Enhancing Systems of Care for Children with Medical Complexity:

Environmental Scan Report

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Key Takeaways

This scan was conducted as part of a two-year project aimed at supporting Medicaid policymakers to improve care for children with medical complexity (CMC) and their families. The goal of this research was to find challenges and opportunities in turning the concepts of CMC and family-centered health homes (FCHH) into practical, workable Medicaid policies. It also examined where current measurement tools may not fully capture the important features and outcomes of quality care for CMC.

How Information Was Gathered

To answer the key research questions (*Figure A1*), the project team conducted an environmental scan using information from multiple data sources, including:

1. reviewing existing research and measurement tools;
2. interviewing experts, including state officials, subject matter experts, and families with lived experience;
3. holding a family focus group, and;
4. surveying Medicaid programs in four states (Alaska, Michigan, Texas, and Washington).

Figure A1. Environmental Scan 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?

What Was Learned

Definition of CMC. There is no single, standardized definition of CMC that is widely accepted. Defining CMC is challenging because experts disagree on terms like “high” resource use or “substantial” care needs. However, this scan identified four key domains of definitions to describe the CMC population (*Figure A2*).

Figure A2. Domains of a CMC Definition

- Chronic conditions
- Health care use
- Functional limitations
- Care needs

Since none of the four domains can capture the needs of CMC fully, a step-by-step approach is recommended. This approach should define each domain clearly while also recognizing how they are connected. Using this approach can support the creation and implementation of effective policies for CMC.

Not all states surveyed had an official definition for CMC, and those states that did varied in how they defined this group. When different agencies within a state serving the same population use different definitions, it can lead to

- unnecessary costs;
- challenges in coordinating care;
- duplicative services;
- and missed opportunities for quality improvement.

Definition of FCHH. There are multiple definitions for FCHHs, however this scan identified seven key domains of the definition of FCHH (*Figure A3*). Like the domains identified for the definition of CMC, these domains are challenging to implement in practice. Each domain needs to be more clearly defined, there are several barriers relating to lack of infrastructure and resources—such as workforce shortages, payment models, and technology gaps—making it harder to implement these domains of FCHH care. A greater understanding is needed of how these seven domains can be applied in practice to best support CMC and their families. It is also important to determine which measurement approaches are most effective for assessing the quality of care in these domains.

Figure A3. Domains of an FCHH

- Comprehensive care
- Patient/family-centered care
- Coordinated care, care integration, and transitions
- Accessible and convenient services
- Compassionate care
- Quality and safety
- Care management and support infrastructure

The state Medicaid survey results showed differences in the types of services being provided to CMC across states. However, all four states that were surveyed prioritized care coordination and integration for the CMC population. Additionally, there were differences in how states provide case management and help CMC move into adult care.

Health Home Performance Measures for CMC

The scan of existing measures found a total of 103 experiential (largely survey-based) and 39 administrative/clinical measures that can be used to assess the quality and effectiveness of FCHH for CMC in Medicaid programs. These measures were mapped to the seven key domains of the FCHH definition. The majority of measures identified aligned with comprehensive care (23 measures); coordinated care, care integration, and support for children moving into adult care settings (22 measures); compassionate care (20 measures); quality and safety (28 measures); and care management and support infrastructure (20 measures) domains. Fewer measures were found that aligned with the patient-/family-centered care (13 measures) or accessible and convenient services (11 measures) domains of FCHH care. This scan revealed notable gaps in Medicaid performance measurement relating 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 suggest that better data sharing across Medicaid and Title V programs could improve tracking, as well as standardized ways to analyze and break down data to ensure all CMC populations are accurately represented.

Recommendations

The scan found key knowledge gaps, areas of disagreement, and important considerations, which informed recommendations for ways Medicaid could strengthen its role in improving systems for CMC. These recommendations include:

- The scan found key knowledge gaps, areas of disagreement, and important considerations, which informed recommendations for ways Medicaid could strengthen its role in improving systems for CMC. These recommendations include:
- Use multiple approaches that combine administrative data with provider assessment for identifying CMC for Medicaid programs.
- Move away from rigid program eligibility cutoffs and adopt more flexible, patient-centered approaches.
- Administer Consumer Assessment of Healthcare Providers and Systems (CAHPS), or other patient experience surveys, via digital tools.
- Use experience surveys to fill measure gaps by including assessment of care plan creation, accessibility, and perceived progress on patient and family goals.
- Enhance data collection around administrative and clinical measures to fill 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.
- Develop a standardized approach to assessing measures across subpopulations of CMC
- Incorporate measures of quality of life (QoL) and well-being into ongoing monitoring and quality improvement initiatives.
- Implement Medicaid services to support CMC should proceed according to a three-step process to ensure effective program rollout.

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.

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 wellbeing 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.

1. Background

Children with medical complexity (CMC) account for an estimated 1-4% of all US children.[2] They 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, as well as significant functional limitations, considerable health service needs, and high health service utilization.[3] They are a heterogenous and high-need population, with significant use of health and social services. While pediatric health spending overall is relatively low, spending for this small subset of children is disproportionately high.[4] They compose approximately 5-6% of Medicaid-covered children nationally,[5,6] but research estimates that CMC may account for over a third of pediatric Medicaid spending.[6] They are more likely to require surgery or inpatient services, and to rely on durable medical equipment (DME) and supplies, medical technology, or home health services.[5,7,8] In addition to substantial hospital inpatient and ambulatory care spending, many CMC use at least one prescription medication, often to treat behavioral or developmental conditions.[9]

Parents of CMC are at increased risk of poor mental health,[10] and families of CMC often face financial and social marginalization.[11] Many families with CMC face additional challenges including poverty, housing instability, food insecurity/insufficiency, lack of transportation, language barriers, or foster system involvement.[6] These social complexity factors can make it more difficult for families of CMC to navigate systems of care. Meaningful approaches to improving outcomes for CMC must consider vulnerabilities in specific health domains: care fragmentation; variations in access; financial burden on families; and a dearth of relevant quality and outcomes measures of care.

The National Survey of Children's Health (NSCH), which offers a look at the broader population of CYSHCN, offers compelling insights into the quality of care received by these children and their families. Challenged by a health care system which generally lacks infrastructure for care integration and care coordination, these families struggle with access to specialists, contextually appropriate care, long-term services and supports (LTSS) availability, and staggering costs not covered by insurance.[90] These gaps result in care that is fragmented, of low value, and that fails to meet the priorities of all families.[91]

Enhancing care coordination and care integration are important elements of health system strengthening that, when implemented effectively, can improve quality of care and health outcomes for CMC and their families while reducing costs.[1] However, data from the NSCH 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 transitioning to adult systems of care.[12] State and federal policy in recent years has worked to incentivize strengthened care coordination in the form of medical homes, health homes, accountable care organizations, and other models.[13,14,15] However, implementation of health homes and coordinated care for CMC remains challenging because of workforce training and capacity needs, varying levels of family engagement, scope of care coordination duties, and financial sustainability.[16]

Policy initiatives can accelerate the spread and scale of care models for high-need patients—particularly the programmatic coordination and/or integration of social supports and medical care—through developing a workforce to deliver comprehensive health care, expanding and realigning payment policies, refining quality measurement, and improving the data infrastructure.[17] Specifically, success tactics for expanding effective models of care include substantial financial incentives; technical assistance for model implementation, data feedback, staff support, and reporting requirements; adapting data to reflect differences among practices, health systems, markets, and patients; and monitoring to ensure that programs are implemented as intended.[18,19]

Policy to advance health homes for CMC is needed to fill the substantial care gaps highlighted in the NSCH. 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, most empirical studies present research-oriented definitions for both CMC and health homes, rather than the operational definitions that Medicaid policymakers need to translate evidence into action. Consequently, 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 we are challenged to build the measurement systems that promote quality assurance.

Accordingly, the HRSA-funded Enhancing Systems of Care for Children with Medical Complexity Coordinating Center (ESC CC), is engaged in a two-year project to address these challenges. Work was partitioned into two phases:

- **Phase I.** Conduct an environmental scan to elucidate the definitional and measurement challenges associated with CMC and family-centered health homes (FCHH) and their translation into Medicaid policies.

- **Phase II.** Develop a toolkit of resources to support state-level policymakers with the development of Medicaid policies for the financing and measurement of FCHH for CMC.

Because the definitions for what constitutes CMC and what constitutes an FCHH for CMC are not readily translatable to policy, and available quality measures of FCHH do not necessarily capture the aspects of care that are most salient to families and policy makers, this work was undertaken (Phase I.).

These findings from Phase I, which combines a literature review, a quality measures scan, key informant interviews (KIIs), a family focus group, and a survey of select states, addresses the following questions:

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

This work is intended to surface where the potential opportunities and pitfalls in translating the concepts of CMC and 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.

2. Methods

A multi-step approach was used to gather input from a wide range of inputs about how to define CMC, how to define FCHH for CMC, and what performance measures are available for Medicaid programs to assess FCHH for CMC (**Table 2.1**). First, literature reviews and measure inventory searches were performed in response to the first two research questions. Next, KIIs and a focus group were conducted to discuss the findings from the literature review and measure scan, and to gather key recommendations on the identified information and gaps. Finally, surveys and interviews were conducted among four states to gather insight into how state Medicaid programs currently support CMC in collaboration with Title V programs.

2.1 Literature Review

We conducted two separate scoping reviews on definitions for CMC and FCHH, beginning with seminal articles shared by subject matter experts (SMEs) followed by a PubMed search to identify peer-reviewed literature and a scan of grey literature. To access grey literature, we utilized Google and Google Scholar search engines. We also solicited literature and resource recommendations from the ESC CC Brain Trust, SMEs, KIIs, and HRSA. Search strings and inclusion/exclusion criteria used are included in **Appendix 7.1**. An overview of our search strategy is described below.

For CMC definition, our initial searches yielded 95 peer-reviewed articles in PubMed and 43 resources from grey literature. After deduplication, we had a total of 134 articles. We then assessed whether the articles met our eligibility criteria. Articles were deemed eligible if they: (1) explicitly mentioned child/children with medical complexity; (2) provided either a definition, description, or specific inclusion criteria for CMC; and (3) were in English. Final articles included in the analysis are listed in **Appendix 7.2**.

For FCHH definition, our initial searches yielded 23 peer-reviewed articles in PubMed and 17 resources from grey literature. We had a total of 38 articles after deduplication. For this search, articles were eligible if they: (1) explicitly mentioned CMC, CYSHCN, or the broader pediatric population; (2) provided descriptions of key concepts such as family-centered care, medical homes, care coordination, or health homes; and (3) were in English. Final articles included in the analysis are listed in **Appendix 7.3**.

A summary of the search results is presented in **Table 2.2**. Data from peer-reviewed and grey literature were extracted using a standardized MS Excel extraction tool. A thematic analysis was conducted to identify common themes across literature. This approach allowed for the organization of information into distinct domains, highlighting recurring patterns and key concepts. Results

Table 2.1. Research Questions and Approaches for the Environmental Scan

Research Questions & Approaches for the Environmental Scan
RQ1: What are the necessary domains of definitions for (a) CMC and (b) FCHH for CMC?
Literature Reviews: • Definition for CMC (PubMed & grey searches) • Definition for FCHH (PubMed & grey searches) **Primary Data Collection:** • Key informant interviews (KIIs) to validate literature findings and surface gaps • Family focus group
RQ2: What endorsed quality measures are currently available for assessing FCHH for CMC?
Quality Measure Scan: • Scan of performance measure inventories (CMS, AHRQ, NCQA) **Primary Data Collection:** • KIIs to interpret findings
RQ3: How are select states currently implementing FCHH or related enhanced care coordination programs for CMC?
Primary Data Collection: • Survey of state Medicaid and Title V programs for AK, MI, TX, WA • KIIs with state Medicaid and Title V program representatives for AK, MI, TX, WA

Table 2.2. Literature Search Results by Search Topic

Search Result	CMC Definition	FCHH Definition
Records identified via PubMed	95	23
Records identified via other sources	43	17
Duplicates removed	4	2
Failure to meet eligibility criteria	84	21
Total articles included in review	**50**	**17**

of this analysis were used to build KII guides to interrogate and validate findings and gaps identified in the literature, particularly the identification of definitional domains that are challenging to operationalize in policy.

2.2 Measure Repository Search

Performance measure reporting is a critical component of monitoring quality and outcomes for Medicaid programs. To identify what measures are readily available for uptake in Medicaid programs promoting FCHHs for CMC, we conducted a search of performance measures using a multifaceted approach. Measure sources are described below.

Centers for Medicare and Medicaid Services (CMS) Measures Inventory Tool (CMIT). Our emphasis on readily available performance measures for use in Medicaid programs prompted a comprehensive search of the CMIT. The CMIT is the repository of record for information about the measures which CMS uses to promote health care quality and quality improvement. We focused our search on the database of 525 measures actively in use in current programs. To get the most comprehensive view of pediatric measures, we iteratively searched for the following terms:

- Youth (58 measures)
- Child (69 measures)
- Children (45 measures)
- Pediatric (37 measures)

This resulted in 136 unique measures. Measures were then reviewed for relevance to the seven FCHH definitional domains identified in the literature review. Measures for adult populations and maternal health were also dropped. This resulted in a total of 29 measures.

Patient Surveys. Given the important role of patient experience measurement for FCHH, we explicitly searched measures in existing experience surveys as recommended by SMEs. Surveys reviewed in their entirety for composite measures included:

- CMS Consumer Assessment of Healthcare Providers and Systems (CAHPS) suite
    - CAHPS Children with Chronic Conditions Supplemental (CCS) Item Set
    - CAHPS Clinician and Group Survey (CGS), emphasizing child items
    - CAHPS Health Plan Survey (HPS), emphasizing child items
    - Home and Community-Based Services (HCBS) CAHPS
    - Hospital CAHPS (HCAHPS) Child Survey
- Family Experiences with Care Coordination Survey (FECC)
- Promoting Healthy Development Survey-PLUS (PHDS-PLUS) Survey
- Pediatric Integrated Care Survey (PICS)

Measures were reviewed for relevance to the seven FCHH definitional domains identified in the literature review. Adult measures were included where topics were salient to CMC, but pediatric measures were lacking (e.g., HCBS). This resulted in a total of 92 unique measures.

Hand searches. We conducted hand searches of the Agency for Healthcare Research and Quality (AHRQ) website, National Committee for Quality Assurance (NCQA) Healthcare Effectiveness Data and Information Set (HEDIS) repository of over 90 measures, and National Quality Forum (NQF) Quality Positioning System of over 1170 measures. Search terms were used iteratively to identify measures related to pediatric patients, medical homes, health homes, and the seven domains of the FCHH definition identified in the literature review. We also cross-referenced included measures with the Medicaid Child and Health Home Core Sets. Hand searches resulted in the addition of 21 unique measures.

A summary of included measures by search strategy is presented in **Table 2.3**. Measure title, description, data sources, consensus entity endorsement status, and population (pediatric vs. adult) were extracted using a standardized MS Excel extraction tool. Measure descriptions were reviewed and categorized according to the seven domains of the FCHH definition identified in the literature. Measures were then examined against the FCHH definitional subdomains to elucidate where measurement gaps may exist. A final list of included measures is provided in **Appendix 7.4**. Results of this

Table 2.3. Measure Search Results by Search Strategy

Search Strategy Result	Unique Measures
CMS Measures Inventory Tool	29
Patient Surveys (CAHPS, FECC, PHDS-PLUS, PICS)	92
Hand Searches (AHRQ, HEDIS, NQF)	21
Total measures included in review	**142**

analysis were presented to key informants (KIs) to further interrogate measurement priorities that achieve the dual goals of measuring what matters and parsimony.

2.3 Qualitative Interviews & Focus Group

To supplement our literature review, we conducted a series of qualitative interviews and discussions, including: validation KIIs for CMC definition, validation KIIs for FCHH definition and measurement, a patient perspective focus group, and iterative engagement with targeted SMEs. Purposive and snowball sampling was used to identify interviewee candidates and focus group participants. The project team identified three relevant categories of perspectives a priori, which are policymaker, clinical provider, and patient/family. Specific recommendations were solicited from the ESC CC Brain Trust, SMEs, and HRSA. A total of 17 individuals participated in qualitative data collection activities. A summary of KI and focus group participants is provided in **Table 2.4**. Additional details are provided in the sections below.

2.3.1 Validation Key Informant Interviews

We conducted a series of KIIs between May and July 2024, following the literature review and measure scan. The purpose of these interviews was to prompt review of the literature and measure findings, assess face validity, and solicit feedback on challenges for translation to Medicaid policy. Semi-structured discussion guides were developed for each topic: (1) CMC definition and (2) FCHH definition and measurement. A total of eight (n=8) validation interviews were conducted, four (n=4) for each topic. Informants were contacted via email and provided with the interview guides and literature review findings matrices in advance of their interview. Interviews were approximately 60 minutes in duration, conducted via Zoom, and video and audio recorded with the consent of the participants and transcripts were produced. Content analysis was performed using NVivo software. Insights garnered through the KIIs prompted additional hand searches of the literature and measures to refine concepts related to Medicaid policy translation of FCHHs for CMC.

Table 2.4. Key Informants and Focus Group Participants by Stakeholder Perspective

Perspective	Number Participated
Validation KIIs: CMC Definition	
Policymaker	1
Clinical Provider	2
Family Advocate	1
Validation KIIs: CMC Definition	
Policymaker	2
Clinical Provider	1
Family Advocate	1
Family Focus Group	
Patient/Family	6
Subject Matter Experts	
Policymaker	1
Clinical Provider	1
Family Advocate	1

2.3.2 Family Focus Group

Following the completion of the key informant interviews, in August 2024, a focus group was conducted to discuss findings related to the definitions of CMC and FCHH. The focus group was conducted to ensure the environmental scan reflected the lived experience of those with medical complexity and their family members/caregivers.

Participants were primarily recruited through Family Voices' network of MCHB-funded Family-to-Family Health Information Centers (F2Fs). Family Voices included an announcement in *The Flash*, a weekly newsletter distributed to the F2F Network. Organizations within the network also shared the opportunity with families and other organizations within their local communities.

The ESC CC conducted the focus group with six people who care for a child with complex medical needs and/or identify as having complex medical needs themselves. Participants included four caregivers of CMC and two young adults with medical complexity. These participants represented the five major geographic regions across the country and had a range of experiences and perspectives.

The semi-structured discussion guide was developed to prompt discussion of current experiences related to care for medical complexity and the challenges in our policy system. Materials summarizing interim scan findings were shared with focus group participants in advance of the call. The virtual focus group lasted approximately one hour, was convened via Zoom, and video and audio were recorded. The transcript was analyzed thematically for key findings. Recommended resources were solicited, and insights shared during the focus group also prompted supplemental literature searches to further investigate points raised by participants.

2.3.3 Subject Matter Expert Consultation

SME advisors to the ESC CC were engaged in validation efforts during Project Team meetings, and through asynchronous feedback between January and September 2024. Targeted review of methodology, findings, and discussion topics were presented for their reflections and contributions.

2.4 State Surveys & Interviews

In Winter/Spring 2024, the ESC CC team developed a survey and conducted KIIs among four states participating in a newly-formed SAG. The goal of the SAG is to foster state-level collaboration between Medicaid and Title V agencies to promote sustainable policies and programs supporting CMC and their families.

