The Future of Care for Children with Medical Complexity

Cafe #6 Sustainability and Strategic Partnerships

December 4, 2024

Discussants:
Rahel Berhane, MD
Jeff Schiff, MD, MBA, FAAP
Rich Antonelli, MD, MS, FAAP

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

Discussants:

Rahel Berhane, MD

Rahel Berhane, MD, is a board-certified pediatrician with Dell Children's in Austin, Texas and provides care for infants, children, and teens with medical complexity at a medical health home called Dell Children's Comprehensive Care Clinic. Dr. Berhane serves as the Medical Director of the Children's Comprehensive Care Clinic and is a strong advocate for children with medical complexities. She is a member of the family faculty for the CMC Café series, including co-facilitation of multiple café breakouts. Over the last ten years, Dr. Berhane has spent time working with innovative people to design and implement a patient and family centered comprehensive clinic for families of children with medical complexity. She is interested in transforming the care environment for these families and children and serves on the Health and Human Services Commission Advisory Committee for the STAR Kids program in addition to chairing the subcommittee on health homes.

Richard C. Antonelli, MD, MS, FAAP

Richard has extensive experience working at the national level and in many states evaluating care delivery and informing improvement efforts, focusing on implementation of interprofessional, family-centered care coordination and care integration processes and performance measures to assure equitable, accessible, and sustainable outcomes for all. He previously served as co-principal investigator for the Health Resources and Services Administration (HRSA) and Maternal and Child Health Bureau's (MCHB) Enhancing Systems of Care for Children with Medical Complexity Coordinating Center. Richard also served as the medical director of the HRSA/MCHB funded National Center for Care Coordination Technical Assistance, in partnership with the American Academy of Pediatrics.

Jeffrey S. Schiff, MD, MBA, FAAP
Senior Scholar, AcademyHealth

Jeffrey S. Schiff is a senior scholar at AcademyHealth, a pediatrician, and a health services policy consultant focusing on improving the outcomes for those with limited resources. His work includes the use of policy and the implementation of quality improvement to interface with payment mechanisms to fundamentally change health care systems. He served as the chief medical officer for the Minnesota Department of Human Services (including the state's Medicaid program) from 2006 to 2019. In this role, Schiff worked to implement care programs to directly address disparities, to advance coordinated and integrated care for individuals with chronic and complex needs, and to advance value-driven payment models. He is past chair of Medicaid Medical Directors national network, past co-chair of the Child Core Set Annual Review Committee, and current co-chair of the Health Home Core Set Annual Review Committee.

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

PROGRAM

Enhancing Systems of Care for Children with Medical Complexity (CMC) Coordinating Center

AcademyHealth, in partnership with Boston Children's Hospital and FamilyVoices, is leading a Coordinating Center to support five Health Resources & Services Administration (HSRA)-funded demonstration sites to optimize the health and well-being for children with medical complexity and their families while also achieving health equity for these populations

PEOPLE

Elizabeth Cope, Ph.D., M.P.H., Susan Kennedy, M.P.P., M.S.W., Amanda Brodt, M.P.P., Jeff Schiff, M.D., M.B.A., Lauren Adams, M.A., Jaime Adler, M.S., M.P.H., Richard Antonelli, M.D., M.S.

There are approximately three million children with medical complexity (CMC) nationwide, representing 1-4 percent of all children and 5-6 percent of children covered by Medicaid. CMC are likely to have co-occurring behavioral health diagnoses, with 21 percent having an identified mood disorder, such as anxiety or depression. Some families face additional social determinants of health challenges, including poverty, housing instability, food insecurity or insufficiency, lack of transportation, language barriers, or foster system involvement. To address these needs, AcademyHealth, in

About

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This virtual café series is generously funded by

Lucile Packard Foundation

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Café 6 Objectives

1. Understand how to identify meaningful opportunities for effective sustainability solutions through family co-design
2. Identify approaches for moving from small wins to broader system sustainability of humanistic care
3. Learn strategies for building trust and partnerships across stakeholders (providers, families, payers)
4. Develop practical steps for sustainability planning

