The Future of Care for Children with Medical Complexity

Cafe #3: MEANINGFUL POLICY OPPORTUNITIES THAT MATTER TO FAMILIES

July 24, 2024

Discussants:

Lisa Kirsch, MPAff

Meg Comeau, MHA

BU School of Social Work
Center for Innovation in Social Work & Health

This virtual café series is generously funded by

Lucile Packard Foundation

Children's Health

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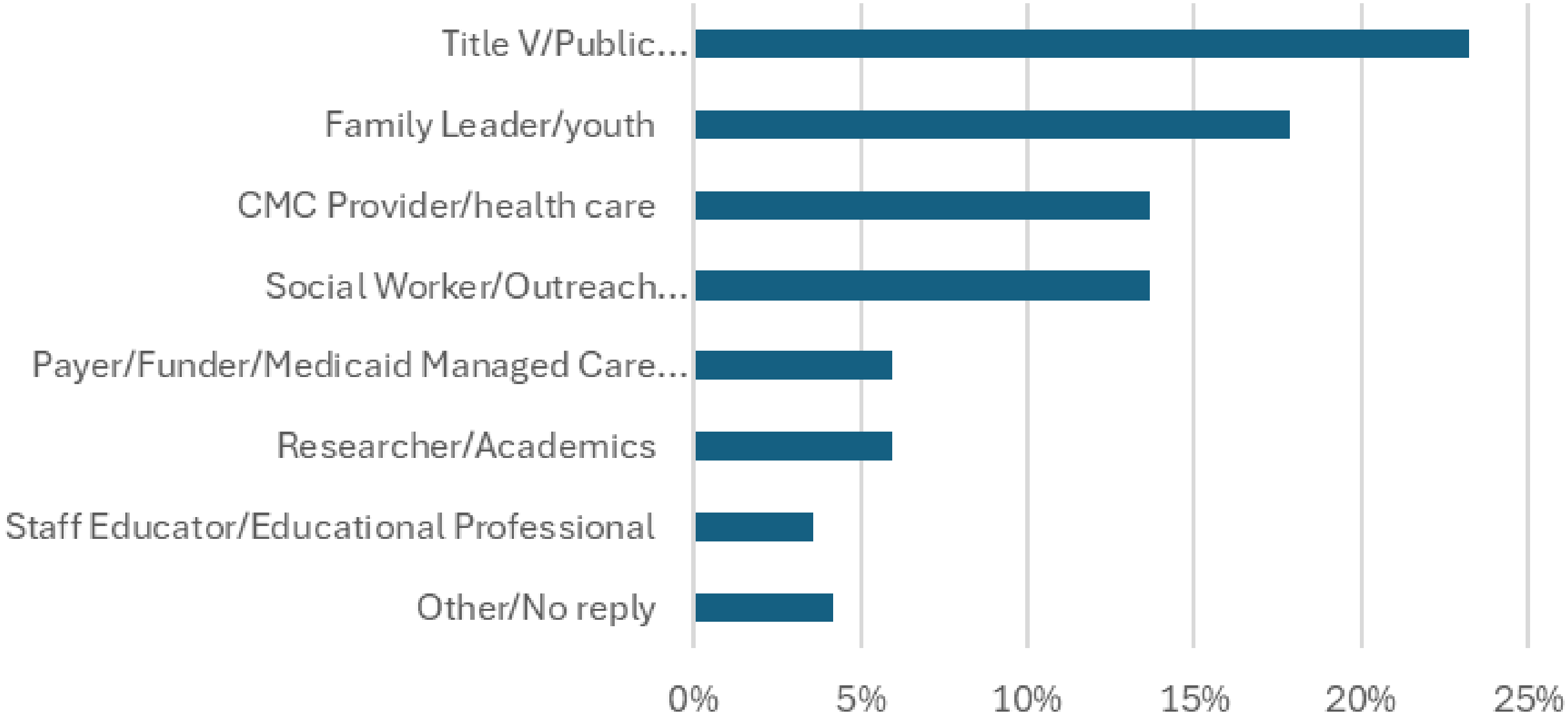
About the Future of Care for CMC Virtual Cafe Series

