DELAWARE'S CHILDREN WITH MEDICAL COMPLEXITY ADVISORY COMMITTEE (CMCAC)

April 8, 2025 9:00 AM – 11:00 AM

Meeting Notes

| Welcome and Roll Call | Dr. Krishna Upadhya introduced herself and welcomed everyone to the CMCAC meeting. |
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| | Attendees announced themselves (name and affiliation) via the Zoom chat box. |
| DMMA Updates | DMMA Director Drew Wilson provided Medicaid policy-related updates. |
| | Congress has been tasked with obtaining \$880 billion in funding to support federal administrative cuts and Medicaid programs are likely a source for these spending cuts. There are also many rules published by the Biden administration that will likely be rescinded; however, this will seem invisible as many of these rules haven't yet taken effect. |
| | There is also discussion about making changes to eligibility for entitlement programs. For example, the Medicaid expansion populations (for adults ages 18-64) that stemmed from Affordable Care Act legislation may be impacted. In Delaware this amounts to approximately 70,000 adults. This could result in a lower Federal match (e.g., moving from 90% to 60% reimbursement for DMMA). In addition, there may be a work requirement with eligibility for Medicaid. Congress may consider lowering the threshold for use of nursing home tax payments. Lastly, there is federal push to not allow coverage for undocumented persons. Delaware currently has an emergency care benefit and a labor and delivery benefit for undocumented persons. Nothing currently shows immediate risk to the persons with disabilities community. |
| | Delaware's share of the cuts could be up to \$200 million. Current Medicaid enrollment is 1 in 4 people in Delaware. There continues to be a significant policy debate at the federal level. Some opinion is that Medicaid has "outgrown" it's original intent from its inception during President Lyndon Johnson's term. Drew indicated that DMMA is continuously following the details. |
| | Workgroup Member (Parent Advocate): Indicated that home and community-based services (HCBS) are being cited as the highest cost services, compared to facility-based services. How DMMA will help ensure that HCBS is not at risk for spending cuts? |
| | Drew Wilson: HCBS has some protections – both under the Olmstead Act, and because it is more cost effective than facility-based care. In Delaware, we have a strong belief that individuals' living in the community is the ultimate objective and goal. |
| | Workgroup Member (Parent Advocate): There are efforts to overturn the 504 Act and Olmstead. |

| | Drew Wilson: Delaware's Attorney General (Kathy Jennings) has been very active in legally fighting against policy changes that would be counter to the attempt to undo these existing laws. Drew encouraged advocates to humanize the program and emphasize [to policy makers and elected officials] why these policies are important. |
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| | Workgroup Member (Parent Advocate): What specifically should advocates bring to the federal government to help with advocacy efforts? |
| | Drew Wilson: Drew reiterated the telling of the personal stories because the cost argument can be less successful and compelling than telling of personal stories. |
| Medicaid Advisory Committee (MAC) and Beneficiary Advisory Council (BAC) Update | Terri Stoneburner, Social Services Senior Administrator, presented on upcoming MAC and BAC opportunities for stakeholders and indicated the legislative rule is effective on 7/9/2025. An overview of the structure, scope of activities, and meeting support for the MAC and BAC was also provided. DMMA will select members for the MAC and BAC. MAC and BAC will each meet quarterly. Minutes, reports and bylaws will be publicly posted. DMMA will support both meetings, including preparation of materials and summary reports. The CMCAC will remain in place and continue work as scheduled. There will be opportunities to collaborate across the groups on topics such as member access, quality of care, data sharing. See attached deck. |
| | CMCAC.PP 4.8.25.pdf BAC Spanish Paper BAC Paper Application.pdf Application.pdf |
| CMC Workgroup and Topic- Specific Updates | Melecia Da Silva and Dr. Upadhya provided CMC workgroup and initiative updates. Topics included: Self-Directed Attendant Care FAQ, ENFit™ Benefit Coverage, and Emergency transportation with Private Duty Nurses (PDNs). See attached deck. CMC Activities and Workplan.CMCAC Q1 |
| | Workgroup Member (Parent Advocate): Why is there a restriction in reimbursement for PDNs to accompany a child during transportation to a facility, and which entity is responsible for approving a PDN to accompany the child? |
| | Dr. Upadhya: Reimbursement decisions and authority rests with home care agencies where nurses are employed. |
| | Workgroup Member (Home Health Agency): Indicated that Bayada reimburses PDN support during emergency transportation; however, once the child is in triage (at the facility), then the PDN shift is over, because the hospital begins its billing/coverage at that point. Bayada will reimburse return travel (e.g., Uber ride) for the PDN at that point. Additionally, PDNs can accompany the child to an outpatient appointment, only if the parent is unable to attend. |
| | Workgroup Member (Home Health Agency): Indicated the safety concern for a single parent driving to an outpatient appointment; a PDN is needed to support the child during transportation while the parent drives. |

| 2025 Workplan | DMMA: Indicated that DMMA will monitor this issue with MCOs, and any grievances received. It was also noted that there are non-emergency medical transportation benefits for families needing travel support for outpatient visits. Melecia Da Silva presented the CMCAC workplan for the remainder of 2025. There are a few topics that will be addressed based on input received via the Parking Lot document. |
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| Future CMCAC Meetings | The next CMCAC meeting will be held on July 8, 2025. |
| | Family Advocate: Indicated that some parents have reached out about a letter from the MCO being sent to the child's school, indicating that parents need to attend a meeting(s). |
| Public Comment | The MCO workgroup members acknowledged that Care Coordinators collaborate with the schools directly to coordinate on services needed for the child; however, the MCOs were not aware of a letter being sent from the MCO to the school (or to the parent) about this topic. |
| | DMMA: DMMA indicated that they will begin to review this matter and will provide the workgroup with an update. |