The survey, which contained separate Medicaid and Title V versions, was developed and piloted in Spring 2024, with input from a wide range of experts with deep Title V and Medicaid expertise, including: ESC CC partners, the Brain Trust, SMEs, and HRSA. The goal of the survey was to understand the current CMC policy landscape in states participating in the SAG, and included questions related to:

- CMC definition
- CMC direct and enabling services covered/provided related to care coordination and integration
- Current approaches to monitoring CMC direct and enabling services

The surveys were administered via Qualtrics in Summer 2024, following the SAG kick-off call in June 24. Participating states receiving the survey included: AK, IN, MI, TX, and WA. Agencies were allowed to determine the appropriate individuals for responding to the survey, and group completion of surveys was encouraged as it was expected that survey content would span multiple staff roles. A single, collective response was received for each survey version from each state.

Following receipt of completed surveys, the ESC CC conducted KIIs with SAG representatives from each of the participating states. The semi-structured interviews lasted approximately one hour and were conducted virtually via Zoom. All interviews were recorded with the consent of the participants and transcripts were produced. States were asked to expand on how they define CMC and provide additional details on specific services offered to this population. They were also asked to provide insights into the level of collaboration between agencies involved in implementing CMC services, as well as the role of family and stakeholder engagement in shaping the delivery of care. This information aimed to capture a more comprehensive understanding of the structures and strategies each state employs to meet the needs of CMC through their Title V and Medicaid programs.

3. Results

Findings from the environmental scan are presented below and are separated into three different sections. We begin by presenting the definition of CMC with its affiliated domains and subdomains. We follow with a discussion of the definition of FCHH. We conclude with a presentation of findings from our measures scan. Results from our qualitative interviews and focus group have been integrated. Key findings from our survey and interviews with states have been split across the three major sections.

3.1 CMC Definition

This section presents findings related to the definition for CMC. Results from the literature review and qualitative discussions are presented first. This is followed by a discussion of findings from the survey and interviews with the four states participating in the ESC CC SAG.

3.1.1 Scan Findings

The findings from the literature on the definition of CMC were varied and, at times, contradictory on various aspects of how to define CMC. For example, there was no consensus on the number of body systems that must be affected to be classified as a CMC, with some sources suggesting one body system, while others suggested two or three. Several articles identified CMC by functional limitations, while others looked at CMC based on their technological dependence. KIs were split when asked whether there is a universally used definition for CMC, as some suggested that there is agreement on key concepts; however, others observed that definitions are applied differently based on the purpose of the definition (e.g. research vs. program inclusion). Many KIs suggested that even after inclusion criteria are identified, there should be leeway for a case-by-case basis, as doctors will “just know” who those children are. This variability highlighted the challenges in synthesizing a unified definition of CMC that would be fit for purpose in policy programs across states.

Initially, we developed seven domains for a definition of CMC based on our literature review. These domains included: (1) care needs, (2) chronic conditions, (3) functional limitations, (4) health care use, (5) technology dependence/assistance, (6) medical fragility, and (7) physical dependency on others. After consulting with SMEs, we refined these into four key domains. The four key domains of the definition of CMC synthesized from findings of the environmental scan were:

- Chronic conditions
- Health care use
- Functional limitations
- Care needs

Technology dependence/assistance and physical dependency were combined with functional limitations, while medical fragility was categorized under chronic conditions.

While this approach helped bring coherence to the literature, it also revealed notable gaps in existing research. Some aspects of the domains were well-supported by the sources, while others lacked sufficient evidence, suggesting areas where further research and clarification was needed from SMEs. **Table 3.1** includes a summary of the results related to defining CMC.

Chronic conditions are consistently cited as a key domain of the definition of medical complexity across sources. For the purposes of defining CMC, a chronic condition is often life-long (e.g., cerebral palsy), or generally expected to last greater than 12 months (e.g., laryngeal stenosis), and is severe by virtue of its association with medical fragility, functional limitations, and/or higher care needs/utilization. Although chronic conditions may be life-long, many children may improve with optimal care and growth. Identification and support of social needs, while not chronic medical conditions, is a key component of optimizing improvement. Chronic conditions may include medical, mental, behavioral, or developmental health conditions. Subdomains related to chronic conditions for medically complex children include the number of chronic condition diagnoses, number of affected bodily systems, and condition severity (see **Table 3.2**).

Health care use among CMC can be frequent and extensive. CMC may have frequent or prolonged hospitalizations, may regularly require various specialist and subspecialist services, and may utilize long-term home nursing, institutional, or community supports and services to meet health care needs. Definitions of CMC identified in the literature often include “high” health care resource use as a criterion, but there is a lack of consensus on how this criterion is defined. Although health care needs of a CMC will fluctuate over time, their utilization is typically much higher than even other populations of CYSCHN. **Table 3.3** summarizes approaches used in the literature to characterize the high resource use of CMC.

In discussion with the focus group, members confirmed that multiple surgeries and hospitalizations have played a significant role in their (or their family members’) medical complexity. However, KIs also noted that there is overmedicalization of CMC and that health care utilization can be low for some children once a successful plan of care has been established. One KI also noted that there may be a strong cultural component to a family’s willingness to seek care for their CMC (e.g., a child who may be medically complex may not meet medical utilization criteria for CMC due to lack of interest in seeking access). Another family may not have access because of subspecialty shortages or insurance coverage, again making health care use a challenging criterion to implement.

Table 3.1. Summary of CMC Definition Domains

Domain	Summary
Chronic Conditions	CMC have one or more chronic conditions[20] that are often life-long,[21,22] or generally expected to last greater than 12 months,[23–25] and are associated with functional limitations.[25,26] These conditions are marked by a severity such that the child is considered medically fragile and hence may result in higher care utilization.[20,22,27]
Health Care Use	Health care use for CMC includes hospitalization, medical appointments, surgeries, or ongoing involvement of multiple subspeciality services and providers.[22] Health care use for CMC encompasses requiring multidisciplinary resources[20,28] and an engaged care team to navigate the health care system.[28] Some CMC may require a need for home nursing services to support medical needs.[29] Health care utilization includes that which is expected (e.g., planned surgery to address severe scoliosis) and unplanned utilizations (e.g., hospitalization for complications of aspiration).
Functional Limitations	Functioning is classified by using key dimensions of body structure and function, performance of activities, and participation in communal life.[22] For CMC, limitations can be in their ability to do activities, and may require assistance from persons or technology more than other developing children of the same age.[30]
Care Needs	The type, intensity, and regularity of support and care required to maintain or improve a child's wellbeing.[22] Factors related to care needs include the need for specialized therapies, complex medications, and transition support.[20,22,31] Identified needs to support the family are included in this section (e.g., respite services).

Table 3.2. Chronic Conditions Subdomains

Chronic Conditions Subdomain	Description	Barriers to Operationalization
Number of Diagnoses	CMC may be diagnosed with one or more chronic clinical conditions.[20,22]	Lack of consensus in the available literature regarding whether a CMC should have at least *one* or at least *two* severe chronic conditions.[20,22,32]
Number of Affected Body Systems	CMC may have chronic conditions that are complex and life threatening in at least two body systems, or in one body system with several sub-diagnoses.[21,23,33–35] Some sources that cite one severe single system disorder (e.g., cerebral palsy) may meet criteria, but exclude common diagnoses such as asthma or psychiatric disorders.[34]	Lack of consensus regarding the number of body systems that must be affected to constitute medical complexity, and whether conditions should be "carved out" of these parameters (and if so, which conditions).
Condition Severity	CMC are diagnosed with chronic conditions that are severe and/or associated with medical fragility (e.g., high morbidity and mortality rates).[20,22,31]	Absence of a clear definition for "severe" or "serious" chronic condition.

Functional limitations identify limitations for which modifications in day-to-day activities are needed (i.e., require assistance from technology, such as a feeding tube, tracheostomy tube, or a wheelchair) to best participate in routine age-appropriate activities. The type, consistency, and severity of functional limitations may vary over the life of the child in the context of environmental and personal factors. CMC typically experience limitations in their ability to fully participate in activities and perform roles/tasks that may be expected of children of the same age without medical complexity. Some CMC may be able to function with minimal limitations with the support of assistive or adaptive technology. Other CMC, categorized as "technologically dependent", may require intense support from medical devices and medical personnel to remain stable and sustain their life and bodily functions. The Office of Technology Assessment (OTA) categorizes technology dependent children into four groups, comprising those requiring mechanical ventilation, intravenous nutrition or medication, respiratory or nutritional support, or apnea monitors.[37] **Table 3.4** describes subdomains associated with functional limitations for CMC.

Care needs comprise factors related to the type, intensity, and regularity of support and care required to maintain or improve a child's wellbeing. Subdomains related to care needs include the need for specialized therapies, complex medications, transition support, and family-identified needs. While these factors arise consistently in the literature, there are barriers to operationalizing these subdomains for an actionable definition (see **Table 3.5**). Care needs can be measured by the Children with Special Health Care Needs screener, with literature sources noting that four or more positive questions on this screener may indicate care needs of a medically complex

Table 3.3. Health Care Use Subdomains

Health Care Use Subdomain	Description	Barriers to Operationalization
Resource/Service Utilization	CMC have substantial health care utilization when compared to other populations of CYSCHN.[22] This utilization can include hospitalizations, outpatient specialist appointments, surgeries, or long-term services and supports.[20–22,25]	There is a lack of consensus on the criteria related to defining and assessing "high" health care utilization. The literature offers parameters for "high resource use" related to the number of subspecialists seen in the preceding 12 months,[25,36] number of inpatient hospital or intensive care unit (ICU) admissions,[25] emergency department visits,[25] length of hospital admissions,[25,34,35] residence in a chronic care facility,[34] or the use of home nursing services.[29,37–39] However, these parameters are highly varied across studies and programs. Most programs find it challenging to separate planned vs. avoidable service utilization across large populations.

Table 3.4. Functional Limitations Subdomains

Functional Limitations Subdomain	Description	Barriers to Operationalization
Modification to Support Activities of Daily Living	CMC may be limited in their ability to complete activities that children without medical complexity can do in their day-to-day lives,[22,40] particularly related to their role/functioning in their family/home, school, and community activities.[30] Consideration has been made to classify children in need of adaptive technology modifications but otherwise with stable chronic conditions differently from those with greater ongoing or intermittent medical needs.	There is a lack of consensus on the parameters related to severity of limitations indicative of medical complexity.
Technological Dependence	CMC may be dependent on medical technology to sustain life or compensate for vital body functions. Other CMC may be stable without technological assistance but may require adaptive technology to successfully complete age-appropriate activities of daily living.[20–22,24,27,29,32,34,37,38,40–48]	The Office of Technology Assessment (OTA) groups may not be sufficiently comprehensive to characterize technology dependence in CMC. It is also unclear if CMCs *must* be technologically dependent and what level of reliance on technology is indicative of medical complexity.

Table 3.5. Care Needs Subdomains

Care Needs Subdomain	Description	Barriers to Operationalization
Specialized Therapies	CMC may require a variety of therapies such as physical, occupational, or speech therapy in order to maintain or improve their quality of life.[20,22,25]	It is unclear what constitutes "specialized" therapy, and what number, duration, intensity, or frequency of these therapies may be indicative of medical complexity.
Complex Medications	CMC may need complex medications (i.e., uncommon medications not usually needed by non-medically complex children).[21,28,31,49]	There is no widely used definition of a complex medication, nor is there consensus on which types of medications would not usually be needed by non-medically complex children.
Transition Support	CMC may require support as they move into from a pediatric care setting to adult care settings.[22]	Parameters for transition support are not clearly defined and may not be consistently documented/ recorded in a manner that can be extracted for use in an algorithm or operational definition.
Family-Identified Needs	CMC often have substantial needs (i.e., medical, educational) that significantly affect the functioning and wellbeing of their family unit.[20,22,31] These family impacts may include time devoted to direct care, frequent provider visits, financial burden on family due to care needs, and the need for care coordination.[22,27,50]	All children have needs that affect their family unit, and there is a gap in understanding regarding what level of need or family impact would be considered "significant" or "substantial".

child.[25] Notably, the type, intensity, and consistency of an individual's care needs may change dynamically over the life of the child depending on a variety of medical, psychosocial, and community factors. Informants noted that social complexity factors (including social drivers of health) are key for comprehensively assessing the full scope of a child's medical complexity, and that these factors were noticeably missing from literature findings.

A prominent theme throughout the focus group discussion regarding defining medical complexity was the impact of a child's care needs on family's wellbeing. Every participant spoke about challenges their family faced, including taking time off from work, lacking natural and community resources to navigate their child's care, the emotional toll and stress of taking care of their child, having to be responsible for care coordination, and having to "prove" why their child's health care services should be deemed necessary. Multiple participants spoke about the impact of unpredictable or unexpected challenges, such as complications from surgery, a rapid increase in medication, or an urgent need for surgery. Participants described this impact as "heavy" and "significant stress."

For policymakers, a definition of CMC might best be considered a process that begins with considerations of complex 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. 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.

3.1.2 State Findings

The examples of the four states we surveyed illustrate the challenges of establishing a universal definition for CMC that can be used across states and programs (**Table 3.6**). Our small sample provided insights into the heterogeneity that may exist in the landscape, including that some states have not yet developed a standardized definition for CMC. Even in the absence of specialized programs, the lack of a working definition means those states are unable to track insurance adequacy, service provision, health care expenditures, and quality of care for this uniquely highly-burdened, high-cost population.

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 identifi-

Table 3.6. Definitions for CMC by State and Program

State	Medicaid CMC Definition	Title V CMC Definition
AK	• Subset of CSHCN • Disability status (SSI application review) • Medical provider attestation of CMC status	• Identified via processed data file from Medicaid
MI	• Diagnoses • Medical specialty use • Functional status • Service utilization • Identified via referral/screening process ◦ MI Medicaid and Title V have worked collaboratively to establish their definition	• Subset of CSHCN • Medical specialty use • Functional status • Service utilization • Identified via claims review, provider attestation, processed data file from Medicaid
TX	• STAR Kids[51] eligibility (e.g., SSI, dual eligibility, HCBS recipient) • Identified via SSI application review & in-person assessment with a standardized screening assessment tool	• No standardized definition
WA	• No standardized definition	• No standardized definition of CMC within a standardized process for identification of CYSHCN

CYSHCN: children with special health care needs; SSI: Supplemental Security Income; HCBS: home- and community-based services

cation, 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.

Finally, approaches to CMC identification appeared to be predominantly multi-factorial, with state programs opting for a combination of administrative data (e.g., Supplemental Security Income [SSI] eligibility) and provider attestation, which could be in the form of provider referral and/or via use of a standardized screening process. Use of a combination of data sources, including provider attestation, may reflect the challenges of articulating an objective severity standard for all of the domains of the definition. While this flexibility may be necessary, the variation in administrative data used for case finding, combined with the subjective components of provider attestation, introduces challenges for making intra and cross-state comparisons.

3.2 Family-Centered Health Home Definition

This section presents findings related to the definition of FCHH for CMC. Results from the literature review and qualitative discussions are presented first. This is followed by discussion of findings from the survey and interviews with the four states participating in the ESC CC SAG.

3.2.1 Scan Findings

Consistent with results for defining CMC, the literature scan uncovered a varied landscape in terms of defining FCHH. We recognize that terminology for the services described below, and first described by the American Academy of Pediatrics (AAP), has evolved. We have chosen to use "family-centered" to acknowledge the central role of families, and "health homes" to support the expectation for a more comprehensive service inclusive of medical care and a wellbeing focus. Our use of "health homes" is not intended to align specifically with the Medicaid Health Home program outlined in 1945 or 1945A, where the term "health home" is also used.

While the literature review for the definition revealed variations of how to define a health/medical home, only one article directly addressed defining a family-centered model, and no articles specifically addressed health homes for CMC. Most articles focus on patient-centered medical homes or medical homes more broadly, which overlook a crucial element for CMC, the involvement of family. There were significant gaps in the literature regarding operational parameters to define necessary components of a health home, and a lack of discussion of which aspects of health home care may be most important for CMC. When considering defining an FHCC, KIIs emphasized the importance of addressing upstream drivers of health , along with medical and functional issues, and how the interplay of the varied social complexity and identities held by and experienced by CMC and their families influences what could be considered appropriate health home care for CMC.

Seven domains of the definition of a FCHH were identified based on findings from the environmental scan:

1. Comprehensive care
2. Patient/family-centered care
3. Coordinated care, care integration, and transitions
4. Accessible and convenient services
5. Compassionate care
6. Quality and safety
7. Care management and support infrastructure.

An initial framework including these domains was developed from the literature and informed by AAP's definition of FCHH.[52] **Table 3.7** includes a summary of the domains related to defining health/medical homes.

Comprehensive care is structured, team-based care that helps address the patients' challenges related to all types of physical and mental health care needs and to social risk factors. This type of care is essential for CMC due to their extensive care needs. Key subdomains of comprehensive care—team-based approach, providing all necessary medical care, and addressing upstream drivers of health—also have significant barriers to operationalization (see **Table 3.8**).

Table 3.7. Summary of FCHH Definition Domains

Domain	Summary
Comprehensive Care	Team-based care that provides structure for practice leadership and care team responsibilities, includes care for physical and mental/behavioral care needs.[52,53] Comprehensive care helps address patient challenges related to upstream drivers of health.[54]
Patient/Family-Centered Care	A holistic approach tailored to the needs, values, culture, and preferences of each unique child and family, that recognizes the vital role that families play in the health and wellbeing of CMC.[52,55,56]
Coordinated Care, Care Integration, and Transitions	Care that coordinates medical and social services (e.g., from acute hospitalization, to specialty and home visits, to primary care, and serves as a bridge when transitioning back to community after hospitalization).[52,55,57,58] Coordination includes access by family and the health home team, to shared information technology (IT) resources. Emphasis includes continuity of care, access to needed community-based services, and clear and open communication among patients/families, the health home, and members of the broader care team.[53,55,58] Transitions to adulthood and adult care providers are included.
Accessible and Convenient Services	Services are provided at a time and in a way that is convenient for the patient and family. Families are served by the health home through a variety of different referral mechanisms. Support by the health home to obtain these needed services (including use of specific services or community supports) is provided.[52,58,60,61] Care and resources are easy to obtain through adequate geographic access and sufficient insurance coverage without untoward barriers.[59]
Compassionate Care	Care that recognizes, values, and respects the family and child's culture, language, beliefs, and traditions.[59] This care compassionately addresses a CMC's multidimensional identities, as well as cultural and linguistic needs.[56,59,62,63]
Quality and Safety	High-quality care using evidence-based (or evidence-informed) practices to guide shared decision-making.[52–54,58,64] Practices collect, monitor, and share performance, quality, and safety data. Practices engage in ongoing quality improvement activities.[52,58]
Care Management and Support Infrastructure	The provider system in which the FCHH operates is designed to provide support to CMC and families. Assistance is available to manage the administrative challenges of care including maintaining and updating accessible records, appointment access, and scheduling of needed services. The provider system has processes that are in place to assure that care can be managed closely as needed.[55,58,61,64,65]

Table 3.8. Comprehensive Care Subdomains

Comprehensive Care Subdomain	Description	Barriers to Operationalization
Team-Based Care	Care that includes a team of physicians, advanced practice practitioners, pharmacists, nutritionists, social workers, educators, and care coordinators working within a structured environment with clear responsibilities.[1,52,53,58]	Payment models ensuring that a team can be developed with adequate infrastructure and with adequate compensation for all team members has been challenging, especially when a holistic payment (e.g., monthly capitation) is absent and expectations are for individual transactional fee-for service payments. Pricing of team-based care, recognizing the integrated team efforts, and required infrastructure has relied upon individual negotiations between provider systems and payers.
Addresses All Necessary Medical Care	Care that addresses physical as well as mental health care needs, including preventive and wellness care, as well as acute and chronic care.[52,58,64]	CMC represent a population with varying types of need, making it important to individually define "necessary" care. Aside from critical life sustaining needs, care can be planned sequentially, but requires follow through to meet comprehensive needs.
Addresses Upstream Drivers of Health	Comprehensive care helps patients address challenges related to social drivers of health, including economic needs of housing, food, transportation, flexible employment, and non-economic family structure needs such as parental mental health.[54,55]	Addressing upstream drivers of health in the context of care of a CMC requires prioritization of efforts both for the FCHH and the family itself. FCHHs should develop infrastructure to effectively address these needs (e.g., social worker liaison to social service providers). Communities may have limited resources to fully close gaps, and CMC families may need to be more highly prioritized.