- Aim: To foster interdisciplinary dialogue among participants interested in meaningful systems improvements for CMC
- 60 min sessions: 20 min intro/presentation/Q&A + 25 min facilitated breakout discussion + 10 min share out
- Family partners co-lead every session
- Discussion questions and analysis created by an interdisciplinary faculty

Who We Are


Title V/Public...
Family Leader/youth
CMC Provider/health care
Social Worker/Outreach...
Payer/Funder/Medicaid Managed Care...
Researcher/Academics
Staff Educator/Educational Professional
Other/No reply
0%
5%
10%
15%
20%
25%

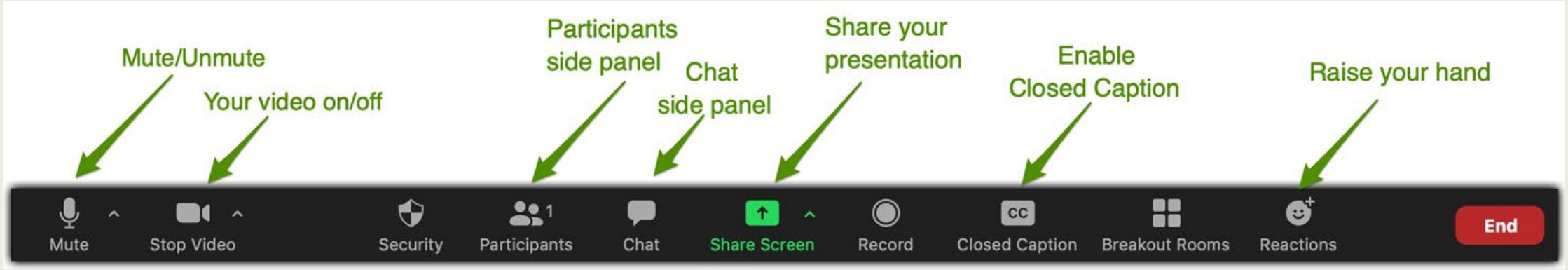
Discussion Format

To participate in the discussion,
please RAISE YOUR HAND via Zoom
or
WRITE IN THE CHAT BOX

Both are equally valuable ways to participate!

This meeting is being recorded and the chat transcript will be saved & analyzed with support from AI

Zoom Platform
Please Use Your Camera & Mute Your Line



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the FUTURE of CARE for CHILDREN with MEDICAL COMPLEXITY

VIRTUAL CAFÉ SERIES

WHERE are WE NOW and WHERE WE NEED to GO

BROADEN & DEEPEN the CONVERSATION

- INTEGRATING PALLIATIVE CARE
- HOLISTIC PERSPECTIVES
- MEASURES
- CARE COORDINATION

OUTCOMES

- QUALITY of LIFE
- FAMILY WELL-BEING
- COST-EFFECTIVENESS of CARE

POLICY

MAKE it...

- FAMILY FINANCIAL SUPPORT
- HOME & COMMUNITY SERVICES

FAMILY-CENTERED

WHERE CAN the SMALLEST CHANGE MAKE the BIGGEST DIFFERENCE?

FAMILIES as EQUAL PARTNERS

NOTHING ABOUT US WITHOUT US!

TELLING STORIES

ATTITUDE

AMPLIFYING UNHEARD VOICES

I DON'T HAVE a DEFICIT... EVERYONE ELSE THINKS I DO...

COMMUNITY of SUPPORT

RELATIONSHIPS

OVERCOMING BARRIERS

- ORGANIZATION
- PHYSICAL
- ATTITUDE

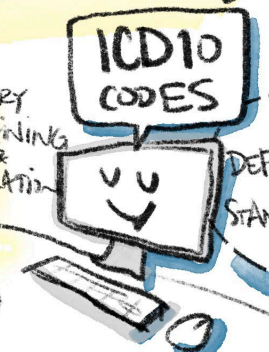
EXPANDING ACCESS to CARE

SHARED VALUES

PROCESSES: SIMPLE & STREAMLINED

HOW CAN WE THINK ABOUT INNOVATION & IMPROVEMENT DIFFERENTLY so AS TO GET IMPROVED/NEW RESULTS?

