




Key Highlights: WHERE WE ARE NOW & WHERE WE NEED TO GO

The Future of Care for Children With
Medical Complexity Virtual Cafe Series
Family-Driven Priorities & Change Ideas
from Cafe 1



**March
27,
2024**



Ideas for Systems Solutions From and With Your Peers, Including Family Leader Colleagues

Following is an AI-supported in-depth synthesis of priorities for unmet needs and actionable ideas for systems improvements discussed by interdisciplinary participants during Cafe 1 "Where We Are Now, and Where We Need To Go" of The Future of CMC Virtual Cafe Series. Family/youth leader colleagues comprised 30% of participants, alongside professionals spanning health care, public health, policy, payers, education, social services, and research. The key highlights synthesize audio and chat transcripts, as well as registration and evaluation responses.

Cafe 1 took place Wednesday, March 27, 2024, 3-4p ET, introducing the series. Meg Comeau, MHA, and Cara Coleman, MPH, JD, offered a brief 15-minute overview on key topics, major frameworks, and emerging trends to advance the quality of life and well-being of CMC and their families through federal, state, and local initiatives. They were joined by Bethlyn Houlihan, MSW, MPH, to co-facilitate a deeper dive into participants' pain points and insights in systems of care for CMC, and to consider together actionable strategies, resources, and leverage points for change.

The series, funded by the Lucile Packard Foundation for Children's Health, aims to connect diverse and interdisciplinary professionals from around the country, to learn from each other on topics that matter most to CMC and their families. This café-style series runs March - December 2024 and includes short presentations by nationally recognized experts in the care of CMC, including families, with a primary focus on facilitated discussion aimed at advancing policy, clinical practice, research, and medical education.

Key Unmet Needs and System Gaps in Care Design

"Nothing about us without us!"



Overall, systems leaders are not yet partnering with family leader colleagues effectively

While recognizing the importance of family partnership for children with medical complexity (CMC), many stakeholders lack the knowledge and skills to effectively partner. This disconnect leads to missed opportunities for families' essential lived expertise to drive the most impactful and practical system changes. Bridging this gap requires intentional efforts to overcome the existing significant power differentials between healthcare professionals and family leaders including adequate support, education, and training for all.



Significant fragmentation in care delivery

Lack of effective coordination and communication among professionals significantly reduces quality of care and well-being for CMC and their families. This issue impacts continuity of care and places an additional burden on families who often must act as intermediaries between different care teams.

"Shared plans of care created in partnership between families and professionals offer integration and continuity in care."



Negative impact from ongoing lack of family partnership in the care process

"Families need to be at the tables where decisions about their child's care are being made."

Families emphasize the need for greater family partnership in clinical-level improvements, care planning, and decision-making about their child's care. The current system often fails to meaningfully engage families as partners in their child's care, leading families to a sense of isolation and distrust. This gap highlights the necessity of implementing genuine patient- and family-centered care (PFCC) in care re-design, emphasizing collaboration and teamwork at all levels, for improved outcomes for all.



Key Unmet Needs and System Gaps in Care Design



Burdensome administrative and bureaucratic processes

"Being forced to travel over an hour every month to one pharmacy for one medication because insurance only covers that one medication at one pharmacy, when all your other medications are able to be filled at the pharmacy down the street - this is a considerable burden on resources for families."

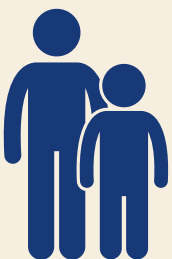
Families face challenging and time-consuming processes daily to access necessary medications, supplies, and services. These bureaucratic hurdles lead to delays in care and compounding stress for already overstretched families, especially when social drivers of health make it harder to overcome the many administrative barriers. Streamlining these processes could greatly improve the care experience and health and well-being outcomes for CMC and their families.



Major gaps in health care services to support home- and community-based living

"Workforce shortages for nursing and direct support in the home are leaving families unsupported."

Participants noted a significant lack of home-based essential medical services and supplies, including durable medical equipment, respiratory therapy, and the critical shortage of skilled home health workers and nurses. This places additional strain on family caregivers, who are often managing intensive care settings at home for their CMC. These major gaps can lead to compromised care quality, increased financial hardship, and reduced quality of life for CMC and their families. Building the needed infrastructure is crucial for enabling CMC to receive appropriate care in home and community settings instead of institutions.



