Executive Summary

Background

Children with medical complexity (CMC) are a subset of children and youth with special health care needs (CYSHCN) characterized by having serious, chronic, and often multiple medical, behavioral, or developmental health conditions.[1] Despite their relatively small percentage of the overall pediatric population, CMC account for a disproportionately high share of health care spending due to their complex needs and frequent reliance on specialized services.[2] Data from the National Survey of Children's Health (NSCH), which offers a look at the broader population of CYSHCN, indicate that 85% of CYSHCN (including CMC) do not receive services in a well-functioning system, fewer than half are served by a medical home, and nearly all face challenges when moving into to adult systems of care.[3]

Despite efforts in recent years among state and federal policymakers to incentivize strengthened care coordination in the form of health homes and related models, implementation of enhanced care coordination and integration remains challenging, with substantial geographic variation in uptake. Given the disproportionate rates of medical complexity and associated care spending among children covered by Medicaid, there is heightened attention on the role Medicaid can play in developing these policies, whether independently or in collaboration with other programs such as Title V. However, implementation of effective policies for CMC and for their care coordination remains a patchwork across the nation. Children with complex needs are inconsistently identified, there remain gaps in services covered, and policymakers are challenged to build the measurement systems that promote quality assurance.

As the first part of a two-year project designed to develop resources for supporting Medicaid policymakers and their collaborators in the uptake of programs supporting CMC, an environmental scan was conducted to surface where the potential opportunities and pitfalls in translating the concepts of CMC and family-centered health homes (FCHH) to operational policy exist, and where our current measurement landscape may fall short of being able to assess the most salient features and outcomes of enhanced care for this population.

Methods

The project team, composed of members of the Enhancing Systems of Care for Children with Medical Complexity Coordinating Center (ESC CC), conducted an environmental scan to address the following research questions:

- What are the core domains of the definitions for (1) CMC and (2) FCHH for CMC, and which elements are difficult to operationalize?
- What quality measures are currently available for uptake in Medicaid programs for assessing FCHH performance for CMC and what gaps exist?
- How are select states currently implementing FCHH or related enhanced care coordination programs for CMC?

Initial activities included scoping reviews of peer-reviewed and grey literature relevant to definitions for CMC and FCHHs, as well as a scan of performance measure inventories and repositories for measures aligned with the FCHH definition and fit for the CMC population. Findings were supplemented and validated by lived and learned experts through key informant interviews, a focus group, and subject matter expert (SME) consultation. Finally, a survey was administered to four states participating in the ESC CC Sustainability Affinity Group (SAG) to offer insights into how states are currently operationalizing CMC and FCHH definitions and measuring quality and outcomes. A series of thematic analyses were conducted to identify potential pitfalls when operationalizing CMC and FCHH definitions in the context of Medicaid policy, and to surface measurement gaps that limit Medicaid's ability to monitor quality and outcomes for FCHHs serving CMC. This culminated into a series of recommendations for the road ahead that provide the foundation for a future toolkit designed to assist state Medicaid programs in adopting policies for better supporting CMC.

Results

Findings from the environmental scan and state surveys and interviews comprise three key areas: the definition of CMC, the definition of FCHH, and FCHH performance measures relevant to CMC.

CMC Definition

Environmental Scan Findings

The findings from the literature on the definition of CMC were wide-ranging regarding how to specifically define CMC. While there is no broad consensus on operational criteria to define CMC, four key domains of the definition of CMC emerged from the literature: (1) chronic conditions; (2) health care use; (3) functional limitations; and (4) care needs. Synthesis in partnership with key

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[1] Berry JG, Agrawal RK, Cohen E, Kuo DZ. The Landscape of Medical Care for Children with Medical Complexity. Children's Hospital Association. June 2013.

[2] Berry JG, Hall M, et. al. Children With Medical Complexity And Medicaid: Spending And Cost Savings. Health Affairs. 2014; 33(12): 2199-2206.

[3] Data Resource Center for Child and Adolescent Health. National survey of children with special health care needs, NS-CSHCN 2009/10. Accessed October 16, 2024. https://www.childhealthdata.org/learn-about-the-nsch/NSCH

informants (KIs) and SMEs yielded a set of subdomains, which have some known parameters, as well as gaps in understanding that currently create barriers for operational use in Medicaid programs (see **Table E1**). Some aspects of the domains were well-supported by the sources, while others lacked sufficient evidence, highlighting areas where further research and clarification was needed from SMEs.