Patient/family-centered care is a partnership approach to health care decision-making between the patient/family and health care provider that results in care that is respectful of and responsive to a patient or family's needs, values (including specific family and cultural values), and preferences. This care focuses on the child as a whole person. While in recent years health systems and those delivering care often prioritize a patient-centered approach, there are barriers to operationalizing this domain of a health home definition in a standardized, measurable way. Subdomains related to patient/family-centered care include respect and dignity, information sharing, participation, and collaboration[66] (**Table 3.9**). Family focus group participants elevated patient/family-centered care as a core domain of the health home approach for CMC. A child's autonomy should be respected (as developmentally appropriate), and a patient-centered approach should allow the child to make decisions about their own care whenever appropriate. However, focus group participants also highlighted that the family needs to be included in discussions and decisions about the child's health care. Moreover, supporting the entire family and the family's needs is essential to ensuring a child's wellbeing. One participant remarked, "it is imperative that practitioners understand that you have to look at the totality of need within the family."

Coordinated care, care integration, and transitions comprise subdomains ensuring that a patient's care is seamless and integrated across providers and settings, including support built-in to facilitate continuity of care during transitions between care settings, health states, or from pediatric to adult services. Coordinated and integrated care also facilitates access to community-based services to help promote the healthy development and wellbeing of children and their families outside of a strictly physical health or behavioral care setting. As CMC generally have frequent and dynamic care needs, appropriate transition support is essential as CMC move between providers or settings. Appropriately coordinated and integrated care removes barriers to needed services, minimizes cost, confusion, and inappropriate care for the patient, and relieves burden on families who often become de-facto care coordinators for their child. Coordinated care consistently ranks highly as a crucial domain of health homes across the literature, and particularly as a driver for improving care for CMC.

Table 3.9. Patient-/Family-centered Care Subdomains

Patient-/Family-Centered Care Subdomain[66]	Description	Barriers to Operationalization
Respect and Dignity	Care that is respectful of the patient and their family; treating the patient as a whole individual. Providers listen to the patient and family, and incorporate their perspectives, choices, knowledge, and values into care planning and delivery.[58,59,61,63,64]	Training staff to address underlying assumptions , and then to communicate to support families, are important first steps that require adequate system infrastructure. There is a lack of standardized approaches or ways to assess respect and dignity as a facet of health care delivery. Experience survey-based approaches to assess respect and dignity suffer from logistical challenges such as costs of administration and low response rates, limiting their value as performance feedback tools.
Information Sharing	Providers freely communicate and share complete, timely, and accurate information with the patient and their family in a way that they can understand, is useful, and empowers their participation in care and decision-making.[52,53,55,58]	Optimal process, structure, or parameters for information sharing are known, but time-consuming and difficult to implement.
Participation	Care that encourages and supports CMC and their families to be active participants in their care, including shared decision-making.[52,53,55,58,59,63,64]	Developing processes for CMC participation in shared decision-making at sites requires adherence to certain ethical principles (e.g., beneficence, non-malfeasance) while evaluating these principles in the context of the family, culture, and the child's development is a dynamic process. Evaluation of the aspects of this process must similarly be sensitively assessed.
Collaboration	Patients and their families are respected and impactful members of the care team, working to participate in programmatic and policy development and evaluation, as well as research.[58,63,64]	There is a lack of consensus regarding best practices in engaging CMC and their families to collaborate in ways that are empowering, appropriate, and avoid adding undue burden to the family or patient.

When reviewing the identified domains of the definition of a health home, KIIs discussed the importance of coordination for a CMC health home but emphasized that it is important to understand what is achievable for all families of CMC, and the need to identify who is coordinating all aspects of the child's health. Coordinated care and transitions were also key themes that the focus group raised when discussing core health home components. Multiple participants remarked upon the need for providers to regularly communicate with one another and noted that this has generally been lacking from their health care experiences. The specific subdomains and the barriers to operationalizing them in the context of CMC are in **Table 3.10**.

Accessible and convenient services are a hallmark of health home care; CMC should be able to readily access needed services in a timely manner that is convenient for the patient and their family, including care for chronic conditions and acute issues. This domain of a health home also ensures that children can be supported by the health home continuously. **Table 3.11** describes existing barriers to operationalizing key subdomains of accessible and convenient services when defining a health home model: (1) affordability, (2) availability, (3) accessibility, (4) accommodation, and (5) acceptability.

Table 3.10. Coordinated Care, Care Integration, and Transitions Subdomains

Coordinated Care, Care Integration, & Transitions Subdomain	Description	Barriers to Operationalization
Coordinated Care	Patient/family-centered, assessment-driven, team-based activities designed to meet the needs of children and youth.[1,52,57,58] They address interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes, and efficient delivery of services and resources within and across systems.[1]	Resources, infrastructure, and reimbursement mechanisms are often not in place to facilitate coordinated care for CMC, particularly for those living in rural or urban under-resourced areas.
Care Integration	The seamless provision of health care services, from the perspective of the patient and family, across the entire care continuum. It results from coordinating the efforts of all providers, irrespective of institutional, departmental, and community-based organizational boundaries.[55,56]	Resources, infrastructure, and reimbursement mechanisms are often not in place to facilitate integrated care for CMC, particularly for those living in rural or urban under-resourced areas.
Transitions	The infrastructure and supports to ensure continuity of care when a patient moves between settings (i.e., returns home post-hospitalization), health states (i.e., from curative care to palliative care), or transition to adult provider systems. Supports required during these transitions of care often include logistical arrangements (e.g., insurance coverage, selecting and scheduling adult providers), a robust person-centered care plan, coordination among providers who are knowledgeable about the patient, and education of the patient and family.[67]	The resources and infrastructure to support seamless care transitions for CMC are often not available, particularly for those living in rural or urban under-resourced areas. It is unclear what uniform parameters for "appropriate" transition support for CMC may be given the wide-ranging needs of the population.

Table 3.11. Accessible and Convenient Services Subdomains

Accessible & Convenient Services Subdomain[68,69]	Description[68,69]	Barriers to Operationalization
Affordability	Affordable services are those for which the patient and their family can and will pay, or the patient's insurance will cover as needed services. Affordability must include assessment of underinsurance (e.g., large co-pays, deductibles, and co-insurance costs). Affordability is particularly key for CMC and their families, who are at high risk of financial marginalization, often compounded by the financial impacts of intensive caregiving (i.e., caregiver reducing workforce participation) and the high level of need for health care services.[1]	Barriers to affordable care are more significant for those who are marginally insured than for those who are on Medicaid due to being categorically needy (e.g., poverty). Many children who are eligible for Medicaid based on a disability determination then have Medicaid as secondary coverage, reducing or eliminating underinsurance concerns. States have opportunities to support families via state insurance coverage laws or expansion of Medicaid eligibility, but this coverage is inconsistent across states. Economic measures of the burden of the family spend are available, but difficult to apply to individual cases, and serve only to inform state policy.
Availability	Availability relates to the provider's ability to meet the service needs of their patient. That is, the provider has the required resources, including personnel, equipment, technology, and training, to be able to successfully offer and provide the needed care. CMC have wide ranging care needs and may require services or supports that are not widely available and services from multiple providers.[52]	Availability must be individualized and is predicated on what type of care is "needed" for the patient. Assessment of availability of some specific critical services (e.g., home private duty nursing) can be assessed to assure adequate care and appropriate efforts to fill care gaps. Considerations for availability of services must consider the ability of the health home to compel insurance payment.
Accessibility	Accessible services are those that are easily (physically) accessed by the patient. That is, the services are geographically close, and the patient can reach the location of care delivery in a timely and convenient manner. Telehealth is a promising practice for improving the accessibility of services.[59]	Considering their wide-ranging care needs, the resources and infrastructure to ensure CMC have appropriate access for their geographic location is not always possible particularly for those in rural areas. Assessing and then remediating limited geographic access is a persistent challenge for both subspecialty medical services and home and community-based services.
Accommodation	Accommodation relates to a provider's ability to organize care in a manner that addresses the preferences and constraints of the patient. Accommodation can relate to after-hours and weekend availability, scheduling processes, and providing accommodation on-site to ensure that patients and their families can fully participate in their care (i.e., medical translation, adaptive technology, an accessible physical environment, etc.).[52,58,60,64]	Given the wide-ranging constraints and need for accommodation often experienced by CMC and their families, the resources and infrastructure to ensure that CMC can be readily accommodated by their providers are not always in place. Assessment and implementation of accommodation for CMC can be incremental. Certain aspects of accommodation are consistent with the Americans with Disabilities Act, but alone are often inadequate for CMC (e.g., the Americans with Disabilities Act [ADA] only requires wheelchair accessible exterior doors).
Acceptability	Acceptable services are those that the patient feels comfortable with, taking into account provider and patient/family attributes as well as relational traits and other personal or contextual factors that may influence the relationship between patient and provider.[54]	Many aspects of acceptability overlap with aspects of compassionate care and are addressed below.

Compassionate care is care that is provided with genuine concern for the wellbeing of the child and family, that includes a respectful and trusting relationship between patient and provider, allows the patient and family to understand the information communicated about their health, and that ensures the family and child's culture, language, beliefs, and traditions are recognized, valued, and respected. CMC and their families come from a wide range of backgrounds, and a FCHH model to serve CMC would need to be able to provide care in a manner that is respectful of, and responsive to, their culture and preferred language.

Many patients and their families experience challenges in health care settings due to preconceived notions and underlying assumptions about their background, identity, or personal circumstances. These challenges can lead to adverse health outcomes and exacerbate existing gaps in care.[70] For an already vulnerable population such as CMC, it is imperative that care is provided in a way that is compassionate, responsive, and supportive of their unique needs. When patients receive care that is contextually responsive and compassionate, they are more likely to adhere to their provider's recommendations, be more satisfied with their care, and have improved outcomes.[71] Providing compassionate care includes ensuring that the provider is contextually aware and responsive, that culturally and linguistically appropriate services are available (including medical interpretation in American Sign Language or the family's preferred spoken/written language), that the family is supported to develop health literacy, and that the child and their family perceive their providers to be compassionate and trustworthy. Challenges related to implementing these subdomains in policy programs are highlighted in **Table 3.12**.

Table 3.12. Compassionate Care Subdomains

Compassionate Care Subdomain	Description	Barriers to Operationalization
Contextual Awareness and Responsiveness	Contextually responsive care ensures that the care is delivered in a manner that is aware, knowledgeable, and respectful of the patient and family's unique background and culture.[56,59,62,63]	Assessments, evaluation of assumptions, and training by health home providers and staff is a first step but can be difficult to implement due to competing demands. Employment of persons with similar backgrounds and from the same communities is effective. Workforce training issues must be addressed.
Culturally and Linguistically Appropriate Services (CLAS)	Care that is delivered to the patient and their family in a manner that is responsive to their beliefs, practices, and values, and allows them to fully understand information about their care.[56,59,62,63]	As with elements of other domains, there is a lack of standardized approaches or ways to assess provider trust and compassionate communication, and CLAS measures similarly lack best practices. Additionally, experiential survey-based approaches to assess these subdomains suffer from logistical challenges such as costs of administration and low response rates, limiting their value as performance feedback tools.
Provider Trust	Patients and their families should be reassured and have confidence that their doctor has genuine concern for their health and wellbeing.[72]	
Compassionate Communication	Communication between provider and patient/family should be considerate, respectful, helpful, and endeavor to ensure the patient and their family feels safe and that they have been listened to.[55,63]	
Health Literacy	Health literacy relates to whether patients and their families can understand information to maintain or promote their health.[73]	Health literacy is sometimes conflated with health system literacy (needed to navigate appointments, insurance, etc.). Both are needed by families of children with CMC.

Quality and safety are key components of effective health care delivery, including care provided through an FCHH. There are known metrics associated with assessing the quality of health home care, including measure sets used by AHRQ and CMS. These measure sets are typically oriented to evaluation and performance measurement of patient-centered medical homes and focus on assessments of core preventive care utilization metrics, utilization and clinical outcomes associated with behavioral, chronic, and acute care, as well as assessments of care coordination and health care cost. However, these measurement areas are not specific to, and do not necessarily correspond directly with what is most important to measure for CMC and their families.[74] To date, there has been inadequate effort to understand modifications to accurately measure quality for an FCHH, particularly those specific to the CMC population. Generally, the literature supported quality measurement and associated ongoing quality improvement activities as hallmarks of quality health home care.

Additionally, health home care should be safe for the patient, meaning that the care provided should avoid harm to patients, focusing on error prevention. When errors do occur, the health home should learn from these errors and be able to implement process improvements to reduce errors in the future, working within a culture of safety, prevention, and continuous improvement.

Health homes should also ensure emergency planning activities are robust.[75] CMC and their families are a vulnerable population, and due to the intermittent acuity of their complex care needs, may be less able to advocate for themselves or their child when acute care is not of high quality or safe. Regarding safety for CMC in particular, one KI emphasized that facilities should be cognizant to avoid inappropriate use of restraints and seclusion in their provision of care. Health home providers should include emergency care planning, especially for those with life sustaining technology (e.g., informing and educating emergency medical services personnel about the care needs and potential emergencies of a trach dependent child).

The literature emphasized the importance of a health home publicly sharing their quality and safety data, as well as their record of improvement activities in both domains. Generally, there are two key subdomains associated with the quality and safety domain of the FCHH: (1) continuous quality improvement and (2) avoidance of harm & prevention of error. Each of these subdomains have barriers to operationalization in a standardized way for CMC (**Table 3.13**).

Table 3.13. Quality and Safety Subdomains

Quality & Safety Subdomain	Description	Barriers to Operationalization
Continuous Quality Improvement	Continuous quality improvement (CQI) comprises iterative refinements to the delivery of care to ensure that the care delivered is aligned with clinical practice guidelines and progresses the FCHH towards goals for high-quality care delivery. CQI requires repeated measurement to assess the quality and functioning of existing care delivery processes.[76]	There is a gap in understanding regarding which measures, particularly outcomes, are appropriate, relevant, and actionable for quality improvement activities within FCHH for CMC. The development of FCHH as a learning health system requires nuance in supporting the development and testing of new quality efforts.
Avoidance of Harm & Prevention of Error	Processes should be in place in an FCHH to avoid patient harm and prevent errors, (i.e., patient impact from a process of care failure). Causes of harm may include, but are not limited to, diagnostic or medication errors. Harm may cause impairment of patient's physical condition but also may have psychological impacts. When harm has occurred, process improvements should be implemented to avoid further or repeated harm.[77,78]	There is currently a lack of consensus regarding which measures to prioritize for assessment of avoidance of harm and prevention of error in CMC.

Care management and support infrastructure include the processes and structures in place to support patients and their families in managing their health conditions. Care management comprises processes that enable the patient and family's records and appointment management, medication and treatment management, and support in arranging social services and school-based needs. Care management can include connecting patients and their families with information and education to enable self-management of their conditions, assistance with medication management and reconciliation, and referrals to community and social service resources.[79] Support infrastructure includes the physical site of care, as well as personnel, and tools such as web portals that enable the patient and their family to access and manage their health information and care. At the most basic level, care management and support infrastructure must be in place to enable all other components of quality health home care. Given the many medications, accommodations, appointments, and treatment plans often required for CMC and their families, care management and support infrastructure are essential for this population to successfully manage their health and health information.

Table 3.14. Care Management and Support Infrastructure Subdomains

Care Management & Support Infrastructure Subdomain	Description	Barriers to Operationalization
Information Management	Processes to support patients and their families in managing their health-related information, including health records, appointments, treatment plans, and referrals.[53,60,65]	Access to health records can be limited by technology or by assessing choices provider systems make on the platform.
Community Referral Network	Support via referrals to community-based organizations or resources to assist with access to appropriate medical or non-medical services and supports, including social services, legal, and educational supports.[53–55,57,61,65]	Structures for maintaining an up-to-date community referral network are difficult. Projects like "Aunt Bertha" have been effective in some communities.[92]
Technological Infrastructure	Virtual infrastructure, including the provider's website, electronic health record (EHR) portals, and other technology established to allow patients to access their health records, submit inquiries, and schedule appointments.[58,60,64]	Technology infrastructure must be maintained by the provider system and support these parameters of the FCHH. Often resources for this infrastructure and the assessment of its efficacy for CMC and their families is lacking
Care Plans	Processes to support patients and their families in accessing and managing their care plan.[53,58,61,65] Care plans for CMS have some key components that are addressed in coordinated care and care integration above. System infrastructure supports this care planning by assuring access to these tools by family members, the patient, the FCHH, and all relevant providers.	Care plans for CMC are not uniformly developed and are hard to keep up-to-date. Resources that integrate care plans into the EHR are most appropriate and take time to develop.
Physical Infrastructure	Physical infrastructure refers to the characteristics of the physical location of care delivery, including office staff, cleanliness, and facility accessibility modifications as required in order to promote comfortable access to care for all patients.[57,64]	There is currently a lack of consensus regarding which measures to prioritize for assessment of physical infrastructure as it relates to FCHH for CMC.

3.2.2 State Findings

In our survey of four states, we identified variation in the types of direct and enabling services being provided to CMC and their families to achieve the goals of FCHHs, with an emphasis on care coordination and integration. **Table 3.15** presents the services offered to support CMC, and whether those services are administered by Medicaid or Title V, or both, as was the case in several circumstances. **Table 3.16** shows how states provide payment to service providers. It should be noted that not all states were reporting on services provided specifically to CMC. Where a definition for CMC does not exist, namely WA and TX Title V, states were asked to apply their definition for disability (e.g., SSI eligibility) as a proxy. 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 transition to adulthood.

Notably, case management support was not provided in AK and WA, and MI Medicaid is just on the verge of rolling out a case management program but does not currently offer this type of intensive support for CMC. Case management aligns with one of the core domains of an FCHH and plays a pivotal role in ensuring that CMC and their families receive the comprehensive, coordinated care they need by helping to bridge gaps in care, improve outcomes, and reduce the burden on families. Our survey suggests this is not a universally supported service by either Medicaid or Title V, and that there may be benefits to making tools available that will assist states in the consideration and, potentially, adoption of these types of programs.

In addition, only three of the four states provided support for planning for transition to adulthood, suggesting there may be other states where gaps in this type of service support exists. Transition to adulthood services are crucial for CMC, because they ensure a smooth transfer from pediatric to adult health care, allowing for continued access to necessary medical care, while empowering young adults to manage their own health needs, ultimately improving their QoL and long-term health outcomes as they mature. This process requires proactive planning and coordination between pediatric providers, adult specialists, and the patient/family to address complex medical needs, and navigate the transition to a new healthcare system.[80]

Table 3.15. Care Coordination/Integration Direct & Enabling Services Definition by State and Program

	AK		MI		TX		WA*	
Services Covered	**Medicaid**	**Title V**	**Medicaid**	**Title V**	**Medicaid**	**Title V***	**Medicaid**	**Title V**
Case Management			X**	X		X		
Family Support Services				X		X		X
Supporting & Providing Access to services	X			X	X	X	X	X
Primary Care-Specialists Coordination	X		X	X	X	X	X	X
Physical-Behavioral Health Coordination	X			X	X	X	X	X
Planning for Medical Needs	X		X	X	X	X	X	X
Planning for Medical & Health-Related Social Needs Integration	X		X	X	X	X	X	X
Planning for Medical & Educational Needs Integration	X			X	X	X		X
Planning for Transition to Adulthood				X	X	X	X	X

*Where no standard CMC definition exists, agencies were asked to use disability (SSI) as a proxy.