Pressing challenges in transitioning from pediatric to adult care

The process of transition for CMC often lacks clear pathways and adequate support, leading to disruptions in care continuity and potential health risks. Challenges include lack of proactive planning (including considerations around HIPAA, health care proxies, guardianship, etc.), limited availability of adult care systems, lack of willingness to take on CMC in adult practices, and the shortage of adult-trained physicians for patient transfer.



Key Unmet Needs and System Gaps in Care Design



Limited access to mental health supports and services

Major system shortcomings have a profound impact on the health and mental well-being of parents/caregivers for CMC. There is a critical need for better access to mental health care, enhanced care support including respite care, and fostering interpersonal connections by linking families with each other for both tangible and emotional support. Such supports are crucial for maintaining overall caregiver well-being and, by extension, ensuring optimal care for CMC.



Insufficient professional knowledge on complex health and social needs and related bias

Major knowledge gaps, particularly in underserved areas and non-specialized settings, can lead to suboptimal and inconsistent care of CMC across settings, misunderstandings, and increased stress for families. There is limited access to hospitals and hospital-based professionals with essential knowledge, forcing families to travel long distances. Further, education and training need to address stigma and bias for all professionals; for example, supporting parents/caregivers with substance use disorders (SUDs) and CMC related to substance use exposures.



Inequitable access to services and supports across states

"State 'boundaries' create a wall between the child patient and closest appropriate care."

Participants noted that addressing state-to-state variations in care access and quality is crucial for ensuring that all CMC receive appropriate and equitable care, regardless of where they live. Notably, licensing and benefit restrictions create significant barriers across state boundaries that impede access to the closest appropriate care for CMC.



Lack of a standardized definition for CMC

"...would be transformational for hospitals, programs, population health, metrics, and policy."

Without a common definition of CMC, it becomes challenging to track outcomes, quantify needs, allocate resources, and develop targeted interventions for this population. Establishing a standardized classification for CMC could facilitate better data collection, inform policy decisions, and improve overall care delivery and outcomes.

Strategies, Recommendations, Innovations, Methods, & Solutions



Co-Design Solutions with Families and Youth as Equal Partners

Co-designing solutions with families can lead to more effective, practical, and sustainable improvements in CMC care. Lived expertise and family/youth partnership are essential for truly transforming healthcare systems in ways that matter most. How we talk about and invest in quality relationships as essential represents a significant cultural shift in healthcare. This shift needs to permeate every aspect of care delivery for CMC, becoming ingrained in day-to-day practices at every level. Child- and family-centered care must evolve towards mutually beneficial partnerships, where all members of the care team, including paid and unpaid caregivers, work collaboratively as interprofessional colleagues. Training from organizations like Family Voices can equip all team members with the operational principles and strategies necessary to facilitate system-wide transformation, while emphasizing the importance of engaging both seasoned and emerging family leaders as valued contributors.

"Families need to be viewed as colleagues in not only their child's care, but in policy and program development, implementation and evaluation. A core foundation of family-centered care."

Highlighted Resource:
[Family Voices](#)
[Family Engagement and Leadership in Systems of Care](#)

*"In the mind of the expert, there are few possibilities; in the mind of the beginner, there are many."
We need everyone in this work!"*

In this collaborative approach, it's essential to prioritize partnership before solution-seeking, ensuring that the problems themselves are defined collectively. Inclusivity in decision-making processes is crucial for fostering innovation and ensuring that the diverse needs and experiences of all stakeholders are adequately addressed at both the clinical and system levels.



Advocacy & Systems Change

Share best practices and lessons learned across states and organizations

There is a desire for more connection among professionals for knowledge sharing and collaboration across different states and organizations. This approach can help disseminate successful strategies, avoid duplication of efforts, and accelerate improvements in CMC care. Creating platforms or networks for sharing learnings and best practices, similar to the CMC Collaborative Improvement and Innovation Network (CMC CoIIN), could foster innovation and help scale up effective interventions more quickly.

Two current initiatives were mentioned:

- CMC List Serv - [contact Rishi Agrawal to be added](#)
- [Enhancing Systems of Care for Children with Medical Complexity project \(funded by HRSA\)](#)

Participants also shared resources on promising models and innovations, including:

- [Caregiver to Caregiver Respite Network](#) - Valeryia Pedersen (Chat Transcript, 01:18:19)
- [Daystar Kids](#) - Cate Brooks (Chat Transcript, 01:17:32)
- [Coastal Kids Home Care](#) - Kelli Brown (Chat Transcript, 01:15:34)

"There's lived experience, and then there is learned and authentic experience and trying to do the very best you can for another human being. Working in a setting where you're unable to do that can be extremely difficult."

