



Delaware Health and Social Services
Division of Medicaid and Medical Assistance

1901 N. DuPont Highway Newcastle, DE 19720

(302) 255-9040

dhss.delaware.gov

Delaware's Children with Medical Complexity
Advisory Committee
2020 Year End Summary

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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 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 accomplishments. Additional information regarding the group’s 2019 activities can be found in the 2019 Year-End Report, which is 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 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.
- Started working with Family Voices to develop competency/family-centered training materials for providers.
- Developed a Private Duty Nursing Emergent Care Decision Tree.

Organizing the Work for 2020 and Developing 2020 Objectives

CMCAC started 2020 by reflecting on its 2019 activities and developing objectives for 2020 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 2019. Additionally, the group sought to carry over tasks that were not completed in 2019. Among these carryover tasks were: 1) completing data analyses and surveys, 2) developing parent, caregiver and provider resources, 3) continuing to work to expand provider capacity, and 4) 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 2020 would be the following:

1. Continue the work of the CMCAC.
2. Evaluate provider capacity of private duty nurses via a PDN Workforce Capacity Study.
3. Improve the transparency of the Prior Authorization process and develop and disseminate the Prior Authorization Toolkit.
4. Develop Family Centered Competency Training resources for working with children with medical complexity and their families.
5. Finalize processes for supporting children with medical complexity when parents/caregivers are presented with emergent situations and develop the PDN Emergent Care Decision Tree and the Delaware Community Legal Aid Society, Inc. (DECLASI) Affidavit for Temporary Health Care Authorization.
6. Develop and distribute the Family Satisfaction Survey.

The CMCAC assigned its workgroups—the SHHN Workgroup and the Data Workgroup—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 throughout the year to share updates, make decisions, plan for upcoming activities, and keep their work plan up to date. The Data Workgroup met biweekly at the beginning of the year, primarily to finalize the data summaries for the 2019 report. However, the other tasks of the Data Workgroup were shifted to the SHHN Workgroup mid-year, as it was determined that the SHHN Workgroup provided a better venue for moving those tasks forward. The Data Workgroup was on hiatus for the third and fourth quarters of 2020, pending additional CMCAC activities that would need data analytics support.

Additional information regarding the major activities and accomplishments that the Workgroups achieved in 2020 can be found later in this report.

Impact of COVID-19

Much of 2020 was marked by the COVID-19 pandemic, which has 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. On March 13, 2020, the President issued a proclamation that the COVID-19 outbreak in the United States constituted a national emergency. State Medicaid programs across the country, including Delaware, promptly made changes to their program to ensure the continuity and availability of medical care for their members. Delaware quickly made the following policy changes in response to the pandemic:

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 public health emergency to non-residents
5. Extended all Prior Authorizations for 6 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 have faced unique challenges during the pandemic. At the April, July, and November CMCAC meetings, families provided their perspective on the toll of COVID-19. Parents communicated their feelings of exhaustion, fears of contracting the virus, concerns about services, DME, and medication shortages, and concerns about the economic impact of the pandemic, among others. Parents also shared the difficulties they experience day-to-day with coordinating service coverage and navigating public health guidance to prevent spread of the virus. The CMCAC meetings provided an opportunity for members to hear the perspective of families and to provide updates on measures taken to address member and family needs during the pandemic.

The pandemic also impacted the work of the CMCAC. State offices were closed for the majority of the year. With state staff and other CMCAC members working remotely, the group continued its meetings virtually. The CMCAC held its April, July, and November meetings remotely. The SHHN Workgroup also held its meetings remotely. Despite these challenges, the CMCAC and the SHHN Workgroup continued their work in the spirit of addressing the needs of children with medical complexity and their families.

Summary of 2020 Activities

The CMCAC made significant progress in 2020 towards achieving its objectives for the year. The following narrative documents the group's accomplishments in each area of focus, followed by a chart that summarizes the 2020 activities.