**Policy currently undergoing implementation planning.

Table 3.16. Care Coordination/Integration Direct & Enabling Services Payment by State and Program

	AK		MI		TX		WA*	
Services Covered	Medicaid	Title V	Medicaid	Title V	Medicaid	Title V*	Medicaid	Title V
Claims coded individually (e.g., FFS)	X		X		X		X	
Claims coded individually (e.g., FFS) & reconciled with Medicaid				X				
Claims coded not individually (e.g., capitated)								
State pays county to contract services				X				X
State pays other entity (e.g., HCBS provider)	X		X		X	X		X
State pays MCO					X		X	
MCO self-funded (in contract)							X	
MCO pays provider for services coded individually			X		X		X	
MCO pays provider for global services			X		X			

FFS: fee-for-service; MCO: managed care organization
*Where no standard CMC definition exists, agencies were asked to use disability (SSI) as a proxy.
**Policy currently undergoing implementation planning.

Finally, expected variation was observed 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. This is unsurprising given that one of the central roles of state Title V programs is to "facilitate the development of comprehensive, family-centered, community-based, contextually responsive, coordinated systems of care for children with special health care needs."[81] Title V programs nationally prioritize supporting efforts for women, children, and families at the population- and system-levels.[103]

Medicaid can play an important role in ensuring services are adequately financed and provided. Here, we see more variation in the types of services supported. Case management has only just been added to MI's portfolio, and it is lacking in all other states surveyed. Family support services were also universally missing from the services provided by Medicaid, and adult transition support was absent from AK and MI.

With respect to payment, Title V's role in direct reimbursement to service providers was limited. Texas and WA Title V programs played a role in payment to entities such as HCBS providers, and WA Title V also paid the country for contract services. Only in MI was Title V responsible for fee-for-service (FFS) payments that are ultimately reconciled with Medicaid. With respect to Medicaid programs, there was consistency in the use of FFS payments to providers as well as direct payment to other entities, such as HCBS providers. More variation was apparent when examining managed care organization (MCO) payments. Alaska is a FFS state and does not use MCOs, however, all of the other three states do provide payment to MCOs. In these states, we see enhanced care coordination services being handled as a health plan carve out that are billed and reimbursed as FFS. In the case of MI and TX, this includes billing codes for ongoing referral and care coordination services as well as monitoring and follow-up activities that is collectively billed as a per member per month (PMPM) benefit for eligible patients. This approach was not mirrored in WA.

As noted by MI in their interview, their approach is heavily informed by the approach taken in WI, where it was determined that a risk-based payment structure would not work well because the CMC population is characterized by extreme utilization risk that is difficult to forecast with a relatively small number of patients in a predictable way. As a result, a supplemental FFS structure was adopted to achieve benefits similar to those ascribed to global payments. This entailed making targeted case management funds available to clinical complex care programs by creating specialized codes that were compatible with existing electronic billing systems. Programs had to provide specific case management services and have monthly contact with enrollees to qualify for the payment.

This example of cross-state learning and adaptation to local settings could be a model for other states exploring sustainable payment approaches where risk-based payment is falling short. Our survey and subsequent interviews suggest there is opportunity to develop resources that would support broader uptake of sustainably financed direct and enabling services for CMC that promote the goals of FCHHs, specifically in Medicaid programs.

3.3 Health Home Performance Measures for CMC

This final results section presents findings related to performance measurement of FCHHs for CMC. Results from the performance measure scan and qualitative discussions are presented first. This is followed by discussion of findings from the survey and interviews with the four states participating in the ESC CC SAG.

3.3.1 Scan Findings

The measure scan for performance measures potentially applicable to assessing the quality and effectiveness of FCHH for CMC in Medicaid programs garnered a total of 103 experiential and 39 administrative/clinical measures. These measures were mapped to the key domains of the FCHH definition outlined in the findings above: (1) comprehensive care; (2) patient/family-centered approach; (3) coordinated care, care integration, and transitions; (4) accessible and convenient services; (5) compassionate care; (6) quality and safety; and (7) care management and support infrastructure. 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. **Table 3.17** describes the distribution of experiential and administrative/clinical measures across these domains. It is important to note that some measures are relevant to assessing care in more than one health home domain. Notably, experiential measures were predominantly composite measures, tying together multiple survey items. It was not uncommon to find overlap among composite measures for the patient/family-centered care and compassionate care domains when teasing apart individual items. This also occurred for experiential measures in the comprehensive care, coordinated care, and care management domains. Measures were categorized based on the strongest conceptual alignment, but it is important to remember these categories of measurement may not always be mutually exclusive.

In our search for measures potentially applicable to FCHH for CMC in Medicaid programs, we were careful to include relevant measures from the Child Core Set, Health Home Core Set, CAHPS Health Plan Survey (with Chronic Conditions Supplemental item set), and HCBS CAHPS survey to ensure we were considering measures already in use by Medicaid. However, we broadened our search to include additional measures endorsed by or developed for CMS programs (e.g., Pediatric Quality Measures Program) and/or the CMC population to ensure we had an expansive view of measures available for use in Medicaid programs. It should be noted that measures not already in use by Medicaid programs may be subject to additional requirements and/or constraints prior to implementation, but we wanted to ensure a comprehensive view of available measures.

Table 3.17. 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 and are thus not included in the overall total.

In particular, to ensure consideration of measures specific to pediatric populations with complex care needs, we included assessment of FECC and PICS instruments in the scan. These instruments offer insights into the types of care experiences and processes that specifically address the needs of CMC. However, their more narrowly defined target population (FECC) and more granular level of focus on care processes may hinder their utility in the context of Medicaid performance measurement programs. These instruments may be best suited for use by providers in the context of clinical quality improvement.

Because of their ongoing use in Medicaid and CMS programs, we reviewed a number of CAHPS surveys. While the CAHPS HPS and CCS instruments were prioritized, we additionally included HCBS CAHPS for its relevance to coordination of community-based services—despite not having a child version—and CG CAHPS and HCAHPS, which have child versions but are not currently used in Medicaid programs. In the event that these surveys had additional measures of relevance to CMC served by FCHH, and fill gaps found in the HPS and CCS item sets, there may be more limited barriers to adoption than with other types of survey instruments.

While measures were found to correspond with all domains of the FCHH definition, these measures were not equally distributed, and many more experiential measures (n=103) were identified than administrative/clinical measures (n=39). Additionally, while a majority of the measures identified were specific to pediatric populations, most identified measures were not specific to the CMC population, leading to the need for program administrators to ensure the identified measures are fully relevant, actionable, and responsive for assessing the quality of care received by CMC in particular.

To support parsimony in measure sets, it may be preferred to identify measures of broad relevance either to pediatric populations, or to populations with complex needs. In these cases, stratification would become an important mechanism for leveraging quality measurement to assess quality of FCHH care for CMC. This underscores the need for standardized operational definitions for CMC in order to accurately stratify measure results in a way that is comparable across measurement periods and programs.

A discussion of measure scan results by FCHH domain is provided below. A complete listing of measures, complete with measure descriptions, is provided in **Appendix 7.4**.

Comprehensive Care Measures

As noted in the FCHH definition findings, comprehensive care comprises three main subdomains: (1) team-based care; (2) addressing all necessary medical care; and (3) addressing upstream drivers of health. There were 16 experiential measures identified for the comprehensive care domain, and seven (7) administrative/clinical measures.

The experiential measures for comprehensive care are all survey-based measures specific to pediatric populations. The surveys from which these measures are derived include the FECC instrument, the CG CAHPS Child instrument, PHDS-PLUS, and PICS. Of these instruments, only FECC was specifically developed for use with the CMC population.

Comprehensive care measures identified were not evenly distributed across subdomains, as described in **Table 3.18**. Most of the comprehensive care measures, both experiential and administrative/clinical, were related to assessing whether the child is receiving all needed care.

Table 3.18. Comprehensive Care Measures by Subdomain

Comprehensive Care Subdomain	Experiential Measures (N)	Administrative/ Clinical Measures (N)
Team-based Care	4	0
Addresses All Necessary Medical Care	12	5
Addresses Upstream Drivers of Health	0	2
Total Measures	**16**	**7**

Experiential Measures

Experiential comprehensive care measures mostly focused on measuring whether all necessary medical care was received (12 of 16 experiential measures). These measures assess concepts such as whether a caregiver feels the doctor understands the child and their health conditions, and pays appropriate attention to the child's development, safety, and the caregiver's concerns. Only one (1) of these 12 measures is currently used in Medicaid to assess pediatric care: a measure from the CAHPS CCS related to Parents' Experiences with the Child's Personal Doctor or Nurse. None of the experiential measures correlating with this factor are currently used by Medicaid for adult populations.

Four (4) of the 16 experiential comprehensive care measures assessed aspects of the patient's care plan to enable team-based care. Notably, these care plan focused measures were less likely to be endorsed; only one of these four measures was endorsed and none of these four measures are currently in use by Medicaid. There were no experiential measures related to addressing upstream drivers of health, though there is some conceptual overlap with care coordination measures from HCBS CAHPS (see below).

The CAHPS measures included as relevant to comprehensive care were identified in CG CAHPS, and related to the parents' experiences with providers, the providers' attention to the child's growth and development, and whether the provider gave advice on keeping the child safe and healthy. Leveraging existing CG CAHPS data collection related to patient experiences of comprehensive care would be important to allow Medicaid programs to assess comprehensive care in FCHH models. Additionally, regardless of CAHPS instrument, there are opportunities to strengthen CAHPS by adding measures related to team-based care or care that addresses upstream drivers of health.

Administrative/Clinical Measures

Administrative/clinical comprehensive care measures comprised measures related to addressing all necessary medical care (5 of 7 measures) and addressing upstream drivers of health(2 of 7 measures). Measures related to addressing all necessary medical care comprised concepts such as related to continuity of care and utilization of well-child, dental, and mental health services. The mental health utilization measure that was identified was not specific to pediatric populations. Three of the measures related to addressing all necessary medical care are (or were previously) included in the Medicaid and CHIP Child Core Set: Child and Adolescent Well-Care Visits, Well-Child Visits in the First 30 Months of Life, and Annual Dental Visits (retired measure). None of the measures related to addressing all necessary medical care are currently used by Medicaid for adult populations.

Two (2) measures were identified related to addressing upstream drivers of health. These measures assessed food security and housing stability for pediatric patients. Notably, these two measures were not endorsed and represent a gap in the Child Core Set.[82] There were no administrative/clinical measures identified that assess team-based care.

Patient/Family-Centered Care Measures

Patient/family-centered care comprises subdomains related to respect and dignity, information sharing, participation, and collaboration. There were 11 experiential measures identified for the patient/family-centered care domain, and two (2) administrative/clinical measures.

Measures identified were not distributed equally across subdomains of patient/family-centered care as described in **Table 3.19**. Five (5) measures were identified that assessed patient/family-centeredness on a more global or high-level.

Table 3.19. Patient/Family-Centered Care Measures by Subdomain

Patient-/Family-Centered Care Subdomain	Experiential Measures (N)	Administrative/ Clinical Measures (N)
Respect and Dignity	2	0
Information Sharing	0	0
Participation	4	1
Collaboration	1	0
Overall Patient/Family-Centeredness*	4	1
Total Measures	**11**	**2**

*Overall patient/family-centeredness measures assessed the patient- or family-centeredness of care at a high-level, not corresponding directly to one specific subdomain of patient-/ family-centered care.

Experiential Measures

The majority of experiential measures related to patient/family-centered care were associated with assessing patient and family participation in care (i.e., participation in shared decision-making, being engaged as an expert on the patient's preferences and well-being) or assessing patient/family-centeredness overall. Of these measures, one participation measure is currently included in the Medicaid Child Core Set: Parents' Experiences with Shared Decision-making (CAHPS CCS). Additionally, one measure related to participation was identified from the HCBS CAHPS that is utilized by Medicaid for adult populations: Choosing the Services That Matter to You.

There were two (2) measures related to respect and dignity, which were both sourced from HCBS CAHPS and related to whether the patient felt personally safe and treated with respect, and that care delivery included consideration of a patient's ability to do the activities most important to them. Notably, neither of these measures related to respect and dignity from HCBS CAHPS were specific to pediatric populations, but they are used by Medicaid for adult populations. There was one (1) measure identified in the FECC survey related to collaboration, which assessed whether caregivers were invited to participate in hospital rounds during their child's hospitalization. This measure, however, is not endorsed.

Experiential patient/family-centered care measures were drawn from surveys such as CAHPS CCS, HCBS CAHPS, and FECC. While CAHPS measures spanned subdomains related to participation and respect and dignity, there is a notable gap in terms of the ability to utilize CAHPS measures to assess patient/family-centered information sharing and collaboration. In fact, no measures were identified (either experiential or administrative/clinical) related to patient-centered information sharing. Although measures related to information sharing were identified as relevant to other FCHH domains, there is a general gap related to assessing patient/family-centered information sharing (i.e., information sharing in a way that empowers shared decision-making).

Administrative/Clinical Measures

Notably, there are no measures of patient/family-centeredness included in either the Child Core Set or the Health Home Core Set. The two administrative/clinical measures identified for this domain of the FCHH included the Patient Activation Measure and a measure assessing alignment of a person-centered service plan with the patient's functional needs. These measures offer insights into how administrative and clinical data may be used to assess patient/family-centeredness. At present, it appears this domain is best measured through patient surveys.

Coordinated Care, Care Integration, and Transitions Measures

Eighteen (18) experiential and four (4) administrative/clinical measures were identified as relevant to assessing the quality of coordinated care, care integration, and transitions in the FCHH model. Measures were identified across all subdomains of coordinated care, care integration, and transitions, but the measures were not evenly distributed across these subdomains. As described in **Table 3.20,** the majority (10 of 18) of experiential measures were related to the quality of care coordination, while the majority (3 of 4) of administrative/clinical measures were related to care integration.

Table 3.20. Coordinated Care, Care Integration, and Transitions Measures by Subdomain

Coordinated Care, Care Integration, and Transitions Subdomain	Experiential Measures (N)	Administrative/ Clinical Measures (N)
Coordinated Care	10	0
Care Integration	2	3
Transitions	6	1
Total Measures	**18**	**4**

Experiential Measures

Measures related to care coordination were the most commonly identified experiential measures for this domain of the FCHH. Half of these measures (5 of 10) were identified in FECC. As previously stated, FECC is an instrument well suited for quality improvement activities specific to care for CMC, but may face challenges related to adoption in Medicaid programs. Nevertheless, it is an informative benchmark for measurement concepts of particular salience to CMC. Items included in FECC related to care coordination covered specifics related to patient access to a care coordinator, frequency of contact with the care coordinator, and how the coordinator arranged referrals and coordinated community services. While these concepts are essential to properly assessing care coordination for CMC, their lack of generalizability to children without complex needs may limit their utility for performance measurement in the context of Medicaid programs.

Measures identified from CAHPS related to care coordination covered concepts such as how providers used information to coordinate care and parental experience with coordination of their child's care. One CAHPS measure identified for the coordinated care factor, Parents' Experiences with Coordination of Their Child's Care (CAHPS CCS), is currently included in the Medicaid Child Core Set. None of the coordinated care experiential measures are currently used by Medicaid for adult populations.

Six (6) experiential measures were identified related to transitions of care. Half of these measures (3 of 6) were identified in the HCAHPS Child Survey. These measures assess whether the patient and their family felt they were adequately prepared to leave the hospital setting post-discharge, including whether teens specifically were involved in their discharge preparedness care, and communication about medications in anticipation of leaving the hospital. CMC may transition between many types of care settings, providers, or health states that do not require transitions from hospital care specifically. There is a lack of CAHPS measures that may be leveraged to assess transition between non-hospital settings. Two measures were identified as relevant to assessing transitions from child to adult health care services, including the Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Health Care, suggesting a gap in this area for off-the-shelf measures amenable to use by Medicaid programs. No experiential measures aligned with the transitions subdomain that are currently in use by Medicaid (for adult or pediatric populations) were identified in this scan.

Only two (2) experiential measures were identified that specifically address concepts specific to care integration. These measures assessed integrated care team functioning and quality, and how well health care providers communicated with school staff about the educational impacts of the child's condition. There is a gap related to measures suitable for Medicaid uptake that specifically assess experiences with integrated care (as distinct from experiences with coordinated care). No experiential measures specific to care integration that are currently in use by Medicaid (for adult or pediatric populations) were identified in this scan.

Administrative/Clinical Measures

Three (3) of the four (4) administrative/clinical measures identified for this domain focused on assessing integrated care. Specifically, these measures are related to follow-up and referral tracking, leveraging EHR and medical record data to assess how often timely referrals for follow-up appointments are made, and how often the referral loop is closed (i.e., did the referring clinician receive a report from the clinician to whom the patient was referred). One measure was identified related to transferring health information to post-acute care providers upon transition from an inpatient facility. While these measures align with key concepts for assessing FCHH care, there are no similar measures included in the Child Core Set. There is an overall notable gap related to administrative/clinical measures currently used by Medicaid to assess coordinated care among pediatric populations, and there appears to be gaps in the availability of endorsed measures that could be readily adapted.

Accessible and Convenient Services Measures

Accessible and convenient services comprise five key subdomains related to access to care: (1) affordability, (2) availability, (3) accessibility, (4) accommodation, and (5) acceptability. Nine (9) experiential and two (2) administrative/ clinical measures were identified for the accessible and convenient services domain of the FCHH model. As described in **Table 3.21**, the experiential measures identified were related to access and convenient services were related to the availability and accessibility of services, while the two administrative/clinical measures identified were related to service availability. There are meaningful gaps in the measurement landscape (both experiential and administrative/clinical) related to assessing affordability, accommodation, or acceptability of services.

Table 3.21. Accessible and Convenient Services Measures by Subdomain

Accessible & Convenient Services Subdomain	Experiential Measures (N)	Administrative/ Clinical Measures (N)
Affordability	0	0
Availability	5	2
Accessibility	4	0
Accommodation	0	0
Acceptability	0	0
Total Measures	**9**	**2**

Experiential Measures

Seven (7) of the nine (9) experiential measures identified were pulled from CAHPS instruments, including CAHPS CCS, CG CAHPS, HCBS CAHPS, and CAHPS HPS. The instruments leveraged by Medicaid cover both accessible care (HCBS CAHPS and CAHPS HPS) and available care (CAHPS CCS and CAHPS HPS).

Experiential measures related to available services (5 of 9 measures) assessed the patient and family's ability to receive the care, medications, referrals, and information that they needed. Four (4) of these five (5) measures are included in the Medicaid Child Core Set: Parents' Experiences with Getting Needed Information about Their Child's Care (CAHPS CCS), Parents' Experiences Getting Specialized Services for Their Child (CAHPS CCS), Parents' Experiences with Prescription Medications (CAHPS CCS), and Getting Needed Care (CAHPS HPS). No measures aligned with this subdomain are utilized by Medicaid for adult populations.

Experiential measures related to accessible services (4 of 9 measures) covered concepts such as getting timely care (i.e., getting care "as soon as needed") as well as transportation to medical appointments. Even within the subdomains of accessible and convenient services for which measures were identified, the measures assess access and availability related to primary/specialist care or urgent/non-urgent care. There is a meaningful gap in the measurement landscape related to measures that assess access to other services important to CMC, such as DME or LTSS. One (1) of the measures identified for this subdomain is included in the Medicaid Child Core Set: Getting Care Quickly (CAHPS HPS). A second measure identified in this subdomain is used by Medicaid for adult populations: Transportation to Medical Appointments (HCBS CAHPS).

