



Delaware Health and Social Services
Division of Medicaid and Medical Assistance

Delaware's Children with Medical Complexity
Advisory Committee
2022 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 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 website:

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

Summary of 2019–2021 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 2019–2021 accomplishments. Additional information regarding the group's activities can be found in the 2019 through 2021 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 2019–2021 Accomplishments

- Continued active engagement of the CMCAC via quarterly meetings, which have been held virtually during 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 stakeholders 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 PDN Emergent Care Decision Tree and Prior Authorization Toolkit
- Developed 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 Private Duty Nursing (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 managed care organization (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

Organizing the Work for 2022 and Developing 2022

Objectives

CMCAC started 2022 by reflecting on its 2021 activities and developing objectives for 2022 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 2021 but not completed that year. Among these carryover tasks were the review of the Family Satisfaction Survey findings and the PDN Workforce Capacity Study results, and the continuation of work on the transparency of the DME/Supplies Prior Authorization process.

At the beginning of the year, the CMCAC determined that its objectives for 2022 would be the following:

1. Continue the work of the CMCAC
2. Review results of the Family Satisfaction Survey and PDN Workforce Capacity Study to create recommendations for next steps
3. Work with MCOs to streamline, simplify, and make transparent the prior authorization process for children with medical complexity as it relates to DME, supplies, and pharmaceuticals

The CMCAC assigned its Workgroups the task of developing and executing work plans to accomplish these tasks during the year. These work plans were developed and approved in the beginning of 2022 and provided a tool to organize and keep track of the work throughout the year.

In addition to the CMCAC's identification of objectives for the year, DMMA also evaluated next steps related to reviewing the Children's Community Alternative Disability Program (CCADP) policies and processes for potential recommendations. With limited resources for the year, it was determined that the priorities above took precedence over the review of CCADP policies and procedures. As part of the 2023 planning process, DMMA will evaluate the feasibility of reviewing CCADP policies and procedures in 2023.

Another priority for 2022 that spanned across the objectives listed above was continuing to publish information and resources for families of children with medical complexity and their providers. This was accomplished primarily through the CMCAC website. To increase awareness of these resources among providers, DMMA will work in 2023 to identify the best way to include a link to the CMCAC website on the Delaware Medical Assistance Provider Portal.

Lastly, DMMA also determined that as part of its 2022 work plan, DMMA would continue to monitor its non-emergency medical transportation (NEMT) provider as it relates to the provision of transportation services for children with medical complexity. This was accomplished through DMMA's regular vendor monitoring efforts. In 2022, no specific issues were identified related to children with medical complexity.

Impact of COVID-19

Although some pandemic restrictions were relaxed, the public health emergency (PHE) continued through calendar year 2022. During this period, DMMA maintained the following policy changes in response to the PHE, including:

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 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. DMMA also continued to prepare for the unwinding of the PHE to minimize loss of eligibility and maintain continuity of care.

Summary of 2022 Activities

The CMCAC made significant progress in 2022 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 2022 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 Workgroups (SHHN and DME/Supplies) also continued to actively meet during 2022. 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 monthly and the DME/Supplies Workgroup met twice monthly throughout the year. 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.

Review Results of the Family Satisfaction Survey and PDN Workforce Capacity Study for Recommendations and Next Steps

At the beginning of the year, the SHHN Workgroup developed a work plan for 2022 that mapped out the Workgroup's activities and timeframes associated with reviewing the Family Satisfaction Survey and PDN Workforce Capacity Study and developing recommendations for next steps. The Family Satisfaction Survey was conducted by Vital Research to better understand a broad range of family experiences accessing and receiving healthcare and supports for their children. The results of the Family Satisfaction Survey were presented to the CMCAC in 2021 and are available on the CMCAC website.

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 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 results of the PDN Workforce Capacity Study were presented to the CMCAC in 2021 in the form of four reports, which are available on the CMC website.