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
- Family partners co-lead every session
- Discussion questions and analysis created by an interdisciplinary faculty

Who We Are

Public health, policy

Family/youth leaders & advocates

Social work, community-based

CMC provider, care delivery

Payers, funders, admin

Researchers, academics

Educators

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

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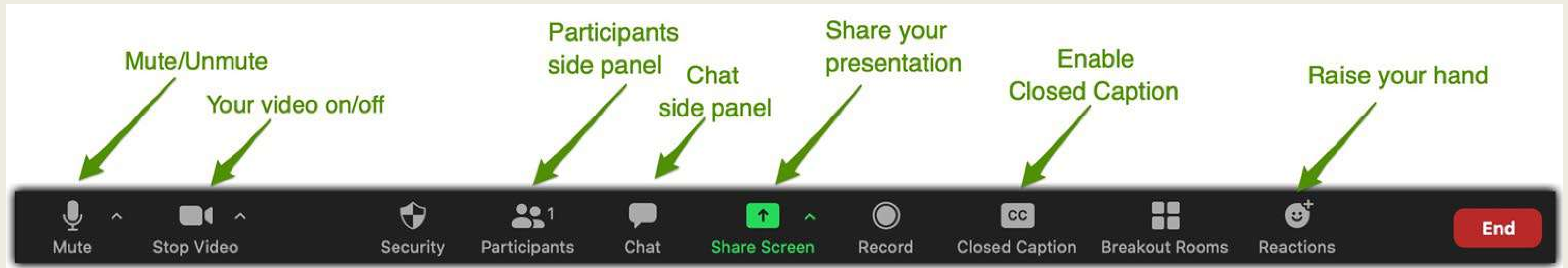
Zoom Platform
Please Use Your Camera & Mute Your Line



Capstone! 6th and Final Café

- Two throughlines of series:
  1. Humanistic care
  2. Radical family partnership
- You know it when you see it!
  - "And it's just so easy to talk the right talk…when you see the walk walked, it's really unmistakable."
- Family expertise leads to more efficient, effective solutions when truly valued
  - "Everyone in my experience wants to do the right thing, there just isn't always a shared understanding of what that is when the outcome from the family perspective isn't represented."
  - Operationalizing the HOW of the process

What are we sustaining?

For whom?

How?

Shaking it up!

- Full group throughout this session
- Highlight the process of true co-design to help you think about how to approach sustainability
  - Applicable to any issue:

  "It's not really about syringes. It's not about … this adapter being given a code so it can be billed. It's not that."
- AND distill key elements of sustainability
- Assembling the start of a playbook for participants in your own ecosystems

Designing Sustainable Systems Centered on Humanism

Examples of the Role of Family Partnership

Rahel Berhane

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Background

- HRSA Project – Policy Analysis team
- Meeting with the family workgroup at the beginning of the year

- Question from the Policy Analysis team to Family Workgroup:
  - “Prioritize the most significant challenges in the Care of your children that can be impacted by a change in (HHSC or MCO) Policy?

- Response from Family workgroup:
  - Supply related issues –specifically syringes
  - Home Support challenges

Examples of Problems with Syringes

- Through Medicaid, 10 syringes are supplied per month and do not last more than a couple of uses each. My child has 15 medications that have to be given three times a day!
- Syringe tips do not fit. DME delivers connectors that don't work well, leading to accidental disconnection of feeding tubes
- Rubber stopper on plunger does not last; after a few uses the rubber part pops off, which causes medication to be lost/spilled. It also then makes syringe unusable.
- My DME sends me syringes whose labels wear out after 2-3 washes. I have to put tape to make sure I draw up the right quantity but that also falls out
- The syringes do not fit the special vial the meds come in. I have to pour out the medicine to draw it up; leads to spillage
- The syringes my DME sends me are unusable. I have boxes of syringes I can't use. I have resorted to ordering the ones that work -paying for them out of pocket.

Additional Examples

- In a separate project – called "Photovoice" where parents were encouraged to document by pictures their daily lives- our team was surprised that 'syringes' made an appearance in some of the pictures as well…

Desperate for sleep, but my girl needs her meds. Coffee for me, meds for her. Desesperada por dormir, pero mi niña necesita sus medicamentos. Café para mí, medicinas para ella.

