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Delaware's Children with Medical Complexity
Advisory Committee
2021 Year End Summary

Table of Contents

Background	3
Summary of 2019 and 2020 Activities	3
Organizing the Work for 2021 and Developing 2021 Objectives	5
Impact of COVID-19	6
Summary of 2021 Activities	7
Establishing 2022 Priorities	9

Background

In 2017, the State of Delaware’s Legislature, 149th Generally Assembly, instructed the Delaware Department of Health and Social Services (DHSS) to develop and publish a comprehensive plan for managing the health care needs of Delaware’s children with medical complexity by May 15, 2018. Under guidance from Kara Odom Walker, MD, MPH, MSHS, the former Cabinet Secretary of DHSS, the Division of Medicaid and Medical Assistance (DMMA) came together with multiple community partners, sister divisions, parents, caregivers, and other advocates to develop a comprehensive plan for identifying and managing the health care needs of Delaware’s children with medical complexity. This group, the Children with Medical Complexity (CMC) Steering Committee, used a comprehensive approach with a range of goals and strategies to clearly identify the population, assess access to services, evaluate models of care, and analyze the relationships between insurance payers.

The planning process was designed to take a systemic approach, focusing on how the current health care system is providing for Delaware’s children with medical complexity, identifying areas where improvements could be made, and suggesting some strategies to strengthen the system so that Delaware can adequately meet the needs of this vulnerable population. The CMC Steering Committee, along with five CMC work groups¹, met for approximately six months to identify areas for improvement and suggest strategies to strengthen the system in order to improve access to care for children with medical complexity.

Through this collaborative planning process, the CMC Steering Committee developed a series of recommendations that ultimately formed Delaware’s Plan for Managing the Health Care Needs of Children with Medical Complexity (the Plan), published May 15, 2018. The full text of the Plan can be found on the DMMA CMC webpage: https://dhss.delaware.gov/dhss/dmma/children_with_medical_complexity.html.

Summary of 2019 and 2020 Activities

In 2019, the work of the CMC Steering Committee was passed to a new group, the CMC Advisory Committee (CMCAC), which was charged with implementing the recommendations described in the Plan. The chart below provides a high-level overview of the group’s 2019 and 2020 accomplishments. Additional information regarding the group’s activities can be found in the 2019 and 2020 Year-End Reports, which are available on the CMC webpage (link above).

¹ The five workgroups were: Population Workgroup, Data Workgroup, Access Workgroup, Payers Workgroup, and the Models of Care Workgroup. The Population Workgroup was established to aid in the development of a Delaware specific definition for Children with Medical Complexity. Once the steering committee approved the definition, the Population Workgroup disbanded.

Summary of CMCAC 2019 and 2020 Accomplishments

- Continued active engagement of the CMCAC via quarterly meetings as well as two Workgroups: the Skilled Home Health Nursing (SHHN) Workgroup and the Data Workgroup.
- Launched a dedicated CMC webpage and posted resources, CMCAC meeting materials, and the Delaware-specific definition of CMC.
- Performed a comprehensive data analysis to identify the Medicaid/CHIP population of children with medical complexity.
- Reviewed emergency department and inpatient hospital utilization and published results in the 2019 year-end report.
- Reviewed gaps in SHHN utilization.
- Began planning for a Family Satisfaction Survey and Private Duty Nursing (PDN) Workforce Capacity Study.
- Developed the Family Satisfaction Survey and obtained Human Subjects Review Board (HSRB) approval.
- Developed the PDN Workforce Capacity Study and obtained HSRB approval.
- Started working with Family Voices to develop competency/family-centered training materials for providers.
- Developed a PDN Emergent Care Decision Tree.
- Continued active engagement of the CMCAC via quarterly meetings, which were held virtually in response to the COVID-19 pandemic.
- Finalized the PDN Emergent Care Decision Tree and Prior Authorization Toolkit.
- Developed MCO What to Expect and Welcome letters.
- Reviewed initial drafts and provided input into the Delaware Family Voices Family Centered Care Competency Training Curriculum.
- Collaborated with Delaware Community Legal Aid Society, Inc. (DECLASI) to develop the Affidavit for Temporary Health Care Authorization.
- DMMA, a parent representative on the CMCAC, Vital Research and Mercer presented at the 2020 national ADVancing States HCBS virtual conference, highlighting the work on the Family Satisfaction Survey.
- Researched online materials/webinars for Family Centered Care and posted links on the CMC website.
- Developed revisions to the DMMA Medicaid Policy Manual to address MCO processes for PDN Prior Authorizations.
- Continued active engagement of the CMCAC via quarterly meetings, which were held virtually in response to the COVID-19 pandemic, as well as two Workgroups: the SHHN Workgroup and the Data Workgroup. Representation on the Workgroups reflected a broad array of stakeholders including families.

