



Delaware Health and Social Services
Division of Medicaid and Medical Assistance

Delaware's Children with Medical Complexity
Advisory Committee
2023 Year End Summary

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Background

In 2017, the State of Delaware’s Legislature, 149th General Assembly, instructed the Delaware Department of Health and Social Services (DHSS) to develop and publish a comprehensive plan for managing the healthcare 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 healthcare 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 healthcare 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 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 website:

https://dhss.delaware.gov/dhss/dmma/children_with_medical_complexity.html.

Summary of 2019–2022 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 2019–2022 accomplishments. Additional information regarding the group’s activities can be found in the 2019 through 2022 Year-End Reports, which are available on the CMC website (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 2019–2022 Accomplishments

- Continued active engagement of the CMCAC via quarterly meetings. These meetings have been held virtually since the COVID-19 pandemic.
- Continued active engagement of the CMCAC Workgroups: the Skilled Home Health Nursing (SHHN) Workgroup (2019–2022), the Data Workgroup (2019–2021), and the Durable Medical Equipment (DME)/Supplies Workgroup (2022). Representation on the Workgroups reflected a broad array of interested parties, including families.
- Launched a dedicated CMC website and posted resources, CMCAC meeting materials, and the Delaware–specific definition of CMC.
- Performed a comprehensive data analysis to identify the Medicaid/Children’s Health Insurance Program (CHIP) population of children with medical complexity and published results in the 2019 year-end report.
- Reviewed emergency department and inpatient hospital utilization and published results in the 2019 year-end report.
- Reviewed gaps in SHHN utilization.
- Reviewed initial drafts and provided input into the Delaware Family Voices Family Centered Care Competency Training Curriculum.
- Finalized a Private Duty Nursing (PDN) Emergent Care Decision Tree and Prior Authorization Toolkit.
- Developed managed care organization (MCO) “What to Expect” and “Welcome” letters and posted to the CMC website.
- 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 home- and community-based services (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.
- Completed a PDN Workforce Capacity Study.
- Completed a Family Satisfaction Survey.
- Reviewed existing care coordination standards of practice, researched additional standards and recommended the CMCAC endorse use of the National Academy for State Health Policy’s *National Care Coordination Standards for Children and Youth with Special Health Care Needs (CYSHCN)*.
- Reviewed the DMMA Medicaid PDN Policy Manual.
- Added language to the Medical MCO contract clarifying the types of documentation that can be accepted as evidence of third-party liability, and that this documentation shall be accepted on a one-time calendar year basis.

- MCOs delivered care coordinator training related to the role of the care coordinator in helping families order and maintain DME and supplies for their children.
- DMMA and the MCOs gathered information on the availability of patient portals and provider websites among DME/supply providers.
- Developed two informational sheets for families that answer frequently asked questions related to DME and supplies as well as pharmaceuticals.
- Completed edits to the PDN provider policy manual.
- Reviewed research of innovative solutions from other states regarding PDN workforce capacity challenges.
- Initial exploration of Health Homes option and ideas for caregiver training.

Organizing the Work for 2023 and Developing 2023 Objectives

CMCAC started 2023 by reflecting on its 2022 activities and developing objectives for 2023 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 carry over tasks that were initiated in 2022 but not completed that year. Among these carryover tasks was the review of the PDN Workforce Capacity Study results to create recommendations for next steps regarding strategies to support the PDN workforce and to identify additional subject matter experts to include in the Workgroup.

At the beginning of the year, the CMCAC determined that its objectives for 2023 would be the following:

1. Continue the work of the CMCAC.
2. Pursue strategies to address the PDN workforce shortage through the engagement of additional community partners and the development of an assessment methodology to better identify the care that a subset of the CMC population requires to live at home and thrive in their communities.
3. Identify opportunities to support families when there is a change in their child's DME/supplies.

To address the priorities regarding the PDN workforce shortage, the Skilled Home Health Nursing (SHHN) Workgroup formed two subgroups: the SHHN Medicaid-Focused subgroup and the SHHN Community Partners subgroup, in recognition that addressing PDN workforce issues requires collaboration among a variety of interested parties, including Medicaid and other community partners. The subgroups each created a work plan with activities and timelines to meet their identified objectives and each met once a month. The two subgroups were consolidated in October 2023.

To identify opportunities to support families when there is a change in their child's DME/supplies, the DME/Supplies workgroup developed and executed a work plan and met once a month in 2023.

These work plans were developed in the beginning of 2023 and provided a tool to organize and keep track of the work throughout the year.

