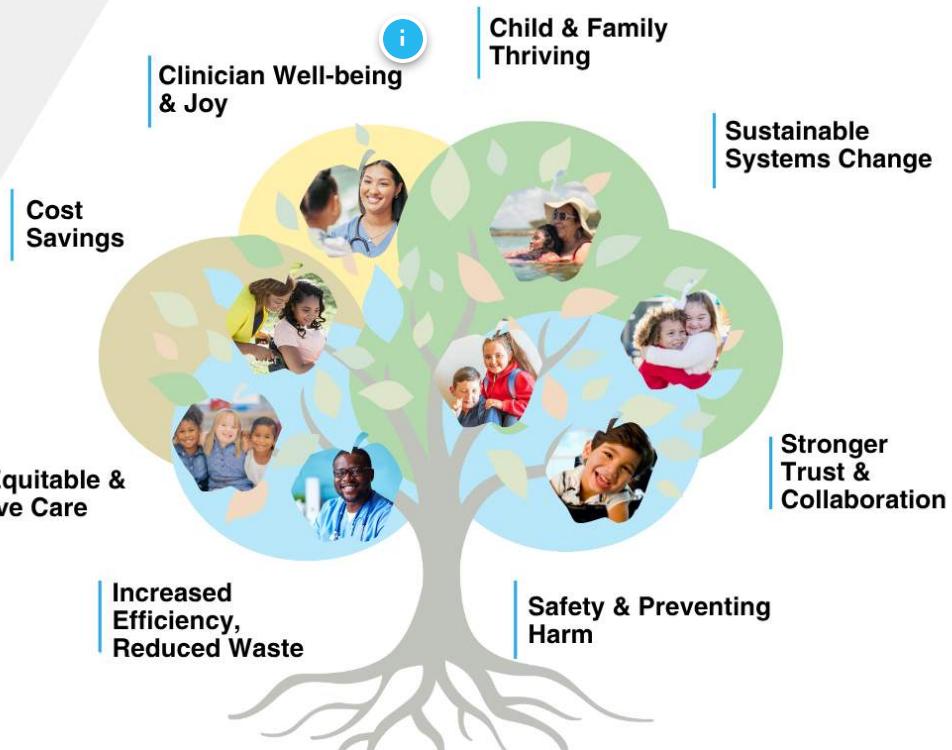
Child & Family Thriving

How it works:
Humanistic care focuses on what brings joy and meaning to CMC and their families' daily lives, removing barriers that create stress and supporting overall well-being and moments of play.

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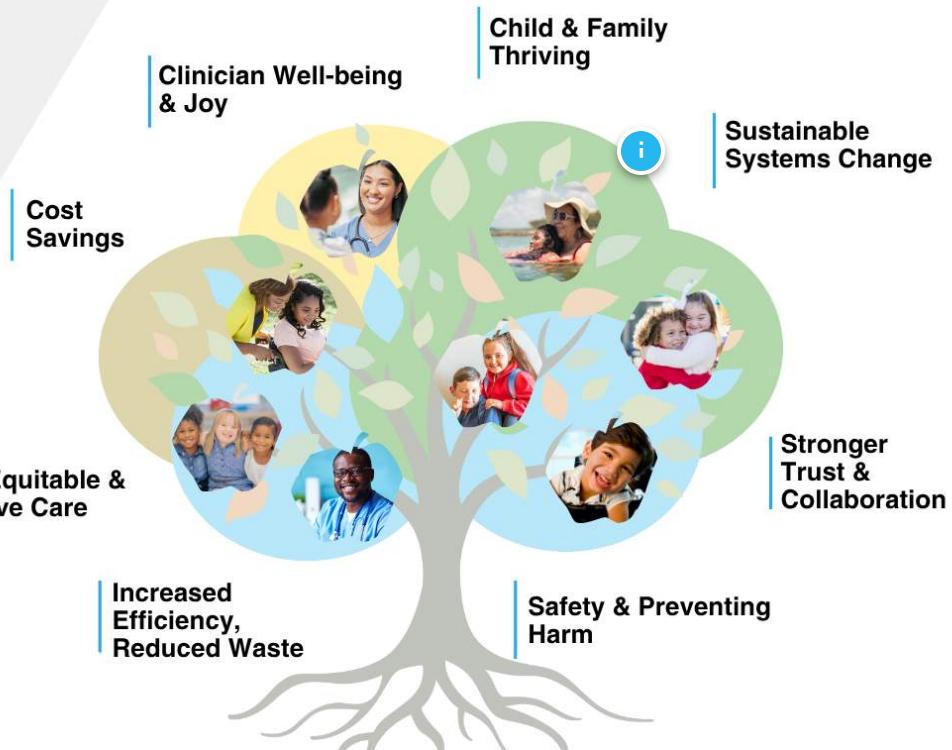
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Parent liaison to fully meet needs

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"We put into place a parent liaison, a parent with lived experience, a parent in the program...It has been truly magical because that individual understands it from all areas, from the lived experience and from the professional experience as well... and it has been transformative for families to be able to get what they need."
~CMC Cafe 2 Clinician Participant

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Affirm child's strengths

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"The child was being bullied...And by affirming the child's strengths, the child actually came off of all their medications. And an interesting follow up is that not only is the child more heavily engaged in school, at home and thriving, the child's continent testing actually went up, which I think is a testament to affirming the joy of childhood."
~CMC Cafe 2 Clinician Presenter (sharing about a case illustrating humanitstic care)

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Sustainable Systems Change

How it works:
By starting with family expertise and building trust, humanistic care creates solutions that are both high-impact and sustainable. Humanistic approaches often identify cost-effective solutions that systems can maintain long-term because they address root causes rather than symptoms.

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Trust in families yields sustainability

"If what we want to sustain, in order for it to become sustainable, having it being built on trust of families and around the expertise that they bring."
~CMC Cafe Family/Clinician Faculty

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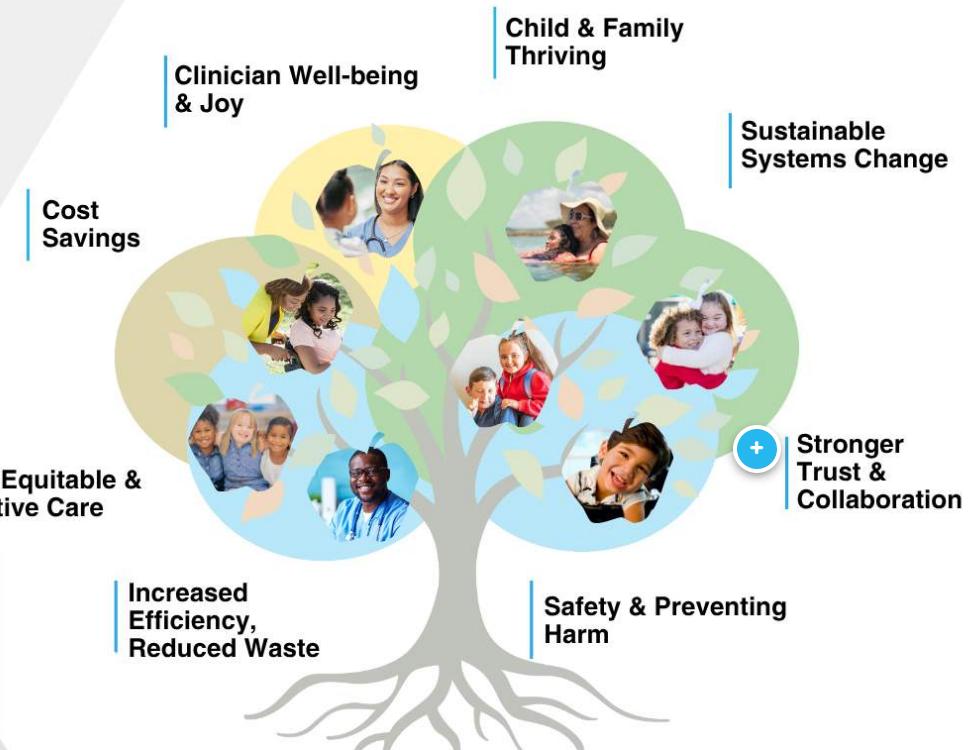
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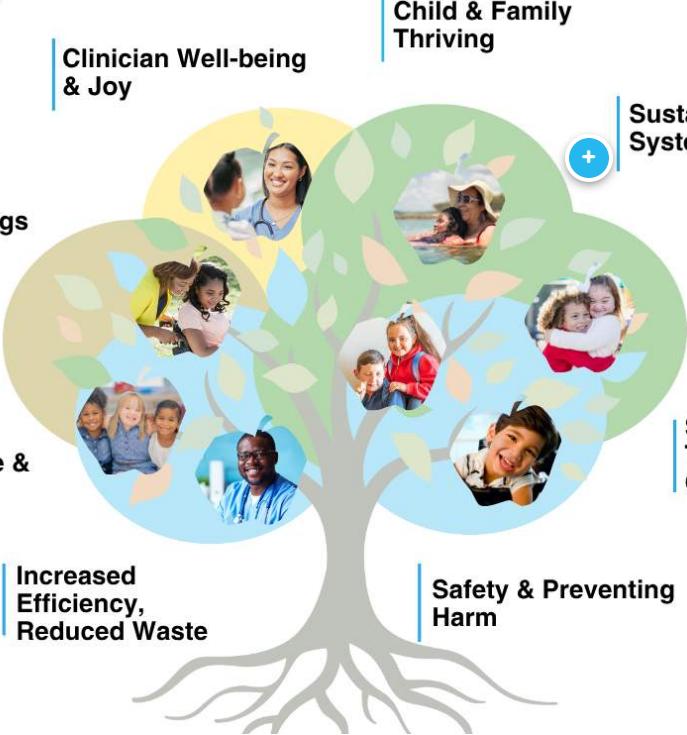
Transmission of empathy is key

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"I think that transmission of empathy is key to sustainability. You don't really get stuff done if you just present policy makers with facts and demand things. The personal stories really allow for empathy transmission in talking to policy makers ...for the policymakers to see the families and see themselves as being able to make it work (what families and clinicians need)."

~CMC Cafe Clinician Faculty

FRUIT: Better Outcomes
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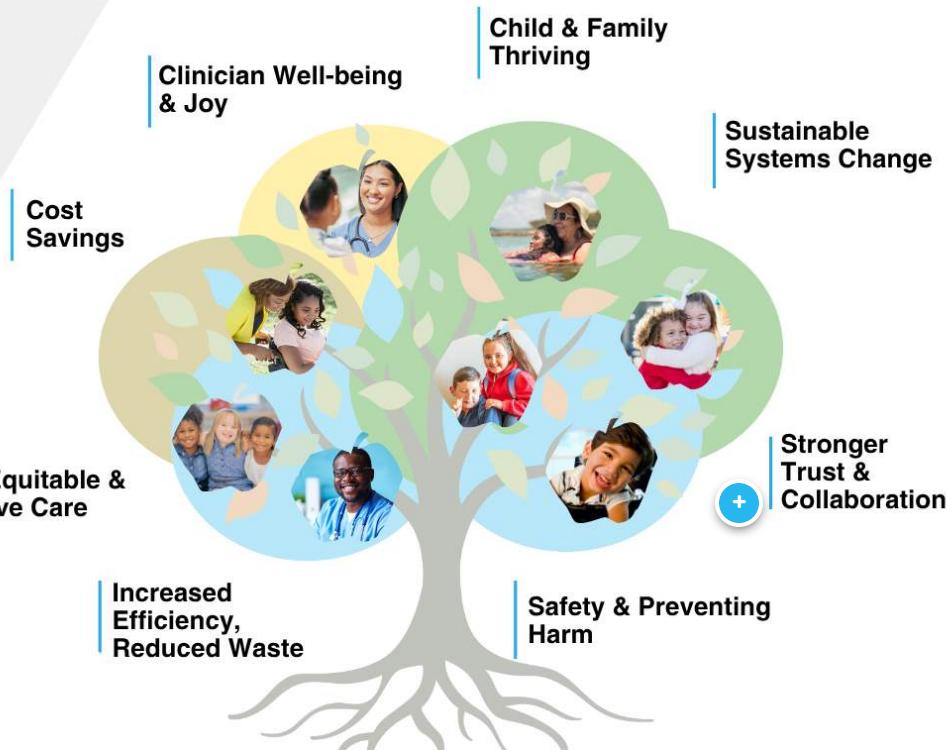
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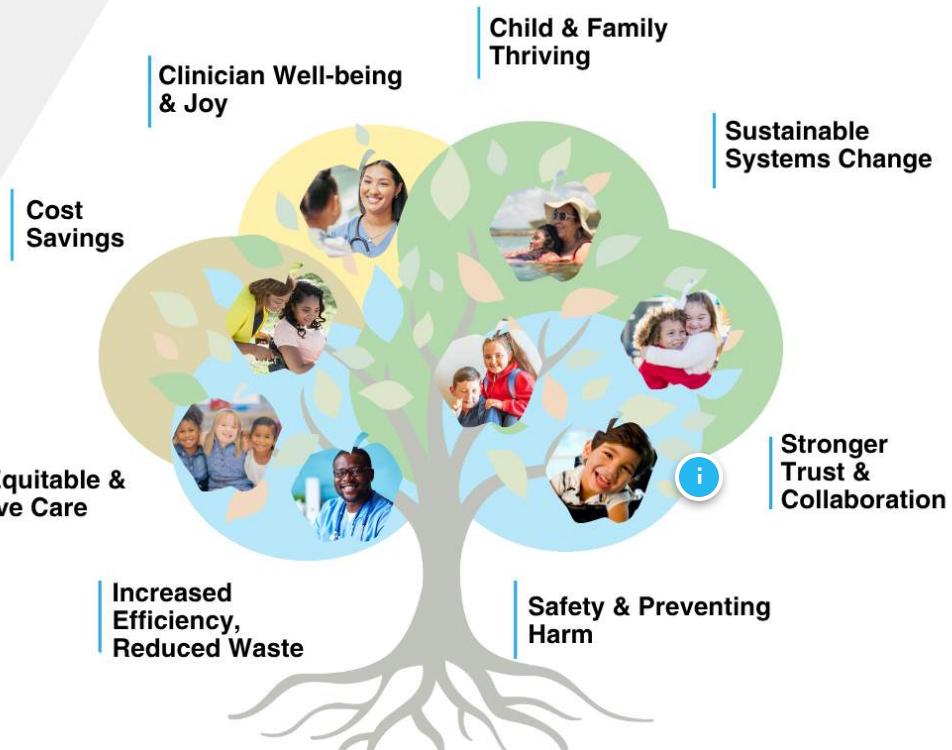
Stronger Trust & Collaboration

How it works:

When systems demonstrate they value family expertise through concrete action it builds a foundation for ongoing partnership.