Organizing the Work for 2021 and Developing 2021 Objectives

CMCAC started 2021 by reflecting on its 2020 activities and developing objectives for 2021 to continue progress towards achieving the short-term priorities drawn from Delaware's Plan for Managing the Health Care Needs of Children with Medical Complexity. In developing these priorities, the group sought to build upon the foundation of data and information that was established in 2020. Additionally, the group sought to carry over tasks that were initiated in 2020. Among these carryover tasks were: 1) completing the PDN Provider Capacity Study and the Family Satisfaction Survey; and 2) continuing to post relevant materials and resources on the DMMA CMC webpage.

At the beginning of the year, the CMCAC determined that its objectives for 2021 would be the following:

1. Endorse care coordination standards specifically for the CMC population.
2. Complete the PDN Provider Capacity Study.
3. Complete the Family Satisfaction Survey.
4. Develop a new Workgroup to explore how best to streamline, simplify, and make transparent the prior authorization process for the CMC population as it relates to durable medical equipment (DME), supplies, and pharmaceuticals.

The CMCAC assigned its Workgroups the task of developing and executing work plans to accomplish these tasks during the year. Each Workgroup continued to be comprised of a broad variety of stakeholders, each representing an important perspective on the work of the committee. The membership of each Workgroup fluctuated during the year as some members needed to step away while others were added.

The SHHN Workgroup met biweekly during the first half of the year and then transitioned to monthly meetings in order to share updates, make decisions, plan for upcoming activities, and keep their work plan up to date.

The Data Workgroup remained on hiatus and its tasks were shifted to the SHHN Workgroup pending additional CMCAC activities that would need data analytics support.

The DME/Supplies Workgroup was launched and kicked off its work in May 2021 to streamline, simplify, and make transparent the prior authorization process for the CMC population as it relates to DME, supplies, and pharmaceuticals. The DME/Supplies Workgroup met bi-weekly to perform tasks.

Additional information regarding the major activities and accomplishments that the Workgroups achieved in 2021 can be found later in this report.

Impact of COVID-19

The first half of 2021 continued to be marked by the COVID-19 pandemic, which upended normal routines, closed businesses, moved schools and offices to remote operations, stretched resources, and forced families of children with medical complexity, in many cases, to forgo daily nursing supports due to fears related to contracting the coronavirus. Critical school supports were lost and families faced job losses and the loss of other natural supports due to the need to strictly quarantine to protect their children's health and safety.

Although some pandemic restrictions were relaxed, the public health emergency (PHE) continued through calendar year 2021. During this period DMMA maintained the following policy changes implemented in 2020 in response to the PHE:

1. Waived all premiums
2. Kept Medicaid eligibility in place (i.e., paused Medicaid eligibility redeterminations)
3. Provided coverage for COVID-19 testing
4. Provided coverage of COVID-19 diagnosis, testing, and treatment during the PHE to non-residents
5. Extended all Prior Authorizations for six months
6. Waived all pharmacy copays
7. Relaxed early refill limits and limits on certain DME items
8. Changed status of hydroxychloroquine to require a PA unless the member was previously established on this medication for lupus, rheumatoid arthritis and other autoimmune conditions
9. Instituted telehealth using Zoom and telephonic audio only where appropriate
10. Suspended all provider revalidations
11. Allowed temporary enrollment in Delaware Medicaid for providers who are appropriately enrolled in other states' Medicaid programs

Children with medical complexity and their families continued to face unique challenges during the pandemic. At the quarterly CMCAC meetings, families provided their perspective on the toll of COVID-19 and shared the difficulties they experience day-to-day with coordinating service coverage and navigating public health guidance to prevent spread of the virus.

The pandemic also continued to impact the work of the CMCAC. State offices remained open during the year, although many services were provided virtually or by appointment only. With State staff and other CMCAC members often working remotely, the group continued to meet virtually. Despite these challenges, the CMCAC and its Workgroups continued their work in the spirit of addressing the needs of children with medical complexity and their families.

Summary of 2021 Activities

The CMCAC made significant progress in 2021 towards achieving its objectives for the year. The following narrative documents the group's major accomplishments in each area of focus, followed by a chart that summarizes the 2021 activities.

1. Continue the work of the CMCAC

The CMCAC met virtually on a quarterly basis throughout the year. The meetings provided CMCAC members an opportunity to hear updates from the DMMA Medicaid Director and from the Workgroups, to provide input on their activities and to make decisions regarding next steps. CMCAC meetings also provided an opportunity for members to discuss the impact of COVID-19 on their lives and to receive updates on steps taken by DMMA and its sister agencies to address member and family needs during the PHE. A portion of each meeting was also reserved for public comment.

