



**Delaware Health and Social Services**  
Division of Medicaid and Medical Assistance

**Delaware's Children with Medical Complexity**  
**Advisory Committee**  
**2024 Year End Summary**

# Table of Contents

Background .....	3
Summary of Previous Years' Activities .....	3
Objectives and Work Plan for 2024 .....	6
New Initiatives or Program Changes .....	7
Summary of 2024 Activities .....	7
Establishing 2025 Priorities .....	11

## 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 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 to identify and manage 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 provides for Delaware's children with medical complexity, identify areas where improvements could be made, and suggest 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 workgroups<sup>1</sup>, 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 Plan can be found on the DMMA CMC website: [https://dhss.delaware.gov/dhss/dmma/children\\_with\\_medical\\_complexity.html](https://dhss.delaware.gov/dhss/dmma/children_with_medical_complexity.html).

## Summary of Previous Years' Activities

In 2019, the work of the CMC Steering Committee 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 accomplishments to date. Additional information regarding the group's activities can be found in the Year End Reports, which are available on the CMC website (link above).

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<sup>1</sup> The initial 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 in 2019, the Population Workgroup disbanded.

<b>Summary of CMCAC Accomplishments</b>	
<b>2019</b>	<ul style="list-style-type: none"> <li>● 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</li> <li>● Launched a dedicated CMC webpage and posted resources, CMCAC meeting materials, and the Delaware-specific definition of CMC</li> <li>● Performed a comprehensive data analysis to identify the Medicaid/Children’s Health Insurance Program population of children with medical complexity</li> <li>● Reviewed emergency department and inpatient hospital utilization and published results in the 2019 Year End Report</li> <li>● Reviewed gaps in SHHN utilization</li> <li>● Began planning for a Family Satisfaction Survey and Private Duty Nursing (PDN) Workforce Capacity Study</li> <li>● Started working with Family Voices to develop competency/family-centered training materials for providers</li> <li>● Developed a PDN Emergent Care Decision Tree</li> </ul>
<b>2020</b>	<ul style="list-style-type: none"> <li>● Continued active engagement of the CMCAC via quarterly meetings, which were held virtually in response to the Coronavirus Disease 2019 pandemic</li> <li>● Developed the Family Satisfaction Survey and obtained Human Studies Review Board approval for the survey</li> <li>● Kicked off the PDN Workforce Capacity Study</li> <li>● Finalized the PDN Emergent Care Decision Tree and Prior Authorization Toolkit</li> <li>● Developed the Managed Care Organization (MCO) What to Expect and Welcome letters</li> <li>● Reviewed initial drafts and provided input into the Delaware Family Voices Family Centered Care Competency Training Curriculum</li> <li>● Collaborated with the Delaware Community Legal Aid Society, Inc. to develop the Affidavit for Temporary Health Care Authorization</li> <li>● DMMA, a parent representative on the CMCAC, Vital Research, and Mercer presented at the national ADvancing States Home- and Community-Based Services virtual conference, highlighting the work on the Family Satisfaction Survey</li> <li>● Researched online materials/webinars for Family Centered Care and posted links on the CMC website</li> <li>● Developed revisions to the DMMA Medicaid Policy Manual to address MCO processes for PDN Prior Authorizations</li> <li>● Continued active engagement of the CMCAC via quarterly meetings as well as two workgroups: the SHHN Workgroup and the Data Workgroup. The Data Workgroup’s tasks were shifted to the SHHN Workgroup mid-year, and the Data Workgroup remained on hiatus for remainder of year</li> </ul>