Impact of COVID-19

As pandemic restrictions were relaxed, the public health emergency (PHE) related to COVID-19 was formally ended at the federal level on May 11, 2023. DMMA maintained the following policy changes through the end of the PHE:

1. Waiving all premiums and copays.
2. Keeping Medicaid eligibility in place (i.e., paused Medicaid eligibility redeterminations).
3. Providing coverage for COVID-19 vaccinations, testing, and treatment.

The return to more typical operations, or "unwinding" of particular pandemic-era policies began in Delaware as of April 1, 2023, including Resuming Medicaid eligibility redeterminations and resuming copays effective December 1, 2023.

DMMA continued to support families during the unwinding of the PHE to minimize loss of eligibility and maintain continuity of care. In quarterly CMCAC meetings, COVID-19 remained a standing agenda item and DMMA updated families and interested parties on the status of unwinding activities. DMMA informed the group that most CMC families would continue to be eligible and unlikely to lose coverage due to unwinding.

The pandemic also continued to impact the work of the CMCAC. With State staff and other CMCAC members working remotely or in hybrid fashion, 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 2023 Activities

The CMCAC made significant progress in 2023 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 2023 activities.

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 the review of recommendations and work products developed by the work groups. A portion of each meeting was also reserved for public comment. The CMCAC welcomed the new Committee Chair in 2023, DMMA Acting Medicaid Director Theodore Mermigos.

The CMCAC Workgroups also continued to actively meet during 2023. Each Workgroup continued to be comprised of a broad variety of interested parties, 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 Workgroup meetings provided an opportunity to share updates, make decisions, review draft work products, plan for upcoming activities, and keep the work plans up to date.

The Workgroups continued to maintain the CMCAC website throughout the year by posting quarterly meeting materials and other relevant information for CMC families.

Address the PDN Workforce Shortage

At the beginning of the year, the SHHN Workgroup developed a work plan for 2023 that mapped out the Workgroup's activities and timeframes associated with pursuing strategies to strengthen the PDN workforce. The Workgroup planned activities to support the following strategies:

- Engage additional interested parties to identify and champion PDN workforce capacity strategies based on findings in the University of Delaware's 2021 PDN Capacity Study that require community partnership beyond Medicaid.
- Further define the CMC population in need of private duty nursing to better align private duty nurses competency with each child's unique needs.

Engage Additional Interested Parties

The SHHN Community Partners subgroup was formed to pursue strategies to address the PDN workforce shortage outside of Medicaid's direct sphere of influence. To build the Community Partners subgroup, outreach was conducted across Delaware nursing groups to identify interested parties and recruit participants. Participants included representatives from a variety of organizations including but not limited to: Delaware Nursing Board, Delaware Nursing Association, and nursing home care provider agencies. The first activity of the year was to review the results of the PDN Workforce Capacity Study to determine next steps. The PDN Workforce Capacity study was conducted by the University of Delaware's Center for Disabilities Studies and Center for Research in Education and Social Policy in 2021 and examines the capacity of the home health nursing workforce in Delaware to meet the needs of CMC. The study includes interviews of family caregivers, PDN providers, non-PDN nursing providers, and

PDN agencies. The group's review and associated recommendations focused on the major findings from the reports, which included:

1. Inconsistent staffing and/or lack of staffing available for approved and medically necessary PDN hours.
2. Families covering unstaffed or understaffed hours intended to be filled by nurses.
3. Shortage of nurse educators and programs to address PDN homecare niche for new graduates.

The subgroup pursued activities to address the themes above, including exploring nurse educator programs and ways to highlight home-care nursing. Nurse educator programs were identified as a key step in recruiting nurses to work in private duty settings, particularly for CMC families. A representative from Bayada presented to the group on Bayada's Private Duty Nurse Education Program.

To learn more about other nurse education programs in Delaware and develop strategies to increase capacity for PDN agencies, the subgroup developed a survey for nursing agencies to gather information on: LPN and RN hiring practices, recruitment of retired nurses, clinical onboarding training, use of an established nurse training curriculum, relationships with nursing schools, use of the Clinical Nexus program, and interest in promoting PDN education and employment opportunities. The survey was sent to all PDN agencies in Delaware (17) and the group received responses from eight PDN agencies. The results of the survey were shared with the CMCAC during the October meeting.

One significant finding from the survey was that most agencies did not have an established relationship with nursing schools to help with recruitment and ongoing training of PDN. The majority of respondents indicated that they would be interested in learning more about how to establish these relationships. To address these issues, the subgroup began planning for an educational session in 2024 to provide information and opportunities for PDN agencies to build relationships with Delaware nursing programs and to work together toward solutions for the nurse educator shortages identified in the 2021 University of Delaware study.