Ultimately, a definition of CMC might best be considered a process that begins with considerations of chronic conditions for the purpose of documenting medically necessary coverage needs, followed by considerations of domains in health care use, functional limitations, and care needs. No single definitional domain is adequate. In addition to clarifying parameters for the domains, a stepwise process that honors the interrelationship of these domains, but also independently documents them, is a promising approach for the creation and implementation of policy.

State Findings

Not all states surveyed had an operational definition for CMC (namely, WA). Among states that did have definitions, heterogeneity was observed across programs. Both AK and MI appear to have some reconciliation of case identification between Medicaid and Title V. In TX, however, Medicaid had a multi-factorial process for CMC identification, whereas Title V had no standardized definition. States that lack alignment in definitions for populations served by multiple agencies risk missed opportunities to coordinate coverage, reduce unnecessary costs, avoid duplication of services, and conduct collaborative quality improvement efforts.

FCHH Definition

Environmental Scan Findings

Consistent with results for defining CMC, the literature scan uncovered a varied landscape in terms of defining FCHHs. Despite this heterogeneity, seven domains of the definition of a family-centered health home emerged based on findings from the environmental scan: (1) comprehensive care; (2) patient/family-centered care; (3) coordinated care, care integration, and transitions to adult care; (4) accessible and convenient services; (5) compassionate care; (6) quality and safety; and (7) care management and support infrastructure. Each domain of the FCHH definition corresponds with at least one subdomain. Similar to the CMC definition, these domains were also associated with notable barriers for operational uptake in Medicaid programs (see **Table E2**).

State Findings

We observed expected variation in the types of direct and enabling services being provided to CMC and their families to achieve the goals of FCHHs across states, with an emphasis on care coordination and integration. Overall, supporting coordination and integration of services was addressed by all states. There was some variation in the provision of case management, as well as planning for the transition to adulthood.

Survey results also suggested variation in the types of services provided by Medicaid versus Title V. Generally, services provided by Title V were comprehensive in MI, TX, and WA—the one exception was AK, where it was reported that Title V does not pay for or provide direct or enabling services in the state. Our survey suggests there is opportunity to develop resources that would sup-

Table E1. CMC Definition: Domains, Subdomains, and Barriers to Operationalization

CMC Definition Domain	Subdomains	Barriers to Operationalization
Chronic Conditions	Number of diagnoses; Number of affected body systems; Condition severity	Lack of consensus regarding the number of chronic conditions diagnoses or body systems that must be affected to meet criteria, and absence of clear parameters for classifying condition severity.
Health Care Use	Resource/service utilization	Lack of consensus in defining “high” resource use or health care utilization as a criterion.
Functional Limitations	Modification to support activities of daily living; Technological dependence	Gap in understanding regarding the level of technological dependence or severity of limitations that are indicative of medical complexity.
Care Needs	Specialized therapies; Complex medications; Transition to adult care support; Family-identified needs	General lack of actionable parameters regarding how to define “specialized” therapies, “complex” medications, or “significant/substantial” need for use as operational criteria.

Table E2. FCHH Definition: Domains, Subdomains, and Barriers to Operationalization