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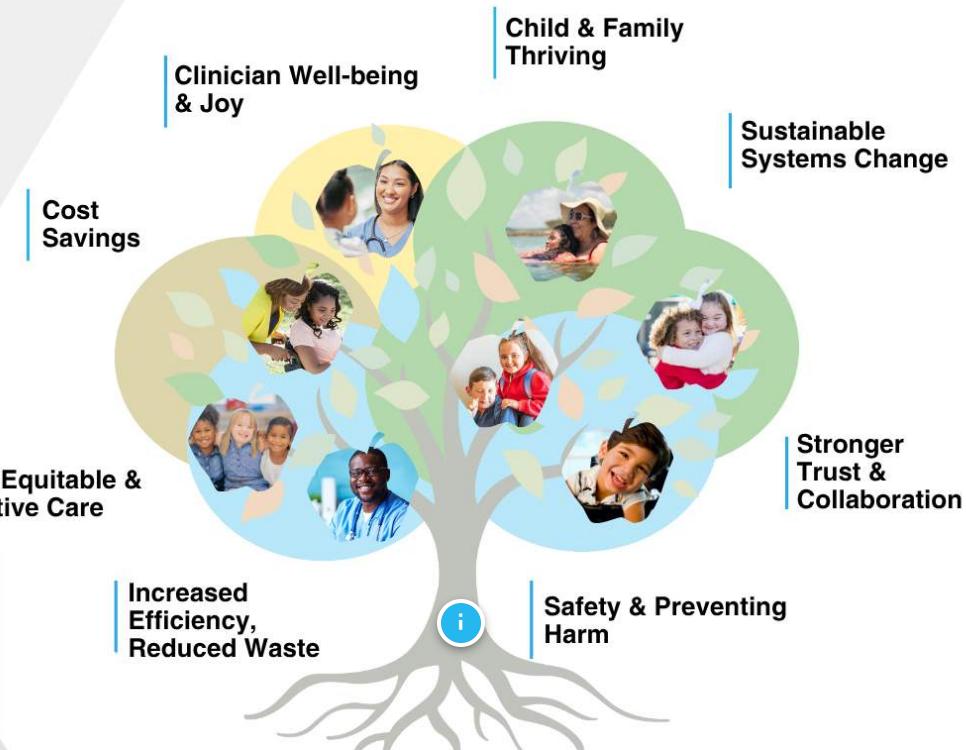Click the + icon for illustrative quotes

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Joy from trust

"Joy comes from the relationships and being invited by the families in a place of trust. Trust that I need to earn...And those relationships last years and decades."
~CMC Cafe 2 Clinician Participant

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Constantly learning

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"Constantly learning from children and families. Also, working to solve seemingly impossible problems as a team!"
~CMC Cafe 2 Clinician Participant

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Safety & Preventing Harm

How it works: Family expertise directly identifies safety risks that clinical assessments miss. When systems listen to families about what actually works for their child's specific needs – like care teams during inpatient stays for CMC – it prevents the harm that comes from incomplete or biased understanding.

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Addressing bias prevents harm

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"Dealing with bias is not about building character... it is life threatening to experience bias... For many patients, we know bias is life or death, and the stats we see about maternal and infant mortality, for example, show us that bias is life or death."
~CMC Cafe 5 Family Presenter

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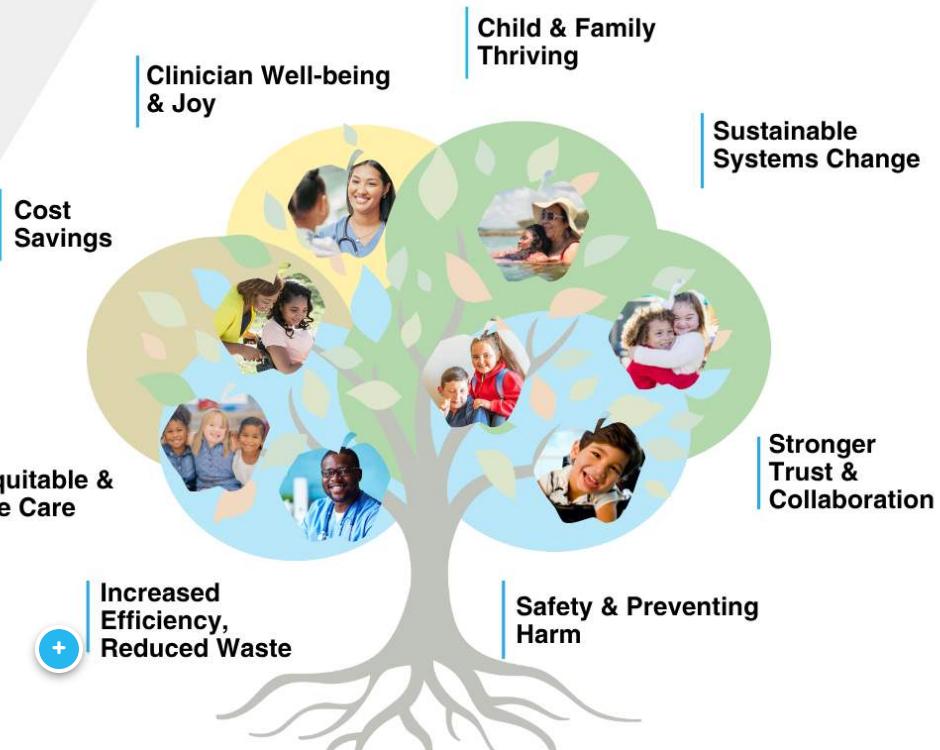
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Family's vital medical expertise

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From "The Signs Phenonemon":

"I was literally trying to keep really bad things from happening with the signs [in the hospital room], and clinicians treated it like it was a preference of mine versus something that [my daughter] really needed."

~CMC Cafe Family/Clinician Faculty
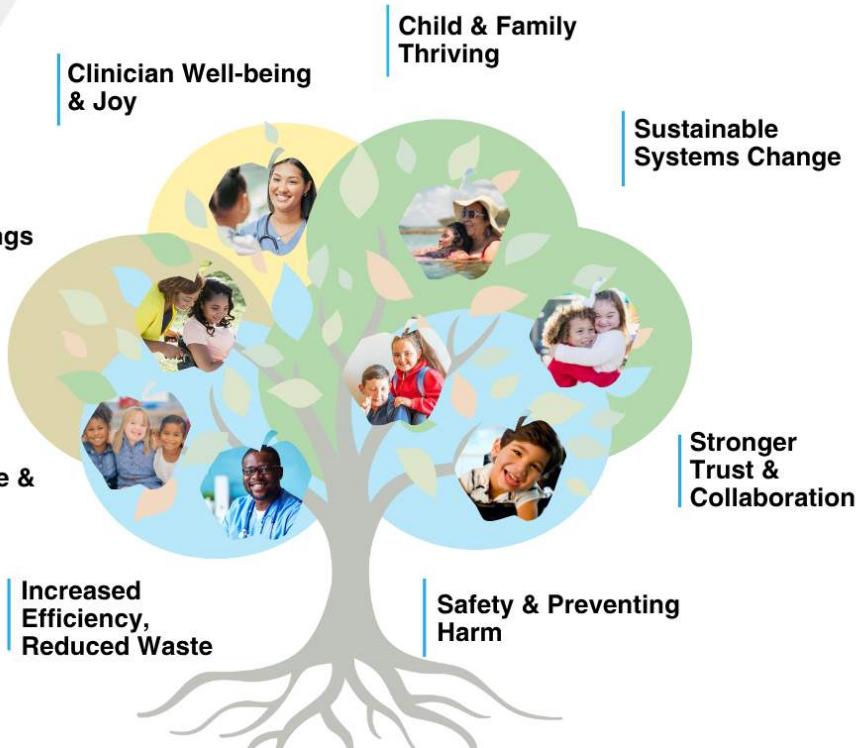
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Safety & Preventing Harm

Increased Efficiency, Reduced Waste

How it works: Family partnership reveals where systems create waste through mismatch between what's provided and what's actually needed. The syringe story demonstrates this well: how "boxes and boxes of syringes that don't work" represents significant waste, while humanistic approaches eliminate this waste by trusting families to identify what actually serves their child.
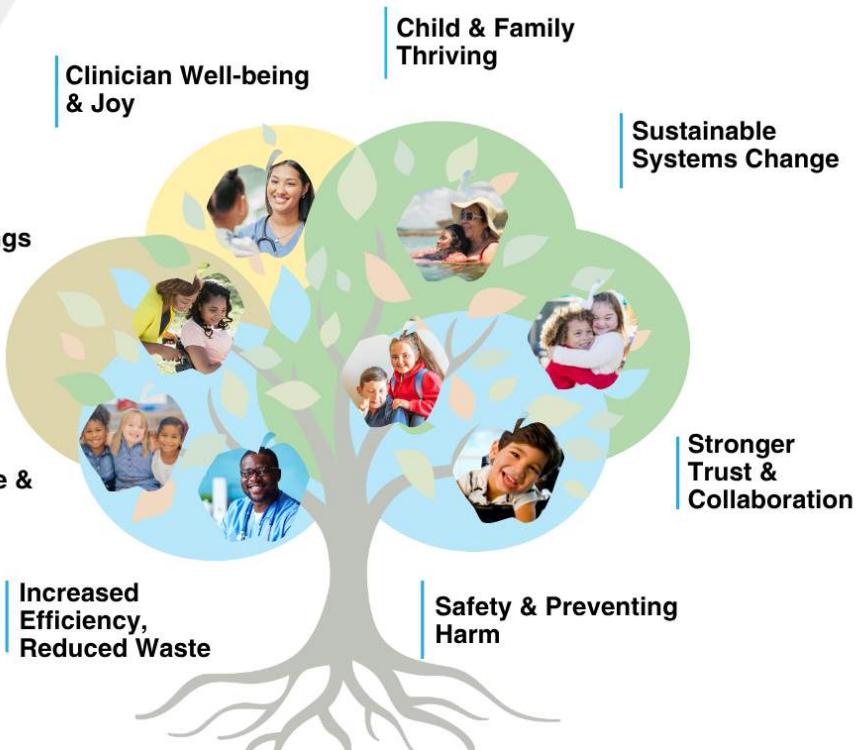
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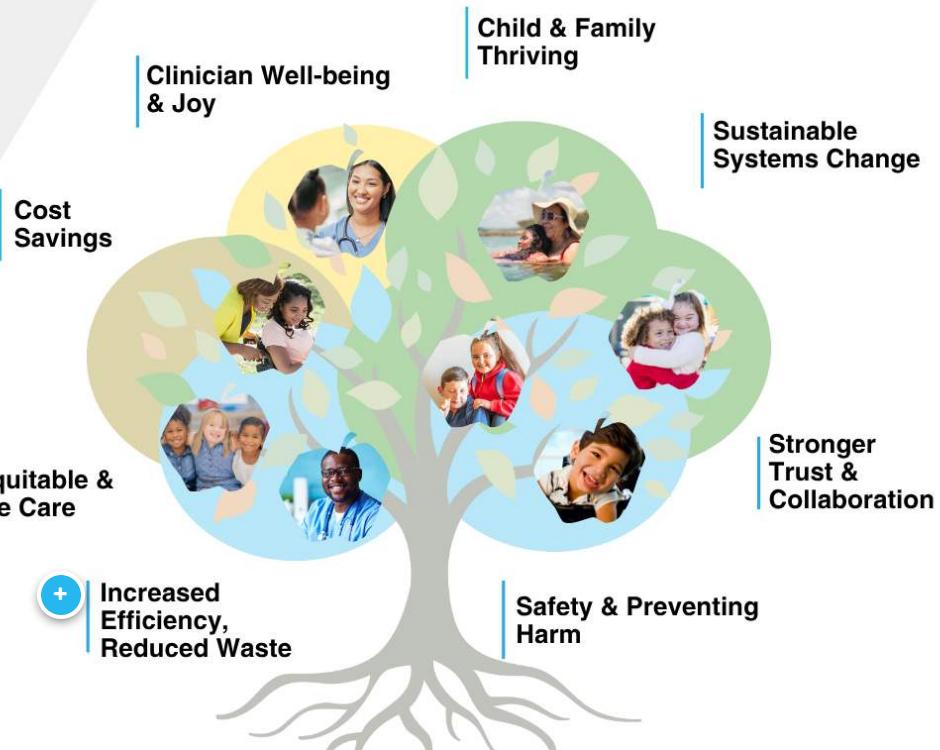
Quote 1 Efficiency