The subgroup also engaged in efforts to highlight private duty nursing as a rewarding career path for current and future nurses. The subgroup celebrated Nurse Appreciation Month in May 2023 to encourage CMC families to nominate their home-care nurses for the Daisy Award, an award given by the Delaware Nursing Association. To further illustrate the vital role of home care nurses for CMC families, in fall of 2023, the subgroup began the process to create a Public Service Announcement (PSA) highlighting the experience of a CMC family and the benefits and rewards of home-care positions for nurses in Delaware.

The SHHN Community Partners and the Medicaid-Focused subgroups were re-consolidated in October 2023 and all members were invited to participate in the SHHN workgroup moving forward.

Further Define the CMC Population in need of homecare and private duty nursing

In 2023, the Medicaid-Focused subgroup focused on the development and recommendation of a Complex Care Supports Assessment Methodology. The original definition of CMC was not intended to serve as the basis for a particular benefit or service, nor denying or authorizing care and/or payment for care for children served through the Delaware Medicaid Program. As such, to implement additional strategies to support CMC and their families, the Workgroup developed a Complex Care Supports Assessment Methodology to focus on the usage and intensity of care that a subset of the CMC population requires to live at home and thrive in their communities. This methodology may help DMMA with current or future programming, service development or rate considerations to provide the right level and type of support from the appropriately credentialed medical professional. The Workgroup and CMCAC formally recommended the Complex Care Needs Assessment Methodology to DMMA in October 2023.

Identify Opportunities to Support Families when there is a Change in DME/Supplies

The DME/Supplies Workgroup met monthly throughout 2023 to address priorities related to the provision, maintenance, and coordination of DME and supplies for children with medical complexity. The group began the year by reviewing potential priorities for 2023 based on previous topics and issues identified by the Workgroup. Navigating unexpected changes in DME/Supplies can be burdensome and challenging to CMC families, and workgroup members identified challenges that families were currently experiencing related to supply changes. To address this, the Workgroup defined the 2023 priority as further supporting families when there is a change in DME/Supplies. To begin this work, the Workgroup collected information from a variety of perspectives including MCOs, DME/supply providers, and families to better understand situations when there are changes in DME or supplies and what happens currently in these situations. This enabled the workgroup to have a full picture of the current system of supports for families when there is a change in DME/Supply. Families face challenges in a variety of situations related to a change in equipment or supplies including when a child comes home from the hospital with new equipment or supplies, a child's needs change, there is a shortage or recall of a product, or a manufacturer stops making a product. The Workgroup brainstormed potential solutions to address these challenges, including additional education for families on new supplies and further communication channels to inform families in advance when there is going to be a change in supply. Based on a review of the potential solutions, the Workgroup identified the opportunity to improve information for families about these situations and the resources and supports available. The Workgroup worked collaboratively to develop an informational brochure for families titled "What to Expect When Your Child's Medical Equipment or Supplies Change". The brochure explains a variety of scenarios in which there can be an unexpected change in DME supplies, describes the sources of support families can reach out to for assistance, and provides tips and tricks for families. The brochure was posted to the CMCAC website and is [available here](#).

Toward the end of the year, the Workgroup also discussed supports for families to develop Care Notebooks as a helpful tool for families to keep all relevant information about their child in the same place, and as a place to keep educational resources from the CMCAC website. The Workgroup explored options available in Delaware and easy-to-access resources online to create Care Notebooks. The Workgroup began identifying resources in Delaware to help families develop a Care Notebook, including resources available through the Parent Information Center.

Summary of CMCAC 2023 Accomplishments

- Engagement of additional community partners outside of Medicaid sphere.
- Development and completion of PDN Nurse Educator Survey.
- Began process to develop a PSA to highlight the experience of a CMC family and the rewards and benefits of home care positions for nurses.
- Development of a Complex Care Support Needs Assessment Methodology to further define the CMC population requiring home care.
- Developed and published a brochure titled “What to Expect When Your Child’s Medical Equipment or Supplies Change.”
- Delaware First Health provided DME/Supply Care Coordination training.

Establishing 2024 Priorities

Looking ahead to 2024, the CMCAC and its Workgroups anticipate wrapping up the important work that was started in 2023. Carryover tasks include completion of the PSA regarding PDN, finalizing plans for an event for PDN agencies and Delaware Nursing schools to meet about the PDN workforce needs, and continuing to identify resources and supports for families in developing a care notebook. It is anticipated that the CMCAC will finalize prioritization of activities and develop a formal plan for addressing its 2024 priorities at the Q1 2024 CMCAC meeting.