FCHH Domain	Subdomains	Barriers to Operationalization
Comprehensive Care	Team-based care; Addresses all necessary medical care; Addresses upstream drivers of health	Lack of payment models to facilitate team-based care, lack of clarity regarding “necessary” care, and infrastructure to support addressing upstream drivers of health.
Patient/Family-Centered Care	Respect and dignity; Information sharing; Participation; Collaboration	Resources for staff training to facilitate patient/family-centered care are not always available, lack of feasible methods to assess respect and dignity, and lack of consensus regarding ways to engage CMC and their families in care in ways that are empowering, appropriate, and avoid adding undue burden.
Coordinated Care, Care Integration, and Care Transitions	Coordinated care; Care integration; Care Transitions	Resources, infrastructure, and mechanisms are often not in place to facilitate coordinated and integrated care, and seamless care handoffs , particularly for those living in rural or urban under-resourced areas.
Accessible and Convenient Services	Affordability; Availability; Accessibility; Accommodation; Acceptability	Lack of sufficient insurance coverage for many families, unclear parameters for “needed” care for CMC, and the resources and infrastructure to ensure that CMC can be readily accommodated is not always in place.
Compassionate Care	Contextually responsive care; Provider trust; Compassionate communication; Health literacy; Culturally and linguistically appropriate services	Workforce contextually responsive care training and assessments on preconceived notions are not always available, and there is a lack of standardized, feasible approaches to assess aspects of this domain.
Quality and Safety	Continuous quality improvement; Avoidance of harm & prevention of error	Gap in understanding related to measures that are appropriate, relevant, and actionable for continuous quality improvement, and a lack of standardized approaches regarding measurement to assess avoidance of harm & prevention of error.
Care Management and Support Infrastructure	Information management; Community referral network; Technological infrastructure; Care plans; Physical infrastructure	Structures for enabling access to information and community referral networks can be difficult to implement and maintain. The resources required for technological infrastructure are not always available and there is a lack of consensus regarding which measures to prioritize to assess physical infrastructure.

port broader uptake of direct and enabling services for CMC that promote the goals of FCHHs, specifically in Medicaid programs.

Health Home Performance Measures for CMC

Measure Scan Findings

The measure scan garnered a total of 103 experiential (largely survey-based) and 39 administrative/clinical measures applicable for assessing the quality and effectiveness of FCHH for CMC in Medicaid programs. These measures were mapped to the key domains of the FCHH definition outlined in the findings above. Additional “general health home” measures were also identified, largely comprising measures that provide a high-level or “global” rating of care received through a health home. While measures were found to correspond with all domains of the FCHH definition, these measures were not equally distributed. **Table E3** describes the distribution of experiential and administrative/clinical measures across these domains.

The measure scan included measures currently in use by Medicaid from the Child Core Set, Health Home Core Set, Consumer Assessment of Healthcare Providers and Systems (CAHPS) Health Plan Survey (with Chronic Conditions Supplemental item set), and

Table E3. Performance Measures Relevant to FCHH for CMC Potentially Applicable to Medicaid Programs

FCHH Domain	Experiential Measures (N)	Administrative/ Clinical Measures (N)
Comprehensive Care	16	7
Patient-/Family-Centered Care	11	2
Coordinated Care, Care Integration, and Transitions	18	4
Accessible and Convenient Services	9	2
Compassionate Care	20	0
Quality and Safety	5	23
Care Management and Support Infrastructure	19**	1
General Health Home*	9	0
Total Measures	**103**	**39**

*General Health Home measures do not correspond with a specific domain of the FCHH definition but are applicable to assessing the overall quality of FCHH care.

**This includes four measures cross-listed with comprehensive care, which are not included in the overall total.

Home and Community-Based Services (HCBS) CAHPS Survey. Also included were measures endorsed by or developed for CMS programs and/or the CMC population to encompass measures available for use to fill current gaps in Medicaid performance measurement.

Some FCHH domains were well represented in the measure scan: there were a number of measures well suited or already in use to assess comprehensive care, patient/family experiences of care coordination, compassionate care, as well as quality of care. The measure scan uncovered a few meaningful measurement gaps in the current Medicaid performance measurement landscape. Namely, there are gaps related to measures that assess care plans and goals, aspects of upstream drivers of health , and access to care/services important to CMC such as durable medical equipment (DME) and long-term services and supports (LTSS).

State Findings

Findings from the four states participating in the ESC CC SAG highlighted a variety of approaches to measurement and monitoring of direct and enabling services being provided to CMC and their families to achieve the goals of FCHHs. Title V programmatic data collection was relatively consistent across states, focusing on assessing national performance and outcome measures, including the proportion of CYSHCN who have a medical/health home. Some locally developed process measures were utilized by MI and TX, and these states also noted monthly reporting requirements. Medicaid programs capture administrative data related to access to services and utilization. Additionally, all Medicaid programs and two Title V programs (MI and TX) reported collection of patient experience data, however, there are feasibility-related concerns with the use of patient surveys to collect these data.

