

# DELAWARE'S CHILDREN WITH MEDICAL COMPLEXITY ADVISORY COMMITTEE

April 9, 2024

9:00 AM – 11:00 AM

## Meeting Notes

<b>Welcome and Roll Call</b>	<p>The Children with Medical Complexity Advisory Committee (CMCAC) Chair and Division of Medicaid and Medical Assistance (DMMA) Director Andrew Wilson welcomed everyone and opened the meeting. He introduced new DMMA staff, including Collen Yezek, Chief of Managed Care Operations, Chief Medical Officer, Dr. Krishna Upadhy, and Chief of Program Integrity, Joel Riley. Dr. Upadhy introduced herself to the CMCAC.</p> <p>Attendees recorded their name and affiliation in the chat box.</p>
<b>DMMA Update</b>	<p>DMMA Chief of Policy and Planning provided an update on the following information:</p> <ul style="list-style-type: none"> <li>• DMMA is awaiting CMS approval on the 1115 demonstration waiver renewal application.</li> <li>• DMMA, along with the Delaware Department of Education, applied to CMS for the State Grants for the Implementation, Enhancement, and Expansion of Medicaid and CHIP School-Based Services. Awards will be announced in July 2024.</li> <li>• Follow ups to the January 2024 CMCAC Quarterly Meeting:             <ul style="list-style-type: none"> <li>○ DMMA is still researching the topic of transportation and Private Duty Nursing (PDN) as it relates to CMC traveling to and from the hospital in ambulance and private vehicles.</li> <li>○ DMMA is still working on finalizing the plan for the Public Service Announcement regarding PDN for CMC families.</li> <li>○ Updates on the above will be provided at the next CMCAC Quarterly Meeting.</li> </ul> </li> </ul> <p>DMMA Senior Administrator shared that DMMA, and the Division of Services for Aging and Adults with Physical Disabilities (DSAAPD) collaborated to apply for direct care workforce technical assistance grant. The goal of this assistance is to improve the retention, training, and development of direct service workforce as it relates to workforce shortages.</p>
<b>SHHN Quarterly Report</b>	<p>DMMA provided an overview of the Skilled Home Health Nursing (SHHN) Workgroup Quarter 1 Report. The report includes workgroup actions, key issues, and upcoming activities. The report is available on the CMCAC website.</p>
<b>ENfit® Supplies Taskforce</b>	<p>DMMA provided an update on the ongoing work of the ENfit® Supplies Taskforce. The ENfit® Taskforce has been meeting monthly since February 2024, and has identified challenges related to the transition to ENfit® Enteral Feeding Supplies, including the following areas of concern: coordination and clarification of coverage, family support and training, and support for school nurses.</p> <p>The taskforce compiled details related to these challenges into a presentation that was distributed with the materials for today's meeting. The presentation will be posted to the CMCAC website along with the other CMCAC materials.</p> <p>The taskforce will continue to work towards the identification of solutions that can support families and providers.</p>

<p><b>SDAC/Respite Town Hall Meeting</b></p>	<p>DMMA provided an update regarding the Self-Directed Attendant Care (SDAC) and Pediatric Respite Town Hall, which occurred on 3/6/24. The Town Hall was requested by advocates at the January 2024 CMCAC Meeting and included frequently asked questions and answers that had been submitted prior to the town hall. The remainder of the meeting was devoted to additional live questions and answers.</p> <p>During the live question and answer session, DMMA responded to questions about (1) payment for SDAC and pediatric respite, (2) eligibility criteria to access the services, (3) enrollment processes, (4) tracking SDAC and respite hours, and (5) the 40-hour weekly limit for a parent providing SDAC.</p> <p>DMMA provided answers to the questions during the town hall meeting and will post an updated FAQ document on the CMCAC website.</p> <p>See the public comment section of this document for the questions and comments on this topic.</p>
<p><b>Groups with Work that Align with CMCAC</b></p>	<p>DMMA Director Wilson shared an update regarding CMS proposed federal rules, which have since been finalized. New regulations will require additional partnership with Medicaid beneficiaries. DMMA will share updates about how to get involved with the Medicaid beneficiary groups at future meetings.</p>
<p><b>COVID-19 PHE Unwinding Update</b></p>	<p>DMMA Chief of Policy and Planning provided an update regarding COVID 19 Unwinding:</p> <ul style="list-style-type: none"> <li>• The next CMCAC meeting will be the last meeting in which there will be a formal agenda item dedicated to a COVID unwinding update.</li> <li>• DMMA is finalizing renewals and will internally look at the processes required for renewals that families have expressed concern about. A family representative expressed that the renewal process was very complicated.</li> </ul>
<p><b>Future CMCAC Meetings</b></p>	<p>July 9, 2024, at 9:00AM</p>
<p><b>Public Comment</b></p>	<p><b>DMMA Update Comments</b></p> <p>During the DMMA Update portion of the meeting, a parent representative requested that information about the CMS School Based Services Grant Application be coordinated with other efforts occurring through the Governor’s Advisory Council for Exceptional Citizens sub-committee on Individuals with Complex Medical Conditions and Education.</p> <p><b>Groups that Align with CMCAC Comments</b></p> <p>A family representative requested that families be given the opportunity to be involved with any beneficiary engagement work initiated by DMMA.</p> <p><b>Medicaid Pediatric Respite Comments</b></p> <ul style="list-style-type: none"> <li>• A representative from a home health agency asked about a required timeframe of advanced notice that families need to provide to request respite hours.</li> <li>• Concerns regarding the current Medicaid Pediatric Respite program were shared from parent representatives and home health agency representatives including: <ul style="list-style-type: none"> <li>○ Challenges posed by not being able to pay nurses directly.</li> <li>○ There is a smaller pool of nurses to choose from since the nurses must be employed by an agency.</li> <li>○ The former state-only funded respite program allowed more freedom for families to choose and pay providers.</li> </ul> </li> <li>• Questions included: <ul style="list-style-type: none"> <li>○ Is there a way to self-direct respite?</li> </ul> </li> </ul>

- Are respite summer camps going to be available this year?
- More information about respite will be provided in the FAQ posted to the CMCAC website.


**SDAC Comments**

- Concerns were expressed by a family representative regarding the payment rate for SDAC providers. They explained there is inconsistency in the pay from agency to agency and families are experiencing different rates.

**General Comments**

The public comment portion of the meeting included concerns about the process for Letters of Medical Necessity (LMON). A representative from the Parent Information Center (PIC) explained that families are reporting a hard time in obtaining LMON. Representatives from Managed Care Organizations pointed out the LMON templates, which are available on the CMCAC website.

One commenter expressed that they hope to more fully understand how “money flows” to CMC and their families. They explained a flow chart that shows how money is distributed would be helpful as Medicaid is a complex area to navigate.

 All CMCAC meetings are currently held via Zoom.