

DELAWARE'S CHILDREN WITH MEDICAL COMPLEXITY ADVISORY COMMITTEE

January 14, 2025

9:00 AM – 11:00 AM

Meeting Notes

Welcome and Roll Call	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. Attendees announced their name and affiliation via the chat box.
Update from DMMA Director	Director Drew addressed Federal and State administration changes as the Biden administration transitions out. Bethany Hall-Long will be transitioning in as Governor for two weeks as Governor John Carney transitions out. Matt Myer will then transition in as Governor later this month. Director Wilson informs that we do not yet know what changes will look like, but DMMA values the crucial feedback that the CMC Workgroup provides for CMC as this information is very impactful. Director Drew assures that upcoming changes will not alter DMMA's commitment to Delaware's families.
SHHN Quarterly Report	An overview of the Skilled Home Health Nursing (SHHN) Workgroup Quarter 3 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.
ENfit™ Taskforce	DMMA completed work with stakeholders and CMCAC members which include MCOs and families, and DME providers, home health agencies and hospital(s) regarding the challenges families are facing around ENfit™ supplies. The last Enfit taskforce meeting was held on October 23 rd . Future Enfit Updates will be provided via email to the existing CMC workgroup.
DMMA Update	<p>DMMA leadership attended a meeting focused on children with complex medical needs. DMMA was able to obtain information regarding transition of care around pediatrics and expanding EPSDT services through age 26 which one other state is doing. There was discussion around Attendant Care models in other states as well. We are looking at these programs as ideas that can support families in addition to existing services.</p> <p>With the onset of the calendar year, the biggest change was related to house bill 110, which Delaware has implemented as of 1/1/2025. Delaware is also looking at launching services related to substance use disorders.</p> <p>2024 Highlights</p>

	<ul style="list-style-type: none"> • CMCAC Leadership Changes: <ul style="list-style-type: none"> ○ DMMA - Director Andrew Wilson is the new CMCAC Chair ○ DMMA - Maternal & Child Health Clinical Director, Dr. Alethea Miller is the new CMCAC Lead • Approval of the 1115 Demonstration Waiver: Extended through December 2028 to support Medicaid services for children with medical complexities. • School-Based Services Expansion: \$2.5M CMS grant awarded to enhance school health facilities and to support service delivery • Key Events: <ul style="list-style-type: none"> ○ Private Duty Nursing Event (June 2024): Over 50 participants engaged in PDN discussions. ○ Care Notebook Initiative: Training sessions and support provided for families to manage care documentation. ○ PSA Campaign: A public service announcement on private duty nursing to launch in Spring 2025. <p>Year End Review: CMCAC Activities in 2024</p> <ul style="list-style-type: none"> • Quarterly Meetings Held • Created Enfit Supplies Taskforce <ul style="list-style-type: none"> ○ DMMA Pharmacy Director continues working on updating codes for ENFIT supplies. Email updates will be sent to CMC Workgroups as this work becomes finalized. ○ SDAC FAQs: This document is now complete and will be placed on the DMMA CMC Website <p>Proposed Activities for CMCAC in 2025</p> <p>Respite FAQs –The next step is to work on Pediatric RESPITE FAQs. This will be a collaborate effort as well.</p> <p>2025 Activities - DMMA hosted a PDN Event on 6/28/24 which was related to workforce challenges. There were over 50 participants which included Nursing agencies, families, licensing bodies, and MCOs. DMMA created a survey for attendees to complete and the survey will help shape what we do in 2025.</p> <p>PSA Campaign – DMMA continues work on the Public Service Announcement on Private Duty Nursing and anticipates completion in the spring of 2025.</p> <p>Care Notebook – training was provided by PIC + Delaware Family voices in 2/2024. DMMA will be looking back at the care notebook and would like to revise it with the workgroup to add additional information that will better help families.</p> <p>Parking Lot – DMMA has viewed this and will be addressing this with the workgroup DMMA is looking forward to these initiatives and also looking forward to getting things done.</p>
<p>MAC and BAC Update</p>	<p>Beneficiary Advisory Council</p> <p>DMMA has created an application for this group, and are currently working on creating group Bylaws, and working with a media company to create a campaign. There will be a 2-3 yr term limits for the Beneficiary Advisory Council. The federal deadline for this is 7/9/25. At this time, DMMA</p>