State findings suggest there is opportunity to promote stronger data sharing across Medicaid and Title V programs with a need for more standardized disaggregation and stratification schema development for measures. For Medicaid specifically, there is need to improve the mechanisms for patient experience data collection to ensure their meaningful use in performance monitoring and improvement programs, and there may be important gaps in the availability of administrative/clinical measures, which are a key domain of assuring the quality of programs serving CMC.

Discussion

This report presents findings from an environmental scan designed to highlight the needs and challenges associated with translating the concepts of CMC and FCHH to operational policy and define the state of our current quality measure portfolio in serving CMC programs administered by Medicaid. The work surfaced several key considerations and gaps in knowledge and/or consensus that formed the basis for a series of recommendations that would enable Medicaid to enhance its role in improving systems for CMC. These recommendations include:

- ***Use of multifaceted approaches that combine administrative data (e.g., eligibility for SSI, specialized waivers) with provider attestation for identifying CMC for Medicaid programs.*** While states may have standardized definitions for CMC based on diagnoses, functional limitations, and/or service needs, these states and other states may benefit from adopting a multifaceted approach, which captures the nuances of individual cases (via provider attestation) on top of a standardized definition (e.g., via claims and SSI determinations).
- ***Moving away from rigid program eligibility cutoffs and adopting more flexible and patient-centered approaches.*** Creating effective FCHH for CMC will require that families have options

for support as their child improves or is intermittently improved so that care can effectively continue. A definitional "cliff" could have inadvertent effects on utilization or delineation of unmet needs to retain participation in the FCHH. A tiered approach based on changes to diagnoses or functional needs, and providing for adequate transition out of the more intensive FCHH would be more effective.

- ***CAHPS (or other patient experience) surveys should be administered via digital tools.*** Modern digital survey tools would make it easy for participants to respond on a smartphone, tablet, or other electronic device. A move to digital technology would reduce the costs associated with paper or telephone administration, enabling the removal of random samples for population measurement, which is a critical benefit when working with small populations like CMC.

- ***Experience surveys need to fill measurement gaps related to the creation and accessibility of care plans, as well as perceived progress on patient and family goals.*** These topics were identified in other surveys more precisely targeted for children with complex needs. Surveys need to be improved with family input, so they focus on: aspects of care for which the patient/family is the best or only source of information; care patients/families have experienced or observed; and explicit reference to time, event, and provider.

- ***Administrative and clinical measures need to fill measurement gaps related to upstream drivers of health and access to key services for CMC such as subspecialty care, mental health care, DME, and LTSS for children.*** The development of age-appropriate measures will be important for topics such as this in the context of children with complex needs, where needs can change rapidly. Measures should be developed to account for these factors.

- ***Develop measure stratification schema that enables sub-analyses of measures specific to the CMC population.*** Stratification enables examination of performance by specific subgroups and may effectively detect potential gaps in care/outcomes among populations related to the measure focus. This approach supports movement toward more parsimonious, broadly applicable measure sets while retaining the ability to segment by high-risk populations.

- ***Need to incorporate measures of quality of life (QoL) and well-being into surveillance and quality improvement initiatives.*** As an initial step, Medicaid and managed care organizations (MCOs) could support local site QoL and wellbeing measurement, focusing on aspects of wellbeing that can be impacted by the local site. Assuring that QoL and wellbeing is incorporated into the site's quality improvement efforts acknowledges the site's potential ability to impact results without placing undo accountability on the site. Pay-for-participation mechanisms could elucidate local changes being made to support families. This could have important effects such as incentivizing infrastructure investment for providers and/or MCOs to collect the data, promoting a quality improvement focus by ensuring data is readily available to providers, and make data potentially available for site reporting, thereby improving transparency for patients and their families.

- ***Medicaid implementation of services to support CMC should proceed according to a three-step process.*** This process includes 1) costing out the provision of services of FCHH including infrastructure; 2) identifying and agreeing upon state authority for FCHH and receiving federal authority to draw federal matching funds; and 3) development of a workable billing mechanism for providers to submit claims to receive payment for services.

Conclusion

This environmental scan surfaces key considerations for Medicaid programs in their promotion of optimal systems of care for CMC and their families. This preliminary work lays the foundation for the development of additional resources designed to support state Medicaid programs in their collaboration with Title V to better serve CMC and their families.