"Coastal Kids Home Care has a model for home-based pediatric palliative care that is relatively low-cost and emphasizes high quality of life for children in 4 counties of northern/central California. Our partnership with our local managed care plan has helped this program to expand to serve more children."



Strategies, Recommendations, Innovations, Methods, & Solutions | Advocacy & Systems Change

Leverage technology to streamline processes and reduce paperwork burden

Utilizing technology to simplify administrative processes and reduce paperwork was suggested as a cross-cutting improvement. This could help alleviate some of the bureaucratic burdens faced by families and professionals. Streamlining things like enrollment and eligibility, communication, and documentation processes through technology could lead to more efficient care delivery, reduced stress for families, and more time for direct patient care. Technology could also be particularly useful in connecting cross-team members for co-managed care to save resources and improve quality of life for caregivers.

Engage policymakers to drive systemic change

Participants stressed the importance of actively engaging with policymakers to advocate for systemic changes in CMC care. This engagement could help ensure that the unique needs of CMC and their families are represented in policy decisions, which often benefit all children and families, as well as adults with complex health and social needs. By providing policymakers with evidence and personal stories, advocates can work towards creating more supportive and comprehensive policies for CMC care.

Highlighted Resource:
[About the Blueprint for Change and the National Center \(aap.org\)](#)

Utilize data to demonstrate the impact and value of care innovations

"A shared clinical definition ... would allow for scalable change, because we could quantify impact."

Robust data can provide compelling evidence to support the adoption and scaling of successful interventions. By quantifying the impact of care innovations, stakeholders can make stronger cases for funding, policy changes, and wider implementation of effective practices.



Strategies, Recommendations, Innovations, Methods, & Solutions | Advocacy & Systems Change

Address social determinants of health and health-related social needs

Social determinants of health (SDoH) and health-related social needs (HRSN) were identified as a critical aspect of comprehensive CMC care. Efforts to recognize and address these factors should prioritize racial equity, involve families in decision-making processes, and enhance coordination among healthcare professionals and community resources. This holistic approach acknowledges that health outcomes are influenced by a wide range of factors beyond medical care. By addressing social needs alongside medical needs, care for CMC can become more effective and equitable.

Multiple resources were mentioned as examples of family networking for support:

- [Fighting HARD \(Having a Rare Disease or Chronic Illness\) Foundation](#)
- [Developing the Illuminate Collaborative](#)
- [Family Resource Network – NJ](#)

"Better community engagement is key for supporting family and child needs in addition to clinical needs of children."

Highlighted

Resource:

[Medical-Legal Partnerships](#)



Policy Improvements

Implement budget authority waivers and paid family caregiver programs

Participants strongly advocated for policies that financially support family caregivers to give them more control over healthcare resources. Paid family caregiver programs recognize the crucial role families play in caring for CMC. These programs can provide financial relief, giving families control to make care decisions, and potentially improve care quality by leveraging families' expertise in their children's needs. Georgia's Medicaid waiver for paying family caregivers highlights a potential avenue for other states to follow.

“When families can direct those dollars quickly and individually, it can make a dramatic difference in the lives of CMC.”

Streamline and expedite prior authorization processes for treatments and medications

Current authorization requirements often lead to significant delays in care, increased stress for families, and administrative burdens for professionals. Streamlining these processes could improve timely access to necessary treatments and medications, potentially leading to better health outcomes and reduced frustration for families and professionals alike.



Strategies, Recommendations, Innovations, Methods, & Solutions | Policy Improvements

Policy and Payer support dedicated complex care clinics and programs

"We are building a Pediatric Complex Care and Rare Disease program here in Charlotte. We currently have an MD, NP, RN patient navigator, and myself, the clinical social worker. This would not have been possible without the major funding from a local foundation. We absolutely need more policy support for funding from insurance!"

Participants called for more policy and payer support of the rising number of specialized clinics and programs dedicated to CMC care is rising nationwide. These programs can offer comprehensive, coordinated care that brings together multidisciplinary teams focusing on the specific challenges and needs of CMC and their families. In turn, these programs have the potential to significantly improve care quality and outcomes.