<b>Summary of CMCAC Accomplishments</b>	
<b>2021</b>	<ul style="list-style-type: none"> <li>● Continued active engagement of the CMCAC via quarterly meetings</li> <li>● The SHHN Workgroup continued to meet regularly, first bi-weekly and later monthly</li> <li>● The DME/Supplies Workgroup was established and adopted a bi-weekly meeting schedule</li> <li>● Provided feedback to the Center for Research in Education and Social Policy, University of Delaware on the PDN Provider Workforce Capacity Study</li> <li>● Completed the PDN Workforce Capacity Study</li> <li>● Completed the Family Satisfaction Survey</li> <li>● Finalized and posted the MCO Welcome Letter and What to Expect Letter on the CMC website</li> <li>● Finalized and posted the 2020 Year End Report of CMCAC activities and accomplishments on the CMC website</li> <li>● Updated the CMCAC Short Term Priorities document for 2021 and posted on the CMC website</li> <li>● Reviewed existing care coordination standards of practice, researched additional standards and recommended the CMCAC endorse use of the National Academy for State Health Policy National Care Coordination Standards for Children and Youth with Special Health Care Needs</li> <li>● Initiated a review of the DMMA Medicaid PDN Policy Manual</li> <li>● Initiated discussions with the DMMA Program Integrity Unit regarding Third Party Liability and Coordination of Benefits related to obtaining Durable Medical Equipment (DME)/Supplies for CMC</li> <li>● Recommended the development of an MCO Care Coordinator training focused on best practices for supporting families with DME/Supply needs</li> <li>● Explored the potential development of a standardized template for DME/Supply 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</li> </ul>
<b>2022</b>	<ul style="list-style-type: none"> <li>● MCOs delivered care coordinator training to assist families with ordering and maintaining DME/Supplies for their children</li> <li>● DMMA and the MCOs gathered information on the availability of patient portals and provider websites among DME/Supplies providers</li> <li>● Developed two informational FAQ sheets for families that address DMEs/supplies and pharmaceuticals</li> <li>● Completed edits to the PDN Provider Policy Manual</li> <li>● Initial presentation of an extraordinary care definition as a possible option to address PDN workforce solutions</li> <li>● Initial exploration of the Health Homes option and ideas for caregiver training</li> <li>● Reviewed and updated the composition of then SHHN Workgroup</li> </ul>

Summary of CMCAC Accomplishments	
<b>2023</b>	<ul style="list-style-type: none"> <li>● Engagement of additional community partners outside of the Medicaid sphere such as nursing schools, trade associations, and employment agencies</li> <li>● Development and completion of PDN Nurse Educator Survey</li> <li>● Began to develop a Public Service Announcement (PSA) to highlight the experience of a CMC family and the rewards and benefits of home care roles for nurses</li> <li>● Development of a Complex Care Support Needs Assessment Methodology to further define the CMC population requiring home care</li> <li>● Developed and published a brochure titled “What to Expect When Your Child’s Medical Equipment or Supplies Change”</li> <li>● Delaware First Health provided DME/Supply Care Coordination training</li> </ul>

## Objectives and Work Plan for 2024

Based on 2023 activities and accomplishments, CMCAC developed objectives for 2024 to continue progress in achieving the short-term priorities drawn from Delaware’s Plan for Managing the Health Care Needs of Children with Medical Complexity. The committee continued to focus on the following tasks that began in 2023: completion of a PSA regarding PDN, finalizing plans for an event for PDN agencies, Delaware Nursing schools to meet about the PDN workforce needs, and identifying resources and supports for families to develop a Care Notebook.

At the beginning of the year, the CMCAC determined that its objectives for 2024 would be to:

1. Continue the work of the CMCAC
2. Continue the work of the SHHN Workgroup including completing the PSA regarding PDN and convening an in-person event to engage nursing schools and in-home agencies regarding the PDN workforce challenges
3. Create a taskforce to explore ways to further support families and create solutions related to changes in ENFit™ supplies (a brand of enteral feeding supplies)
4. Conduct a town hall for families regarding the Self-Directed Attendant Care (SDAC) and Respite programs added to the 1115 Waiver in January 2023 to address questions that families had regarding new services
5. Continue to research and identify solutions that address transportation concerns about having a PDN accompany a child to the hospital (in an ambulance or private vehicle)
6. Evaluate the structure, composition, and goals of CMCAC including review of the “parking lot,” a collection of topics of interest initiated in 2020

7. The Parent Information Center of Delaware and Delaware Family Voices provided training to CMC families on how to create a Care Notebook in February 2024.