SHARED LANGUAGE



DEFINITIONS & STANDARDIZATION

INTERDISCIPLINARY TRAINING & EDUCATION

SUPPORTING CARE GIVERS

CLEAR & COLLABORATIVE CARE COORDINATION

LEVERAGING INNOVATIVE MODELS of CARE

STATE & GOV LEVEL SUPPORT NEEDED

TIME for CONNECTION

HUMAN CONNECTION

→ NOT JUST TECHNOLOGY

UTILIZING TECHNOLOGY + DRIVE CHANGE

HOW DO WE LEVERAGE CARE INNOVATION & BRING IT to SCALE SO THERE'S MORE COLLECTIVE POWER BEHIND IT?

BLUEPRINT for CHANGE

HOLISTIC

Illustrated by KARINA BRANSON
ConverSketch.com

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Virtual Café Series

Café 2: Humanism in Clinical Care to Meet Whole Child/Family Needs

Human Experiences, Values, & Dignity are First & Foremost

What Families Told Us Matters Most for Humanism in Care:

- Understanding what matters to patients & families
- Developing authentic relationships: trust & respect!
- Treating patients & families as whole people (not just a diagnosis)
- Providing individualized, whole-person care aligned with family goals & priorities

What Techniques, Strategies, & Tools Can We Draw Upon to Operationalize Humanism in Care?

- Active listening & humble inquiry
- Narrative tools to understand family perspective
- Flexible care delivery to meet family needs
- Multidisciplinary teams that include families as partners

What Changes Need to Happen to Better Integrate Elements of Humanism into Care?

- Redesigning systems to enable relationship-centered care.
- Training providers: start early in their education
- Transforming culture & mindsets across all members of the care team

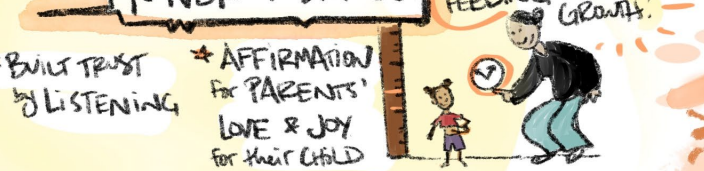
Societal Bias

"The system has shortcomings... not the child"

What Humanism Looks Like to Families:

Relationship & Trust

- Creativity for whole child
- Partnership & communication for providers:
  - Built trust by listening
  - Affirmation for parents' love & joy for their child
- Power of family-to-family support



Key Ideas from Breakout Discussions

- Presumption of confidence.
- Recognize the expertise in the room!
- Competing priorities:
  - Detrimental
  - But also necessary to push us

- The Power of Listening

Joy comes from earning the trust of families!

Healthcare is good at dehumanizing care...

Illustrated by Karina Branson
ConverSketch.com

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Policy Opportunities that Matter Most

- Everyone feels the moral distress – we all want to do better
- Visceral connection to human-driven care re-design to restore dignity and uphold relationships for families AND providers
- Know what it looks like, but now how to enable it to happen!
- Key takeaway: Predicated on upstream changes in Policy and policy to support humanism
- CAFÉ 3 → Specific policy priorities that codify family-driven elements of humanism in care

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January 2024

SUPPLEMENT ARTICLE | JANUARY 01 2024

Financing Policy Considerations From Texas to Optimize Care for Children With Medical Complexity FREE

Lisa Kirsch, MPAff ✉; Rahel Berhane, MD; Kendall Sharp, MBA, MSN, APRN, CPNP; Mari-Ann Alexander, PhD, RN; Sherry Santa; Adam H. Rosenbloom, MD, MPH; Maureen Benschoter, MD; Steve Fitton, BA; Carisa Magee, MPA; Ardas Laurel, MSW

Enact the Accelerating Kids' Access to Care Act

Led by Senators Grassley, R-Iowa, and Bennet, D-Colo., and Representatives Trahan, D-Mass., and Miller-Meeks, R-Iowa.