(c) 2023 CCC Photovoice Participant | Photovoice

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.

(c) 2024 Adriana | Photovoice

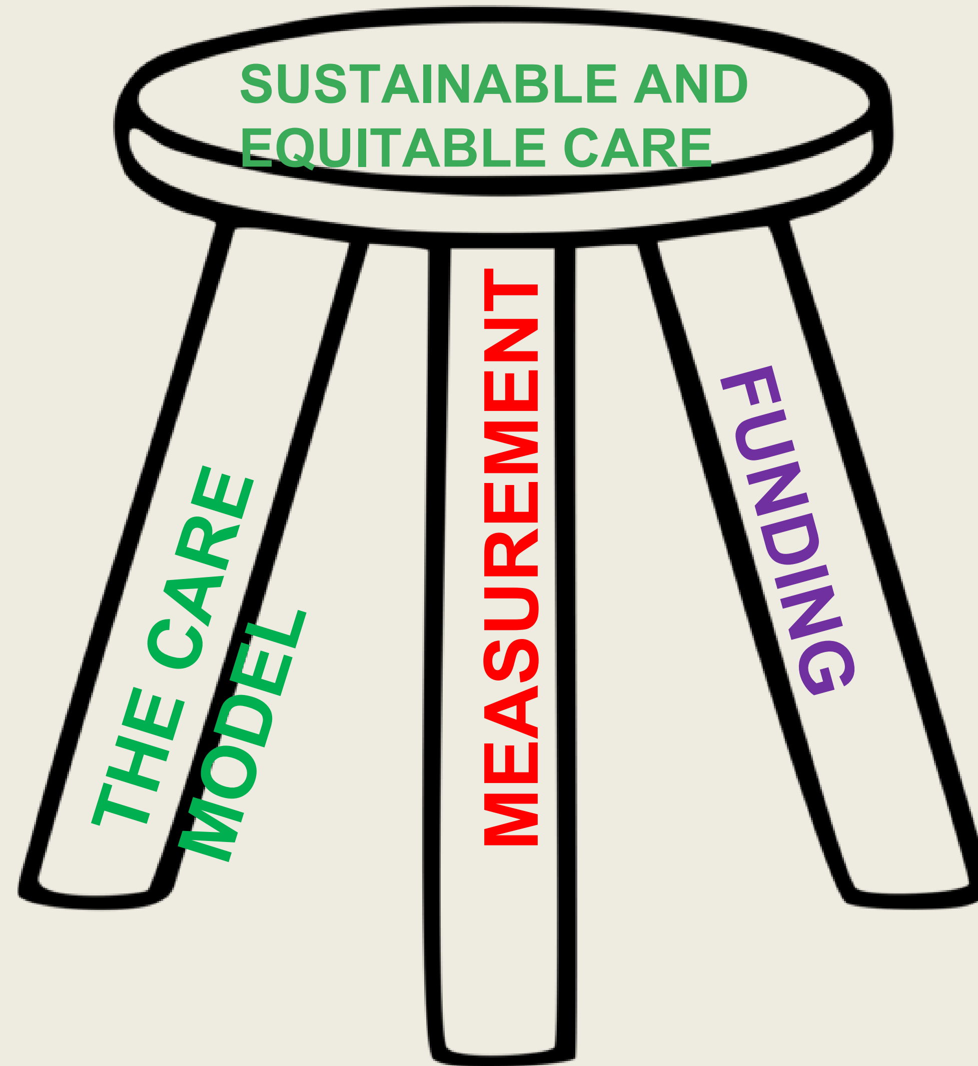
Families offered specific solutions about sustainable approaches to the ‘supply’ challenges: Examples

ENFit is a way to standardize all connectors in enteral feeding systems the variety of syringes and connectors available (luer lock, slip-tip, catheter-tip, and Christmas tree) fit both tube feeding equipment and many other medical systems, including IV, catheters, tracheostomy, etc.