## New Initiatives or Program Changes

**School-Based Services Grant** — In July 2024, DMMA was awarded a \$2.5 million grant from the Centers of Medicare and Medicaid Services (CMS) to support the expansion of school-based services. DMMA is working with the Delaware Department of Education to implement this grant.

**1115 Waiver Renewal** — In May 2024, Delaware’s 1115 Demonstration Waiver, the Diamond State Health Plan, was approved by CMS for a 5-year extension. The 1115 Waiver authorizes programs that impact CMC families, including SDAC and Medicaid Pediatric Respite. It is effective through December 31, 2028.

## Summary of 2024 Activities

The CMCAC made significant progress in 2024 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 2024 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 SHHN Workgroup 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 workgroups. A portion of each meeting was also reserved for public comment.

This year, the CMCAC welcomed the following new members:

- CMCAC Chair: Andrew Wilson, DMMA Division Director
- CMCAC Lead: Dr. Alethea Miller, Maternal and Child Health Clinical Director

The following DMMA staff were also introduced to the Committee:

- Dr. Krishna Upadhya, Chief Medical Officer
- Colleen Yezek, Chief of Managed Care Operations
- Joel Riley, Chief of Program Integrity

- Lenora Miller, Chief of Policy & Planning
- Michele Stant, Chief of Administration
- Malik Shakur, Executive Assistant in the Office of the Director

The SHHN Workgroup continued to actively meet during 2024. The Workgroup and its associated taskforces continued to be comprised of a broad variety of interested parties, each representing an important perspective on the work of the committee. The membership 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 Workgroup continued to maintain the CMCAC website throughout the year by posting quarterly meeting materials and other relevant information.

### **SDAC and Pediatric Respite Services**

One of the 2024 priorities for CMCAC was to address stakeholder questions about SDAC and pediatric respite services, two new services that were added to the 1115 Waiver in January 2023. On March 6, 2024, DMMA hosted a virtual town hall meeting to discuss these services. Materials from that event can be accessed [here](#). This town hall clarified eligibility criteria for both new services and included a public Q&A session which demonstrated that additional educational materials may be needed to support families whose children use these services and providers who deliver these services.

A workgroup was convened following the town hall to develop a FAQ document and workflow to help improve stakeholder understanding of these services. Collectively the workgroup's efforts focused on understanding eligibility, hour limits, the roles of the Employer Representative, family, MCO, and the Financial Management Services agency. The SDAC FAQ document is near completion and once finalized, will be posted to the CMCAC website. MCO care coordinators should continue to provide support to families with questions regarding SDAC.

In July 2024, public comments were gleaned from the CMCAC quarterly meeting about the pediatric respite service. A new workgroup will be convened in 2025 to develop a FAQ document or similar resource that further addresses pediatric respite.

### **Continue to Address the PDN Workforce Shortage**

Among the carryover activities from 2023, the SHHN Workgroup continued to engage interested parties to identify and champion PDN workforce capacity strategies based on findings in the University of Delaware's 2021 PDN Capacity Study (available on the DMMA CMC website) that require community partnership beyond Medicaid. Two of the suggested activities were to:

- (1) Develop a PSA about PDN to encourage new nursing graduates to pursue careers in-home care



nursing and to educate the public about the importance of in-home nursing care for CMC families.

- (2) Organize and deliver an in-person event for nursing schools, home care agencies, government programs, and other stakeholders to address initiatives and resources that will promote in-home nursing care for CMC families.