TOOLKIT

Everything You Need to Know About the ACE Kids Act

Health Care Financing Policy - What Is It?

Health care financing involves mobilizing funds, pooling them and using them to purchase (pay for) health care services

According to the CDC's Office of Policy, Performance and Evaluation, policy "is a law, regulation, procedure, administrative action, incentive, or voluntary practice of governments and other institutions"

Policies can range from formal (a law) to informal (a custom)

Policy can be conceived, implemented and evaluated on the national, state, organizational and/or individual levels

Current Financing Policy Tools for Advancing Care of Children with Medical Complexity

Required for every Medicaid enrollee under age 21

- Early, Periodic Screening, Diagnostic and Treatment (EPSDT)

Optional for States to Implement

State Plan Amendment (SPA) to Expand Eligibility

- Family Opportunity Act (FOA) Medicaid Buy-in
- Tax Equity and Fiscal Responsibility Act (TEFRA)

SPA to Finance Care Coordination

- Advancing Care for Exceptional Kids (ACE Kids) Act
- Section 2703 of the Affordable Care Act
- Targeted Case Management

Waivers to expand eligibility and/or services/supports

- 1915 Home- and Community-based Service Waiver
- 1115 Demonstration Waiver

Advancing Care for Exceptional (ACE) Kids Act

Enacted Federal Legislation

- Creates **health homes option** tailored to children with medical complexity
- Provides **state incentives** for participation: enhanced federal matching funds 15% above state's current match, not to exceed 90% for two quarters for health home services
- Requires **data and quality measure reporting** for states and health homes
- Allows **new payment models** that better align payment with best outcomes
- Includes **national definition** for children with medically complex conditions

Effective on October 1, 2022

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ACE Kids Legislation: Implementation Update

Currently represent a relatively small proportion of overall CMC initiatives nationally

- Utah is receiving ACE Kids planning grant
- Early legislation passed in **Colorado** to opt in before law enacted
- Legislation to opt in recently enacted in **Florida and Washington**
- Pilot project in **Texas** to develop a program "substantially similar" to ACE Kids
- Pilot in **Missouri** provides $1.5M for a pilot to reduce hospital and ED use and improve quality of life for CMC using a team-based model
- **To date, no state has yet submitted SPA to CMS to participate**

Accelerating Kids' Access to Care Act

Pending Federal Legislation

Aims:

Creating a new pathway for pediatric providers to enroll in multiple state Medicaid programs if certain requirements are met, including being in the lowest category for potential program integrity issues and enrolled in their home state's Medicaid program.

Improving children's timely access to essential health care and eliminating administrative burdens for providers and states and delays in care.

Focusing only on provider screening and enrollment, and not on authorization of care by an out-of-state provider nor payment rates for such care, leaving both issues within the purview of state Medicaid agencies.

Latest Update:

CBO score reduced from $7B to $218M over ten years. Passed out of House committee.

The bill is led by Sens. Grassley, R-Iowa, and Bennet, D-Colo., and Reps. Trahan, D-Mass, and Miller-Meeks, R-Iowa, and a growing list of bipartisan supporters.

July 24, 2024

A FAMILY-CENTERED HEALTH HOME FOR COMPLEX CARE IN AUSTIN, TEXAS – WORKING TO IMPROVE POLICY[2]

THE DELL CHILDREN'S COMPREHENSIVE CARE CLINIC (CCC)

- CCC is a medical home dedicated to the care of over 850 children with medical complexity (CMC). Most are enrolled in Medicaid, and many have low incomes and/or do not speak English.
- CCC strives to increase the wellbeing of children and their families by providing relationship-based, timely, comprehensive care and empowering families.
- Since 2012, CCC has worked to transform care for CMC. As a site in HRSA's current demonstration - Enhancing Systems of Care for Children with Medical Complexity, the Austin team aims to evaluate CCC's benefit to CMC and their families and Texas (through a health equity lens) to inform policy and payment change.
- **We believe relationship-based care and care integration is optimal for CMC and their families.** Looking at big P policy, care planning and coordination and treatment determination should be delegated to comprehensive health homes with alternative payment structures that appropriately reimburse and align incentives with optimal care delivery and outcomes. These comprehensive health homes also potentially can serve as hubs to support smaller and rural clinics.