Successful Example Highlighted:

Wisconsin Targeted Case Management Alternative Payment Model, as highlighted in ["Mending, not Ending, Fee-for-Service for Children With Medical Complexity"](#)

Improve Medicaid reimbursement for family-centered care coordination, home care, and more

Adequate reimbursement could help address workforce shortages, improve the quality and availability of home-based care, and support more comprehensive care coordination efforts. This change could potentially lead to better care outcomes and improved quality of life for CMC and their families.

"We need more support for care coordination with family at the center and better provision of required benefits under Medicaid, including home care and much more."



Strategies, Recommendations, Innovations, Methods, & Solutions | Policy Improvements

Make the Katie Beckett/TEFRA program mandatory

“Katie Beckett” is an umbrella term sometimes used to refer to both Medicaid waivers and TEFRA state plan options that create a pathway to Medicaid for disabled children who require an institutional level of care, to instead receive care and community-based services in their homes (TEFRA refers to the Tax Equity and Fiscal Responsibility Act which created the state plan option). One priority that would greatly impact quality of life and well-being for CMC and families and reduce disparities across states is to federally mandate this benefit; states currently have the option to implement the program (or not).

[Learn more about these pathways here.](#)

Develop national care coordination standards for CMC

Several participants called for national care coordination standards specifically for CMC, mirroring those recently developed for children and youth with special health care needs. They point out the unique, diverse constellation of needs for CMC and their families, more significant health and social needs, and greater degree of compounding impact to quality of life and well-being when needs remain unmet. Such standards could provide a framework for best practices and help align care coordination efforts to improve consistency and quality in care delivery for CMC across different healthcare settings and geographic areas.

"Care coordination to avoid multiple visits to the same facility. Also PCPs connecting the dots between specialists instead of parents being the case manager."

[Learn more about National Care Coordination Standards for Children and Youth With Special Health Care Needs here.](#)



Strategies, Recommendations, Innovations, Methods, & Solutions | Policy Improvements

Prioritize investment in community-based care

Participants emphasized the need at the state and federal level to broaden access to community-based services to ensure that children receive access to care in spaces and places that promote their well-being and preserve their dignity. Implementing relevant policies could lead to more person-centered care and better integration of medical and social supports for CMC.

Allow for Medicaid portability across state lines

This policy change could help ensure continuity of care and reduce administrative and financial burden, and family and job disruption for families in traveling between states. It could also potentially expand access to specialized care services that may not be available in every state and prevent the need for a family to relocate their primary residence.

"Implement interstate portability of ... Medicaid benefits to reduce bureaucratic barriers to care and increase family self-determination."

Strategies, Recommendations, Innovations, Methods,
& Solutions

Practice Improvements



Develop local capacity for transition from pediatric to adult care

Developing comprehensive transition programs and improving coordination between pediatric and adult care systems could greatly benefit CMC as they age into adulthood. This includes local linkages between pediatric and adult professionals, training and support to equip adult professionals to receive CMC, and establishing reimbursement structures to support co-management for transition.

Build capacity to integrate mental health support and services as standard care

"Access to care, support for the health/mental health of parents and caregivers."

Integrating comprehensive mental and behavioral health services into the care model for CMC - including for caregivers - could significantly improve overall well-being for both children and their families.



Strategies, Recommendations, Innovations, Methods, & Solutions | Practice Improvements

Integrate pediatric palliative care principles and techniques into primary and other specialty care practice

"We need more deliberate and routine integration of primary pediatric palliative care principles into standard practice."

Highlighted Resource for Families:

[The Courageous Parents Network](#)
[Neurojourney](#)

Integrating this evidence-based approach could help address the holistic needs of children and families, including pain management, quality of life considerations, and psychosocial support, for more comprehensive, family-centered care that better aligns with the goals and values of CMC and their families. Some also advocated to expand outpatient and home-based palliative care to better meet diverse needs .

Develop CMC- and family-driven quality measures

"Quality measures co-designed with patients and their families, ensures that the whole child is seen, valuing not only physical health, but also spiritual, emotional, and material well-being and quality of life."