DMMA continued development of the PSA in 2024 including defining the media scope and content and identifying consenting families and home care agencies to showcase the work of PDN. DMMA anticipates release of the PSA in the spring of 2025.

On June 28, 2024, DMMA hosted an event titled, **Promoting Relationship Building and Collaboration between Delaware Nursing Schools and Delaware Home Health Agencies** at the Del-One Conference Center, Terry Campus, Delaware Technical Community College, Dover. Three nursing schools, 16 home care agencies, the Delaware Association of Home and Community Care, the Delaware Nurses' Association, the Delaware Board of Nursing, and DMMA participated. Below is a photo of some of the attendees at the event.



The following recommendations came from participants:

- Complete and release the PSA regarding PDN
- Evaluate availability and utilization of home care placements by new nursing graduates including how clinical supervision is afforded in these placements
- Develop a recorded presentation that highlights several home care agencies for use in enhancing existing nursing school curricula that introduces nursing students to home care opportunities
- Develop an assessment tool for nursing students to self-evaluate and inform on their likelihood of success and fulfillment from working in a home care setting

The SHHN Workgroup will continue collaboration with participants from the in-person event in 2025 to initiate these recommendations and continue to evaluate the impact that these have on the recruitment and retention of PDN for CMC families.

## **ENfit™ Supplies Taskforce**

At the end of 2023, the decision was made to discontinue the routine work of the DME/Supplies Workgroup. In February 2024, a new taskforce was developed to address challenges that families were experiencing with the transition to ENfit™ enteral feeding supplies. The areas of concern expressed by families included coordination and clarification of benefits coverage for these supplies, family support and training regarding the supplies, and support for school nurses who may also need to be aware of the change.

In March 2024, DMMA provided education and training to the CMCAC regarding the ENfit™ transition. Materials from that presentation can be accessed [here](#). The taskforce continued their work throughout the remainder of the year to address availability of supplies through pharmacies instead of through DME vendors, education efforts with families, and creating proper bill codes for pharmacies and DME vendors to ensure that all components of ENfit™ supplies had the correct coverage.

Appreciation goes to Brian Mabie, DMMA Pharmacy Director, who worked collaboratively with the taskforce members and sought solutions at both the state and federal levels. Brian looked to identify how best to set up billing codes and procedures for providers, but also to seek a one-stop solution with pharmacies to help minimize stress for families. While a final solution remains to be published, the taskforce concluded their work in November 2024 with high confidence that concerns had been heard and addressed effectively.

## **Providing PDN during Emergency and Non-Emergency Medical Transportation**

DMMA followed up on transportation concerns raised in 2023 regarding having a PDN accompany a child to the hospital (in an ambulance or private vehicle). DMMA consulted with CMS to provide technical guidance on possible duplication of services. Utilization data is under evaluation to determine the scope and breadth of CMC families' use of PDNs during emergency and non-emergency medical transportation to guide any policy updates. This work will continue into 2025.

### Summary of CMCAC 2024 Accomplishments

- Convened a Town Hall regarding SDAC and pediatric respite services
- Completed a FAQ document and workflow regarding SDAC
- Conducted an in-person event to promote collaboration among community agencies interested in promoting PDN for CMC families
- Convened an ENfit™ taskforce to address enteral feeding supply changes and benefits coverage concerns (taking the place of DME/Supplies Workgroup that disbanded in 2023)
- Began to research and identify options for providing PDN during emergency medical transportation

## Establishing 2025 Priorities

Looking ahead to 2025, the CMCAC and its workgroups anticipate wrapping up the important work that was started in 2024. These tasks include developing a FAQ document for pediatric respite, completion of the PSA regarding PDN, initiation of PDN promotion activities with nursing schools and home care agencies, and continued evaluation of PDN and family use of emergency transportation. It is anticipated that the CMCAC will finalize prioritization of activities and develop a formal plan for addressing its 2025 priorities at the Quarter 1 2025 CMCAC meeting.