Review of Family Satisfaction Survey and PDN Workforce Capacity Study and Development of Recommendations

The SHHN Workgroup spent much of Q1 2022 reviewing and analyzing the Family Satisfaction Survey and PDN Workforce Capacity Study then developing action steps in response to the findings. The group's review and associated recommendations focus 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

Two activities were developed in response to this analysis — a need for review and revision of state policies related to PDN and a need for solutions in response to the aforementioned workforce

shortages. In terms of the work to be accomplished in 2022, the group prioritized edits to the Medicaid PDN Provider Policy Manual, exploring policy solutions to the PDN workforce shortages, and evaluating the composition of the Workgroup to ensure that all relevant stakeholders are included.

Edits to PDN Provider Policy Manual

Much of the SHHN Workgroup's time in Q2 and Q3 was spent reviewing and finalizing edits to the PDN Provider Policy Manual. DMMA collected input from the Workgroup members on required edits. Input was provided by a variety of stakeholders participating in the group. Through its monthly meetings, the Workgroup finalized updates to the manual. The updates were intended to:

1. Clarify that the manual's scope is specific to children under age 21 and clarify the policy basis for PDN within Medicaid regulations
2. Regarding medical necessity, provide a more detailed definition that aligns with the General Policy Manual, and clarify that medical necessity could allow for the maintenance of adaptive functioning, not solely attaining or retaining independence
3. Regarding service definitions:
 - a) Clarify the types of settings where PDN is provided
 - b) Include flexibility for the provision of Home Health Agency and Certified Nursing Assistant (CNA) services for individuals who do not meet entrance or maintenance criteria for PDN
 - c) Remove language referencing cost of care, stressing that review of medical necessity for PDN services will be considered according to Early and Periodic Screening, Diagnosis, and Treatment
4. Regarding qualified providers, remove detail about total hours worked per shift to align with Department of Labor regulations.
5. Add language indicating that care coordination will be provided to all children receiving eight or more hours of PDN when the child is served by a Medicaid MCO.
6. Regarding documentation:
 - a) Add language regarding documentation standard
 - b) Clarify that assessments must be comprehensive and detail specifically the nursing skills required to meet the child's care needs
7. Regarding reimbursement:

- a) Add language to indicate that MCOs establish rates for reimbursement
 - b) Remove language indicating that rates will be reviewed annually, as this is not a current practice
8. Regarding prior authorization:
- a) Remove language referencing sending requests to specific state office locations, as some offices are no longer receiving requests
 - b) Update to reflect current DMMA prior authorization practices
 - c) Add language regarding MCO authorization processes

DMMA anticipates publishing the updated PDN Provider Policy Manual in 2023.

Exploration of Extraordinary Care Definition

For the remainder of Q3 and Q4, the SHHN Workgroup reviewed possible solutions to address the PDN workforce shortage. In August, the Workgroup reviewed innovative solutions in Colorado, Texas, Hawaii, Arizona, Oklahoma, Minnesota and Missouri. Solutions ranged from flexible family reimbursement options, HCBS waiver flexibilities allowing families to serve as paid caregivers for minor children, state efforts to offer CNA credentialing to families to be paid as personal care attendants, and the use of travel nursing agencies and flexible scheduling for nurses. A common theme among states employing such creative solutions to the nursing workforce shortage was the evaluation, development, and implementation of an extraordinary care definition to distinguish the more intensive and complex care needs that CMC require.

The SHHN Workgroup continued its exploration of these topics by considering three possible options for application of an extraordinary care definition in Delaware:

1. The creation of enhanced reimbursement rates to help incentivize nurses to accept CMC work
2. The creation of an option to pay family members who are caregivers of minor children through approved HCBS waivers
3. The creation of paid stipends for families covering hours not staffed by nurses due to workforce shortages

The consideration of how and if to recommend the development of an extraordinary care definition is expected to continue into next year's work plan for the SHHN Workgroup.

Exploration of New Federal Health Homes Option

DMMA and the Workgroups continued to explore further ways to support families of CMC in 2022, including pursuing a Health Homes option published by the Centers for Medicare and Medicaid Services in August 2022. The Health Homes option gives states the opportunity to cover health home services for Medicaid eligible children under age 21 with medically complex conditions who choose to enroll in a health home by selecting either a designated provider, a team of healthcare professionals operating with a designated provider, or a health team as the child's health home services provider. The goal of this benefit is to support the coordination of prompt care and improve health outcomes for children with medical complexity.