1. Continue the work of the CMCAC

The CMCAC met quarterly throughout the year. The meetings provided CMCAC members an opportunity to hear updates from the Workgroups, provide input on their activities, and make decisions regarding next steps. As noted previously, the April, July and November meetings also provided a forum for members to discuss the impact of COVID-19 and hear updates on steps taken by DMMA and its sister agencies to address member and family needs during the public health emergency. A portion of each meeting was also reserved for public comment.

2. Evaluate provider capacity of private duty nurses via a PDN Workforce Capacity Study

Another significant accomplishment was the kickoff of the PDN Workforce Capacity Study, which is being conducted by the University of Delaware Center for Disabilities Studies. The overall goal is to understand what is happening with the PDN workforce and to identify gaps. The study will involve interviews and a survey of nursing agency providers, nurses and families. The SHHN Workgroup has been engaged to act as a Steering Committee to help guide the project. Surveys are expected to be distributed in 2021 following the distribution of the Family Satisfaction Survey.

3. Improve the transparency of the Prior Authorization process and develop and disseminate the Prior Authorization Toolkit

The SHHN Workgroup made significant progress on the Prior Authorization Toolkit in 2019. The Toolkit is intended to provide families, providers and others with tools and information about the Prior Authorization process. The Toolkit is considered “a work in progress”. Materials will be added as they are developed by the Workgroup. Toolkit materials were posted on the CMC webpage and include:

- Delaware CMC PDN Emergent Care Decision Tree
- Delaware CMC Highmark Health Options Process for Urgent Prior Authorization PDN Requests
- Delaware CMC Highmark Health Options PDN Letter of Medical Necessity Checklist
- Delaware CMC Highmark Health Options PDN Letter of Medical Necessity
- Delaware CMC AmeriHealth Caritas of Delaware Policy for Urgent Prior Authorization PDN Requests
- Delaware CMC AmeriHealth Caritas of Delaware Letter of Medical Necessity Template
- DECLASI Temporary Custodian Healthcare Authorization

Families on the SHHN Workgroup identified the need for two additional documents to be used by Delaware’s managed care organizations (MCOs), Highmark Health Options and AmeriHealth Caritas of Delaware. The What to Expect Letter provides a description of family expectations, nursing agency expectations and common issues/challenges associated with the provision of private duty nursing. The second document, the Welcome Letter, provides information about private duty nursing care coordination and how MCOs and families can partner with one another to support the best possible care and supports. These documents are undergoing final revision and are expected to be completed and posted on the CMC website in the first quarter 2021.

4. Develop Family Centered Care Competency Training resources for working with children with medical complexity

Delaware Family Voices led the development of a PowerPoint training to address family centered care competency for providers supporting children with medical complexity and their families. The training materials are under development and, when complete, will be posted on the Family Voices website. In support

of the goal to provide family centered care competency resources, DMMA posted links to relevant webinars, including two that are Delaware specific, on the CMC website, which can be found at https://dhss.delaware.gov/dhss/dmma/cmc_resources.html.

5. Finalize processes for supporting children with medical complexity when parents/caregivers are presented with emergent situations and develop the PDN Emergent Care Decision Tree and the DECLASI Affidavit for Temporary Health Care Authorization

Workgroup members, and families in particular, provided input and guidance into the development of two key documents addressing supports for children with medical complexity when emergent issues arise impacting their parents/caregivers capacity to provide direct supports to them. The PDN Emergent Care Decision Tree was developed to outline the process for ensuring safe and appropriate supports for children during parent/caregiver emergencies and can be found online at https://dhss.delaware.gov/dhss/dmma/files/cmc_pdn_emergent_care_decision_tree.pdf. As noted above, the Decision Tree, as well as a number of other resources are part of the Toolkit developed to provide information for families, primary care providers, nursing agencies and others committed to supporting children with medical complexity and their families. All of the resources are posted on the CMC website.