	<p>would like to recruit family members, caregivers, or beneficiaries that would be interested in participating in this group. DMMA would like the caregiver and member voices to be captured within this group. Please reach out to DMMA if you would like to participate. DMMA is currently working on web content for this group. The email and website will be provided later. This will fall under Health and Human Services. DHSS is actively working on revamping the DMMA website, utilizing professional entities. We are working towards being more transparent. CMCAC will provide updates on this work as it progresses</p> <p>Question from Workgroup Member: Are families already included in this committee?</p> <p>DMMA Response: The committee is still coming together.</p>
<p>Groups with Work that Align with CMCAC</p>	<p>Family to Family Health information centers- A workgroup member informs that this group has upcoming webinars and learning lunches. This group works with families around Medicaid-related concerns. Invites can be sent out to DMMA in the future. They are currently working on a Healthcare pediatric transition to adult summit and are looking for partnerships.</p> <p>PIC - The representative informs that they can collaborate with DMMA on Care notebook revisions that DMMA will be working on.</p> <p>GACEC – The representative informed the group that DMMA has met with the Executive Director of the GACEC to discuss the school-based grant that was awarded in July 2024. Another taskforce is scheduled by ICE this year regarding PDN in schools.</p> <p>DECLASI- Provided overview of DECLASI’s public report which is posted to their website. DECLASI recommended the use of online registries and federal resources for families with children in need of care.</p> <p>A Workgroup Member feels that DECLASI’s study will be very helpful to families and professionals in the area of skilled nursing and direct care. She feels that it is a great resource and looks forward to getting a plan together that will be helpful to families.</p>
<p>Future CMCAC Meetings</p>	<p>The next CMCAC meeting will be held on April 8, 2025, and will be Hybrid, with both in-person and virtual options.</p>
<p>Public Comment</p>	<p>Renewals</p> <p>PIC informs that they have received calls from families regarding renewal letters. PIC provided families with information, but families believe the process is still confusing and need additional information. PIC is asking to have an FAQ completed for information such as renewals, transitions, and other processes for families of children with medical complexities. PIC is asking to add this to the list of items completed for 2025.</p> <p>Workgroup Member: Would like to add the item of Transitioning children from the CCADP (pediatric) waiver to adult LTC to our CMC 2025 agenda. She feels there should be something available to guide parents through this process. She informs that this transition is very complex process and informs that families receive a lot of misinformation.</p> <p>PIC: PIC informs that they have a coordinator available who can assist with some of these items. PIC also made a recommendation to invite DSS and DDDS to future CMC meetings.</p> <p>DMMA Response: DMMA informs that these transition concerns will be taken offline and DMMA will provide follow up on this.</p> <p>Workgroup Member: There are no providers on the adult side that are specifically trained to provide care to children transitioning to adult services who have complex medical needs. We should look into our ability to provide care for this population.</p>

	<p>DMMA Response: We acknowledge family advocates needs for training materials around transition of care for children. We will be working on addressing this in 2025.</p> <p>DMMA Response: Deputy Director informs that DMMA can work on an overview to provide education on the renewal process on how things work. It will take a while to develop a presentation since there are different groups that participate in the renewal process.</p> <p>Workgroup member: There are concerns from individuals regarding Care.com and other services. She does not recommend that families use the care.com site for children with medical complexities</p> <p>DMMA Response: clarified the above, stating that one state has families that help one another with their children with medical complexities and this was discussed during a conference</p> <p>PIC Rep. - Feels there would be a liability issue with the above and informs that she is now helping to launch a program where parents support each other emotionally</p> <p>Workgroup Member – How will residual updates be shared from the Enfit taskforce.</p> <p>DMMA Response: Updates will be provided through the existing CMC workgroup</p> <p>Workgroup Member: wanted to know if there is any updated information on another townhall on RESPITE and SDAC</p> <p>DMMA Response: DMMA informs that we will look into obtaining information from DDDS regarding the townhall they are working on and will also look into whether or not DDDS needs any information from DMMA</p> <p>Workgroup Member: Suggested including PIC template or sample of the care notebook on PIC’s website.</p> <p>PIC Rep: PIC can work on revising the current comprehensive care notebook and will work on ensuring that families have access to it.</p>
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