

DELAWARE'S CHILDREN WITH MEDICAL COMPLEXITY ADVISORY COMMITTEE

January 9, 2024

9:00 AM – 11:00 AM

Meeting Notes

Welcome and Roll Call	<p>New DMMA Director Andrew Wilson introduced himself as the Chair of CMCAC. He welcomed everyone to the CMCAC meeting and thanked the CMCAC for the work that has been done thus far for children in Delaware. He also announced the retirement of the DMMA Chief of Managed Care Operations in December, 2023. Attendees announced their name and affiliation via the chat box.</p>
DMMA Update	<p>DMMA Chief of Policy and Planning provided an update on the following information:</p> <ul style="list-style-type: none"> • DDDS has submitted their lifespan waiver for renewal which is up for public comment at this time. • The Consolidated Appropriations Act requires states to provide children up to age 19 with 12 months of continuous eligibility for Medicaid and CHIP. Children will remain eligible for a full 12 months regardless of changes in family circumstance, with some exceptions DMMA will continue providing updates on this topic • DMMA is working with the Delaware Department of Education regarding School Based Services and new guidance from CMS. <p>DMMA followed up on transportation concerns raised in the last CMCAC meeting regarding having a Private Duty Nurse (PDN) accompany a child to the hospital (in an ambulance or private vehicle).</p> <ul style="list-style-type: none"> • A parent advocate described an example situation of how families experience challenges with transportation to and from the hospital with PDN. Parent advocates explained the importance of a child's nurse accompanying them to the hospital, as they are the one who knows the child well and can act as a support system in these situations. • Parent advocates stated that in the past there was a waiver form families could fill out to allow their PDN to ride with the child. In some cases, nurses have more recently been able to accompany the child with the family in the family's vehicle, though this practice is not uniform. • Representatives from PDN agencies and home care agencies provided their perspective regarding transportation. One agency confirmed that in some cases nurses are able to ride in the car with the family. Another agency stated that nurses can accompany children to medical appointments when it is deemed medically necessary to provide care during transport. • The group discussed medical necessity for nurse level of care during transport. One representative shared information from the DMMA PDN policy manual. The group discussed MCO care coordinators as a potential source of support for families in coordinating assessment of the child's medical need for nurse level of care during transport. • DMMA will continue to look into this issue and potential resolutions.

CMCAC Year End Report	DMMA provided an overview of the 2023 CMCAC Year End Report and asked for any suggested edits from the group by the end of the week. Once finalized, the report will be published to the CMCAC website.
SHHN Quarterly Report	An overview of the Skilled Home Health Nursing (SHHN) Workgroup Quarter 4 Report was provided. The report includes Workgroup actions, key issues noted, and upcoming activities. The Quarter 4 Report is available on the DMMA CMCAC website.
DME and Supplies Quarterly Report	An overview of the DME and Supplies Workgroup Quarter 4 Report was provided. The report includes Workgroup actions, key issues noted, and upcoming activities. The Quarter 4 Report is available on the DMMA CMCAC website.
Priorities and Planning for 2024	<p>DMMA Chief of Policy and Planning provided an update on proposed priorities and planning for CMCAC in 2024. DMMA thanked the CMCAC for all of the hard work and accomplishments since the creation of the group five years ago. In terms of priorities and planning for 2024, DMMA proposes continuing the work of the SHHN workgroup to pursue 2023 carryover tasks and pausing the DME and Supplies workgroup as the workplan was completed in 2023. DMMA proposes also focusing 2024 on evaluation and planning on the structure, composition, and goals of the CMCAC moving forward. The group discussed strategic planning and parent advocates suggested that this should include evaluating past concerns including the CMCAC "parking lot".</p> <p>Parent advocates raised concerns about the pausing of the DME and Supplies workgroup due to ongoing challenges regarding Enfit Supplies, as discussed in the DME and Supplies workgroup in 2023. Parents described the challenges of feeding their children with the new supplies. The Enfit supplies issue was discussed in detail by family advocates, a representative from a DME and Supply Company, and a school nursing representative, including the below:</p> <ul style="list-style-type: none"> • A parent advocate explained that they are unable to use the new Enfit supplies to vent their child through their feeding tube and if pharmacies could be required to provide adapters with the Enfit devices. • Another parent advocate cited the Enfit supply as a challenge for many families of children with feeding tubes, and parents/caregivers have turned to each other for support as well as sharing workarounds they have discovered. • A representative for a DME/supply provider explained that this is not just an issue in Delaware, that this change to Enfit supplies has been widespread across states. They cited the DME/supply providers as a potential support for parent training and education regarding the new supplies. <p>As the concerns related to Enfit Supplies are still prevalent and challenging for families, DMMA proposed the creation of a taskforce to explore ways to further support families and create solutions related to the changes in Enfit Supplies. DMMA will reach out to CMCAC members soon about the development of the Enfit Task Force.</p>
Groups with Work that Align with CMCAC	<p>Groups with work that align with CMCAC provided updates:</p> <p>A member of the Governor’s Advisory Council for Exceptional Citizens (GACEC) provided an update. The GACEC created a committee to focus on education for children with complex conditions. GACEC is focusing on a variety of issues related to education such as PDN staffing during the school day including for medication administration or skin care. GACEC is working with DOE on resolutions. The group is also working to define the population of children, including reviewing the CMCAC</p>

	<p>definition, in order to identify the number of children with medical complexity in school settings. A representative from the Parent Information Center of Delaware (PIC of Delaware) provided an update regarding upcoming trainings. PIC, in collaboration with Delaware Family Voices, is organizing a Care Notebook Training, scheduled for February 2024. The Care Notebook training was created because of requests by CMC families during workgroup meetings. Information about the training will be posted to the CMCAC website. PIC also has an upcoming training regarding health homes.</p>
<p>COVID-19 PHE Unwinding Update</p>	<p>DMMA provided an update regarding COVID-19 unwinding and answered questions from the group. A parent advocate described the challenges associated with their Children’s Community Alternative Disability Program (CCADP) renewal process and suggested that DMMA explore how this process could be easier for families, including additional training for call center staff and a simpler online renewal process.</p> <p>DMMA explained that since renewals were on hold for a while, some call center staff may be processing renewals for the first time at this time. DMMA will follow up on these concerns.</p>
<p>Future CMCAC Meetings</p>	<p>April 9, 2024 at 9:00AM</p>
<p>Public Comment</p>	<p>A parent advocate requested a town hall for families regarding the Self-Directed Attendant Care (SDAC) and Respite programs to discuss the status of the programs and potential changes for the future. Parent advocates explained that there are unresolved challenges in relation to SDAC. DMMA will work on setting up a town hall and will reach out to families with additional information.</p> <p>An attendee voiced concern regarding care manager attendance at Individualized Educational Program (IEP) meetings. A representative from an MCO explained that care managers only attend IEP meetings if asked.</p>

📌 All CMCAC meetings are currently held via Zoom due to the COVID-19 PHE.