2. Evaluate capacity of PDNs via administration and analysis of the PDN Workforce Capacity Study

A significant accomplishment was the completion and final analysis of the PDN Workforce Capacity Study conducted by the Center for Research in Education and Social Policy, University of Delaware. The overall goal of the study was to understand what is happening with the PDN workforce and to identify gaps. The study involved interviews and survey of nursing agency providers, nurses and families. The SHHN Workgroup was engaged to act as a Steering Committee to help guide the project. Final study results were provided in November 2021 and are posted on the CMC website.

3. Conduct the Family Satisfaction Survey

The Family Satisfaction Survey was completed in 2021. Focused interviews were conducted with families whose children varied in age and in the severity of their medical conditions. All families of children with medical complexity were invited to participate in an online or paper survey to describe their level of satisfaction with the services they receive. Final survey results were provided in November 2021 and are posted on the CMC website.

4. Convene the DME/Supplies Workgroup

The DME/Supplies Workgroup was convened in May 2021 to explore how best to streamline, simplify, and make transparent the prior authorization process for children with medical complexity as it relates to DME, supplies, and pharmaceuticals. The Workgroup met on a bi-weekly basis and explored Third Party Liability considerations, the DME/Supplies Prior Authorization process, and the impact on families of needing to contract with multiple providers in order to access all of the supplies needed. Both MCOs provided an overview of their DME/Supplies Prior Authorization process. Also, families and DME providers shared their perspectives on issues, challenges and successful approaches for navigating the process of obtaining DME/Supplies.

5. Finalize the MCO Welcome and What to Expect letters

The SHHN Workgroup worked collaboratively with MCO representatives and their organizations to develop letters for use by care coordinators when communicating with families about PDN services. The *Welcome Letter* is used when families are approved for PDN services and outlines care coordination and other resources available to the family. The *What to Expect Letter* provides information about working with home care agencies and includes suggestions about how to manage PDN staffing issues and concerns. Both documents are posted on the CMC website.

6. Endorse nationally recognized care coordination standards of practice for CMC

The SHHN Workgroup reviewed resources of care coordination standards of practice for CMC that had been previously identified during the development of the Plan to determine if any of the work done previously could be leveraged for this task. Additional research was done to identify standards that may have been developed more recently.

Ultimately, the Workgroup recommended the CMCAC endorse use of the 2020 National Association for State Health Policy (NASHP) National Care Coordination Standards for Children and Youth with Special Health Care Needs (CYSHCN). The standards are designed to help state officials and other stakeholders develop and strengthen high-quality care coordination for children with the goal of identifying and assessing the need for care coordination, engaging families in the care coordination process, building a strong and supportive care coordination workforce, and developing team-based communication processes to better serve children and families².

²National Association for State Health Policy (NASHP). *National Care Coordination Standards for Children and Youth with Special Health Care Needs (CYSHCN)*. 2020. <https://www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/>

Summary of CMCAC 2021 Accomplishments

- Continued active engagement of the CMCAC via quarterly meetings.
- The SHHN Workgroup continued to meet regularly, first bi-weekly and later monthly.
- The DME/Supplies Workgroup was established and adopted a bi-weekly meeting schedule.
- Provided feedback to the Center for Research in Education and Social Policy, University of Delaware on the PDN Provider Workforce Capacity Study.
- Completed the PDN Workforce Capacity Study.
- Completed the Family Satisfaction Survey.
- Finalized and posted the MCO *Welcome Letter* and *What to Expect Letter* on the CMC website.
- Finalized and posted the 2020 Year End Report of CMCAC activities and accomplishments on the CMC website.
- Updated the CMCAC Short Term Priorities document for 2021 and posted on the CMC Website.
- Reviewed existing care coordination standards of practice, researched additional standards and recommended the CMCAC endorse use of the NASHP *National Care Coordination Standards for Children and Youth with Special Health Care Needs (CYSHCN)*.
- Initiated a review of the DMMA Medicaid Private Duty Nursing Policy Manual.
- Initiated discussions with the DMMA Program Integrity Unit regarding Third Party Liability and Coordination of Benefits related to obtaining DME/Supplies for CMC.
- Recommended the development of an MCO Care Coordinator training focused on best practices for supporting families with DME/Supply needs.
- Explored the potential development of a standardized template for DME/Supplies Prior Authorization requests. Ultimately, the Workgroup did not coalesce around this idea but did recommend development of a Frequently Asked Questions (FAQ) document specific to DME/Supplies.

Establishing 2022 Priorities

Looking ahead to 2022, the CMCAC and its Workgroups anticipate wrapping up the important work that was started in 2021. Carryover tasks include review of the Family Satisfaction Survey findings and the PDN Workforce Capacity Study results to determine how best to use the information gathered to develop actionable steps for addressing identified family satisfaction and workforce capacity issues. The DME/Supplies Workgroup is expected to continue its work to make the DME/Supplies Prior Authorization process transparent and to address issues/challenges identified by the Workgroup. It is anticipated that the CMCAC will finalize prioritization of activities and develop a formal plan for addressing its 2022 priorities at the January 2022 CMCAC meeting.