GOAL: ACCESS TO CARE THAT IS INTEGRATED, EASY TO NAVIGATE, AND HIGH QUALITY

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

- A primary nurse coordinator is assigned for each patient and family.
- Providers who know the child and family are available 24/7.
- CCC holds daily team huddles and coordinates care transitions with inpatient providers.
- The full care team, including the family, has access to a shared data platform (MySTORY) with the child's care plan.
- CCC strives to integrate care with specialists & other providers, including by leveraging telemedicine/other technology – e.g. Biannual Whole Child Visits for meaningful, comprehensive care planning.

GOAL: FAMILY AND CHILD WELL-BEING AND QUALITY OF LIFE - WHAT MATTERS MOST

- The family voice is the CCC's North Star. Work to engage families centers on an innovative model that allows the care team to intimately know families' stories and journeys. This is foundational to providing high-value medical care based on what matters to families.
- At the core of the CCC are:
  1. the Family Liaison (a clinic parent) and
  2. the Family Workgroup - highly-engaged parents of CMC who meet monthly to monitor progress, inform model improvements, help design family surveys, and ensure family priorities remain paramount.
- As part of the current HRSA demonstration, the CCC is:
  - Expanding its Family Workgroup to better represent the diversity of clinic families by race, ethnicity, and language. Experienced members will mentor new members.
  - Partnering with Texas Parent to Parent, the state's Health Information Center and Family Voices affiliate, to ensure meaningful family involvement at all stages of care model implementation and evaluation.

GOAL: FINANCING SHOULD INCENTIVIZE CARE INTEGRATION AND FAMILY-CENTERED CARE

- Accessing needed care for CMC is challenging and time consuming for families and providers in a complex system.
- CCC has partnered with Texas Medicaid and one of its STAR Kids health plans, BCBSTX, on alternative payment models.
- Health plans are required to provide service coordination. CCC accepted delegation of many nurse service coordination functions over 4 years for 175 of its most complex patients for a per member per month (PMPM) payment. While we continue to believe nurse service coordination by a trusted health home is beneficial (vs. at the health plan level or by another 3rd party), this arrangement recently ended due to administrative barriers (e.g. double documentation, audit burden).
- CCC currently is piloting with BCBSTX an enhanced payment for Whole Child Visits, which are biannual, interdisciplinary visits to integrate and streamline care planning.
  - Goals of these visits are to reduce redundant assessment, improve health and well-being by identifying what matters most to the family, foster shared decision making, and create a single, comprehensive shared care plan.
  - These visits require significant time of the care team over 6 weeks pre-, during, and post-visit.

GOAL: PROMOTING HEALTH EQUITY

A HRSA project priority is to understand current systemic barriers and challenges and assess CCC's capacity to reduce health disparities. We are doing this through:

- Family surveys,
- Family experience group feedback, and
- **Photovoice**, which enables families to increase awareness, encourage dialogue, and create change using photos of their caregiving experience.

A parte del quehacer diario de la casa, también se juntan con las tareas extras que involucran a las necesidades especiales de mi nena. Una de esas tareas, lavar las jeringas, es la pesadilla de mi existencia.

Apart from the daily housework, they also come together with the extra tasks that involve my daughter's special needs. One of those tasks, washing syringes, is the bane of my existence.

POLICY ANALYSIS WORKGROUP

One of three workgroups informing Austin's HRSA demonstration, guided by lived experience, the **Policy Analysis Workgroup** is analyzing relevant federal and state statutes and regulations, Medicaid administrative requirements, and evidence-based research to inform recommendations to remove barriers to optimal quality and experience of care.