- Product that would meet the need: Avanos (NEOMED 120001780 – 3 ml from hospital/PNM-S12NC 120001790 12 ml at home) ENFit Reusable Syringe with an O-Ring Plunger:
- ENFit safety tip that twists on to feeding Silicone 0-ring plunger for easy glide operation even after multiple washings; designed for 20 uses; for oral or enteral use. (Higher quality syringes can be provided less frequently; instead of monthly, NeoMed syringes could be provided quarterly)

Elements of Sustainability

Jeff Schiff


SUSTAINABLE AND EQUITABLE CARE
THE CARE MODEL
MEASUREMENT
FUNDING

Line of sight

Adequate insurance

Service coverage

Access to services

Integration of Service

Service Quality

Health outcomes

Quality of life and wellbeing

Measurement – fit for purpose

- Surveillance – measures that are population based and have broad multifactorial inputs (low birth weight, high school graduation)
- Accountability – measures that can be *primarily* attributed to one aspect of the health care "Line of sight"
  - Measures of access – adequacy of networks/ burden of authorization/ case management
  - Measures of process quality – clinical care processes/ care coordination and integration
- Measures to improve quality- measures that are designed for rapid learning and improvement *primarily* at the local site level

Radical Incrementalism

- Pioneer activity
- Develop coalitions
- Prove value with a
  line of sight to payment

Via-

- Persistence
- Shared stories and data
- Skills for policy implementation

Achieving Equity, Health, and Social Justice

Care Integration for Children, Youth, and Young Adults with Complex Needs

Café 6

Richard Antonelli, MD, MS – Medical Director, Integrated Care
Boston Children’s Hospital
Harvard Medical School

December 04, 2024

One Family's Care Map

G
Our Family

School
Clinical director
SpEd Director
SpEd Teacher
PT
OT
Nurse
>6 ABA therapists
BCBA
Sped-Pac
Out-of-district School
City Sped
Sped Liaison
Sped Director
Sped Parent-Advisory Council
DESE
Transportation
Bus Driver
Dispatch
District Coordinator

Developmental Assessments
Neuropsych
Speech
OT/AT

Health
Dentist
Private insur.
Medicaid
Dental
Pediatric specialty Hosp
Pharma co.
Endocrine
Genetics
Cardiology
G/I
Opthalm.
Ortho
Pedi Practice
Pediatrician
Referrals, triage, scripts
Specialty Hospital
Neuro
Physiatry
Meds + Equip.
Specialty pharm.
Local pharm
Toileting supplies
Foot Braces

Info, Advocacy & Leadership
Family-Prof. Partnerships
CHIPRA
LEND
Reps
Nat'l
State
Local
school committee
List serves
Family Voices
Arc
Disability Scoop
Catalyst Center
Various orgs
Federation for Children w/SN
Mass Advocates
Mass Families Organizing for Change
DPH

Recreation & Community
Town Rec
Adaptive sports coach
Swim teacher
Comm. Arc
PCA
Medicaid
DDS

Legal & Financial
Trust + Estate
Attorney
$ Planner
Education
Attorney
Ed. consultant

Support
People
Family
Friends
Neighbors
Support groups
NS
CLSF
Therapists
Indiv.
Family
Daughter
SibShops
Sibling Support Network
Blog: Durga's Toolbox

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from Cristin Lind
www.cristinlind.com

www.childrenshospital.org/care-coordination-curriculum/care-mapping

Complexity is Multifactorial

Including Social, Medical, and Behavioral Needs

Children with chronic conditions

--Behavioral (ADHD, depression, anxiety, PTSD)
--Asthma
--Obesity
--Diabetes
-- Social Risk Factors
-- Adverse Childhood Experiences