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"If you are a patient of the [complex care clinic] when you call the 24/7 line. It is being answered by a [complex care clinic] provider who knows your child and knows you and can really help you understand whether you may need to go to the emergency department, or whether they might be able to manage that at home."
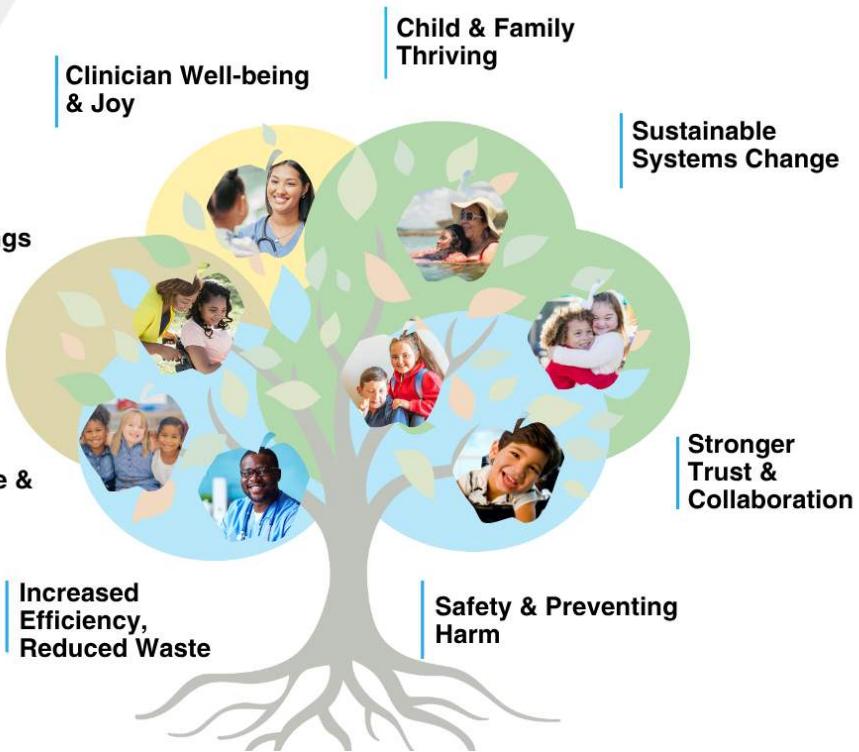
~CMC Cafe 3 Co-Presenter

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Remove costly unneccessary bureaucracy

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From the Syringe Story:

"Maybe $50,000 a year ... DME companies all spend this kind of money [approving medical supplies] for low-budget items...Why don't we just provide an interface for families to just order what they need. And there is a cap to this budget."
~CMC Cafe Family/Clinician Faculty

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More Equitable & Effective Care

How it works: Humanistic care addresses systemic inequities by ensuring all families – not just those with more resources – can access what they need. The syringe story reveals how current approaches create inequity where families with means purchase alternatives while others cannot, and shows how partnership–based solutions serve everyone.

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Effectiveness tied to caring

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"My little clinic here. The type 2 diabetes program has some of the best outcomes in a free clinic, because the person who's doing it cares, and the parents and the families know that."
~CMC Cafe Clinician Faculty

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Focusing concrete action in urgent impact areas for humanistic care drives the kind of change we all value, benefiting not only CMC, their families, and clinicians but also systems of care overall.

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Practical solutions

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"You're not going to find solutions without involving the people who are experiencing the problem... families typically have practical solutions rather than wanting to change entire systems."
~CMC Cafe 4 Family Presenter

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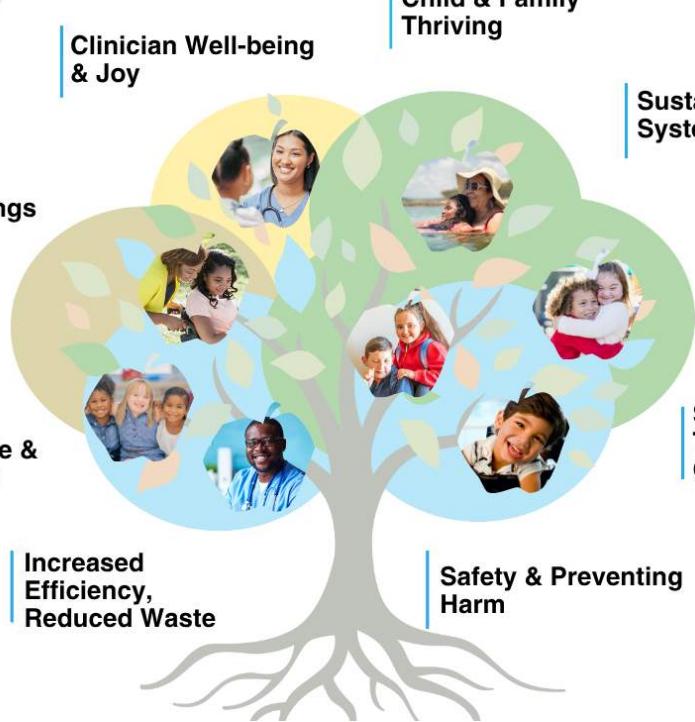
Cost Savings

How it works: Humanistic care prevents expensive downstream consequences by addressing root causes early. Preventing waste while reducing families' out-of-pocket expenses creates savings across the system, while relationship-based care prevents costly crisis interventions.

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The right outcomes save money

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"[There are] economic consequences as well as effectiveness and efficiency consequences for not including humanism in health care... part of the reason why we spend so much money and don't get the right outcomes for the money we spend is because humanism is absent from much of health care delivery."
~CMC Cafe Family/Clinician Faculty

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Concrete innovative ideas for better long-term fiscal outcomes

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"The thought that sometimes there are concrete ideas for innovative improvement ideas [from families] that create better outcomes and improved fiscal outcomes longterm through better outcomes for the patient and familes themselves"
~CMC Cafe 3 Family Participant

Explore & share more about humanistic systems of care:

Intro to Framework: What Makes Humanistic Elements of Care Indispensable?

Clinicians and families speak to three reasons why humanistic care is essential to the right kind of systems change.

GO TO "INTRO TO FRAMEWORK"

The Sweetest Fruit: Humanistic Care Celebrates Meaning & Joy Above All Else

In our second CMC cafe, on the need for humanistic care, we asked our indisciplinary participants "What brings you joy in raising or caring for a child with medical complexity?". Their responses highlight the driving force behind humanistic care.

GO TO "THE SWEETEST FRUIT"

Resources, Examples, and Supporting Materials

This list was developed from both suggestions of CMC Cafe participants and the CMC Cafe Family & Clinician Faculty. Anything referenced throughout the framework & guide will be listed here.

GO TO "RESOURCE & EXAMPLES"

The Sweetest Fruit: Humanistic Care Celebrates Meaning & Joy Above All Else

"What brings you joy in raising or caring for a child with medical complexity?"

In the second session of our CMC cafe series, focused on the need for humanistic care,

we asked our indisciplinary participants the above question. Their responses

powerfully describe the depth of meaning and joy in being part of a child's life:

1. **"Small milestones"** (Parent and professional)

2. **"Seeing growth and development even though it is at a different rate than their peers"** (Healthcare clinician)

3. **"Longitudinal care over time for the patient and whole family"** (Medical director)

4. **"Watching the progress"** (Healthcare clinician)

5. **"Seeing my child find joy in life"** (Parent)

6. **"Witnessing and illuminating experiences of connection, beauty, love, and joy"** (Healthcare clinician)

7. **"I love seeing her growing up... amazing"** (Parent)

8. **"Learning what's important in life"** (Healthcare clinician)

9. **"Finding things that bring joy to a medically complex child & their family, and allowing them to feel seen and celebrated"** (Healthcare clinician)

10. **"I loved the presence involved in caring for my son"** (Bereaved parent)

11 "Feeling like I am part of a collaborative team" (Parent of young adult)

12 "Focusing on the big picture and choosing the things I can help with to make them better" (Complex care pediatrician)

13 "Make every day the best day it can be" (Mom of several CMC, family leader)

14 "Sharing funny moments, solving small challenges together" (Healthcare clinician)

15 "Milestones that neurotypical families take for granted" (Healthcare clinician)

16 "Seeing inclusion work!" (Healthcare clinician)

17 "Constantly learning from children and families. Also, working to solve seemingly impossible problems as a team!" (Clinician)

18 "I find it gratifying to support parents in accessing the resources that allow their child to reach their full potential" (Healthcare clinician)

19 "Knowing that someone doesn't struggle as I did" (Healthcare clinician)

20 "Reaching the family's goals, big or small" (Healthcare clinician)

21 "Helping families thrive even during the challenging times" (Medical social worker)

22 "ALL the untimely expected and unexpected moments!" (Healthcare clinician)

23 "I find joy in seeing parents' pride in their children and their accomplishments" (Primary care pediatrician)

24 "The successes, love and things they share each day" (Healthcare clinician)

25 "The chance to meet families and professionals we would have never encountered. Many have become dear family friends!" (Healthcare clinician)

26 "Supporting their goals and them reaching milestones" (Healthcare transition manager)

27 "Appreciative of taking things day by day" (Healthcare clinician)

28 "Improving quality of life" (Healthcare clinician)

29 "Being a parent and seeing my child have QoL and experiencing his well being socially" (Family leader/advocate)

30 "I find joy in providing care to children and youth with complex needs as a result of the families inviting me as a partner into soliciting and pursuing all that is important to them" (Healthcare clinician)

31 "I learn something from her every single day and it's almost always something so deeply beautiful" (Parent)

32 "#1 SMILES! #2 Celebrating the inch stones!" (Bereaved parent, family-to-family director)

33 "Watching them grow into adults who now help others who live with complex medical needs" (Healthcare clinician)

34 "Learning. I learn something new from my child every day" (Parent)

35 "Learning to see life from his perspective" (Parent)

36 "What brings me joy is taking what I've learned with my own child and making the path a little easier or less stressful for other parents"** (Parent caregiver and advocate)

37 "Ensuring youth have their needs met for them to live their best life"** (Child welfare clinical)

38 "Witnessing families grow from survival to thriving & meaningful lives"** (Complex care social worker)

39 "I find joy in the privilege of supporting work that makes accessing health care easier and more equitable for all people and families"** (Funder)

40 "Meeting the unique needs of medically fragile children in the comfort of home"** (Home care provider)

41 "Before we care how much you know, we want to know how much you care!"** (Healthcare clinician)

Trust is Paramount: Stories of the "Signs Everywhere" Phenomenon & Humanistic Care

The "Signs Everywhere" Phenomenon

Examples of real signs on hospital door (AI-generated image)

"The more and more times that families are traumatized by the hospital system, there ends up being more and more signs in the patient's room."
~CMC Cafe 5 Participant