Administrative/Clinical Measures

Both administrative/clinical measures identified were pertinent to the availability of services for children: access to outpatient specialty care, and access to primary care practitioners. Notably, neither of these measures are endorsed. There is room for improvement in terms of utilizing administrative/clinical data to assess all aspects of accessible and convenient services. This domain also represents a notable gap in the Child Core Set and Health Home Core Set.

Compassionate Care Measures

Compassionate care comprises five subdomains: contextual awareness and responsiveness, culturally and linguistically appropriate services (CLAS), provider trust, compassionate communication, and health literacy. Twenty (20) experiential and no administrative/clinical measures were identified for the compassionate care domain of the FCHH definition. As described in **Table 3.22**, a large majority (16 of 20) of experiential measures were related to compassionate communication.

Table 3.22. Compassionate Care Measures by Subdomain

Compassionate Care Subdomain	Experiential Measures (N)	Administrative/ Clinical Measures (N)
Contextual Awareness and Responsiveness	0	0
Culturally & Linguistically Appropriate Services	1	0
Provider Trust	2	0
Compassionate Communication	16	0
Health Literacy	1	0
Total Measures	**20**	**0**

Experiential Measures

Sixteen (16) total experiential measures were identified that align with the compassionate communication subdomain of compassionate care. These measures assess a wide range of concepts such as how well providers communicate with patients, how helpful and reliable staff are, whether patients and families feel that their provider listens to them and that they had privacy, and whether parents feel supported in their ability to care for their child via their communication with providers. Measures related to compassionate communication were identified in CG CAHPS, HCBS CAHPS, HCAHPS, FECC, PHDS-PLUS, and PICS. There is a gap in understanding related to which of these aspects of compassionate communication may be most important to measure for the CMC population. One identified measure related to compassionate communication is included in the Medicaid Child Core Set: How Well Doctors Communicate (CAHPS HPS). Three additional identified compassionate communication measures from the HCBS CAHPS are used by Medicaid to assess adult populations: Case Manager is Helpful, Staff are Reliable and Helpful, and Staff Listen and Communicate Well.

Two (2) experiential measures were identified that assessed provider trust. Both measures were from CG CAHPS (not currently utilized by Medicaid) and were not specific to pediatric populations. There may be opportunity for Medicaid programs to utilize the CG CAHPS items (and stratification) to fill current knowledge gaps related to provider trust.

Two (2) measures from the FECC survey were identified as related to health literacy and CLAS. These measures assessed whether written visit summaries were useful and easy for caregivers and patients to understand, and whether a caregiver has access to a medical interpreter when needed, respectively. Importantly, the measure related to the written visit summary is not endorsed. As previously discussed, FECC may encounter barriers to uptake in Medicaid programs due to its narrow target population, rendering it potentially more valuable as an instrument for quality improvement activities in the clinical setting. This scan revealed an important gap in measures related to health literacy and CLAS that are suitable for use in Medicaid performance measurement contexts. No measures used by Medicaid programs were identified that were relevant to health literacy or CLAS.

Administrative/Clinical Measures

There is a notable lack of measures (experiential and administrative/clinical) relevant to assessing contextual awareness and responsiveness . Additionally, the scan revealed a significant gap in availability of administrative/clinical measures for assessing compassionate care. This gap may reflect broader challenges in measurability through means beyond patient experience.

Quality and Safety Measures

For the purposes of defining FCHH, the quality and safety domain includes two key subdomains: continuous quality improvement (CQI) and avoidance of harm and prevention of error. Five (5) experiential and 23 administrative/clinical measures were identified as relevant to assessing quality and safety in FCHH. While measures were identified in alignment with both subdomains, the measures were not equally distributed. As described in **Table 3.23**, a large majority (26 of 28) of both experiential and administrative/clinical measures were related to continuous quality improvement.

Table 3.23. Quality and Safety Measures by Subdomain

Quality & Safety Subdomain	Experiential Measures (N)	Administrative/ Clinical Measures (N)
Continuous Quality Improvement	3	23
Avoidance of Harm & Prevention of Error	2	0
Total Measures	**5**	**23**

Experiential Measures

Comparatively few (5) experiential measures were identified for the quality and safety domain. The majority (3 of 5) of these measures related to CQI. In the context of FCHH domains, CQI relates to aligning care with best quality practices and clinical guidelines for care. The three experiential measures identified under this subdomain related to minimizing patients' unmet need, and provider responsiveness/attention to the call button and a child's pain. One of these measures, the Unmet Need Measure (HCBS CAHPS) is used by Medicaid to assess adult populations.

Two (2) measures were identified as relevant to avoidance of harm and prevention of error. This includes the Physical Safety Measure (HCBS CAHPS) that also is used by Medicaid for adult populations. A second measure related to preventing mistakes and helping patients report concerns was also identified, however, this measure is not currently used by Medicaid for pediatric or adult populations.

Pediatric experiential measures identified for this domain were sourced from the HCAHPS Child Survey (Preventing Mistakes, Responsiveness to Call Button, Paying Attention to the Child's Pain). There are opportunities to strengthen the ability to leverage CAHPS to assess concepts related to quality and safety, particularly for children. While HCBS CAHPS is utilized by Medicaid, the questions related to physical safety and unmet need are not specific to pediatric populations and would require adaptation. Medicaid does not currently utilize the HCAHPS Child Survey, but the questions related to preventing mistakes, responsiveness to the call button, and paying attention to the child's pain present opportunity for Medicaid to better utilize the CAHPS data collection mechanism to assess CQI and error prevention. There are currently no experiential measures related to quality and safety in the Medicaid Child Core Set.

Administrative/Clinical Measures

All 23 administrative/clinical measures identified as relevant to quality and safety aligned with the CQI subdomain. In particular, these measures assessed various dimensions of quality pediatric care in alignment with clinical guidelines. These included a majority of measures (18 total) from the Child Core Set related to primary and preventive care, care of acute and chronic conditions, behavioral health care, and dental and oral health services. One identified measure had previously been included in the Medicaid Child Core Set but has since been retired – Ambulatory Care: Emergency Department Visits.

All 23 administrative/clinical measures for this domain were specific to pediatric populations and 20 of the 23 measures were endorsed. This scan revealed there is a meaningful set of administrative/clinical measures that are relevant and useful for assessing core indicators of quality for pediatric populations. However, additional consideration is needed to determine if gaps specifically pertaining to CMC remain. Additionally, the scan also revealed a gap related to how administrative/clinical data may be utilized to assess avoidance of harm and prevention of error for CMC.

Care Management and Support Infrastructure Measures

The care management and support infrastructure domain of a FCHH comprises five subdomains: information management, community referral network, technological infrastructure, care plans, and physical infrastructure. Nineteen (19) experiential and one (1) administrative/clinical measure were identified as relevant to assessing care management and support infrastructure during the measure scan. While measures were identified in alignment with all five subdomains, the measures were not equally distributed (**Table 3.24**).

Table 3.24. Care Management and Support Infrastructure Measures by Subdomain

Care Management & Support Infrastructure Subdomain	Experiential Measures (N)	Administrative/ Clinical Measures (N)
Information Management	8	0
Community Referral Network	1	0
Technological Infrastructure	4	0
Care Plans	4*	1
Physical Infrastructure	2	0
Total Measures	**19**	**1**

*These four measures are cross-listed with comprehensive care.

Experiential Measures

Of the experiential measures identified as relevant to care management and support infrastructure, the majority (8 of 19) were oriented to assessing information management. These measures assessed access to and aspects of the EHR, whether written visit summary content was appropriate, whether the provider kept the family informed about the child's care, and whether the patient/family were provided with appropriate and helpful information. These measures were sourced from the FECC survey, the HCAHPS Child Survey, and PHDS-PLUS—only PHDS-PLUS is in use by select Medicaid programs. The FECC items related to appropriate visit summary content and access to/aspects of the patient EHR, while specific to CMC populations, are generally not endorsed and may not lend themselves to broad uptake in Medicaid programs due to narrowly defined target population. The items from the HCAHPS Child Survey related to keeping parents informed about their child's care, and the items from PHDS-PLUS related to whether helpful health information was provided, are both specific to pediatric populations and endorsed. These measures highlight opportunities to leverage existing instruments to fill the identified gap related to information management in current Medicaid data collection mechanisms.

Four (4) experiential measures from CG CAHPS were identified as relevant to technological infrastructure. These measures assess the helpfulness of the provider's use of computers, and the functionality of a provider's website/email services to receive timely answers to medical questions, access health-related information, and schedule appointments. While all four measures are endorsed, they are not specific to pediatric populations. Although CG CAHPS is not currently used by Medicaid, these four measures present an opportunity to fill gaps related to assessing technological infrastructure for FCHH care.

Four (4) experiential measures were cross-listed with the comprehensive care domain. These measures focused on the patient's care plan, which also facilitates team-based care. As described above, only one of the four measures is endorsed, and none are currently in use by Medicaid, which reflects a significant gap given the significance of shared care plans in the management of CMC.

Additionally, two (2) experiential measures were identified for the physical infrastructure subdomain. Both measures related to personnel; assessing whether office staff and customer service are helpful and respectful. These measures were identified in CG CAHPS (Helpful, Courteous, and Respectful Office Staff) and CAHPS HPS (Health Plan Customer Service). Of these measures, the measure related to health plan customer service is included in the Medicaid Child Core Set. These findings highlight a gap in experiential measures related to non-personnel aspects of physical infrastructure such as cleanliness or physical accessibility.

One (1) experiential measure was identified related to community referral networks: a PHDS-PLUS measure related to the provision of information about resources in the community for parents. This measure is both specific to pediatric populations and endorsed. There were no measures identified related to community referral networks that are in wide use by Medicaid.

Administrative/Clinical Measures

One (1) administrative/clinical measure was identified related to care plans (which includes medication management): a drug regimen review conducted with follow-up for identified issues. While this measure is endorsed, it is not specific to pediatric populations. The scan revealed gaps in the ability to use administrative/clinical data to assess care management and support infrastructure for FCHH. There are no administrative/clinical measures related to care management and support infrastructure included in the Medicaid Child Core Set or Health Home Core Set.

General Medical Home Measures

The general health home measures identified spanned nine (9) composite and global ratings experiential measures assessing the patient/family's perception of the quality of their providers, health care, interpretation services, and health plan. These measures were primarily found in CAHPS instruments, including CG CAHPS, HCBS CAHPS, CAHPS HPS, and HCAHPS Child Survey. These measures were typically endorsed (8 of 9 measures) and specific to pediatric populations (8 of 9 measures). Four (4) identified general health home measures are included in the Medicaid Child Core Set: Patient's Rating of All Health Care, Patient's Rating of the Personal Doctor, Patient's Rating of the Specialist, and Patient's Rating of the Health Plan. One (1) additional Global Ratings Measure was identified in the HCBS CAHPS that is used for Medicaid adult populations.

Global ratings measures may be useful for performance measurement, but often are too high-level to be actionable. When discussing how quality should be measured in health homes, one KI noted that general/global ratings measures can be particularly helpful in assessing quality of care for CMC since the care and service needs, conditions, and preferences of the population can vary so widely.

3.3.2 State Findings

Our survey of 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 (**Table 3.25**). This initial data collection highlights the complementary nature of measurement activity between Medicaid and Title V. It also reveals meaningful gaps in performance measurement of Medicaid programs that would accurately characterize quality of care and surface areas of needed improvement specifically for CMC.

In general, Title V is the program most focused on assessing national performance and outcome measures, including the proportion of CSHCN who have a medical/health home, whereas Medicaid captures administrative data related to access to services and utilization (in the form of metrics examining topics such as hours of services provided, beneficiary caseload and staffing, etc.). Additionally, survey responses indicate Title V is in a position to examine gaps in care for key subpopulations, for example by various demographics, which is comparatively much more challenging

Table 3.25. Care Coordination/Integration Measurement and Monitoring by State

	AK		MI		TX		WA*	
Monitoring Approach	**Medicaid**	**Title V**	**Medicaid**	**Title V**	**Medicaid**	**Title V***	**Medicaid**	**Title V**
Patient/family experience surveys	X		X	X	X	X	X	
National performance (% CSHCN who have a medical home) &/or outcome measures		X		X		X		X
Locally developed process measures				X		X	X	
Cost avoidance analysis				X				
Access to services (e.g., HCBS authorized hours compared to hours provided; utilization review)			X		X		X	
Monthly report submitted by provider/MCO			X		X			
Subpopulation analysis		X		X		X		

CSHCN: children with special healthcare needs; HCBS: home and community-based services; MCO: managed care organization

*Where no standard CMC definition exists, agencies were asked to use disability (SSI) as a proxy.

**Policy currently undergoing implementation planning; MI did not provide a survey response for this item, so answers were extracted from their *Notice of Proposed Policy*.[83]

for Medicaid. Indeed, we see from this analysis that none of the state Medicaid programs surveyed perform subpopulation analyses during their monitoring of services for CMC, whereas all state Title V programs do.

Where there was limited variation in some of the key data captured by Title V, likely in part due to the use of national survey data, there was some variation in the use of locally developed process measures, which are in use in MI and TX, but not AK or WA. Additionally, MI was the only state where Title V reported conducting cost avoidance analyses. Variability in Medicaid programs emerged in the use of access and utilization analyses, which were not used by AK. Additionally, only MI and TX indicated the use of monthly reporting. In MI, the targeted case management program being launched is a fee-for-service program, so the monthly reporting is submitted by providers. In TX, these monthly reports are submitted to Medicaid by MCOs.

The complementarity of data collection suggests there could be benefit to greater data sharing across programs to support improvement. However, Title V data, such as those sourced from the NSCH, can be challenging to link to specific providers to support quality improvement. Additionally, both programs are challenged to disaggregate data that are rarely specific to CMC. Screener questions available in national surveys like NSCH may or may not align with how Medicaid programs define CMC, and Medicaid programs may or may not have stratification schema available to consistently assess CMC care quality, utilization, and outcomes.

All Medicaid programs and two Title V programs (MI and TX) reported collection of patient experience data. Patient experience data are critical for the assessment of health homes and are foundational for the Title V medical/health home access performance measure. In Medicaid, this is captured primarily through the use of CAHPS surveys. The Child Core Set includes CAHPS HPS and allows for the supplemental set of questions regarding the care experience of children with chronic conditions.[82] It is notable that use of CAHPS in Medicaid is currently optional but required for the Children's Health Insurance Program (CHIP) (§ 2108(e)(4) of the Social Security Act), which may impact data completeness. Medicaid programs also administer CAHPS surveys related to HCBS, which may be of value in the context of CMC.

Between CAHPS HPS and CCS, nearly all domains of the FCHH definition are captured. The exceptions are (1) Quality & Safety and (2) Care Management & Support Infrastructure. While Quality & Safety could be addressed through complementary administrative/clinical measures, surveys such as FECC and PICS highlight the importance of assessing care management for the CMC population. Additionally, the CAHPS surveys address shared decision-making generally, but they do not assess the creation of care plans and consideration of progress toward goals, two areas of importance as identified by KIIs as well as state representatives.

While patient experience measure gaps are meaningful for CAHPS surveys in use by Medicaid, they are relatively modest, and example questions exist on other validated instruments to inform compensatory data collection, if needed or desired. The more pressing challenges for Medicaid programs and their use of CAHPS surveys are feasibility-related, with states citing poor response rates, slow speed of delivering survey results, cost of administration, and questionnaire length in particular. For an already small patient population, poor response rates create difficulties for use of subsequent measures in the context of monitoring and performance improvement.

The slow speed of delivering results compounds these challenges by resulting in data that are not timely enough to inform quality improvement. States are identifying pathways around this, for example by requiring providers to conduct annual family interviews as is the case in MI, but gaps remain in Medicaid program monitoring of patient experience.

Finally, state Medicaid programs did not discuss the use of the Child Core Set or other administrative/clinical measures to assess the quality of direct or enabling care coordination/integration services for CMC. As noted in the section above, Child Core Set measures are largely focused on the Comprehensive Care and Quality & Safety domains of the FCHH definition. There are currently meaningful gaps in the availability of administrative/clinical measures to assess other domains of the definition that could be used "off the shelf" (endorsed) in pediatric contexts; however, measures have been developed and could be explored for adaptation.

Collectively, our survey and follow-up interviews 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.

5. 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. This work surfaced a number of key considerations and gaps in knowledge and/or consensus that must be addressed to better support Medicaid's role in improving systems for CMC. These considerations are provided in the sections below. Our findings outlined above combined with these considerations lay the foundation for future work to capture real-world examples of Medicaid activities to enhance systems of care for CMC and develop a toolkit of resources for states looking to bolster their current efforts.

5.1 Identifying Eligible CMC

Creating a comprehensive, universal definition of CMC remains a top priority as we seek to create effective policies and care systems for the population that address differences in access and outcomes, including by geography. The use of diagnosis codes to identify CMC via administrative data is an established approach in research. However, relying solely on diagnosis codes risks including children with complex diseases who are largely asymptomatic (e.g., stable children with cystic fibrosis), while excluding children with conditions that have high functional needs that are not inherent in a coded diagnosis. Children who have difficulty accessing needed care—thus not generating claims—could be excluded if service utilization is too highly weighted in a CMC definition.[6] As a result, other algorithmic approaches have been taken, such as the example of the Massachusetts Health Policy Commission, which used an algorithm focused on ambulatory, inpatient, and pharmacy utilization and spending.[84]

Our work examining definitions for CMC revealed coalescence around these four domains: chronic conditions, functional limitations, care needs, and health care use. While elements related to chronic condition diagnoses, care utilization and/or spending, and functional supports such as the use of DME may lend themselves to objective criteria and algorithms based on administrative data, our analysis surfaced several aspects that are challenging to operationalize in policy. In particular, characterizing care needs in terms of the impact on the family unit emerged as especially salient among the KIIs and focus group participants and is likely to be information that is inaccessible to standardized algorithms.

Of the criteria domains of functional limitations, care needs, and health care use; KII participants identified overlap in these domains. Concern was raised about the use of health care utilization or unmet health care needs because they could represent the interaction of the family and the service system more than the inherent needs of the child and family. Functional limitations (from which care needs and utilization are derived) were most consistently identified as the more reliable domain after condition diagnoses.

Lived and learned experts also raised concerns about the overmedicalization of CMC. They also identified social complexity as a major challenge for supporting families and providing comprehensive care. Although not part of the classic definition of CMC, experts felt strongly that social needs needed to be considered in policy development starting with inclusion in the definition of CMC.

Review of state activities indicate the ***use of multifaceted approaches that combine administrative data (e.g., eligibility for SSI, specialized waivers) with provider attestation***—whether via personal referral or standardized screening assessment. 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). Such flexibility would allow for adaptation to changes in healthcare practices or new treatment modalities. These approaches also infuse the potential for wider variability and heterogeneity in case identification from state to state based on demographic factors (e.g., access to services, social risks). However, this potential heterogeneity underscores the need for quality assurance procedures and mechanisms to ensure children with complex needs are not missed and that the quality of their care (and access to care) is adequately measured.

5.2 Making the Case for Tiering the Health Home

Person- and family-centered care remains of the upmost importance when identifying what a successful health home model looks like for CMC, and this was continually elevated by our family focus group and KIs with lived experience. The uniqueness of each child's medical and social context requires that systems be adaptable and responsive to these complexities. This includes the recognition that caregivers of CMC need robust support, as their wellbeing is tied to the health and outcomes of the CMC. A good, successful health home for CMC involves addressing the needs of both the child and the caregiver, providing family-centered support and care.