Priority policy issues identified by CCC clinic team and Family Workgroup

- Access to covered services – start with Private Duty Nursing (PDN)
- Durable Medical Equipment (DME) quality and quantity issues – start with syringes
- Sustainability of CCC's Biannual Whole Child Visits

Process

- Families' lived experience is at the forefront of identifying policy/administrative barriers and possible solutions.
  - Family caregivers are very resourceful in finding supplies to fill the gaps of what they are not able to get through insurance.
- Collaborative approach with families, TX Medicaid, health plans and providers.
- "Diving deep" to outline "As Is" and "To Be" and what changes are needed to reach "To Be."

FOCUS ON SYRINGES – CHANGING POLICY

- A common barrier identified by the Family Workgroup includes the number and type of syringes required for CMC with a G-tube for which syringes and often syringe extensions are used to provide nutrition (formula) and administer oral medicines.
- A series of meetings and survey is in process with family caregivers and the CCC clinic team to educate and share information to identify needs and solutions to **propose changes to state Medicaid benefits and policy**:
  - Identify type and quality of syringes and syringe adaptors needed for CMC and what is not currently available through Texas Medicaid.
  - Identify where enough supplies are not currently authorized without significant administrative challenges, including needed emergency supplies.
  - Process challenges with DME and supplies include prior authorization spacing, redundant processes with monthly orders, backlogs of supplies, lack of choice when what is available is not meeting the need.

FOCUS ON SYRINGES - PATIENT SAFETY

What we have learned so far:

- Medications from pharmacies come in various sizes with syringes used to administer them that are not designed for use with a g-tube.
  - With with incompatible adaptors/extensions, medication can be spilled, which results in further challenges having to get additional medication.
  - There are not syringes and syringe adaptors/extensions that are compatible across the board.
  - G-tubes also are different sizes.
- Quantity and quality of syringes – for caregivers, there is a hypervigilance with supplies like syringes.
  - Wear and tear on syringes can occur with reuse.
  - Measurement markings can also become unreadable after multiple uses – can cause medication errors.
  - Doctors may dispose of a syringe if used during a doctor visit – should caregivers have to intervene when a doctor disposes a syringe in a sharps container?
  - A syringe could be dropped, even by a nurse, which then is not allowed to be used.

Questions?
Comments?

Facilitated Breakout Discussion – Grab your coffee!

- Aim: To consider together actionable strategies, resources, and leverage points for change
- “Our Whole Life is a Quality Improvement Project”
- Collective **wisdom** and collective **impact**:
  It’s going to take ALL of us; we ALL matter
- Keep larger aspirational vision in mind AND make changes where we can now
- Multiple modes to capture breadth of perspectives – spoken AND chat
- ConverSketch: Karina Branson will bring the discussions alive visually afterwards

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Going into Breakouts

- Randomly pre-assigned
- 4 breakouts w/ 2 co-facilitators each (one family partner)
- 25 minutes for discussion
- Automatically close
- Family Partner Facilitators share out one highlight
- Participants chat key takeaways