Powerful Illustration of Real-Life Impacts of Dehumanizing Systems of Care

The café series and faculty discussions revealed why parents of children with medical complexities (CMC) find it hard to trust healthcare systems. The "signs everywhere" phenomenon illustrates the impact of communication breakdowns, compelling families to take extra steps to keep their children from harm. These experiences highlight the urgent need for a cultural shift that prioritizes trust the partnership between families and clinicians, both as experts. This shift is crucial for achieving better outcomes.
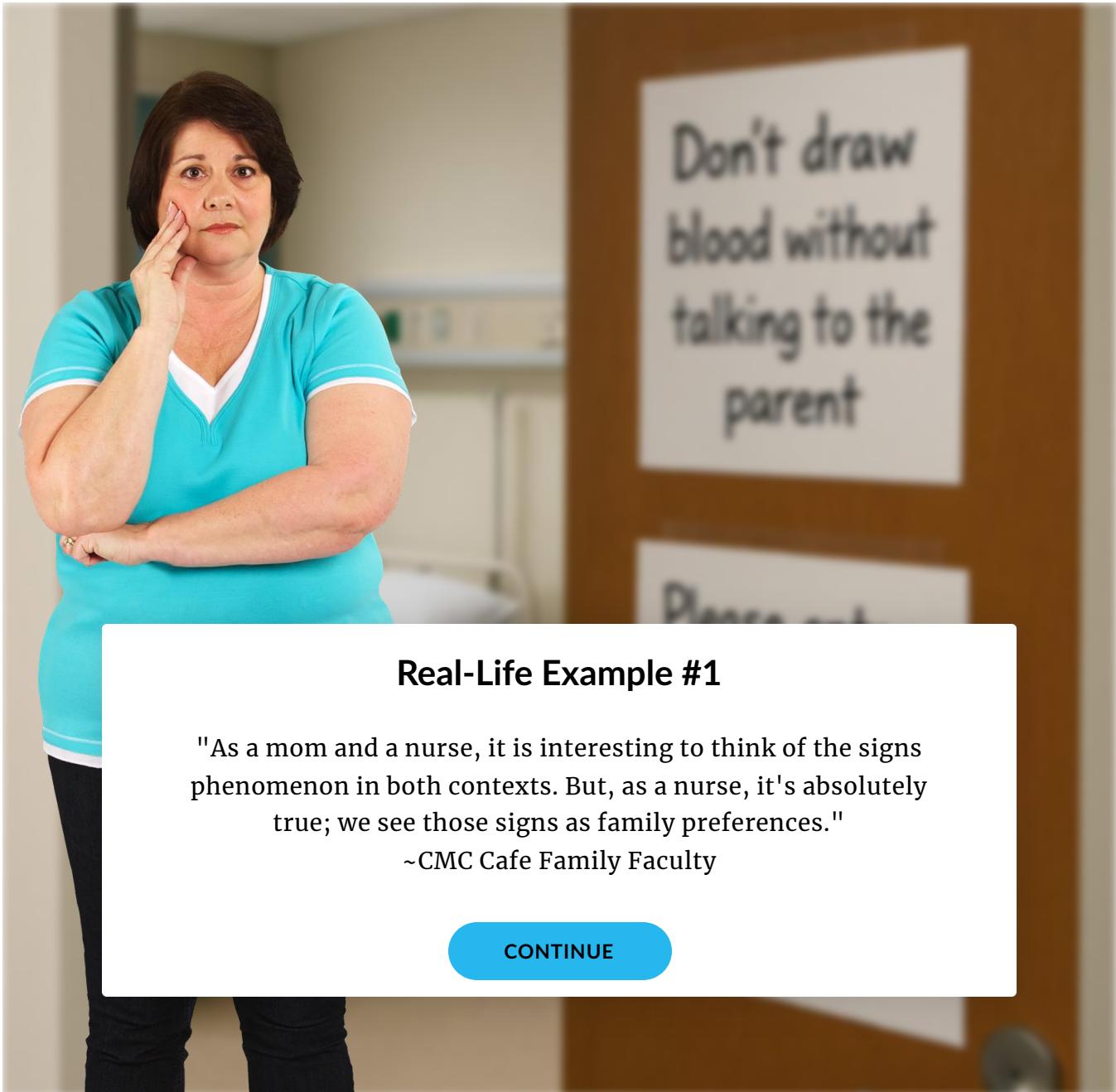
Real-Life Example #1

"As a mom and a nurse, it is interesting to think of the signs phenomenon in both contexts. But, as a nurse, it's absolutely true; we see those signs as family preferences."
~CMC Cafe Family Faculty

CONTINUE

Scene 1 Slide 1

Continue → Next Slide

Scene 1 Slide 2

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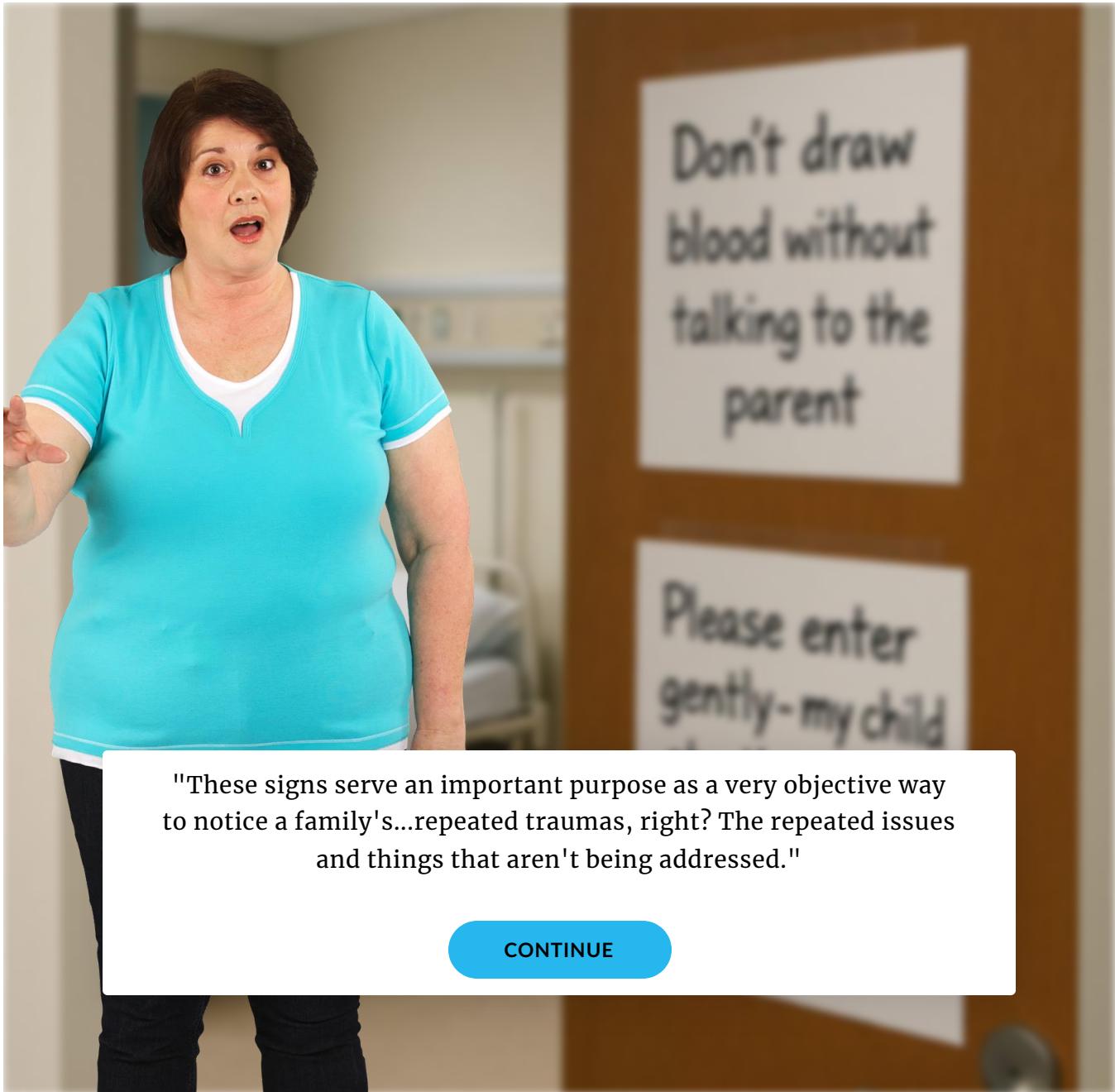
"These signs serve an important purpose as a very objective way to notice a family's...repeated traumas, right? The repeated issues and things that aren't being addressed."

CONTINUE

Scene 1 Slide 3

Continue → Next Slide
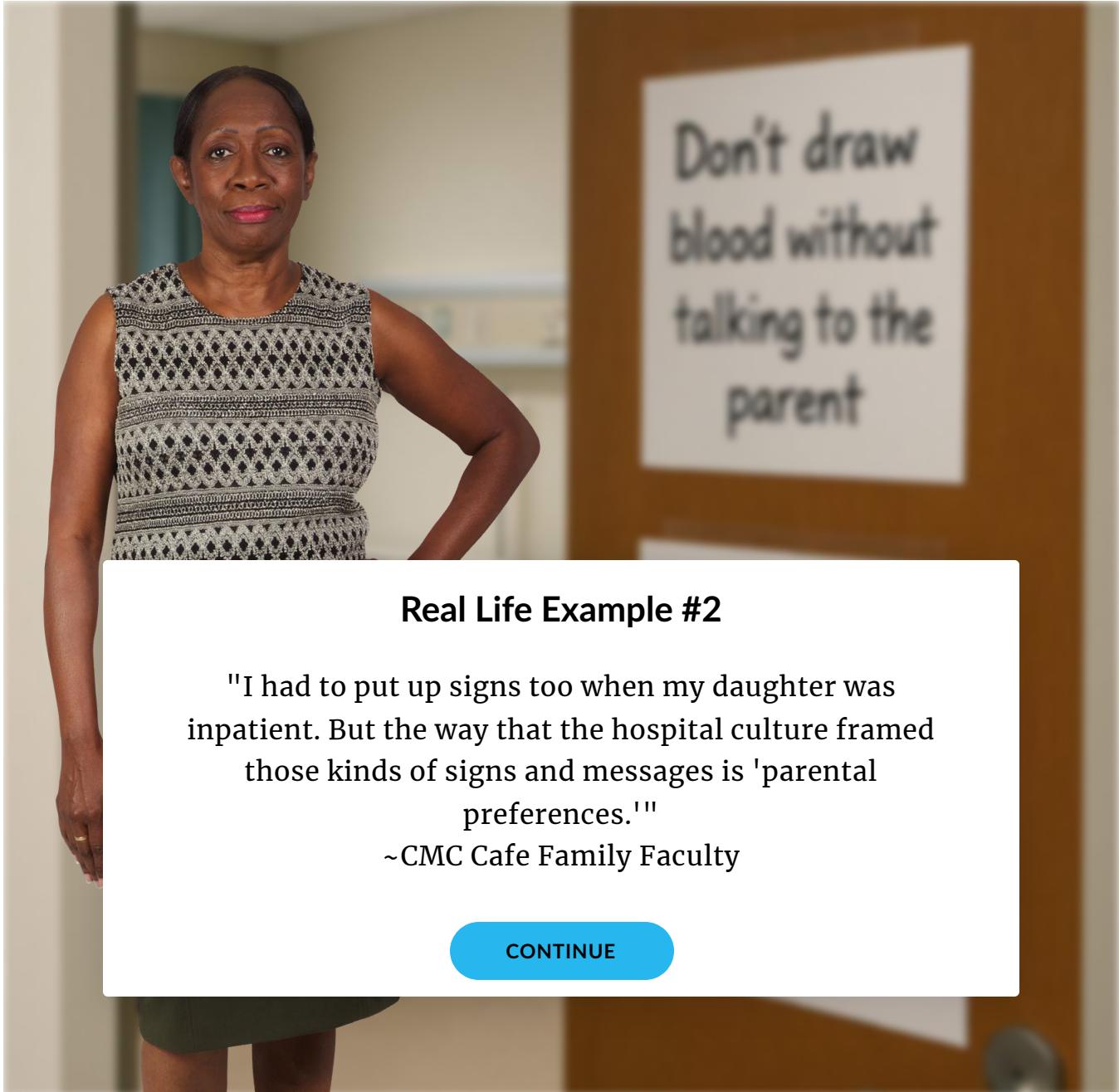
Real Life Example #2

"I had to put up signs too when my daughter was inpatient. But the way that the hospital culture framed those kinds of signs and messages is 'parental preferences.'"
~CMC Cafe Family Faculty

CONTINUE

Scene 2 Slide 1

Continue → Next Slide

Scene 2 Slide 2

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Connecting these real-life examples to humanistic care

These examples illustrate the essential role of trust as the soil for humanistic systems of care. Trust is paramount to meaningful change.

START OVER

↻

Scene 2 Slide 3

Continue → End of Scenario

The humanistic care framework offers a different path forward where harmful experiences are not inevitable...

CONTINUE

Personal Stories of What Humanistic Care Looks Like

Both CMC cafe participants and family faculty recounted experiences of humanistic care and the utter difference it makes for them and their child in connecting with their clinician. These stories collectively paint a picture of humanistic care as: seeing people as whole human beings beyond their medical conditions, taking time for genuine connection, recognizing everyone's expertise and humanity, focusing on what brings meaning and joy, and building authentic relationships based on trust and mutual respect.

"So he sang to her as she fell asleep [for surgery]" —

"One time before surgery, the surgeon asked my daughter what music she'd like to hear 'as you're falling asleep' and it's a great example of humanism as she had a lot of procedures the same day as surgery. So, Annie's her favorite musical, and the anesthesiologist apparently had a real voice for singing. So he sang it to her as she fell asleep."
~CMC Cafe 2 Participant

This story shows humanistic care as: connecting with the child as a whole person, not just a patient; taking time to ask about their preferences; and bringing comfort and humanity into a medical procedure for the child, family, and clinician.