A recurring theme was tied to the challenge of using strict cutoffs for the CMC definition (e.g., involvement of 3 or more organ systems) in the context of providing FCHH. The use of fixed, precise thresholds does not align with the ways CMC needs can fluctuate over time. Rigid cutoffs can cause children to enter a cycle of losing and regaining benefits, leading to gaps in care independent of enhanced service comprehensiveness. All of this fluctuation leads to increased administrative burden in terms of confirming eligibility as well as increased family stress, where the family will be in the position of making up for the gaps that must be filled as care needs fluctuate.

By ***moving away from rigid eligibility cutoffs and adopting more flexible and patient-centered approaches***, healthcare policies could improve access to care, reduce inconsistences in health care delivery, and enhance overall health outcomes. Tiered approaches, which categorize patients based on their level of complexity and resource needs, are increasingly used in the context of behavioral health complexity to allocate resources more effectively and provide targeted care. In their State Health Official letter from September 26, 2024, the Center for Medicaid and CHIP Services (CMCS) released their guidance, *Best Practices for Adhering to Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Requirements*.[85]Diagnostic, and Treatment (EPSDT In their description of EPSDT care coordination and case management best practices, they highlighted the use of tiered approaches to support children with moderate and intensive care needs. Additionally, a recent scan of intensive care coordination programs for children and youth with complex mental and substance use disorders conducted by the Substance Abuse and Mental Health Services Administration (SAMHSA) identified several states with mature implementation of tiered approaches, including MA, NJ, OK and TX.[86] Some tiered models in the behavioral health space build in consideration of social need, which participants of our focus group and KIs suggested would be important for CMC as well.

Additionally, the Guiding an Improved Dementia Experience (GUIDE) Model recently launched by the Center for Medicare and Medicaid Innovation (Innovation Center), offers a comprehensive package of care coordination and care management, caregiver education and support, and respite services. Notably, GUIDE beneficiaries are assigned to one of five tiers, based on (1) their disease stage, (2) whether they have a caregiver, and (3) the degree of burden their caregiver is experiencing, if applicable. Though outside of the Medicaid pediatric context, this serves as another useful example of structuring care with the goals of enhancing QoL for patients, reducing strain on their caregivers, and enabling patients to remain in their homes and communities. It is noteworthy in its attention to caregiver strain as an independent factor in risk tiering, a feature that is consistent with needs expressed by participants of our focus group and KIs.

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. Creating supported community-based, less intensive interventions would be an effective mechanism for this transition.

Taken together, these Medicaid behavioral health and Innovation Center dementia models may provide insights into how these approaches could be adopted in the context of CMC to offer more tailored care, efficient resource allocation, predictable costs, and improved outcomes.

5.3 Measuring the CMC Health Home

Overall, our findings in the review of quality measures available for use in Medicaid programs highlight the challenging heterogeneity of this population, and the conceptual overlap on select specific topics reflects the nuance often needed when moving between site-based measurement for quality improvement and payer-based measurement for surveillance and accountability. Realizing the promise of measurement as a vehicle for collecting data that may be used to inform decision-making, drive improvement, and deliver better care is about knowing what should be measured, and by whom. This stems from a clear understanding of the roles and spheres of influence at each level within the health system (i.e. provider, managed care, and state). Measures should not be the same at each level but rather fit-to-purpose (performance vs. quality improvement) and aligned with the sphere of influence, authority, and capacity to drive change of that health system level. Insights from our scan are intended to inform measurement in the context of state Medicaid programs and MCOs in their work to assess resource allocation needs, monitor programs, and drive improvement through provider accountability. Our analysis raises three significant points discussed below. These relate to: operationalizing measures of patient experience, addressing gaps in administrative and clinical measures of FCHH quality, and considerations for measuring QoL as a key outcome.

Measuring Patient Experience. Measurement of patient experience serves as a vital barometer of the quality of care delivered, and it is of particular salience to CMC and their families who spend so much of their time engaging with health care systems. Indeed, all four of the states surveyed as part of this scan noted using patient and family experience surveys in their assessment of programs serving CMC. Our scan surfaced a number of measures drawn from FECC, PICS, PHDS-PLUS, and the CAHPS suite of surveys. Endorsed measures were identified for the CAHPS, FECC, and PHDS-PLUS surveys, with precedent for use in Medicaid programs identified for CAHPS and PHDS-PLUS.[93,94] No single survey covered all of the domains for FCHH, however, pulling from multiple CAHPS surveys would offer broad coverage across many domains and benefit from the Children with Chronic Conditions Supplement, making it more suited for the CMC population. There are clear benefits to using surveys already in use by Medicaid programs, however, challenges remain to be addressed to ensure their administration is able to drive performance.

Measuring patient experience currently suffers from a number of challenges, chief among them are the low and declining response rates due to factors such as survey length and the fact that they are mostly paper-based and conducted by mail or telephone.[95] Notably, response rates are below 20 percent for Medicaid. Moreover, results are based on a random patient sample, which provides insights about typical health plan members but is poorly suited to identifying the concerns of specific patient groups, such as CMC.[95] Small, highly burdened populations like CMC suffer from the intersection of these problems. A random sample of a small population combined with a low response rate produces very little data offering limited insights into the true landscape of experience and where improvements are needed most. Annual meetings between care coordinators and family members may provide opportunities to collect data for measures requiring caregiver report. It may be worth exploring whether capitalizing on these types of existing touchpoints and encounters may increase response rates for surveys querying patient/family experience.

To best align with existing Medicaid infrastructure and optimally serve CMC and their families, ***CAHPS surveys would benefit from administration via digital tools that are already widely available and in use***. 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 removal of random samples for population measurement. Additionally, rapid online experience ratings are the norm in many industries today. When applied to measuring patient experience, these same tools have the potential to increase the availability of timely feedback.

Across CAHPS surveys, there was collective conceptual overlap with many of the domains covered by FECC and PICS, two surveys designed specifically for quality improvement targeting children with complex needs. While FECC and PICS are more granular, and thus well-suited to site-based quality improvement implementation, there is reasonable conceptual mapping with much of the content in CAHPS. Important gaps in CAHPS that may need to be addressed for CMC and their families include ***specific attention to the creation and accessibility of care plans as well as perceived progress on patient and family goals***. A key challenge in finalizing surveys for this population may stem from identifying the necessary and sufficient set of CAHPS measures that keeps survey length manageable while still covering all key areas. Deeper review of survey content with family input would be important to ensure surveys are parsimonious while including core elements of priority to families that also provide actionable feedback to providers. Achieving this will entail improving the surveys so they focus on: aspects of care for which the patient/family is the best or only source of information; care patients/families have themselves experienced or observed; and explicit reference to time, event, and provider.

Gaps in Administrative and Clinical Measures. Administrative and clinical measures are measures gathered from sources such as claims, enrollment, managed care quality reporting or sources from clinical systems such as EHRs, paper medical records, standardized assessments. These types of data sources are not without challenges, since their primary purpose is either program administration, billing, or clinical care—rather than quality improvement. Gaps in these types of measures should be considered along two domains. First, measures that look at the quality of care or access to care for the specific population of CMC; and second, stratification of measures by CYSHCN/CMC status to highlight gaps in care for this population.

Our scan focused on non-condition specific indicators, owing to the breadth of conditions potentially involved in medical complexity and in recognition of their unique clinical processes and outcomes. This resulted in the identification of 39 administrative/clinical measures, spanning most domains. There were a number of measures particularly speaking to comprehensive care and care coordination (e.g., well child visits), as well as quality of care (e.g., developmental screenings). However, key domains like access to care had few measures. ***There remain gaps in our ability to assess upstream drivers of health and access to key services for CMC such as access to subspecialty care, access to mental health care, DME, and LTSS for children.*** The development of age-appropriate measures will be important on topics like this in the context of children with complex needs, where needs can change rapidly and measures should be developed to account for these factors. The recent CMCS State Health Official letter including EPSDT guidance (referenced above) outlines Medicaid requirements for states and state oversight of managed care organizations to monitor all aspects of access to services that are medically necessary.[96] Specific aspects such as managed care denials, appeals, and fair hearing results are required and may be specific for some services to CMC (e.g., LTSS, HCBS). By filling these and other gaps, policymakers and health care providers can gain a more comprehensive understanding of care access needs for CMC and implement targeted interventions to improve outcomes.

Secondly, additional considerations for administrative/clinical measures will include the ability to stratify the results by specific subpopulations. As showcased by the recent rollout of the Universal Foundation of quality measures for adult and pediatric populations, CMS is moving toward stronger parsimony and measure alignment across programs.[87] This work aims to focus provider attention, reduce burden, identify gaps in care, prioritize development of interoperable, digital quality measures, allow for cross-comparisons across programs, and help identify measurement gaps.[87] In this spirit, there is likely to be greater attention to adoption of measures that promote cross-program alignment rather than proliferation of subpopulation-specific measures. However, CMS is increasingly requiring that measures (including all new measures) have been tested and stratified by various subpopulations to identify and address differences in care.

Taken together with the recommendation above related to adoption of care models that allow for service adaptation based on risk tiers, it will become important to ***develop measure stratification schema that enable 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 will entail alignment of stratification schema with the CMC population definition noted above.

Quality of Life. Our scan intentionally did not explore measurement of QoL. This work is currently being led by the HRSA-funded CYSHCNet Research Network. However, conversations with lived and learned experts related to measurement repeatedly surfaced the ***need to incorporate measures of QoL and wellbeing into surveillance and quality improvement initiatives***. It is apparent that QoL and wellbeing for both the family and child are outcomes that matter most, but operationalizing these outcomes remains a significant challenge, particularly in the context of Medicaid and MCO measurement. The traditional way of assessing change in patients has been to focus on laboratory or clinical tests. While these give important information about a disease, it is impossible to separate disease from an individual's personal and social context. The underlying reason for using QoL and wellbeing measures in clinical practice is to ensure that treatment plans and evaluations focus on the patient rather than the disease. At present, use of these types of measures is not well-incorporated into the care for CMC or the performance monitoring conducted by Medicaid.

The primary barriers to the routine clinical use (and, relatedly, performance assessment) of QoL and wellbeing include concerns about cost, feasibility, and clinical relevance.[88] For a measure to be clinically actionable, it must not only be valid, reliable, and responsive, it must also be simple, quick to complete, easy to score, and provide useful clinical data.[89]

Current measures of QoL in pediatric patients were developed for use in clinical research where time and budgetary constraints are different from those in clinical practice. These instruments can be time-consuming to complete and do not always focus on topics that can be readily influenced by providers. Moreover, there are concerns that existing measures of pediatric QoL are inappropriate for CMC, as they often relying on preconceived assumptions about ability and health that do not fully capture the needs of this population. Many QoL measures heavily focus on physical abilities, overlooking other essential aspects of life such as social participation, emotional wellbeing, and cognitive function. This can underestimate the QoL for individuals with disabilities. Additional concerns have been raised related to the fact that QoL measures may not adequately account for the impact of upstream drivers of health, which can significantly affect the QoL for individuals with disabilities. Addressing these questions and identifying new methods for assessing QoL among children with complex needs continues to be an area of intense focus for CYSHCNet.

Apart from the need for improved instruments to measure QoL, the challenges in adopting QoL assessments in the context of Medicaid and MCOs would similarly wrestle with a number of the factors described above for patient experience measures. Quality of life and wellbeing would need to be assessed via patient-reported mechanisms, such as surveys. Survey-based approaches often yield insufficient data due to low response rates, underscoring the need for more effective ways to capture the outcomes of most importance to CMC and their families. Here, similar recommendations as above would apply, particularly as it relates to the incorporation of digital tools for implementation.

Finally, there remain questions about the ability to hold providers accountable for changes in QoL and wellbeing measures. These outcomes are often influenced by a host of factors, some more or less amenable to provider intervention, hence accountability is diffuse.[97] Measures are relevant for surveillance and cross state / community evaluation and to support discussion on addressing the multifactorial inputs into care and support.

At the same time, assessment of QoL and wellbeing can be used in clinical practice to screen for potential problems, prioritize problems, facilitate communication, identify preferences, monitor changes or response to treatment, among other tasks.[89] Additionally, there are ways providers can meaningfully influence these outcomes, particularly as they relate to measures symptoms, functional status, social interaction and support, and psychological wellbeing.[98] ***As an initial step, Medicaid and 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, including incentivizing infrastructure investment for providers and/or MCOs to collect the data, promotion of a quality improvement focus by ensuring the data are readily available to providers, and make data potentially available for site reporting—improving transparency for patients and their families. This opens the door for Medicaid programs to build-in future reporting of QoL maintenance and improvement measures as part of CMC program monitoring and performance improvement activities.

5.4 Operationalizing Financial Structures in State Medicaid Programs

To implement the services needed for CMC in states certain specific aspects of policy must be developed and this policy must be implemented effectively. These efforts often proceed state by state, but states mirror each other's efforts. Acceleration of these policies and implementations could occur because of the imperative for care coordination to states laid out in the CMCS State Health Official letter on EPSDT.[99] Our discussions with state representatives indicate that a sequence of steps may be necessary for implementation. ***The sequence of steps include 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.***

The services defined in the FCHH definition section of this environmental scan require significant resources to provide. These resources clearly include the team of providers and support personnel directly facing CMC and their families, and also must account for staff recruitment, training, retention, management support, physical space, and infrastructure for provider-based billing and coding. Time studies have been done estimating these costs for a children with special health care needs population but have not been documented for CMC or outside of single site estimates.[100] However, models of understanding these costs exist for CMC that could be adapted to other state programs.[101] This essential understanding of costs requires more active communication with state Medicaid programs around providers system effort than is typical for other Medicaid services that have preset associated relative value units (RVUs)—for example, well child visit codes.

States have multiple authorities for implementing these services. In states with large managed care programs (MCPs), care coordination and/or case management is often a required service of the MCP. The CMCS State Health Official letter on EPSDT articulated that both case management and care coordination are required for "children with disabilities or other complex health care needs."[102] It is possible for states to provide these services outside of managed care, if a managed care state; and these services could be directly administered by the program in states that do not use managed care.

In either case, state Medicaid programs must identify or seek state authority to implement this service either via requests for legislative authority or via administrative authority. These state authorities often follow federal provisions for funding mechanisms. At present federal provisions include health homes (1945), ACE kids provisions (1945A), targeted case management services, or other provisions of the state's Medicaid plan. Once a state mechanism is identified, the state must request and receive approval of an amendment to its State Plan to provide this service.

While case management can be (and is often) provided in waiver programs, as noted above, the State Health Official letter is clear that these services must be provided via EPSDT mechanisms outside of waivers for all eligible children. For all children who need care coordination to improve or ameliorate medical conditions, these services are considered medically necessary and cannot be provided only to children in waiver programs.

Discussion around how Medicaid can best operationalize these service programs for CMC and their families is ongoing. Notably, states must create a mechanism for provider systems to submit claims for care coordination and/or case management. The development of these claims submission mechanisms is ongoing work of Medicaid programs, and claims processes can be a rate limiting step due to limited state resources for their claims systems or limited managed care resources in their systems.

States must enable care models that strike a balance between being flexible enough to meet the varied needs of CMC while also being structured enough to ensure improvement in quality and outcomes. Financing mechanisms should be aligned to support these care models, and performance measures need to reflect real-world complexities of providing care for this population. Opportunities for alignment across states should be actively pursued, as this could offer easier implementation and streamline future program evaluation.

6. Next Steps

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. Next steps for work in this area includes:

- **State Case Examples:** This environmental scan was limited in its real-world assessment of current state Medicaid activities related to CMC care to the survey of four states participating in the ESC CC Sustainability Affinity Group. Future work will entail building out our understanding of activities in these four states as well as the development of additional state case examples specifically focused on exemplar states to better illuminate real-world examples of Medicaid approaches to defining CMC, providing and paying for enhanced care coordination/integration services, and assessing quality and value. The impact and effective collaboration of Title V and Medicaid will be discussed in these case examples.
- **Engaging Medicaid to Enhance Systems of Care for CMC Toolkit:** As the capstone of this effort, the ESC CC will develop a toolkit with guidance and resources designed to support Medicaid involvement in improving systems of care for CMC and their families. Topics under consideration for inclusion in the toolkit include: strategies for engaging families, defining CMC, defining services to be covered, payment and authority options, and quality measurement. The toolkit will target state actors working within and in collaboration with Medicaid.

7. Appendix

7.1 Literature Search Strategy

Table 7.1. Literature Search Research Questions

Literature Search Research Questions
1. What are the necessary domains of the definition for children with medical complexity (CMC)?
2. What are the necessary domains of the definition for family-centered health homes (FCHH) for CMC?

