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.