Creating quality measures that reflect the priorities and experiences of patients and families was identified as a key practice improvement. These measures could help ensure that care quality is evaluated based on outcomes that matter most to CMC and their families, rather than solely on clinical indicators. Involving families in the development of these measures could lead to more meaningful assessments of care quality and guide improvements that truly enhance the lives of CMC and their families.



Strategies, Recommendations, Innovations, Methods, & Solutions | Practice Improvements

Emphasize access to home and community-based services (HCBS)

Several participants commented on the importance of home- and community-based services and supports (HCBS) being accessible, especially home nursing care. HCBS and related supports are essential to allowing children to receive care in familiar, comfortable environments while maintaining family connections and routines. Emphasizing and integrating these services into clinical care could potentially reduce hospitalizations, as well as playing a vital role to improve quality of life/well-being and provide more comprehensive support for CMC and their families in their day-to-day lives.

“Care plans/hospitals collaborate with home/community-based services to provide training and nursing/caregivers to support children thriving in community environments.”

Improve coordination and training between child-serving entities

It is crucial to collaborate with home and community-based services to provide comprehensive support for children to thrive in community environments. This improved coordination and shared training opportunities could lead to more efficient, higher quality care delivery and better outcomes for CMC.



Strategies, Recommendations, Innovations, Methods, & Solutions | Practice Improvements

Collaborate to offer access to peer support services and mentoring

"Connecting families with other families is a route to support and interpersonal connection."

Particularly for families of CMC, networks of support where experiences and advice can be shared hold unparalleled value. These services can provide emotional support, practical tips and resources, and a sense of community for families, often burnt out from navigating complex care systems. Integrating into care models peer support alongside warm referrals to family-led organizations could support mental health and equip families to better advocate for holistic child/family needs and systems change.

Utilize telehealth to improve access to care

*"Increase telemedicine,
particularly for
immunocompromised so
they don't pick up an illness
in person."*

Telehealth can reduce travel burdens, increase the frequency of check-ins, and facilitate easier access to specialists. This strategy could particularly enhance access to care for those in rural or underserved areas and reduce risk of exposure for the immunocompromised.

Strategies, Recommendations, Innovations, Methods,
& Solutions

Interdisciplinary Education Improvements



Train professionals on implicit bias and disability discrimination

"Eliminating disability bias (misperception of quality of life) and discrimination will address disparities in care for CMC."

Healthcare professionals should undergo targeted training to recognize and challenge their own biases, towards ensuring more inclusive, equitable and respectful care for CMC and families. Further, improving professional awareness and understanding of disability justice in medical training and healthcare settings could contribute to better CMC/family-professional relationships, more positive care experiences for all, and shared advocacy to improve systems of care.

Educate professionals on the unique needs of CMC early in medical training

Incorporating specialized education on CMC care could help ensure that future professionals are better prepared to meet the complex needs of these children and their families. By starting this education early in professional development, it could become a fundamental part of healthcare practice rather than a specialized skill set.

One participant offered the following as an example for care related to tracheostomy, ventilators, and medically complex medication & feeding:
www.breathewellinspiration.com



Strategies, Recommendations, Innovations, Methods, & Solutions | Interdisciplinary Education Improvements

Develop and implement curriculum alongside families and youth

"I believe the biggest change is going to come from what physicians learn about CMC and their impact to them and their families."

Participants stressed the importance of partnering with families in the development and implementation of educational curricula for healthcare professionals. This approach ensures that the realities of living with and caring for CMC are accurately represented in professional education. Incorporating family perspectives can lead to more comprehensive, empathetic, and patient-centered care practices. This includes dynamic approaches such as simulations and role plays.

One participant noted an innovative model designed by three mothers of CMC for pediatrics residents and other clinicians.

[Learn more about Project DOCC \(Delivery of Chronic Care\) here.](#)

Ongoing interdisciplinary education to keep professionals up-to-date on emerging innovation and best practices

Given the rapidly evolving nature of medical knowledge and care practices, ongoing education is crucial to ensure that professionals can understand the latest developments and offer the best possible care. This continuous learning approach can help bridge the gap between research, emerging innovation, and practice, leading to better outcomes for CMC. Interdisciplinary education including family leaders as colleagues supports collaboration and coordination for more integrated care.

Highlighted Resource:

[AAP Brain Trust for
CMC](#)



Research Improvements

Evaluate programs that provide respite and support to families

While not directly quoted, the need to evaluate respite and family support programs was implicit in many discussions. Such research could help identify the most effective types of support and inform the development of evidence-based programs. Evaluating these programs could also provide valuable data to support advocacy efforts for increased funding and resources for family support services.