The DECLASI led the development of the Affidavit for Temporary Health Care Authorization, intended to provide parents/guardians with a way to name a temporary custodian who can serve as a healthcare decision maker, on a short-term basis, for their minor children. Information about this process can be found online at <http://www.declasi.org/downloads/>.

6. Develop and distribute the Family Satisfaction Survey

The Family Satisfaction Survey was developed by a national survey entity, Vital Research. The COVID-19 pandemic also impacted the development of the survey, which originally planned to elicit input from family members of children with medical complexity using focus groups. Instead, focused interviews were conducted with families whose children ranged in age and in the severity of their medical conditions. The survey instrument was crafted using this input, as well as input from MCOs and providers, other nationally recognized surveys for children with medical complexity and significant input from family members on the SHHN Workgroup. Human Subjects Review Board (HSRB) approval was obtained and the survey will be distributed in January 2021.

In addition to the activities described above, DMMA, a parent representative on the CMCAC, Vital Research and Mercer were selected to provide a panel presentation at the national ADvancing States Home and Community Based Services (HCBS) virtual conference held in December 2020. The presentation provided the opportunity to spotlight the CMCAC's collaborative work on the Family Satisfaction Survey and DMMA's commitment to understanding and responding to the needs of children with medical complexity and their families.

A high-level summary of the group's major activities in 2020 is provided in the chart below.

Summary of CMCAC 2020 Accomplishments

- Continued active engagement of the CMCAC via quarterly meetings, which were held virtually in response to the COVID-19 pandemic.
- Developed the Family Satisfaction Survey and obtained HSRB approval for the survey.
- Kicked off the PDN Workforce Capacity Study.
- Finalized the PDN Emergent Care Decision Tree and Prior Authorization Toolkit.
- Developed the MCO What to Expect and Welcome letters.
- Reviewed initial drafts and provided input into the DE Family Voices Family Centered Care Competency Training Curriculum.
- Collaborated with DECLASI to develop the Affidavit for Temporary Health Care Authorization.
- DMMA, a parent representative on the CMCAC, Vital Research and Mercer presented at the 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 Private Duty Nursing Prior Authorizations.
- Continued active engagement of the CMCAC via quarterly meetings as well as two workgroups: the Skilled Home Health Nursing Workgroup and the Data Workgroup. Representation on the Workgroups reflected a broad array of stakeholders including families.

Establishing 2021 Priorities

Looking ahead to 2021, the CMCAC and its Workgroups anticipate continued progress on the 2020 objectives to wrap up the important work that was started but not finished in 2020. Carryover tasks include finishing the Family Satisfaction Survey and publishing the results, finishing the PDN Workforce Capacity Study and publishing the results, and continuing to post relevant materials and resources on the CMC webpage. The group anticipates using the results of the Family Satisfaction Survey and the PDN Workforce Capacity Study to inform its next steps to best meet the needs of children with medical complexity and their families.

In addition to these activities, the group also anticipates expanding its focus to take on other issues that were identified in Delaware's Plan for Managing the Health Care Needs of Children with Medical Complexity. Some potential areas include:

1. Addressing issues related to home-based physical, occupational, and speech therapy.
2. Continuing to work with the Medicaid MCOs in identifying and providing services to children with medical complexity.
3. Continuing to work with Logisticare (DMMA's Non-Emergency Medical Transportation vendor) to clarify, enforce, and revise policies as appropriate for children with medical complexity.
4. Continuing to address the impact of the COVID-19 pandemic.

These items will be presented to the CMCAC for review and, if endorsed, the Workgroups will update their work plans to account for completion of the work. Additional workgroups may be formed as appropriate. As these objectives are completed, the CMCAC will reevaluate the ability to take on additional priorities and will identify resources as needed to continue implementing recommendations from the 2018 Plan for Managing the Health Care Needs of Children with Medical Complexity.