Table 7.2. Literature Search Key Search Terms

Search Terms for PubMed Search	
CMC Definition Search: ("disabled children"[MeSH] OR "children with medical complexit*"[tiab] OR "medically fragile"[tiab] OR "children with medical comorbidit*"[tiab] OR "children with complex chronic condition*"[tiab])	*FCHH for CMC Definition Search:* ("disabled children"[MeSH] OR "children with medical complexit*"[tiab] OR "medically fragile"[tiab] OR "children with medical comorbidit*"[tiab] OR "children with complex chronic condition*"[tiab])
AND	AND
("health status"[MeSH] OR "defin*"[tiab] OR "dimension"[tiab]	("patient-centered care"[MeSH] OR "continuity of patient care"[MeSH] OR "health home"[tiab] OR "medical home"[tiab] OR "family-centered medical home"[tiab] OR "care coordination"[tiab]
	AND
	("defin*"[tiab] OR "components"[tiab])

Table 7.3. Literature Search Inclusion/Exclusion Criteria

Literature Search	Inclusion Criteria	Exclusion Criteria
CMC Definition	• Explicitly mention child/children with medical complexity • Provide either a definition, description, or specific inclusion criteria for CMC • Published in English language	• Only describes children with special health care needs (CSHCN) • Condition-specific
FCHH for CMC Definition	• Explicitly mention CMC, children with special health care needs (CSHCN), or the broader pediatric population • Provide descriptions of key concepts such as family-centered care, medical homes, care coordination, or health homes • Published in English language	• Focus on adult populations

7.2 Included Literature: CMC Definition

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7.4 Included Performance Measures

Table 7.4. Patient Survey Performance Measures

Measure Name	Description	Data Source	Steward	Pediatric	Endorsed	Medicaid Use	FCHH Subdomain
Domain: Comprehensive Care (n=16)							
Follow-Up for Children at Risk for Delays	Assesses whether children who are determined to be at significant risk for developmental, social, or behavioral delays had appropriate follow-up health care.	PHDS-PLUS Survey	CAHMI	X	X		Addresses All Necessary Medical Care
Administration of a Standardized Developmental and Behavioral Screening (SDBS) Tool	Whether the child's health care provider administered a parent-completed standardized developmental and behavioral screening tool.	PHDS-PLUS Survey	CAHMI	X	X		Addresses All Necessary Medical Care
Assessment of Psychosocial Issues in the Family	Assesses whether health care providers asked the parent about their own psychosocial wellbeing, including depression, emotional support, changes or stressors in the home, and how parenting is working.	PHDS-PLUS Survey	CAHMI	X	X		Addresses All Necessary Medical Care
Assessment of Smoking, Substance Abuse, and Safety in the Family	Assesses whether health care providers asked the parent about smoking, substance abuse, safety, and firearms in the home.	PHDS-PLUS Survey	CAHMI	X	X		Addresses All Necessary Medical Care
Children Who Receive Preventive Medical Visit	Assesses how many medical preventive visits in a 12 month period, such as a physical exam or well-child check-up (does not include visits related to specific illnesses)	Survey	CAHMI	X			Addresses All Necessary Medical Care
Children With a Usual Source for Care When Sick	Whether child has a source of care that is known and continuous (categorized as a doctor´s office, hospital outpatient department, clinic or health center, school, friend or relative, some other place, or a telephone advice line)	Survey	CAHMI	X			Addresses All Necessary Medical Care
Child has shared care plan	Caregivers report that their child's primary care provider created a shared care plan for their child.	FECC Survey	COE4CCN	X	X		Team-based Care*
Child has emergency care plan	Caregivers report that their child's main provider created an emergency care plan for their child.	FECC Survey	COE4CCN	X			Team-based Care*
Child has written transition plan:	Caregivers of children (age 15 years or older) should report that their child's main provider created a written transition plan for their child.	FECC Survey	COE4CCN	X			Team-based Care*
Care Goal Creation/Planning	Composite of 2 items related to creation of short- and long-term care goals.	PICS Survey	BCH	X			Team-based Care*

Table 7.4. Patient Survey Performance Measures (Cont'd)

Measure Name	Description	Data Source	Steward	Pediatric	Endorsed	Medicaid Use	FCHH Subdomain
Domain: Patient/Family-Centered Approach (n=11)							
Planning your time and activities	Composite of 6 items related to ability to get together with nearby family, ability to get together with nearby friends, ability to do things in community, needing more help to do things in community, taking part in deciding what to do with their time, and taking part in deciding when things are done each day.	HCBS CAHPS	AHRQ		X	Annual HCBS CAHPS Chartbook	Respect and Dignity
Personal safety and respect	Composite of 3 items related to having someone to talk to if someone hurts you or does something to you that you do not like, none of the staff take money or things without asking, and none of the staff yell, swear, or curse.	HCBS CAHPS	AHRQ		X	Annual HCBS CAHPS Chartbook	Respect and Dignity
Parents' Experiences with Shared Decision-making	Composite of 3 items, including CC2 More than one choice for child's treatment or care; CC3 Child's doctor talked about pros and cons of choices; CC4 Child's doctor asked which choice was best for child.	CAHPS CCS	AHRQ	X	X	Child Core Set	Participation
Care coordinator asked about progress towards goals	Caregivers of CMC report that their care coordinator asked them about progress towards goals documented in the patient's shared care plan.	FECC Survey	COE4CCN	X			Participation
Care coordinator asked about concerns and health changes	Caregivers of CMC report that their care coordinator asked them about the following: caregiver concerns, health changes of the child.	FECC Survey	COE4CCN	X	X		Participation
Choosing the services that matter to you	Composite of 2 items related to person-centered service plan that included all of the things that are important, and staff knows what's on the service plan, including the things that are important.	HCBS CAHPS	AHRQ		X	Annual HCBS CAHPS Chartbook	Participation
Invited to Join Hospital Rounds	Caregivers should report having been invited to join in hospital rounds during their child's last hospitalization	FECC Survey	COE4CCN	X			Collaboration
Family-Centered	Parent reports that child's health care provider delivers care in a family-centered manner, e.g., understands specific needs of child and concerns of parent, builds confidence in the parent, explains things in way the parent can understand, and shows respect for a family's values, customs, and how they prefer to raise their child.	PHDS-PLUS Survey	CAHMI	X	X		Overall Patient-/ Family-Centeredness
Family Impact	Composite of 5 items related to care team members (CTMs) discussing things that cause family stress or made it hard to care for the child, taking the whole family into account, offering other than in-person communication, and offering peer connections.	PICS Survey	BCH	X			Overall Patient-/ Family-Centeredness
Children Who Receive Family-Centered Care	A composite measure designed to assess the family-centeredness of care delivery along several dimensions: whether doctor 1) partners with family in care, 2) listens to patient/parent carefully, 3) spends enough time with child, 4) is sensitive to family values/customs, 5) provides needed information, 6) whether family is able to access interpreter help, if needed.	Survey	CAHMI	X			Overall Patient-/ Family-Centeredness

Table 7.4. Patient Survey Performance Measures (Cont'd)

Measure Name	Description	Data Source	Steward	Pediatric	Endorsed	Medicaid Use	FCHH Subdomain
Person-Centered Primary Care Measure Patient Reported Outcome Performance Measure (PCPCM PRO-PM)	Composite of 11 items, including: 1. My practice makes it easy for me to get care. 2. My practice is able to provide most of my care. 3. In caring for me, my doctor considers all the factors that affect my health. 4. My practice coordinates the care I get from multiple places. 5. My doctor or practice knows me as a person. 6. My doctor and I have been through a lot together. 7. My doctor or practice stands up for me. 8. The care I get takes into account knowledge of my family. 9. The care I get in this practice is informed by knowledge of my community. 10. Over time, my practice helps me to stay healthy. 11. Over time, my practice helps me to meet my goals.	Survey	American Board of Family Medicine		X		Overall Patient-/ Family-Centeredness
Domain: Coordinated Care, Care Integration, and Transitions (n=18)							
Parents' Experiences with Coordination of Their Child's Care	Composite of 2 items, including CC7 Got help needed from child's doctors or health providers in contacting child's school or daycare; CC18 Got help from child's health plan, doctor's office, or clinic to coordinate child's care among different providers or services	CAHPS CCS	AHRQ	X	X	Child Core Set	Coordinated Care
Providers' Use of Information to Coordinate Patient Care	Composite of Q20 Provider knew important information about child's medical history and Q24 Someone from provider's office followed up with respondent to give results of blood test, x-ray, or other test.	CG CAHPS	AHRQ	X	X		Coordinated Care
Has care coordinator	Caregivers of CMC report that their child has a designated care coordinator.	FECC Survey	COE4CCN	X	X		Coordinated Care
Access to care coordinator	Caregivers of CMC who report that they know how to access their care coordinator.	FECC Survey	COE4CCN	X			Coordinated Care
Care coordinator helped to obtain community services	Caregivers of CMC who require community services report that their care coordinator helped their child to obtain needed community services in the last year.	FECC Survey	COE4CCN	X	X		Coordinated Care
Care coordinator contact in the last 3 months	Caregivers of CMC report that their care coordinator has contacted them (via face-to-face contact, telephone, email, or written correspondence) or attempted to contact them at least once in the last 3 months.	FECC Survey	COE4CCN	X			Coordinated Care
Care coordinator assisted with specialist service referrals	Caregivers report that the care coordinator contacted them to confirm they were able to get an appointment with the specialist	FECC Survey	COE4CCN	X	X		Coordinated Care
Care Coordination	Assesses whether children requiring more than one type of health care service received needed help coordinating care.	PHDS-PLUS Survey	CAHMI	X	X		Coordinated Care

Table 7.4. Patient Survey Performance Measures (Cont'd)

Measure Name	Description	Data Source	Steward	Pediatric	Endorsed	Medicaid Use	FCHH Subdomain
Care Coordination	Composite of 6 items, including: When you visited your personal doctor for a scheduled appointment in the last 6 months, how often did he or she have your medical records or other information about your care? Include in person, telephone or video appointments. (Question #32) - In the last 6 months, when your personal doctor ordered a blood test, x-ray, or other test for you, how often did someone from your personal doctor's office follow up to give you those results? (Question #33) -In the last 6 months, when your personal doctor ordered a blood test, x-ray, or other test for you, how often did you get those results as soon as you needed them? (Question #34) -In the last 6 months, how often did your personal doctor seem informed and up-to-date about the care you got from specialists? (Question #42) -In the last 6 months, how often did you and your personal doctor talk about all the prescription medicines you were taking? (Question #35) -In the last 6 months, how often did you get the help that you needed from your personal doctor's office to manage your care among these different providers and services? (Question #38).	Qualified Health Plan Enrollee Survey	AHRQ; CMS		X		Coordinated Care
Children Who Receive Effective Care Coordination of Healthcare Services When Needed	This is a composite measure used to assess the need and receipt of care coordination services for children who required care from at least two types of health care services which may require communication between health care providers, or with others involved in child´s care (e.g. school).	Survey	CAHMI	X			Coordinated Care
Health care provider communicated with school staff about child's condition	Caregivers report that one of their child's health care providers communicated with school staff at least once a year about the educational impacts of the child's condition;	FECC Survey	COE4CCN	X			Care Integration
Team Functioning/ Quality	Composite of 6 items related to care team members (CTMs) knowing about advice from other CTMs, assigning and explaining responsibility, being aware of tests and evaluations, following through on responsibilities, considering the "big picture", and having access to same medical information.	PICS Survey	BCH	X			Care Integration
Preparing you and your child to leave the hospital	Composite of 5 items related to whether the provider asked the parent about the child's readiness to leave, talked with the parent about care after discharge, explained when the child could resume regular activities, explained symptoms or problems to look for after discharge, and whether the parent was given written information about symptoms or problems to look for after discharge.	HCAHPS Child Survey	AHRQ	X	X		Transitions
Involving teens in their care	Composite of 3 items related to whether providers involved teens in their care, asked teens questions about readiness to leave, and talked with teens about care after discharge.	HCAHPS Child Survey	AHRQ	X	X		Transitions

Table 7.4. Patient Survey Performance Measures (Cont'd)

Measure Name	Description	Data Source	Steward	Pediatric	Endorsed	Medicaid Use	FCHH Subdomain
Communication about your child's medicines	Composite of 4 items related to whether the parent was asked about the child's prescription medicines, vitamins, herbal medicines, and over-the-counter medicines; whether a provider explained how to take new medicines after leaving the hospital and the side effects of those medicines.	HCAHPS Child Survey	AHRQ	X	X		Transitions
3-Item Care Transition Measure (CTM-3)	The CTM-3 is a hospital level measure of performance that reports the average patient reported quality of preparation for self-care response among adult patients discharged from general acute care hospitals within the past 30 days.	Survey	Univ of Colorado Center for Bioethics & Humanities				Transitions
Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Health Care	The Adolescent Assessment of Preparation for Transition (ADAPT) to Adult-Focused Health Care measures the quality of preparation for transition from pediatric-focused to adult-focused health care as reported in a survey completed by youth ages 16-17 years old with a chronic health condition. The ADAPT survey generates measures for each of the 3 domains: 1) Counseling on Transition Self-Management, 2) Counseling on Prescription Medication, and 3) Transition Planning.	Survey	PMCoE	X	X		Transitions
Children with Special Health Care Needs (CSHCN) who Receive Services Needed for Transition to Adult Health Care	Whether children with special health care needs (CSHCN) ages 12-17 have doctors who usually/always encourage increasing responsibility for self-care AND (when needed) have discussed transitioning to adult health care, changing health care needs, and how to maintain insurance coverage	Survey	CAHMI	X			Transitions
Domain: Accessible and Convenient Services (n=9)							
Parents' Experiences with Getting Needed Information about Their Child's Care	CC1 Had questions answered by child's doctors or health providers	CAHPS CCS	AHRQ	X	X	Child Core Set	Availability
Parents' Experiences Getting Specialized Services for Their Child	Composite of 3 items, including CC9 Easy to get special medical equipment or devices for child; CC12 Easy to get special therapy for child; CC15 Easy to get treatment or counseling for child	CAHPS CCS	AHRQ	X	X	Child Core Set	Availability
Parents' Experiences with Prescription Medicines	CC23 Easy to get prescription medicines for child through health plan	CAHPS CCS	AHRQ	X	X	Child Core Set	Availability
Getting Needed Care	Composite of Q9 Easy for child to get necessary care, tests, or treatment & Q21 Respondent got child an appointment with specialists as soon as needed	CAHPS HPS	AHRQ	X	X	Child Core Set	Availability
Access to Care	Composite of 2 items related to lack of sufficient services and lack of information.	PICS Survey	BCH	X			Availability
Getting Care Quickly	Composite of Q4 Child got care for illness/injury as soon as needed & Q6 Child got non-urgent appointment as soon as needed	CAHPS HPS	AHRQ	X	X	Child Core Set	Accessibility

Table 7.4. Patient Survey Performance Measures (Cont'd)

Measure Name	Description	Data Source	Steward	Pediatric	Endorsed	Medicaid Use	FCHH Subdomain
Getting Timely Appointments, Care, and Information	Composite of Q13 Child got appointment for urgent care as soon as needed, Q15 Child got appointment for non-urgent care as soon as needed, and Q17 Respondent got answer to medical question the same day he/she contacted provider's office.	CG CAHPS	AHRQ	X	X		Accessibility
Transportation to medical appointments	Composite of 3 items related to having a way to get to your medical appointments, ability to get in and out of ride easily, and ride arrives on time to pick you up.	HCBS CAHPS	AHRQ		X	Annual HCBS CAHPS Chartbook	Accessibility
Children Who Had Problems Obtaining Referrals When Needed	Perceived difficulty in obtaining referrals for children when needed for optimum health.	Survey	CAHMI				Accessibility
Domain: Compassionate Care (n=20)							
How Well Doctors Communicate	Composite of 5 items related to how often their child's personal doctor explained things clearly both to the parent and to the child, listened carefully, showed respect, and spent enough time with the child. (Q12-14, Q16-17)	CAHPS HPS	AHRQ	X	X	Child Core Set	Compassionate Communication
How Well Providers Communicate with Patients	Composite of Q18 Provider explained things in a way that was easy to understand, Q19 Provider listened carefully to respondent, Q21 Provider showed respect for what respondent had to say, and Q22 Provider spent enough time with child.	CG CAHPS	AHRQ	X	X		Compassionate Communication
Providers Are Polite and Considerate	Composite of 3 items, including: CU5 Provider interrupted patient when patient was talking; CU3 Provider talked too fast; and CU8 Provider used a condescending, sarcastic, or rude tone or manner with patient	CG CAHPS	AHRQ		X		Compassionate Communication
How Well Providers Communicate About Medicines	Composite of 3 items, including: C-HL15 Provider gave easy to understand instructions about medicines; C-HL16 Provider gave easy to understand explanations about possible side effects of medicines; and C-HL17 Provider suggested ways to help patient remember to take medicines.	CG CAHPS	AHRQ		X		Compassionate Communication
Care coordinator was knowledgeable, supportive and advocated for child's needs	Caregivers of CMC report that their care coordinator: is knowledgeable about their child's health, supports the caregiver, and advocates for the needs of their child.	FECC Survey	COE4CCN	X	X		Compassionate Communication
Privacy when talking with doctors, nurses, and other providers	How often the parent had privacy with providers when discussing the child's care.	HCAHPS Child Survey	AHRQ	X	X		Compassionate Communication
Helping your child feel comfortable	Composite of 3 items related to whether providers asked about things a family knows best about their child and talked and acted in a way that was age-appropriate for the child, as well as whether the hospital had things like toys, books, and games that were right for the child's age.	HCAHPS Child Survey	AHRQ	X	X		Compassionate Communication

Table 7.4. Patient Survey Performance Measures (Cont'd)

Measure Name	Description	Data Source	Steward	Pediatric	Endorsed	Medicaid Use	FCHH Subdomain
Communication between you and your child's nurses	Composite of 3 items related to how often nurses listened carefully to the parent, explained things to the parent in an easy-to-understand way, and treated the parent with courtesy and respect.	HCAHPS Child Survey	AHRQ	X	X		Compassionate Communication
Communication between you and your child's doctors	Composite of 3 items related to how often doctors listened carefully to the parent, explained things to the parent in an easy-to-understand way, and treated the parent with courtesy and respect.	HCAHPS Child Survey	AHRQ	X	X		Compassionate Communication
How well nurses communicate with your child	Composite of 3 items related to how often nurses listened carefully to the child, explained things to the child in an easy-to-understand way, and encouraged the child to ask questions.	HCAHPS Child Survey	AHRQ	X	X		Compassionate Communication
How well doctors communicate with your child	Composite of 3 items related to how often doctors listened carefully to the child, explained things to the child in an easy-to-understand way, and encouraged the child to ask questions.	HCAHPS Child Survey	AHRQ	X	X		Compassionate Communication
Case manager is helpful	Composite of 3 items related to ability to contact case manager when needed, case manager helped when asked for help with getting or fixing equipment, and case manager helped when asked for help with getting other changes to services.	HCBS CAHPS	AHRQ		X	Annual HCBS CAHPS Chartbook	Compassionate Communication
Staff are reliable and helpful	Composite of 6 items related to staff come to work on time, staff work as long as they are supposed to, someone tells you if staff cannot come, staff make sure you have enough privacy for dressing, showering, and bathing, homemakers come to work on time, and homemaker work as long as they are supposed to.	HCBS CAHPS	AHRQ		X	Annual HCBS CAHPS Chartbook	Compassionate Communication
Staff listen and communicate well	Composite of 11 items related to staff treat you with courtesy and respect, staff explanations are easy to understand, staff treat you the way they want them to, staff explain things in a way that is easy to understand, staff listen carefully to you, staff know what kind of help you need with everyday activities, homemakers treat you with courtesy and respect, homemaker explanations are easy to understand, homemakers treat you the way you want them to, homemakers listen carefully, and homemakers know what kind of help you need.	HCBS CAHPS	AHRQ		X	Annual HCBS CAHPS Chartbook	Compassionate Communication
Effect of Care on Parental Confidence	Parent report on the effect of care on their confidence in: doing things for child to help him/her grow and learn, protecting child from injuries, addressing special concerns, and managing parenting responsibilities.	PHDS-PLUS Survey	CAHMI	X	X		Compassionate Communication
Communication with Care Team Members (CTMs)	Composite of 4 items related to CTMs explaining things in an understandable manner, listening carefully to what the family had to say, treating the family as a full partner, and the family being comfortable voicing concerns with CTMs.	PICS Survey	BCH	X			Compassionate Communication
Providers Are Caring and Inspire Trust	Composite of 5 items, including: CU16 Patient could tell provider anything; CU17 Patient could trust provider with medical care; CU18 Provider always told patient truth about health; CU19 Provider cared as much as patient about health; and CU20 Provider cared about patient as a person	CG CAHPS	AHRQ		X		Provider Trust

Table 7.4. Patient Survey Performance Measures (Cont'd)

Measure Name	Description	Data Source	Steward	Pediatric	Endorsed	Medicaid Use	FCHH Subdomain
Patients' Rating of Trust in Provider	Overall rating of trust in provider (0-10)	CG CAHPS	AHRQ		X		Provider Trust
Written Visit Summary was Useful and Easy to Understand	Written visit summary reports were useful and easy for caregivers or patients to understand.	FECC Survey	COE4CCN	X			Health Literacy
Caregiver has access to medical interpreter when needed	Caregivers or patients who self-identify as having a preference for conducting medical visits in a language other than English should have access to a professional medical interpreter (live or telephonic) at all visits for which an interpreter is needed.	FECC Survey	COE4CCN	X	X		Culturally and Linguistically Appropriate Services
Domain: Quality & Safety (n=5)							
Responsiveness to the call button	Whether the parent and child got prompt help when they pressed the call button.	HCAHPS Child Survey	AHRQ	X	X		Continuous Quality Improvement
Paying attention to your child's pain	Whether providers asked about the child's pain.	HCAHPS Child Survey	AHRQ	X	X		Continuous Quality Improvement
Unmet need measure	Composite of 5 items related to unmet need in dressing/bathing due to lack of help, unmet need in meal preparation/eating due to lack of help, unmet need in medication administration due to lack of help, unmet need in toileting due to lack of help, and unmet need with household tasks due to lack of help.	HCBS CAHPS	AHRQ		X	Annual HCBS CAHPS Chartbook	Continuous Quality Improvement
Physical safety measure	Hit or hurt by staff	HCBS CAHPS	AHRQ		X	Annual HCBS CAHPS Chartbook	Avoidance of Harm
Preventing mistakes and helping you report concerns	Composite of 2 items related to how often providers checked the child's identity before giving medicines and whether providers told the parent how to report mistakes.	HCAHPS Child Survey	AHRQ	X	X		Prevention of Error
Domain: Care Management & Support Infrastructure (n=15)							
Caregiver has access to electronic health record	Caregivers should report having access to an electronic health record to look up information about their child's visits and health care.	FECC Survey	COE4CCN	X			Information Management
Electronic health record has immunization and medication information	Caregivers should report having access to an electronic health record with information about their child's immunizations and medication information.	FECC Survey	COE4CCN	X			Information Management
Appropriate written visit summary content	Written visit summary reports contained current problem list, current medication list, drug allergies, specialists involved in the child's care, planned follow-up, what to do for problems related to the outpatient visit.	FECC Survey	COE4CCN	X	X		Information Management