"90% of what I do (as a parent navigator) is listen." ___

"The most human thing that I find in my work is listening. And that is that most of the people I get calls from, they need somebody to listen more than anything... 90% of what I do is listen. And that's really, really what a lot of the families I get calls from need the most. Someone to listen."
~CMC Cafe 2 Participant and Parent Navigator

This shows humanistic care as: being fully present with families and recognizing that listening is therapeutic and essential care.

"Impossible to ignore context...in somebody's home" ___

"It shifts the dynamic. it shifts the relationship... it is impossible to ignore context when you are in somebody's home... Humanity is like not going to be 2 dimensional. You're seeing, you know, the overflowing sink. You're seeing the children that are screaming. You're seeing life lived in its fullest. So it's impossible for you, despite of training. You're going to see a full human being."
~CMC Cafe Family & Clinician Faculty

This illustrates how humanistic care means: seeing families in their full context, recognizing their complete humanity, and allowing that context to inform care decisions.

"...he became part of the team" ___

"For my kids and for me as a parent, it's when they were brought in as co-workers for the care... They would talk to him about, you know, what was his heart doing? How is it interacting with medication?... he became part of the team."

This story shows humanistic care as: involving children and families as active participants in their care, fostering collaboration, and empowering them to feel like valued members of the healthcare team.

"...treat me as a human being..."   —

"I am a family caregiver with lower back pain and a big advil bill, because I've done so much lifting over the years... I'm not asking you to pay me for that service necessarily, but I am asking you to treat me as a human being in that context, and my mental and physical well-being and health are important... because otherwise kiddo is going to end up in the hospital if I can't do my job."
~CMC Cafe Family & Clinician Faculty

This story highlights humanistic care as: recognizing the physical and emotional toll caregiving takes on family members, treating them with respect and compassion, and acknowledging their critical role in the well-being of the patient.

"...in service to whoever is in front of you..."   —

"Where I see for myself, the professional boundary line is, if you never cry. if you are exposed to that kind of pain and sadness and grief and human suffering every day all day and you never cry, that's a problem. So it's making sure that whatever the emotion is, it's in service to whoever is in front of you, whether that's in service to yourself as an individual, as a human being, or whether it's in service to the patient and family in front of you."
~CMC Cafe Family/Clinician Faculty

This story demonstrates humanistic care as: embracing emotional authenticity, using emotions to connect with others, and ensuring that compassion is always directed toward the needs of the patient and family.

"...both our right as clinicians but also our responsibility..."   —

"We have to carve out that distinction and claim, you know, compassion. And you know, humanism as our both our right as clinicians, but also our responsibility as clinicians."
~CMC Cafe Clinician Faculty

This story emphasizes humanistic care as: recognizing compassion and humanism as essential elements of clinical practice, and understanding that they are both a privilege and a duty for healthcare providers.

"...play is our central therapeutic element..."   —

"For us humanity is demonstrated in behind me on the wall play is our central therapeutic element getting kids up and on their hospital beds and rooms. Interacting with other humans. Caretakers, family members, other patients... letting the kids be their whole selves and do what they would choose. Which is play, right?"

This story highlights humanistic care as: recognizing the importance of play in allowing children to express themselves, fostering social interaction, and creating a sense of normalcy and joy even in a hospital setting.

The Syringe Story: A Real-World Illustration of the Humanistic Care Framework in Action

"Family partnership starts with trusting families. Trust families that they're part of creating a sustainable system. They also do not want things to be wasted."

Dr. Rahel Berhane, CMC Family/Clinician Faculty

Family-clinician partnership catalyzes practical and essential systems change through humanistic care

A Texas complex care clinic, led by Dr. Rahel Berhane and Lisa Kirsch, shows that systems change for humanistic care is practical and rooted in real needs. Their approach leads to better outcomes for everyone involved. During the CMC Cafe discussions, this example became a key reference for understanding the urgent action framework.

Let's walk through the steps the Texas team took for practical systems change driven by families...

The Syringe Story: When "simple" supplies become complex barriers

For CMC, humanistic care is not just a philosophy but a necessity. It emphasizes the importance of relationships, mutual respect, and the recognition of family expertise. This story, derived from the experiences of Rahel Berhane and Lisa Kirsch, exemplifies how unknown small improvements driven by humanistic principles could have a big impact in the lives of families and improve healthcare outcomes.

The Syringe Challenge

Rahel Berhane, a pediatrician and medical director, and Lisa Kirsch, a policy analyst, encountered a significant issue through their work with families of CMC: the challenge of obtaining appropriate medical supplies, particularly syringes. This issue was brought to light during a family workgroup meeting where Rahel described: *"We went to the families and asked, 'What is it that is hard?'"*.

Families described how Medicaid supplies only 10 syringes per month, which is insufficient given that each syringe doesn't last more than a couple of uses. One family had a child who needed 15 medications administered three times a day. The problems were compounded by issues such as syringe tips not fitting, rubber stoppers on plungers wearing out, and syringes with labels that became illegible after a few washes.

Inefficiency & Waste

Rahel shared, *"Families are saying, 'Well, I mean, I have a garage full of things I can't use, because... The DME [Durable Medical Equipment] Company decides what kind of wipes, or diapers, or syringes.' Even there, there is no input... The hierarchy is so strong like, 'We're gonna send you what we have, for whatever reason... And if you don't like it, go out and buy your own.'"*

Lisa added, *"I would never have known this. I'm not even sure the CCC [Comprehensive Care Clinic] team was fully aware of the magnitude of this problem for families."*

Photovoice: Visualizing the Problem

To better understand the impact, Rahel and Lisa implemented a Photovoice project, where parents documented their daily lives through pictures. One powerful image showed a countertop covered with syringes, captioned *"washing syringes is the bane of my existence."* This visual representation highlighted the significant burden these supplies placed on families.

Lisa explained, *"This is just one photo from our current project, which was amazing. This is a Spanish-speaking mom..."*

Family-Driven Solutions

The family workgroup didn't just identify problems; they also proposed solutions. They suggested creating a system where families could order the supplies they needed directly, with a specific budget allocated to each family. This would eliminate the need for extensive paperwork, letters of medical necessity, and peer-to-peer reviews for every supply request.

Rahel emphasized, *"These are low budget items. Why don't we just provide an interface for families to just order what they need. And there is a cap to this budget, and the receipts are going to be there. And why do we have to write letters of medical necessity for every different syringe, for every different split-gauze? And we spend more money on this process than actually the items are worth."*

Trust-Based Policy and Systemic Change

Rahel and Lisa took these insights to Health and Human Services and Medicaid partners. They advocated for a system redesign that would trust families to manage their supplies responsibly. This approach would not only reduce waste but also ensure that families received the supplies that actually worked for them.

"Digitally, we can actually select the things that work for us, and get drop shipped at our home. That thread of using parents' expertise or caregivers' expertise even, and sort of giving options about different things that work for different people... What's wrong with having folks choose what they need? Reorder when they're out."

Rahel noted, *"Family partnership starts with trusting families, you know. Trust families that they're part of creating a sustainable system. They also do not want things to be wasted. They don't like for Medicaid to be paying for piles and piles of diapers that don't work, that they don't have any room to store."*

Practical, Human-Driven Systems Change

The syringe story illustrates how humanistic systems of care can lead to practical, family-centered solutions that improve the quality of life for children with medical complexity and their families. By listening to families, respecting their expertise, and trusting them, healthcare systems can create more efficient, effective and compassionate care delivery that meets real-life needs while better supporting clinicians.

Family Partnership in Action

This story exemplifies the principles of family partnership:

- **Mutual Partnership**: Families were treated as equal partners in identifying problems and proposing solutions.

- **Respect for Expertise**: The unique knowledge and daily experiences of families were valued and integrated into system design.

- **Trust and Dignity**: The proposed system redesign was based on trust in families, recognizing their critical role in managing their children's care.

One CMC Cafe clinician faculty member highlighted, *"The approach gets away from a checklist idea and what can feel to people with lived expertise as token participation versus really a deep and what we're calling radical family partnership, and what that needs to look like, and how that drives technical solutions and drives co-design."*

Connecting the Story to the Humanistic Care Tree Framework for Urgent Action

This narrative illustrates how trust (soil) allowed families to share their experiences, highlighting the need for the key elements of humanistic care (roots). The partnership between families and clinicians (trunk) served as a catalyst for conveying these insights to system leaders, resulting in specific strategies for change (branches) that can lead to transformative outcomes if implemented (fruit). The tabs below provide further details to help guide your thoughts and actions.

Rooted in Humanity

An urgent action framework of essential strategies for care that matters to CMC, their families, and clinicians.

FRUIT:
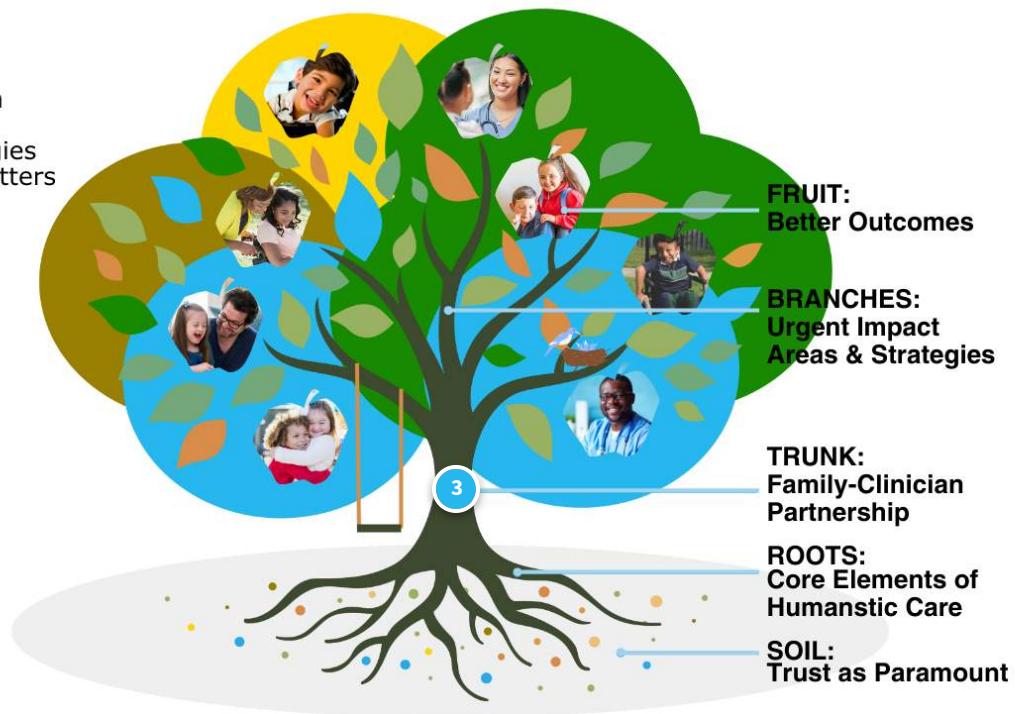**Better Outcomes**

BRANCHES:
Urgent Impact Areas & Strategies

TRUNK:
Family-Clinician Partnership

ROOTS:
Core Elements of Humanstic Care

SOIL:
Trust as Paramount

Rooted in Humanity

An urgent action framework of essential strategies for care that matters to CMC, their families, and clinicians.