DMMA reviewed the option in detail to determine whether pursuing this would be feasible and beneficial for the State from the perspective of alignment with the goals of the CMCAC. As a result of the review, DMMA determined that the health home option is not the best avenue for achieving the goals of the CMCAC, particularly related to care coordination. In discussion of this option with the CMCAC and SHHN work group, DMMA received a suggestion regarding caregiver training and employment as a way to use the health home option. It is expected that DMMA and the SHHN Workgroup will continue to review other opportunities to pursue the goals around caregiver training and the benefits of the health home option.

Composition of the SHHN Workgroup

As part of the review of the PDN Workforce Capacity Study review completed by the Workgroup in Q1, it was recommended that the composition of the Workgroup reflect the diversity of stakeholders intersecting with the PDN workforce. The SHHN Workgroup examined its composition during Q3 and added two additional family members to its membership and welcomed new attendees succeeding previous members. The overall composition of the Workgroup currently includes family members, all contracted Medicaid MCOs with representation from PDN, care coordination and utilization management personnel, DMMA policy leaders, the Delaware Community Legal Aid Society, Nemours Children's Hospital, and several PDN providers. The MCOs also are encouraged to invite subject matter experts to attend SHHN Workgroup meetings that may have agenda items covering specialized subject areas.

Work with MCOs to Streamline, Simplify, and Make Transparent the Prior Authorization Process for CMC as it Relates to DME, Supplies, and Pharmaceuticals.

The DME/Supplies Workgroup met twice monthly throughout 2022 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 developing a work plan that outlined specific tasks and initiatives for the year that were aligned with the priorities identified.

Related to streamlining, simplifying, and making transparent the prior authorization process for children with medical complexity — as it relates to DME, supplies, and pharmaceuticals — the group identified three primary tasks for the year:

1. Completing work that began in 2021 to develop a MCO care coordinator training that reinforces the role of the care coordinator in the prior authorization process
2. Developing an informational fact sheet for families of children with medical complexity that answers frequently asked questions related to ordering, maintaining, and coordinating DME and supplies
3. Developing a separate informational fact sheet for families of children with medical complexity that answers frequently asked questions related to ordering, maintaining, and coordinating pharmaceuticals

MCO Care Coordinator Training

DMMA and the Medicaid MCOs worked with the DME/Supplies Workgroup to finalize the MCO care coordinator training slide deck in early 2022. The feedback provided by the group enhanced the training by ensuring that it represented perspectives and the lived experience of families, providers, and other stakeholders. The final training materials:

1. Reinforce a proactive approach to care coordinator support for members and families
2. Describe the role of the care coordinator in educating caregivers about the often-complicated DME and supply benefit
3. Provide information on how care coordinators can help families select a DME/supply provider
4. Describe what to do when a member also has commercial insurance in addition to Medicaid.

The training also includes scenarios frequently encountered by families regarding DME and supplies as a way to train care coordinators on how to work through these scenarios. The intent of the care coordinator training is to help promote consistent, high-quality care coordination services for members and families as they navigate MCO and provider processes related to DME and supply orders (both initial and ongoing). Both MCOs provided the care coordinator training to their staff in 2022, and the training materials were posted on the CMCAC website for future use.

DME and Supplies Informational Fact Sheet

As the care coordinator training was finalized, the group turned their attention to the second initiative for the year, which was to develop a DME and supplies informational sheet to answer family's frequently asked questions. The development of the informational sheet was a collaborative process

among the Workgroup participants. Families, MCOs, providers, and other stakeholders on the group all offered their input on the most frequently asked questions about DME and supplies and helped to craft answers to these questions. Attention was paid to making sure the questions and answers were phrased in plain language that is easy to understand. As a final step in the process, a graphic designer reviewed the informational sheet to ensure the layout, look, and feel of the document was user-friendly.

The final informational sheet was posted on the CMCAC website at the end of 2022. The informational sheet is intended as an educational tool for families, illustrating how to work with MCO care coordinators to identify DME and supply providers, to obtain prior authorization when required, and to obtain and maintain medically necessary equipment and supplies.