Complex

Chronic

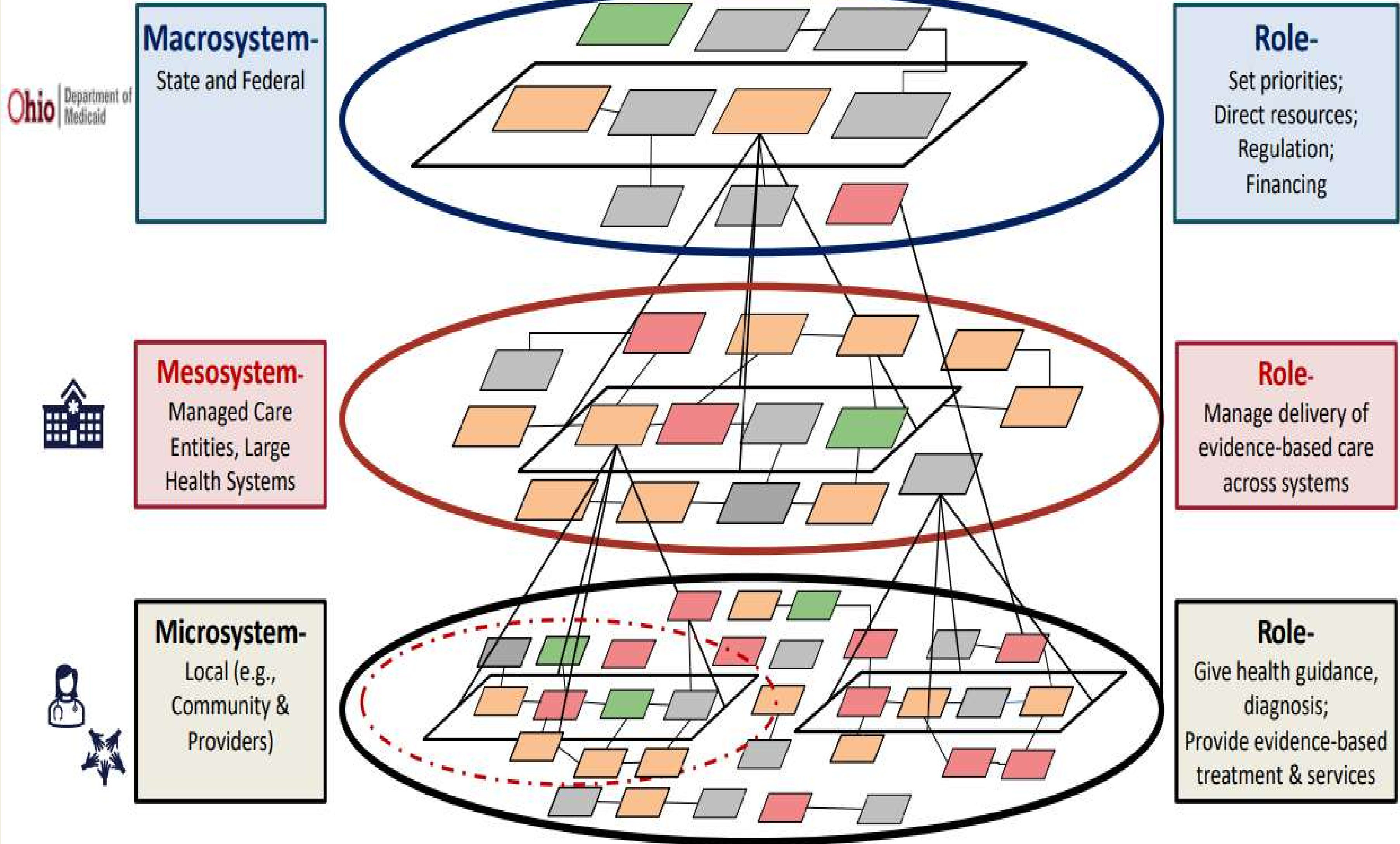
Healthy, Preventive

Children with complex needs

--Neurodevelopmental (Autism, etc.)
--Behavioral/Psychiatric
--Hematology/ Oncology
- Sickle cell
- Hemophilia

--Technology dependent
-- Cystic Fibrosis
--Multiple Chronic Conditions
-- Social Risk Factors
-- Adverse Childhood Experiences

Value–Based Payment Models for Medicaid Child Health Services, Bailit and Houy, United Hospital Fund – July, 2016



Potential Measures

Federally Mandated Measures; eg, Medicaid Child Core Set; Health Home; Title V NPM's, NOM's; ESM's