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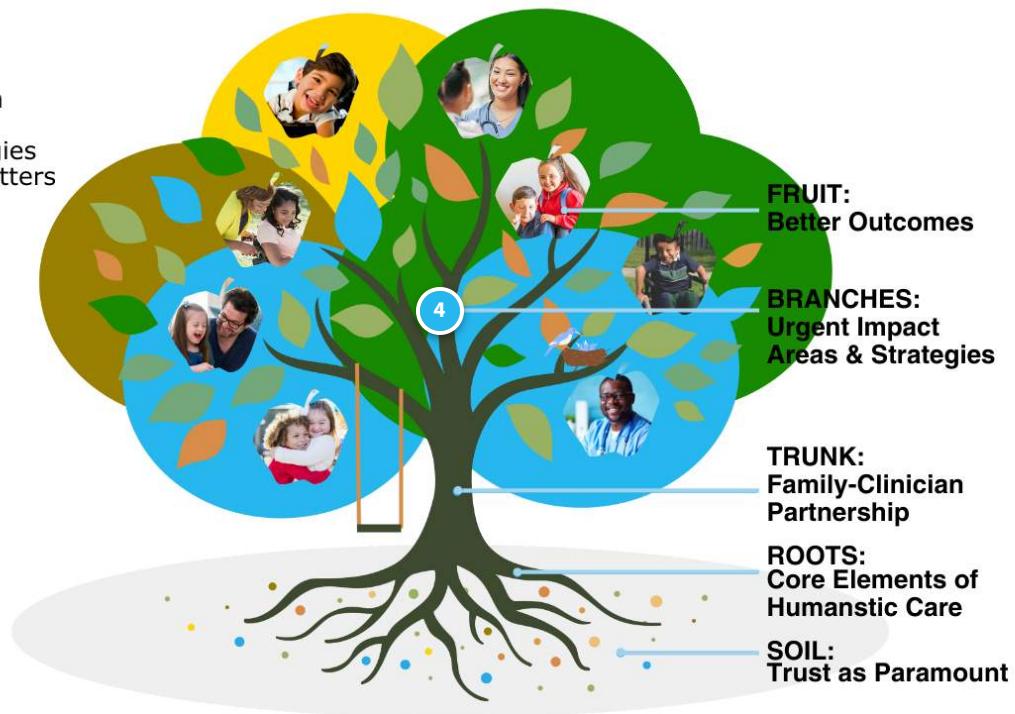Better Outcomes

BRANCHES:
Urgent Impact Areas & Strategies

TRUNK:
Family-Clinician Partnership

ROOTS:
Core Elements of Humanstic Care

SOIL:
Trust as Paramount

Soil

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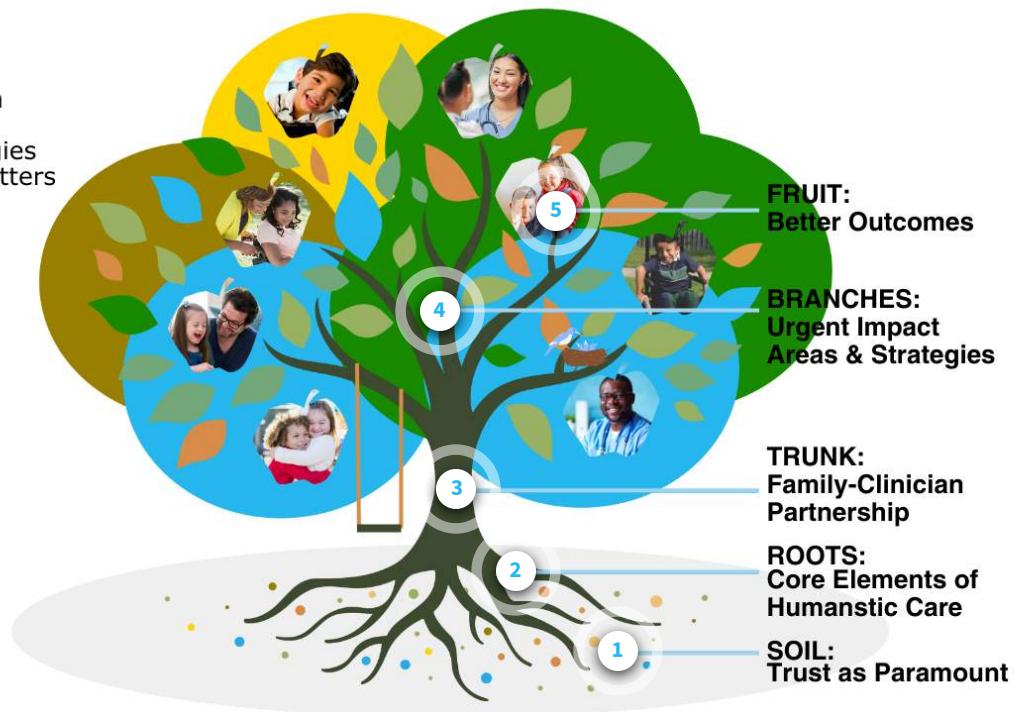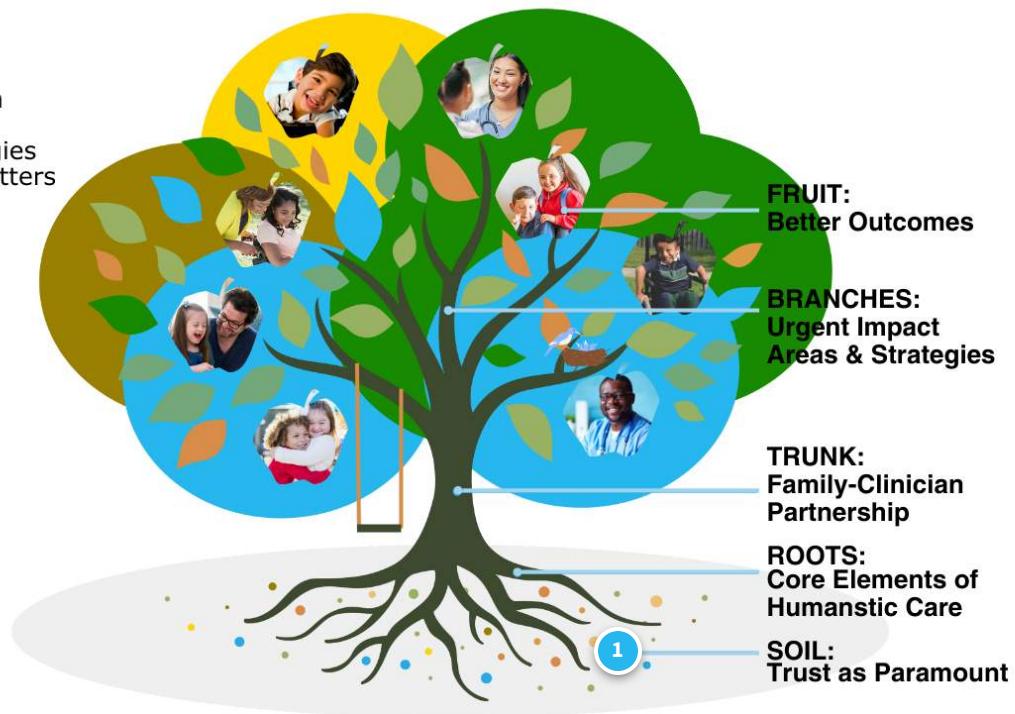
"For little things, for supplies that you need for the duration of the child's life, the constant justifications reveal an assumption of ill will and intent on behalf of people asking for things."
~Dr. Rahel Berhane, Cafe Family & Clinician Faculty

Related:

"We are hearing at least here in our state... there is sort of this overall atmosphere going on around fraud, Medicaid fraud, and that people with lived experience and families are perpetrators of Medicaid fraud... We are not valued as people with helpful or valuable experience. But we are looked at as people who are using a system and at times illegitimately, and that's a real barrier."
~CMC Cafe Family Faculty

Rooted in Humanity
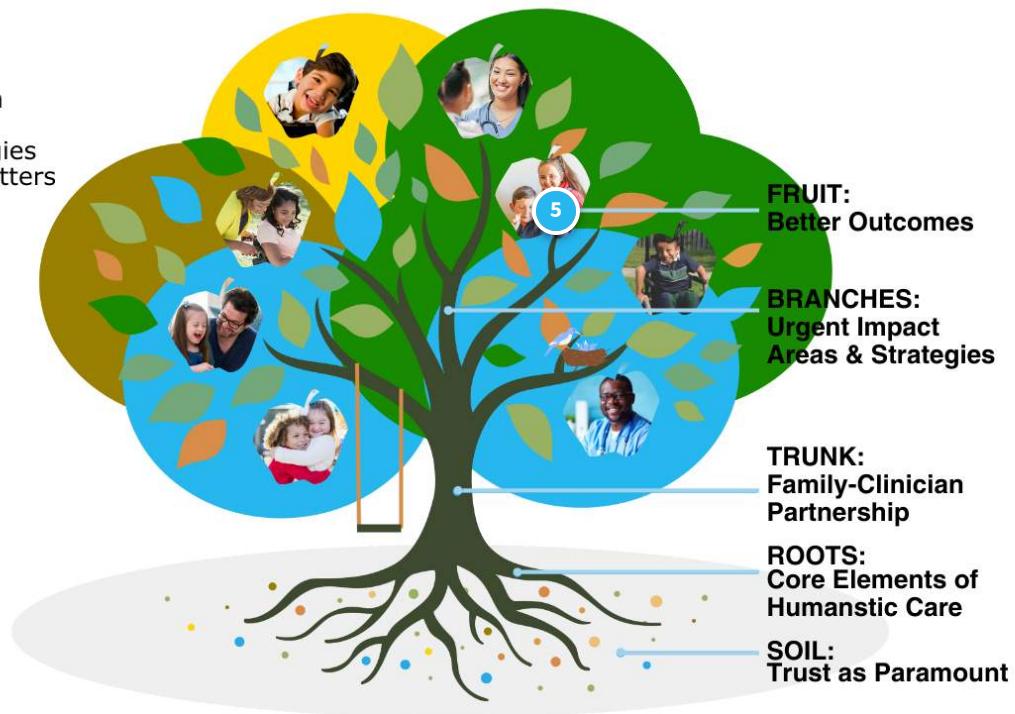An urgent action framework of essential strategies for care that matters to CMC, their families, and clinicians.

FRUIT:
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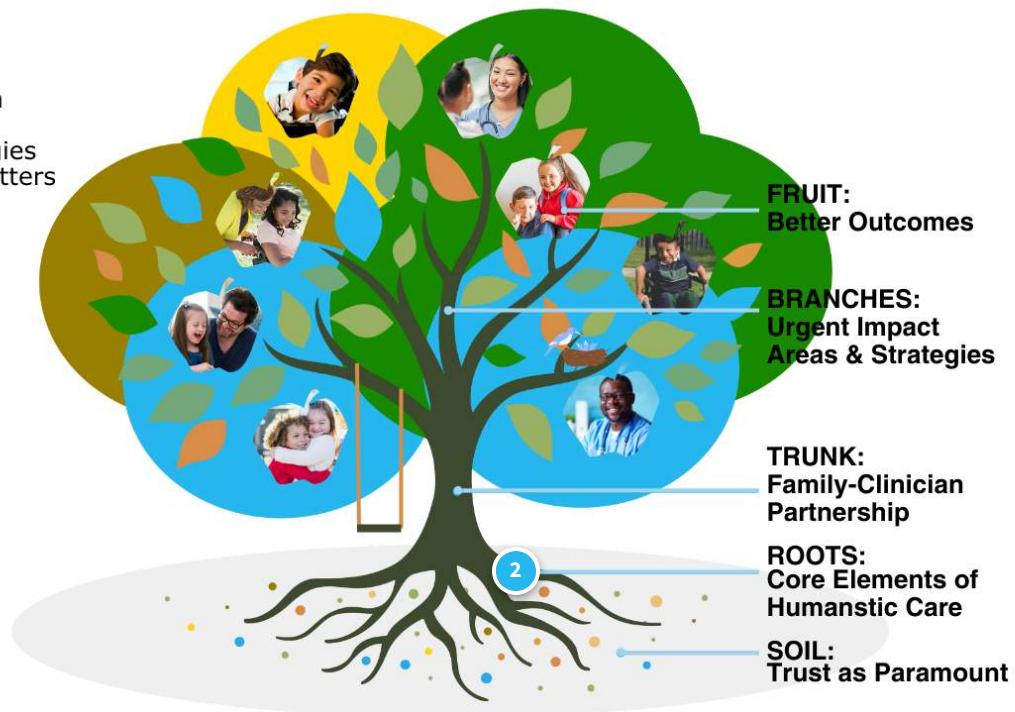
Roots

"As families shared their stories in exquisite detail, everyone listening was pulled into their daily reality as though by a literal magnetic force. Everyone was brought into the plane of daily lived reality and recognized, 'This is hard. There's got to be a different way.'"
~Rahel Berhane, CMC Cafe Family & Clinician Faculty

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Trunk

"We would not have known. That would not have been the thing that we would have settled on if we were just talking amongst ourselves about what was a a primary priority for families."
~Lisa Kirsch, Policy Analyst

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Branches

"Why don't we just provide an interface for families to just order what they need" rather than having "someone else deciding what it is that they should be getting."
~Rahel Berhane, CMC Cafe Family & Clinician Faculty

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Fruit

Eliminating "boxes and boxes of syringes that don't work"

"This was just the most beautiful thing for our community...family partners helped build it, like that's a different. That's a whole different thing."
~Rahel Berhane, CMC Cafe Family & Clinician Faculty

SOIL	ROOTS	TRUNK	BRANCHES	

Trust is the key to meaningful change in healthcare systems. The syringe story shows that listening to families' real experiences builds trust and lays the groundwork for transformation. When healthcare clinicians recognize families as experts in their own situations, they can start to rebuild trust and challenge cultural assumptions, such as the need to justify supplies a child requires for everyday life.

Rahel's insight highlights this shift: *"I do not know what kind of syringe each patient needs, really,"* she said, stressing the importance of trusting families' knowledge. This trust allows humanistic

care to thrive, helping systems create solutions that genuinely address the needs ofCMC and their families.

SOIL	ROOTS	TRUNK	BRANCHES	

The syringe story highlights the key elements of humanistic care by focusing on what truly matters to families: having the right supplies for their child's needs. This approach prioritizes the daily realities and well-being of families over only focusing on clinical outcomes when deciding on what change to make.

Humanistic care also values mutual partnership and dignity. As Rahel noted, *"If you start with the belief that families can be trusted, you'll design a system that reflects that trust."* These core values are essential for creating transformative care practices.