Conduct research on improving quality of life and caregiver well-being to inform programs

Such research could provide valuable insights into effective interventions and support strategies. By addressing both the needs of children and their caregivers, this research could contribute to more comprehensive and sustainable care approaches. This also includes developing unbiased measures that honor lived experience; There is currently a study to see how well existing quality of life measures fit with child/family needs, Several participants noted a desire for research on rest and recovery among family caregivers of CMC, with one study currently underway.



Strategies, Recommendations, Innovations, Methods, & Solutions | Research Improvements

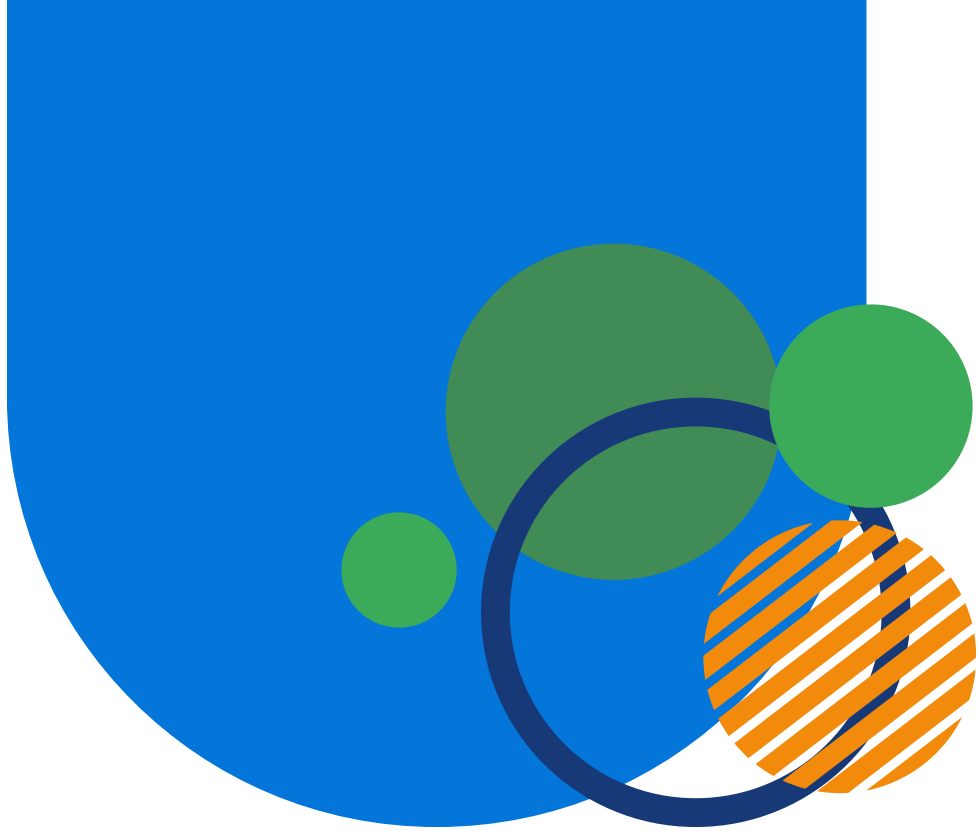
Examine the impact of policy changes on access to services for CMC

Although not directly quoted, the importance of studying the effects of policy changes on service access for CMC was a recurring theme. This research could provide crucial evidence to inform future policy decisions and advocacy efforts. By understanding the real-world impacts of policy changes, stakeholders can work towards creating more effective and equitable policies for CMC and their families.

Study effective models of care coordination and case management

“When case managers and clinical workers truly understand the system's nuances, they then know how to make a positive difference in families' lives.”

Such studies could help identify best practices and innovative approaches to managing the complex care needs of CMC. This research could inform the development of more effective and efficient care coordination strategies, potentially leading to improved outcomes and reduced burdens on families and healthcare systems.



Learn More

[View the Café 1 Recording and Slides Here](#)

Discussion Materials:

- [The Collaborative Improvement and Innovation Network for Children with Medical Complexity, Pediatrics Volume 153, Supplement 1](#)
- [The Collaborative Improvement and Innovation Network for Children With Medical Complexity](#)

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ciswh.org/project/cmc-virtual-cafe



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