EPSDT– access, equity, process oriented

Measures Informed by Local Priorities and Rights Holders– Patient/ Family Experience Measures

Boston Children's Hospital

Measure What Matters

Domains of Integrated Care

Care Coordination

- Care Coordination Measurement Tool (CCMT)
- High Quality Handoffs: Clinician Reason for BCH Visit and Action Grid
- Inter-professional Education: Care Coordination Curriculum and Integrated Care Bootcamp

Person, Patient, Family, Caregiver Experience

- Pediatric Integrated Care Survey (PICS)

Provider Experience

- PCP Experience of Care Integration Survey

Utilization and Financial Outcomes

- Total Medical Expense (as relevant and available)
- Admissions, Readmissions, Emergency Department Utilization

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Integrated Care Program

Care Mapping

Care Coordination Curriculum

Care Coordination Measurement

Patient & Family Experience Outcome

High Quality Handoffs

Multidisciplinary Care Planning

National Center for Care Coordination Technical Assistance

Integrated Care at Boston Children's Hospital

Integrated Care is Important to Everyone!

Family/ Patient Perspective
A national sample of parents whose children have special health care needs reported that 37% of the time, their child's care team members rarely or never explained who was responsible for different elements of their child's care[1]. Families expect this to be 100%.

Referring Provider Perspective
More effective care could be offered in the primary care setting if consulting subspecialists would give clear and actionable information that addressed their concerns.

Subspecialist Perspective
Knowing why the primary care provider refers the patient to the subspecialty setting would allow them to know what has been done to date, and what is expected from them.

Today's care teams are challenged to coordinate activities and recommendations across settings. Often , families must take the lead on these responsibilities. Along with adding substantial strain to families, these challenges often result in uncoordinated and inefficient care. Integrated care is the seamless provision of health services, from the perspective of the patient and family, across the entire care continuum and is essential to achieving the best health outcomes for every patient. Care coordination is the set of activities and functions that is necessary to create and implement a multidisciplinary plan of care in partnership with the patient and family[2].

The Integrated Care Program at Boston Children's Hospital creates and validates processes, tools, and measures

Links to Measures and Specifications

HRSA Title V Measures

- National Snapshot
- National Outcome Measures
- National Performance Measures

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CMS Health Home Core Set

- Health Home Quality Reporting | Medicaid

https://www.medicaid.gov/medicaid/quality-of-care/downloads/2024-health-home-core-set.pdf

CMS Health Home Core Set

- CMS Medicaid Child Core Set Measures
- 2025 Core Set of Children’s Health Care Quality Measure for Medicaid and CHIP (Child Core Set)

https://www.bing.com/ck/a?!&&p=38b51900bad8a8c7a9fc175349f26c3791b2c5d1443b9a1d2266e9c0d7b14d0eJmltdHM9MTczMzI3MDQwMA&ptn=3&ver=2&hsh=4&fclid=2d3a965a-f420-66fc-1a43-9988f5446738&psq=cms++child+health+home+core+set&u=a1aHR0cHM6Ly93d3cubWVkaWNhaWQuZ292L21lZGljYWlkL3F1YWxpdHktb2YtY2FyZS9wZXJmb3JtYW5jZS1tZWFzdXJlbWVudC9hZHVsdC1hbmQtY2hpbGQtaGVhbHRoLWNhcmUtcXVhbGl0eS1tZWFzdXJlcy9jaGlsZHJlbnMtaGVhbHRoLWNhcmUtcXVhbGl0eS1tZWFzdXJlcy9pbmRleC5odG1s&ntb=1

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Questions?
Comments?

Discussion questions

1. Where have you/could you structure family engagement for true partnership vs token representation to enable better technical solutions?

2. Do you have examples of "small changes with big impact" to enable humanistic systems of care? What priority next steps can you take in your environment and with whom?

3. What measures are needed to demonstrate the value of humanistic care when it is designed around trust in families and valuing their expertise? For example, we've discussed the care experience as it relates to care quality; efficiency through reduced admin burden and/or waste.