SOIL	ROOTS	TRUNK	BRANCHES	
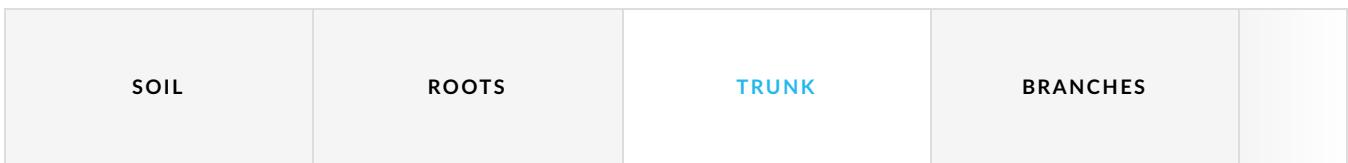
The partnership between families and clinicians is essential for effective change. In the syringe story, families and healthcare providers worked together to identify issues and suggest practical solutions. This collaboration allowed family voices to be central to decision-making.

As highlighted in the framework, *"strategic partnership... between the provider and the family partner"* was crucial for driving change. By building genuine relationships, the trunk of the humanistic care framework fosters trust and teamwork. This partnership not only tackles immediate problems but also lays a strong foundation for lasting systems change that benefits CMC, their families, and clinicians.

SOIL	ROOTS	TRUNK	BRANCHES

The syringe story demonstrates multiple strategies for systemic change, represented by the branches of the humanistic care framework. Leveraging family expertise was key, as families shared their experiences and challenges with medical supplies. This input led to practical and impactful solutions.

Rahel stressed the importance of this approach: *"Why don't we just provide an interface for families to just order what they need?"* By integrating families' lived realities into system design, clinicians can create policies and practices that are both effective and equitable. These branches extend the framework's reach, enabling transformation across multiple levels of care.

SOIL	ROOTS	TRUNK	BRANCHES

The outcomes of humanistic care are the fruits of systemic transformation. The syringe story highlights several key benefits, including improved safety, reduced waste, and stronger trust between families and healthcare clinicians. Access to supplies that actually work enhances the quality of care and reduces daily frustrations for families as well as clinicians trying to support them.

Lisa reflected on the impact of family partnership: *"We would not have known"* without listening to families' real experiences. Additionally, humanistic care fosters clinician well-being and joy by aligning their work with meaningful outcomes. Sustainable systems change becomes possible when solutions are both cost-effective and grounded in mutual trust. These fruits demonstrate the profound impact of prioritizing humanistic principles in healthcare.

Learn more about the syringe change effort by the Texas team

The Future of Care for CMC Cafe 3 (7/24/2024)

Meaningful Policy Opportunities that Matter to Families (Lisa Kirsch, MPAff, Meg Comeau, MHA, CMC Cafe Co-PI)

GO TO CMC CAFE 3

The Future of Care for CMC Cafe 6 (12/4/2024)

Sustainability and Strategic Partnerships (Rahel Berhane, MD, Jeff Schiff, MD, MBA and Rich Antonelli, MD, MS)

GO TO CMC CAFE 6

Photovoice project that shaped the Syringe Story

"This Photovoice project focuses on the lived experience of CMC and their families. Through these photos the project team hopes to illuminate both the joys and challenges for these families in hopes of advancing change and making a world that welcomes and works for their children." Twenty-nine caregivers took part (English- and Spanish-Speaking).

GO TO THE PHOTOVOICE PROJECT

Who We Are

Families & Clinicians Working Together for Humanistic Systems of Care

We are an interdisciplinary group of diverse national system leaders in the care of children with medical complexity (CMC), primarily clinicians and family leaders - or both. Like many of you, we've experienced first-hand the human toll of broken systems of care. We believe that in working together, we can create change in healthcare and service systems that truly matters by:

1. Collaboratively designing more effective systems of care, by making urgent change first and foremost rooted in the full humanity of the people that comprise them

2. Actively working to understand and prevent real harm of system gaps and failings for everyone involved

We worked together on the [CMC Colloborative Improvement and Innovation Network](#) quality improvement project (2017-2022). We then partnered as family and clinician faculty (some in dual roles) to guide [The Future of Care for CMC Cafe Series](#), and reflect upon learnings from the series. This partnership led to **a deep understanding of shared goals and priorities in the field for essential systems change - actions that truly humanize care for CMC, their families, and clinicians.**

Headshots & Bios (in alphabetical order)

Carolyn Allshouse – Executive Director, Family Voices of Minnesota

CMC Café Family Faculty

Carolyn is the Executive Director of Family Voices of Minnesota, a statewide nonprofit organization, Family Voices state affiliate, and Parent-to-Parent USA alliance member. Over the past thirty years, she has coordinated several Federal Maternal & Child Health Bureau grants and contributed to numerous quality improvement projects, including the National Hospital Association's CARE Award and the Minnesota Medical Home Learning Collaborative. She has served on many local and national committees and has written and contributed to several publications about family-centered care and parent-professional collaboration. In

addition to her contributions on the CMC CoIIN and Cafe Series projects, Carolyn serves on the advisory committee for a healthcare transition collaborative with Gillette Children's Specialty Healthcare in Minnesota. Carolyn is the parent of four children, including her youngest son who was born with complex health care needs and passed away at the age of 24.

Richard C. Antonelli, MD, MS, FAAP – Physician & Care Coordination Expert

CMC Café Clinician Faculty

Rich has extensive experience working at state, national, and international levels evaluating care delivery and informing improvement efforts for children with medical complexity and children and youth with special health care needs. His work has informed the evolution of care coordination functions and activities, enabling systems to become high-performing delivery models, including developing and testing models for transitioning youth with complex needs from pediatric to adult care teams. He served as Medical Director of the National Center for Care Coordination Technical Assistance and the National Care Coordination Academy, both funded by HRSA's Maternal and Child

Health Bureau, and contributed to the National Standards for Children and Youth with Special Health Care Needs. He spent nearly a decade on the Centers for Medicare and Medicaid Services Adult and Child Medicaid Core Set Review Workgroup, advising CMS leadership on prioritizing performance measures. Currently, he serves as Co-Principal Investigator of a five-year HRSA award focused on enhancing systems of care for CMC and is a key advisor to the School-Based Health Care Coordination Initiative.

Rahel Berhane, MD - Lead Physician & Medical Director, Children's Comprehensive Care Clinic

CMC Family/Clinician Faculty

Rahel has served as the Lead Physician and Medical Director of the Children's Comprehensive Care (CCC) medical home project since its inception in Austin, Texas. A visionary leader, she was the driving force behind the original HHSC Title V grant request, which funded a community needs assessment and laid the groundwork for the CCC initiative. Under her leadership, the clinic has grown into a nationally recognized model for patient- and family-centered care for CMC. She has overseen the

implementation of numerous innovative programs aimed at improving care coordination, enhancing family engagement, and supporting the long-term well-being of medically complex pediatric patients. Beyond her clinical work, Dr. Berhane is a committed advocate for systemic change, contributing her expertise to various state and national forums and promoting policies and payment models that support integrated, relationship-based care systems.

Jay Berry, MD, MPH – Chief, Complex Care Services; Associate Professor, Harvard Medical School

CMC Café Clinician Faculty

Jay is a general pediatrician and hospitalist specializing in the care of CMC. His research focuses on care delivery, clinical outcomes, and health resource utilization for this population. He pursues projects involving development of contingency plans, machine learning analyses of comorbid conditions, and standards for hospital discharge care. He has led efforts to improve healthcare integration and reduce rehospitalizations using innovative health IT applications. He is active as a principal investigator on NIH and foundation grants in this domain.

Adenike Chon, MHSA - Licensed Social Worker & Family Advocate

CMC Café Family/Clinician Faculty

Adenike developed a passion for advocating for diversity and inclusion in education after the birth of her son, who was born at 25 weeks. As a licensed Social Worker with a Bachelor's degree in Psychology and a Master's in Health Care and Human Services

Administration, she brings both professional expertise and lived experience to her work. She consults on numerous projects focusing on community connecting, advocacy, diversity and inclusion, leadership development, and mental health supports for families of children and youth with special health care needs. Nationally, she has served as a Parent Advisor for the CMC CoIIN and the American Academy of Pediatrics. She is a graduate of Partners in Policymaking Class 34, PACER Family Leadership Training, and Family Voices of Minnesota's CONNECTED Peer Support Program, and served three terms on the Minnesota Department of Education's Special Education Advisory Panel. Currently, she serves as a member of the Complex Care Quality Improvement Team and a Family Engagement Research Partner at Gillette Children's, National Academy for State Health Policy's (NASHP) Project Advisory Committee, and Family-Led Academic Grand (FLAG) Rounds Family Faculty.

Cara Coleman, JD, MPH – Principal, Bluebird Consulting & Director, Bluebird Way Foundation

CMC Café Family Faculty

Cara is Principal at Bluebird Consulting and Director of the Bluebird Way Foundation, a nonprofit committed to using the arts, humanities, storytelling, and narrative medicine to humanize health care and health profession education. The foundation honors and continues the work of her daughter, Justice Hope, who had disabilities and was medically complex. In 2012, Cara and Justice began reading the children's book Cara wrote, "I am Justice, Hear me Roar," to medical students and residents to help humanize medical education. Cara is an Instructor of Medical Education at University of Virginia Medicine INOVA Campus. She also serves as Associate Editor for Family Partnerships on the Pediatrics Executive Editorial Board, where she helps ensure family voices are centered in pediatric research and practice.

Margaret (Meg) Comeau, MHA – Senior Project Director, Center for Innovation in Social Work & Health (CISWH), Boston University

CMC Café Family/Clinician Faculty and Co-PI

Meg is a nationally recognized expert in health policy for children and youth with special health care needs, particularly those with complex medical conditions. At CISWH, she leads research and quality improvement initiatives focused on health coverage, care delivery, and access for medically complex children, securing approximately $14 million in funding. She frequently lectures and writes on Medicaid policy, disability justice, and quality improvement in pediatric care, and has published extensively in peer-reviewed journals including two special supplements to Pediatrics. Meg serves on multiple national committees and until recently co-chaired the Academic Pediatric Association's Complex Care and Disability Special Interest Group. She excels at building collaborative partnerships with state agencies, family organizations, and pediatric provider networks to advance care for CMC.

Allison Gray, MA - Senior Program Officer, Lucile Packard Foundation for Children's Health

CMC Café Family Faculty and Funder

Allison is a senior program officer at the Lucile Packard Foundation for Children's Health, where she leads the Foundation's efforts in family engagement and family-centered care. In her previous role with Family Voices of California, she helped develop and expand a statewide parent advocacy training program for caregivers of children with special health care needs. She has served on various national and state-level committees and is a current member of the California Children's Services Advisory Group. Allison is a graduate of the Women's Foundation of California's Funder's Policy Institute. As the parent of children with special health care needs, she is dedicated to ensuring family partnership is valued at all levels of the health care system.

Bethlyn Vergo Houlihan, MSW, MPH – Senior Project Director, Center for Innovation in Social Work & Health, Boston University

CMC Café Clinician Faculty and Co–PI

Bethlyn leads interdisciplinary, team-based initiatives to transform systems of care via robust partnerships that center lived experience, with a focus on humanistic care, disability justice and health equity. For over 24 years, she has worked at the intersection of social work and public health, guiding community-driven innovation through projects such as the CMC CoIIN and as co-principal investigator for dynamic co-training initiatives around emergency preparedness and the CMC Café Series. She advances both quantitative and qualitative methods for meaningful systems change and applies emerging technologies in care innovation for people with complex health and social needs across the life course. She plays leadership roles in capacity building across health and social systems and supports fellow leaders to partner effectively with people with lived expertise for practical, sustainable change.

Madhavi Kuthanur - Program Associate, Lucile Packard Foundation for Children's Health

CMC Café Faculty and Funder

Madhavi is a Program Associate at the Lucile Packard Foundation for Children's Health, where she supports the Foundation's grantmaking and advocacy program to improve the health care system for children and youth with special health care needs and their families. Prior to her current role, she supported communications, outreach, and partnership-building activities at the Bay Area Global Health Alliance and other nonprofit organizations advancing global health equity. Madhavi holds a Bachelor of Arts in Medical Anthropology and Global Health from the University of Washington. She is passionate about pursuing work that advances equity across systems of care to better serve the most vulnerable and neglected populations.

Shawnna Parker, MSN, RN, CNE, CPN - Pediatric Nurse, Foster Parent & Family Leader

CMC Café Family/Clinician Faculty

Shawnna is a mother to three boys, one of whom has complex medical needs, and over the years has been a foster mom to 13 adults and children with varying medical complexities. She is also a pediatric nurse, focusing on education for clinical team members who care for children with complex medical conditions. Her personal and professional experiences have fueled her passion for family-centered care and the critical importance of including families in every level of decision-making. She is committed to helping healthcare organizations recognize the vital role of family voices when designing and expanding programs to ensure they truly meet the needs of those they serve. Shawnna served as a Family Advisor for the CMC CoIIN, which led to her important work as a Family/Clinician Faculty on the development of a humanistic framework for CMC Cafe Series.