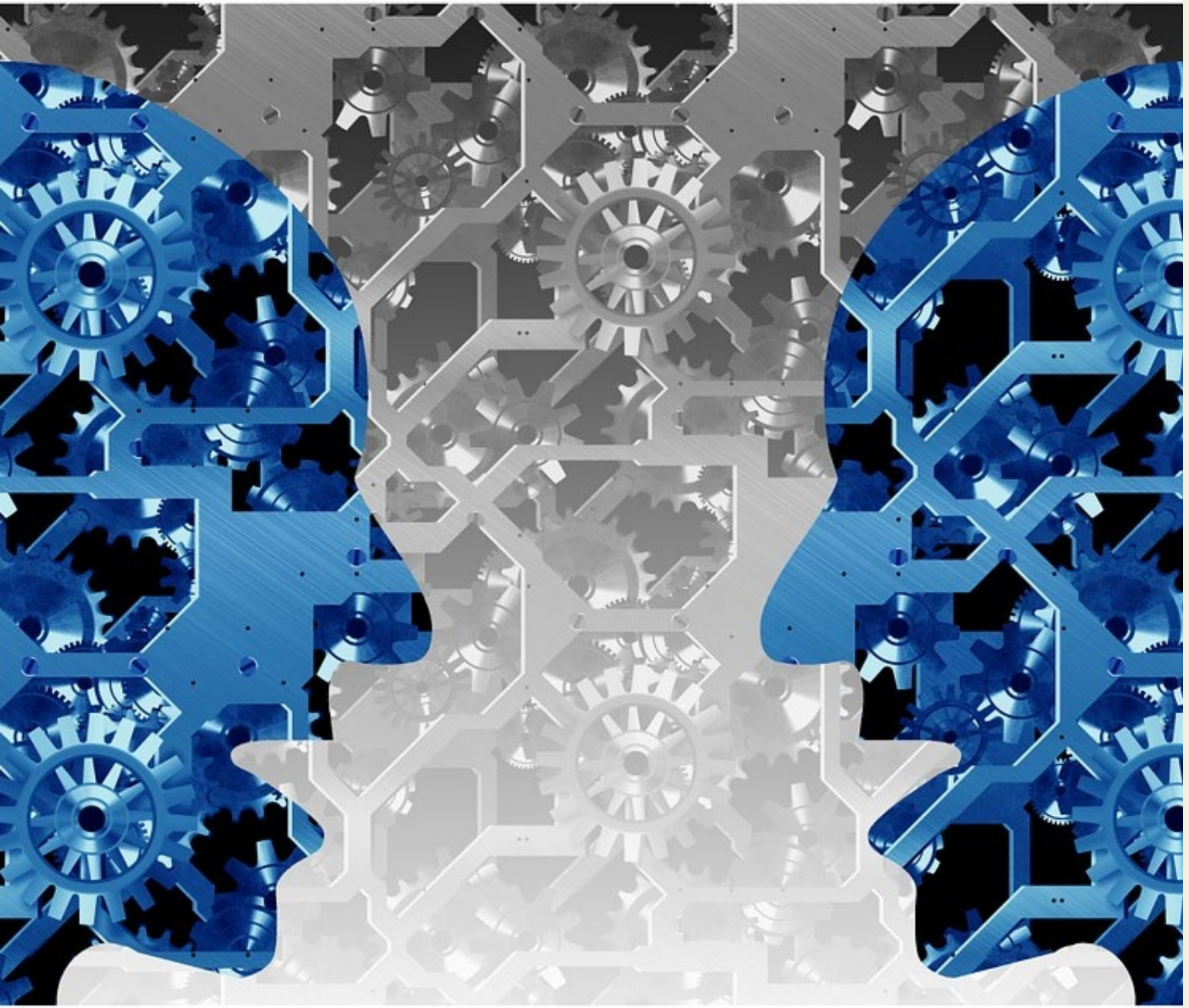
breakouts will be recorded to be synthesized, packaged, and shared out (supported by AI)

Questions to Explore Together

What new ideas or approaches could be tested under Medicaid or more broadly to improve care for CMC?

How can we design policies that benefit multiple stakeholders (families, providers, payers) in the care of CMC?

What are some innovative approaches to addressing specific challenges (like the syringe adapter example) that families of CMC face?



Group Share Out

- Family Partner Facilitators share one highlight out loud
- Participants share one takeaway in the chat

Future Café Topics

- Research: Family-Driven Approach to Understand Family Well-Being & its Facilitators
  Aug 21, 2024 2-3p ET (QR code on next slide!)
- Health Equity and Anti-Ableism through Family Partnership

  Oct 30, 2024 4-5p ET
- Sustainability and Strategic Partnerships

  Dec 4, 2024 4-5p ET

Next Virtual Café:
Family-driven Approach To Understand Family Well-being And Its Facilitators

Wed, Aug 21st, 2-3p ET

Discussants:

Jay Berry, MD, MPH

Katie Huth, MD, MMSc, FRCPC

Boston Children's Hospital

Register to attend the fourth café

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OPENPediatrics Complex Care Journal Club Podcast

Upholding Human Dignity for Children with Medical Complexity and their Families

Bethlyn Houlihan

Meg Comeau

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Evaluation Survey

Link in the chat box:

https://bostonu.qualtrics.com/jfe/form/SV_08GPPzXCwnxAVmu

Contact Us!

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