DME and Supply Provider Websites and Patient Portals

Through development of the MCO care coordinator training and the DME and supply informational sheet, families raised a separate but related issue regarding DME and supply provider websites and patient portals. Often, providers post information about their locations, contact information, and available DME and supplies on their website. They also offer patient portals for members to get information on their particular DME and supply orders and, in some cases, communicate with the provider. However, families sometimes lack information about a provider's website and patient portal. DMMA worked with the MCOs to gather information from providers regarding websites and patient portals. This work was started in 2022 and will carry over into 2023. The end goal is to make information regarding provider websites and patient portals available to families so they can easily use these tools in coordinating DME and supplies.

Pharmaceuticals Informational Fact Sheet

In addition to these activities related to DME and supplies, the Workgroup also focused in 2022 on addressing issues related to pharmaceuticals. In February 2022, the Workgroup held a focused meeting that was dedicated to gathering information on issues that families often encounter related to pharmaceuticals. The issues gathered were documented and the group brainstormed activities and initiatives to address the identified issues. The immediate task identified for 2022 was to develop an informational sheet — similar to the DME and supply informational sheet discussed above — specifically related to pharmaceuticals.

The pharmaceutical information sheet includes answers to questions, that represent pain points or areas of confusion, that families may encounter in requesting, obtaining, and maintaining their children's pharmaceuticals and pharmaceutical supplies. The sheet contains answers to frequently asked questions on topics such as prior authorizations, orders, and co-pays. Like the DME and supply informational sheet, the pharmaceutical information sheet is intended as an educational tool to provide families with the information they need to work with their child's providers, pharmacies, and care

coordinator to obtain and maintain needed pharmaceuticals. The pharmaceutical information sheet was also finalized in 2022.

Summary of CMCAC 2022 Accomplishments

- 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
- Initial presentation of an extraordinary care definition as a possible option to address PDN workforce solutions
- Initial exploration of Health Homes option and ideas for caregiver training
- Reviewed and updated the composition of the SHHN Workgroup

Establishing 2023 Priorities

Looking ahead to 2023, it is anticipated that the CMCAC will finalize prioritization of activities and develop a formal plan for addressing its 2023 priorities at the Q1 2023 CMCAC meeting. Priorities may include continuing to work on carryover tasks from 2022 such as initiatives and strategies to implement the recommendations in the PDN Workforce Capacity Study, and continued work through the DME/Supplies Workgroup to make the DME/Supplies Prior Authorization process transparent and to address issues/challenges identified by the Workgroup.

Letters to Medicaid Director from Families

As a founding member of the Children with Medical Complexity Advisory Committee (CMCAC), I have had the opportunity to work with Director Stephen M. Groff since January of 2018 through the end of this year. I consider it a privilege to have worked so closely with Director Groff over the last five years. This is mostly in part to the empathy, support, and consideration he shows to our community's needs and the struggles and challenges families of medically complex children face. He not only encourages families to speak up and share their experiences, but he also listens to what we have to say and always seeks to assist and attempt to provide solutions.

When I think of Steve's role in the CMCAC, Brian Tracy's words come to mind: "Leaders think and talk about the solutions. Followers think and talk about the problems." Steve's insights and ability to navigate complex situations during our CMCAC meetings have greatly influenced our work on the committee. His inspiring support has motivated me to think creatively and helped all of us to become stronger and more effective advocates for our children, individuals with disabilities, and their families.

Steve will be sorely missed, but I wish him the best on this next chapter in his life. Congratulations, Steve!

Sincerely,

Olga Zapata

I began working with Director Groff in 2018 to help develop Delaware's Plan for Managing the needs of Children with Medical Complexity and continue serving to present. Director Groff not only invited parents (us) to the table, he gave us a favored spot and set the table. He invited key players so that not only would we have a voice, but we would also be "heard"....we would be welcomed....we would become an integral part of the puzzle that was missing previously. Director Groff set the tone so that others at the table would feel the same way. He is sincere in his desire to help our children, to help us. We always left that table feeling that way; knowing that to him we were not a check box.

Director Groff's departure has left some very big shoes to fill. His footprint leaves a mark on our hearts. While he will no longer be sitting at the table with us, we are confident that he will ensure our invitation continues and that we are "heard". It is rare to have someone in a position such as he was to invite families to the table, welcome criticism as a need to change and act on turning that into policy. He is one in a million and we wish him only the best on his well-earned retirement.

Sincerely,

Maria Olivere