Table 7.4. Patient Survey Performance Measures (Cont'd)

Measure Name	Description	Data Source	Steward	Pediatric	Endorsed	Medicaid Use	FCHH Subdomain
Appropriate written hospitalization summary content	Written hospitalization summary reports contained problem list at time of discharge, medication list at time of discharge, drug allergies, specialists involved in the child's hospitalization, planned follow-up, what to do for problems related to the hospitalization.	FECC Survey	COE4CCN	X			Information Management
Keeping you informed about your child's care	Composite of 2 items related to how often providers kept the parent informed about care and gave the parent enough information about test results.	HCAHPS Child Survey	AHRQ	X	X		Information Management
Keeping you informed about your child's care in the ER	Whether the parent was kept informed about care in the emergency room.	HCAHPS Child Survey	AHRQ	X	X		Information Management
Health Information	Assesses whether information was provided outside/inside the health care provider's office (mail, clinic pamphlets, videos, etc.) on the following: safety, health care utilization, developmental information.	PHDS-PLUS Survey	CAHMI	X	X		Information Management
Helpfulness of Care Provided	Parent report of how helpful information from child's health care providers was in specific areas of parenting such as understanding child's behavior, protecting child from injuries, and helping the parent learn to meet their own needs.	PHDS-PLUS Survey	CAHMI	X	X		Information Management
Provision of information about resources in the community for parents	Assesses whether information was provided by the child's doctor or other health providers about resources in the community for the parent.	PHDS-PLUS Survey	CAHMI	X	X		Community Referral Network
Getting Timely Appointments Through E-mail or Website	Patient got an appointment using e-mail or website as soon as needed	CG CAHPS	AHRQ		X		Technological Infrastructure
Getting Timely Answers to Medical Questions by E-Mail	Composite of 2 items, including: HIT5 Patient got an answer to an e-mailed medical question as soon as needed; and HIT6 All of the questions in patient's e-mail were answered.	CG CAHPS	AHRQ		X		Technological Infrastructure
Helpfulness of Provider's Use of Computers During a Visit	Composite of 2 items, including: HIT11 Provider's use of computer or handheld device was helpful to patient; and HIT12 Provider's use of computer or handheld device made it harder or easier to talk with him or her.	CG CAHPS	AHRQ		X		Technological Infrastructure
Helpfulness of Provider's Website in Giving You Information About Your Care and Tests	Composite of 4 items, including: HIT15 Blood tests, x-rays, or other test results were easy to find on website; HIT16 Blood tests, x-rays, or other test results were put on website as soon as needed; HIT 17 Blood tests, x-rays, or other test results were presented in a way that was easy to understand; and HIT21 Visit notes were easy to understand.	CG CAHPS	AHRQ		X		Technological Infrastructure
Health Plan Customer Service	Composite of 2 items related to how often customer service staff were helpful and treated them with courtesy and respect (Q25-26).	CAHPS HPS	AHRQ	X	X	Child Core Set	Physical Infrastructure
Helpful, Courteous, and Respectful Office Staff	Composite of Q26 Clerks and receptionists were helpful, and Q27 Clerks and receptionists were courteous and respectful.	CG CAHPS	AHRQ		X		Physical Infrastructure

Table 7.4. Patient Survey Performance Measures (Cont'd)

Measure Name	Description	Data Source	Steward	Pediatric	Endorsed	Medicaid Use	FCHH Subdomain
Domain: General Medical Home (n=9)							
Patient's Rating of all Health Care	Rating of all health care (0-10)	CAHPS HPS	AHRQ	X	X	Child Core Set	N/A
Patient's Rating of the Personal Doctor	Rating of personal doctor (0-10)	CAHPS HPS	AHRQ	X	X	Child Core Set	N/A
Patient's Rating of the Specialist	Rating of specialist (0-10)	CAHPS HPS	AHRQ	X	X	Child Core Set	N/A
Patient's Rating of the Health Plan	Rating of health plan (0-10)	CAHPS HPS	AHRQ	X	X	Child Core Set	N/A
Patient's Rating of the Provider	Rating of provider (0-10)	CG CAHPS	AHRQ	X	X		N/A
Patients' Rating of the Interpreter	Overall rating of the interpreter (0-10)	CG CAHPS	AHRQ		X		N/A
Global Ratings Measure	Composite of 3 items related to global rating of personal assistance and behavioral health staff, global rating of homemaker, and global rating of case manager	HCBS CAHPS	AHRQ		X	Annual HCBS CAHPS Chartbook	N/A
Patient's Rating of the Hospital	Rating of hospital (0-10)	HCAHPS Child Survey	AHRQ	X	X		N/A
Measure of Medical Home for Children and Adolescents	This composite measure assesses whether or not children and adolescents (age 0-17 years) receive health care within a medical home according to the survey respondent (almost always the child's parent). The medical home measure is based on six of the seven domains of care first proposed by the American Academy of Pediatrics (AAP)—health care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and contextually responsive.	Survey	CAHMI	X			N/A

*Measures also relevant to the Care Management & Support Infrastructure Domain Care Plans Subdomain.

AHRQ: Agency for Healthcare and Quality Research; BCH: Boston Children's Hospital; CAHMI: Child and Adolescent Health Measurement Initiative; CAHPS: Consumer Assessment of Healthcare Providers and Systems; CAHPS CCS: CAHPS Children with Chronic Conditions Supplemental Item Set; CAHPS HPS: CAHPS Health Plan Survey (Child Medicaid Survey); CG CAHPS: CAHPS Clinician and Group Survey Child Items; COE4CCN: Center of Excellence on Quality of Care Measures for Children with Complex Needs; FECC: Family Experiences with Care Coordination Survey; HCAHPS Child: CAHPS Child Hospital Survey; HCBS CAHPS: CAHPS Home and Community-Based Services Survey; PHDS-PLUS: Promoting Healthy Development Survey-PLUS Survey; PICS: Pediatric Integrated Care Survey; PMCoE: Center of Excellence for Pediatric Quality Measurement

Table 7.5. Administrative & Clinical Performance Measures

Measure Name	Description	Data Source	Steward	Pediatric	Endorsed	Medicaid Use	FCHH Subdomain
Domain: Comprehensive Care (n=7)							
Housing Stability Assessment	This measure assesses children who screened positive for housing instability among all attributed Integrated Care for Kids Model (InCK) beneficiaries who have completed a housing instability screening	Patient-Reported Health Data; Standardized Patient Assessment	N/A	X		InCK Model	Addresses Upstream Drivers of Health
Domain: Patient/Family-Centered Approach (n=2)							
Patient Activation Measure (PAM)	The Patient Activation Measure (PAM Registered Trademark) is a 10- or 13- item questionnaire that assesses an individual's knowledge, skills and confidence for managing their health and health care. The measure assesses individuals on a 0-100 scale that converts to one of four levels of activation, from low (1) to high (4). The PAM performance measure (PAM-PM) is the change in score on the PAM from baseline to follow-up measurement.	EHR; Patient-Reported Health Data; Standardized Patient Assessment	Insignia Health, LLC	X	X		Participation
Alignment of Person-Centered Service Plan (PCSP) with Functional Needs as Determined by Functional Assessment Standardized Items (FASI)	The percentage of home and community-based services (HCBS) participants aged 18 years or older whose PCSP documentation addresses needs in the areas of self-care, mobility, and instrumental activities of daily living (IADL) as determined by the most recent FASI assessment. For the purposes of this measure application, the term "home and community-based services" also will refer to community-based long-term services and supports (CB-LTSS).	EHR; Medical Record; Patient-Reported; Standardized Patient Assessments	CMS		X		Overall Patient-/Family-Centeredness
Domain: Coordinated Care, Care Integration, and Transitions (n=4)							
Closing the Referral Loop: Receipt of Specialist Report	Percentage of patients with referrals, regardless of age, for which the referring clinician receives a report from the clinician to whom the patient was referred.	Electronic Clinical Data (non-EHR) or Social Needs Assessments; EHR	CMS	X	X		Care Integration
Follow-Up Referral After Positive Developmental Screen	Percentage of patients aged 6 to 36 months who were referred for follow-up care within 7 calendar days of receiving a positive developmental screening result.	EHR; Medical Record	PMCoE	X			Care Integration
Follow-up Referral Tracking	Percentage of patients aged 6 to 36 months whose primary care clinician received feedback from the follow-up care clinician within 6 months of the date that referral for follow-up care was made	EHR; Medical Record	PMCoE	X			Care Integration
Transfer of Health Information to the Provider Post-Acute Care (PAC)	Percentage of patients, regardless of age, discharged from an inpatient facility (e.g., hospital inpatient or observation, skilled nursing facility, or rehabilitation facility) to home or any other site of care for whom a transition record was transmitted to the facility or primary physician or other health care professional designated for follow-up care within 24 hours of discharge	Claims; Electronic Clinical Data (non-EHR) or Social Needs Assessments; EHR; Medical Record	PCPI Foundation	X	X		Transitions

Table 7.5. Administrative & Clinical Performance Measures (Cont'd)

Measure Name	Description	Data Source	Steward	Pediatric	Endorsed	Medicaid Use	FCHH Subdomain
Domain: Accessible and Convenient Services (n=2)							
Children and Adolescents' Access to Primary Care Practitioners (CAP)	Assess children and young adults 12 months-19 years of age who had a visit with a primary care practitioner (PCP). The measure reports on four separate percentages: Children 12-24 months; Children 25 months-6 years; Children 7-11 years; and Adolescents 12-19 years	Claims	NCQA	X			Availability
Access to Outpatient Specialty Care for Children	Rate of participating cardiologists, dermatologists, endocrinologists, gastroenterologists, hematologists/ oncologists, nephrologists, neurologists, otolaryngologists, pulmonologists, and rheumatologists who have seen ≥1 enrolled child, age <18 years, for at least one outpatient visit during the measurement year. A higher rate indicates better performance as reflected by increased availability of service.	Claims	Q-METRIC	X			Availability
Domain: Compassionate Care (n=0)							
Domain: Quality & Safety (n=23)							
Pediatric Quality Indicator 92 (PDI 92)	Pediatric Quality Indicators (PDI) composite of chronic conditions per 100,000 population, ages 6 to 17 years. Includes admissions for asthma or diabetes with short-term complications.	Administrative (non-claims); Claims	AHRQ	X	X		Continuous Quality Improvement
Chlamydia Screening for Women	Percentage of women 16-24 years of age who were identified as sexually active and who had at least one test for chlamydia during the measurement period	Administrative (non-claims); Claims; EHR	NCQA	X	X	Child Core Set	Continuous Quality Improvement
Developmental Screening	Percentage of children beneficiaries screened for risk of developmental, behavioral, and social delays using a standardized screening tool in the 12 months preceding or on their first, second, or third birthday.	Administrative (non-claims); Claims	Oregon Health & and Sciences University	X	X	Child Core Set	Continuous Quality Improvement
Childhood Immunization Status	The percentage of children 2 years of age who had four diphtheria, tetanus and acellular pertussis (DTaP); three polio (IPV); one measles, mumps and rubella (MMR); three haemophilus influenza type B (HiB); three hepatitis B (HepB), one chicken pox (VZV); four pneumococcal conjugate (PCV); one hepatitis A (HepA); two or three rotavirus (RV); and two influenza (flu) vaccines by their second birthday. The measure calculates a rate for each vaccine and one separate combination rate.	Administrative (non-claims); Claims; EHR	NCQA	X	X	Child Core Set	Continuous Quality Improvement
Immunizations for Adolescents	Percentage of beneficiary adolescents age 13 who had one dose of meningococcal vaccine, one tetanus, diphtheria toxoids and acellular pertussis (Tdap) vaccine, and have completed the human papillomavirus (HPV) vaccine series by their 13th birthday. The measure calculates a rate for each vaccine and two combination rates.	Administrative (non-claims); Claims	NCQA	X	X	Child Core Set	Continuous Quality Improvement
Lead Screening in Children (LSC-CH)	Percentage of children 2 years of age who had one or more capillary or venous lead blood test for lead poisoning by their second birthday.	Administrative (non-claims); Claims	NCQA	X	X	Child Core Set	Continuous Quality Improvement

Table 7.5. Administrative & Clinical Performance Measures (Cont'd)

Measure Name	Description	Data Source	Steward	Pediatric	Endorsed	Medicaid Use	FCHH Subdomain
Weight Assessment and Counseling for Nutrition and Physical Activity for Children and Adolescents	Beneficiaries ages 3 to 17 who had an outpatient visit with a primary care practitioner (PCP) or obstetrician/gynecologist (OB/GYN) and who had evidence of the following during the measurement year: * Body mass index (BMI) percentile documentation present * Counseling for nutrition * Counseling for physical activity	Administrative (non-claims); Claims; EHR	NCQA	X	X	Child Core Set	Continuous Quality Improvement
Avoidance of Antibiotic Treatment for Acute Bronchitis/ Bronchiolitis: Ages 3 Months to 17 Years (AAB-CH)	Percentage of episodes for beneficiaries ages 3 months to 17 years with a diagnosis of acute bronchitis/bronchiolitis that did not result in an antibiotic dispensing event.	Claims	NCQA	X	X	Child Core Set	Continuous Quality Improvement
Asthma Medication Ratio: Ages 5 to 18 (AMR-CH)	The percentage of children and adolescents ages 5 to 18 who were identified as having persistent asthma and had a ratio of controller medications to total asthma medications of 0.50 or greater during the measurement year.	Claims	NCQA	X	X	Child Core Set	Continuous Quality Improvement
Ambulatory Care: Emergency Department (ED) Visits (AMB-CH)	Rate of emergency department (ED) visits per 1,000 beneficiary months among children up to age 19.	Claims	NCQA	X	X	Child Core Set (Retired)	Continuous Quality Improvement
Follow-Up Care for Children Prescribed Attention Deficit/ Hyperactivity Disorder (ADHD) Medication (ADD-CH)	Percentage of children newly prescribed attention-deficit/hyperactivity disorder (ADHD) medication who had at least three follow-up care visits within a 10-month period, one of which was within 30 days of when the first ADHD medication was dispensed.	Claims; EHR	NCQA	X	X	Child Core Set	Continuous Quality Improvement
Screening for Depression and Follow-Up Plan: Ages 12 to 17 (CDF-CH)	Percentage of beneficiaries ages 12 to 17 screened for depression on the date of the encounter or 14 days prior to the date of the encounter using an age-appropriate standardized depression screening tool, and if positive, a follow-up plan is documented on the date of the qualifying encounter.	Claims; EHR	CMS	X	X	Child Core Set	Continuous Quality Improvement
Follow-Up After Hospitalization for Mental Illness: Ages 6 to 17 (FUH-CH)	Percentage of discharges for beneficiaries ages 6 to 17 who were hospitalized for treatment of selected mental illness or intentional self-harm diagnoses and who had a follow-up visit with a mental health provider.	Claims	NCQA	X	X	Child Core Set	Continuous Quality Improvement
Metabolic Monitoring for Children and Adolescents on Antipsychotics (APM-CH)	Percentage of children and adolescents ages 1 to 17 who had two or more antipsychotic prescriptions and had metabolic testing.	Claims	NCQA	X	X	Child Core Set	Continuous Quality Improvement
Use of First-Line Psychosocial Care for Children and Adolescents on Antipsychotics (APP-CH)	Percentage of children and adolescents ages 1 to 17 who had a new prescription for an antipsychotic medication and had documentation of psychosocial care as first-line treatment.	Claims	NCQA	X	X	Child Core Set	Continuous Quality Improvement

Table 7.5. Administrative & Clinical Performance Measures (Cont'd)

Measure Name	Description	Data Source	Steward	Pediatric	Endorsed	Medicaid Use	FCHH Subdomain
Follow-Up After Emergency Department Visit for Substance Use: Ages 13 to 17 (FUA-CH)	Percentage of emergency department (ED) visits for beneficiaries ages 13 to 17 years with a principal diagnosis of substance use disorder (SUD), or any diagnosis of drug overdose, for which there was follow-up.	Claims	NCQA	X	X	Child Core Set	Continuous Quality Improvement
Follow-Up After Emergency Department Visit for Mental Illness: Ages 6 to 17 (FUM-CH)	Percentage of emergency department (ED) visits for beneficiaries ages 6 to 17 with a principal diagnosis of mental illness or intentional self-harm and who had a follow-up visit for mental illness.	Claims	NCQA	X	X	Child Core Set	Continuous Quality Improvement
Oral Evaluation, Dental Services (OEV-CH)	Percentage of enrolled children under age 21 who received a comprehensive or periodic oral evaluation within the measurement year.	Claims	DQA (ADA)	X	X	Child Core Set	Continuous Quality Improvement
Topical Fluoride for Children (TFL-CH)	Percentage of enrolled children ages 1 through 20 who received at least two topical fluoride applications as: (1) dental or oral health services, (2) dental services, and (3) oral health services within the measurement year.	Claims	DQA (ADA)	X	X	Child Core Set	Continuous Quality Improvement
Sealant Receipt on Permanent First Molars (SFM-CH)	Percentage of enrolled children who have ever received sealants on permanent first molar teeth: (1) at least one sealant and (2) all four molars sealed by the 10th birthdate.	Claims	DQA (ADA)	X	X	Child Core Set	Continuous Quality Improvement
Children Who Have Dental Decay or Cavities	Percentage of children, age 0-20 years, who have had tooth decay or cavities during the measurement period.	Electronic Clinical Data (non-EHR); Social Needs Assessments	CMS	X			Continuous Quality Improvement
Pediatric All-Condition Readmission Measure	This measure calculates case-mix-adjusted readmission rates, defined as the percentage of admissions followed by one or more readmissions within 30 days, for patients less than 18 years old. The measure focuses on patients discharged from general acute care hospitals, including children's hospitals.	Claims	CMS	X			Continuous Quality Improvement
Follow-up with Patient Family after Developmental Screening	Percentage of patients aged 6 months to 36 months whose family received a follow-up discussion of developmental screening results on the same day of the screening visit.	EHR; Medical Record	AHRQ; PMCoE	X			Continuous Quality Improvement
Domain: Care Management & Support Infrastructure (n=1)							
Drug Regimen Review Conducted with Follow-Up for Identified Issues	This measure reports the percentage of patient/resident stays in which a drug regimen review was conducted at the time of admission and timely follow-up with a physician occurred each time potential clinically significant medication issues were identified throughout that stay.	Patient-Reported; Standardized Patient Assessments	CMS		X		Care Plans
Domain: General Medical Home (n=0)							

AHRQ: Agency for Healthcare and Quality Research; CMS: Centers for Medicare and Medicaid Services; DQA (ADA): American Dental Association on behalf of the Dental Quality Alliance; NCQA: National Committee for Quality Assurance; PMCoE: Center of Excellence for Pediatric Quality Measurement; Q-METRIC: Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium

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