Kate Robinson, MFA - Artistic Director of Fox Serving Pie Studio for Feminist Inquiry, Family Consultant

CMC Café Family Faculty (Cafe series only)

Kate Robinson has 20 years of experience in the healthcare and non-profit sectors. She has been actively engaged as a senior leader, a consultant to senior leaders, a documentary filmmaker, and a patient advocate. She has two children, one of whom is medically complex. She is a tireless advocate for family-professional partnerships, the healing power of expressive arts, and maternal mental health. As a young nonprofit executive director, she found herself questioning the impact of her organization: is what we're doing here actually working? Those questions led her to explore many types of program evaluation and organizational learning. After serving as Director of Strategic Initiatives for Social Solutions Global, Kate received an MFA and made two successful documentary shorts on using data to learn and improve social programs. She is a sought-after speaker and strategist.

Jeff Schiff, MD, MBA – Pediatrician & Senior Scholar, AcademyHealth

CMC Café Clinician Faculty

Jeff is a pediatrician and health policy expert whose career bridges clinical practice, Medicaid program leadership, and health services research. He served as the Medicaid Medical Director for Minnesota, overseeing quality measurement, benefit policy, and delivery system redesign. His work emphasizes the integration of policy, quality improvement, and social determinants to enhance equitable outcomes for underserved populations. He is a Senior Scholar at AcademyHealth, where he continues to consult and publish on ways to transform health care systems for improved performance and equity. He remains committed to creating a learning health care system grounded in patient and family centeredness.

Resources & Examples for Humanistic Care

"Narrative medicine storytelling and the proper framework to fuel it are necessary to move forward in humanistic care for medicine."

CMC Cafe Family.Clinician Faculty

Resources, Examples, and Supporting Materials

This list was developed from both suggestions of CMC Cafe participants and the CMC Cafe Family & Clinician Faculty. Anything referenced throughout the framework & guide will be listed here.

GO TO RESOURCE LIST

Dedication to Jordyn Valdez

Jordyn Valdez, daughter of Ana & Framil and sister of Landen

This work is dedicated in memory of:

Jordyn Malia Diogo Valdez

2002 – 2025

Jordyn's mom, Ana Valdez, has brought her full self with great generosity first with the CMC Collaborative Innovation & Improvement Network (CMC CoIIN) and now the CMC Cafe series. Ana is tenacious, funny, kind, intelligent, thoughtful, and brave.

Most of us on the project never had the joy and privilege to know Jordyn personally. Yet, knowing her mom, we have a keen sense of the light and love that is Jordyn. Jordyn was the MDA Goodwill Ambassador for both Hawaii and Oregon. She was also her high school's yearbook editor for two years. She graduated with a 4.0 GPA. Jordyn loved volunteering and spending time with the babies at a daycare program. She was an avid writer who loved singing and spending time with family and friends.

Jordyn was a strong and dedicated advocate for anyone with a disability, particularly in school and in the medical setting. She put much thought and effort into providing information and feedback to help improve education for others like her. Her insights were remarkably perceptive—shaped by lived experience that most of us could never fully understand. As Ana recalls, Jordyn once joked that she couldn't make eye contact with students in the hallways because "HER eye level was their crotch and butts!" But after the laughter, Jordyn would make her point clear: being physically lower than everyone else often made her invisible to them. People noticed her wheelchair more than they noticed her. Even in humor, Jordyn revealed profound truths about the world people with disabilities navigate daily.

This clarity and self-advocacy extended to her medical care. Jordyn made a detailed list of exactly how she wanted things handled before surgery or procedures—specifying, for instance, that her dad must accompany her into the OR because he knew best how to position her to prevent skin breakdown. When medical staff hesitated or said "that's not what we typically do," and Jordyn was too tired to argue, Ana would step in: "Actually it CAN be done and, unfortunately if it isn't, she won't have the procedure." Jordyn knew what she needed, and she taught those around her to listen.

Though she couldn't always participate directly, Jordyn was a vital part of the CMC CoIIN work, providing Ana with constant insight and thoughtful discussions. Ana reflects, "She was so incredibly insightful and intelligent."

In her final months, Jordyn wrote over 100 poems—powerful works that she left as gifts for her family. She also wrote instructions for her parents and her brother on how to be their best selves for each other. She told her dad to hug her mom daily. She told her mom to be patient when her dad got distracted by electronics. As Ana says, "She was such an incredibly deep and thoughtful person."

We dedicate this work in celebration of Jordyn's ongoing impact in the lives of all who knew her, and in the lives of countless others who will benefit from the advocacy, wisdom, and love she brought to this world.
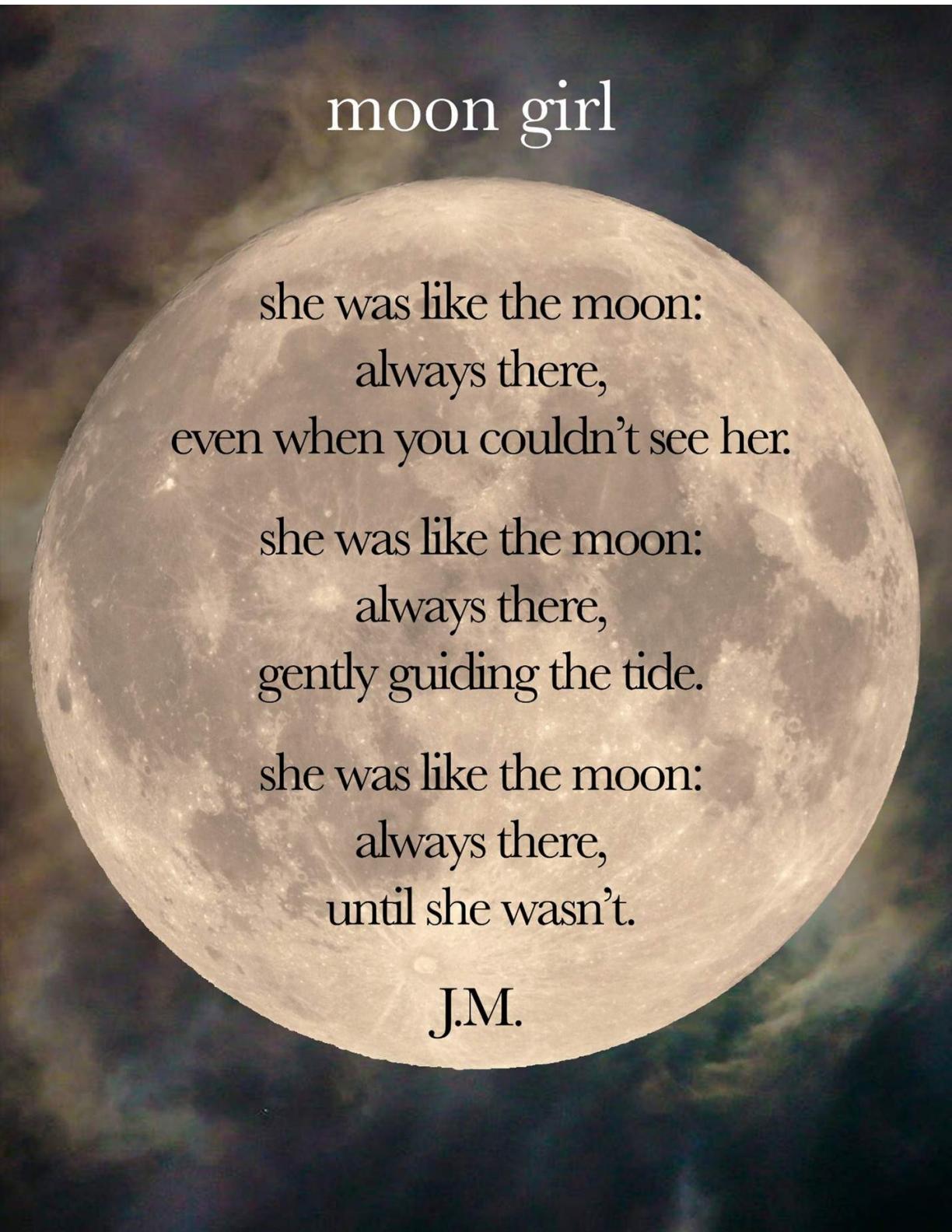
moon girl

she was like the moon:
always there,
even when you couldn't see her.

she was like the moon:
always there,
gently guiding the tide.

she was like the moon:
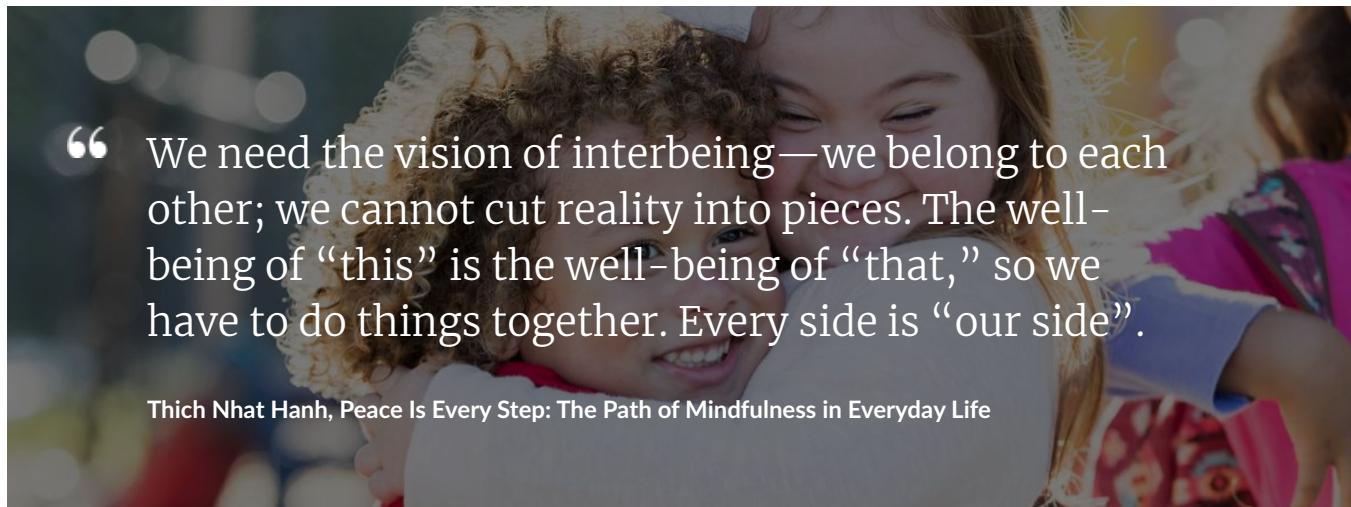always there,
until she wasn't.

J.M.

One of Jordyn's more than 100 poems (poetry artwork by a dear family friend, Suesue Okada)

Acknowledgements

> " We need the vision of interbeing—we belong to each other; we cannot cut reality into pieces. The well-being of "this" is the well-being of "that," so we have to do things together. Every side is "our side".
>
> **Thich Nhat Hanh, Peace Is Every Step: The Path of Mindfulness in Everyday Life**

It takes a village

First and foremost, we are **so grateful to our sponsors and partners the Lucile Packard Foundation for Children's Health** whose inspiration and support was instrumental to bringing this project alive! Learn more about this remarkable organization at the link at the bottom of this page.

This project and resulting framework have been a labor of love, held for many years by a **community of families, clinicians, and other system leaders nationwide working together with joy, candor, and dedication**, most recently from 2023-2025 on The Future of Care for CMC Cafe Series. We would like to thank the CMC Collaborative Improvement and Innovation Network (CMC CoIIN) state teams for their deep work through COVID devoted to interdisciplinary quality improvement driven by family partnership, upon which this work is based.

We are grateful to the **CMC CoIIN family focus group participants and family leaders** who first planted the seed of [humanistic care as essential for systems change](#), including [measures that matter](#). We are indebted to the **many family & clinician co-presenters and over 900 participants throughout the series'** discussions. It is your collective candor and insights that wove together the tapestry of ROOTED IN HUMANITY and its urgency; your stories and quotes are interwoven throughout this guide.

The Co-Principal Investigators, Bethlyn Vergo Houlihan and Meg Comeau, would also like to thank the **Center for Innovation in Social Work & Health Director Tami Gouveia** specifically for providing in-kind support of their time to complete the framework once it became clear that was the necessary path forward to honor this work.

And, of course, to **all of you for the work you do everyday** wherever you sit in the system. Holding space for relational care that honors our shared humanity may be the most important work any of us ever do.

Tell Us What You Think

We'd love to hear from you!

Whether its usability feedback, ideas for what we could do next or ways you'll use ROOTED IN HUMANITY, let us know. Feel free share your interest in spreading the framework as well! We will use your thoughts to shape future projects; share your contact info and we will connect as future projects allow.

GO TO FEEDBACK FORM

(i)   **We welcome your specific inquiries about this project and the urgent action framework for humanistic care! Please contact Bethlyn Vergo Houlihan at bvergo@bu.edu.**