4. Ultimately, how can we advocate for inclusion of these critical outcomes into approaches for sustaining all aspects of the care model, including financing?

You are not obligated to complete the work, but neither are you free to abandon it

Evaluation Survey

Link in the chat box:

https://bostonu.qualtrics.com/jfe/form/SV_5gQxvABViYNyFOS

Contact Us!

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Integrated Care

seamless provision of health care services, from the perspective of the patient and family, across entire care continuum. It results from coordinating the efforts of all providers, irrespective of institutional, departmental, or community-based organizational boundaries.

Care Coordination

activities in “the space between”- Visits, Providers, Hospital Stays that co-create (with patient and family) and implement a plan of care

2014 AAP Policy Statement: Patient-and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems

Opportunity to Improve Care– Mandatory Reporting

2024 Mandatory Core Set of Children's Health Care Quality Measures for Medicaid and CHIP (Child Core Set)

CMIT #*	Measure Steward	Measure Name	Data Collection Method
Primary Care Access and Preventive Care			
760	NCQA	Weight Assessment and Counseling for Nutrition and Physical Activity for Children/Adolescents (WCC-CH)	Administrative, hybrid, or EHR
128	NCQA	Chlamydia Screening in Women Ages 16 to 20 (CHL-CH)	Administrative or EHR
124	NCQA	Childhood Immunization Status (CIS-CH)	Administrative, hybrid, or EHR[a]
761	NCQA	Well-Child Visits in the First 30 Months of Life (W30-CH)	Administrative
363	NCQA	Immunizations for Adolescents (IMA-CH)	Administrative or hybrid[a]
1003	OHSU	Developmental Screening in the First Three Years of Life (DEV-CH)	Administrative or hybrid
24	NCQA	Child and Adolescent Well-Care Visits (WCV-CH)	Administrative
1775	NCQA	Lead Screening in Children (LSC-CH)	Administrative or hybrid
Maternal and Perinatal Health			
413	CDC/NCHS	Live Births Weighing Less Than 2,500 Grams (LBW-CH)	State vital records
581	NCQA	Prenatal and Postpartum Care: Under Age 21 (PPC2-CH)**	Administrative or hybrid
166	OPA	Contraceptive Care – Postpartum Women Ages 15 to 20 (CCP-CH)	Administrative
1002	OPA	Contraceptive Care – All Women Ages 15 to 20 (CCW-CH)	Administrative
508	CDC/NCHS	Low-Risk Cesarean Delivery (LRCD-CH)	State vital records
Care of Acute and Chronic Conditions			
84	NCQA	Avoidance of Antibiotic Treatment for Acute Bronchitis/Bronchiolitis: Ages 3 Months to 17 Years (AAB-CH)	Administrative
80	NCQA	Asthma Medication Ratio: Ages 5 to 18 (AMR-CH)	Administrative
49	NCQA	Ambulatory Care: Emergency Department (ED) Visits (AMB-CH)	Administrative
Behavioral Health Care			
271	NCQA	Follow-Up Care for Children Prescribed Attention-Deficit/Hyperactivity Disorder (ADHD) Medication (ADD-CH)	Administrative or EHR[a]
672	CMS	Screening for Depression and Follow-Up Plan: Ages 12 to 17 (CDF-CH)	Administrative or EHR
268	NCQA	Follow-Up After Hospitalization for Mental Illness: Ages 6 to 17 (FUH-CH)	Administrative
448	NCQA	Metabolic Monitoring for Children and Adolescents on Antipsychotics (APM-CH)	Administrative[a]
743	NCQA	Use of First-Line Psychosocial Care for Children and Adolescents on Antipsychotics (APP-CH)	Administrative
264	NCQA	Follow-Up After Emergency Department Visit for Substance Use: Ages 13 to 17 (FUA-CH)	Administrative
265	NCQA	Follow-Up After Emergency Department Visit for Mental Illness: Ages 6 to 17 (FUM-CH)	Administrative
Dental and Oral Health Services			
897	DQA (ADA)	Oral Evaluation, Dental Services (OEV-CH)	Administrative