CHILDREN WITH MEDICAL COMPLEXITY

ADVISORY COMMITTEE AGENDA

- Welcome and Roll Call – DMMA Director, CMCAC Chair, Steve Groff
- Review Notes from October 16th meeting
- Review Charter
- Review Guiding Principles
- Skilled Home Health Workgroup Quarterly Report and 2020 Projection
- Private Duty Nursing (PDN) Gaps in Care Analysis Update: January 2020
- Emergent Care Decision Tree
- Data Workgroup Quarterly Report and 2020 Projection
- End of Year Summary Report
- 2020 Priorities
- Public Comment
# CMC Advisory Committee Charter

## Purpose
The purpose of Delaware’s Children with Medical Complexity Advisory Committee is to strengthen the system of care, increase collaboration across agencies, encourage community involvement, and ultimately ensure that every child with medical complexity has the opportunity to receive the adequate and appropriate health care services they need and deserve.

A. Delaware’s Children with Medical Complexity Advisory Committee will be chaired by the Director of Delaware Health and Social Services (DHSS)/Division of Medicaid and Medical Assistance (DMMA).

B. Membership is open to:
1. Six (6) Advocates of a child(ren) with medical complexity, and
2. One (1) representative from at least one (1) of the following agencies or types of agencies:
   - Advocacy Group
   - Delaware Department of Children, Youth & Their Families
   - Delaware Department of Education
   - DHSS Division of Developmental Disabilities Services (DDDS)
   - DHSS Division of Medicaid and Medical Assistance
   - DHSS Division of Public Health
   - DHSS Division of Social Services
   - Each Delaware Medicaid Managed Care Organization (MCIO)
   - Home Health Agency
   - Hospital
   - Hospital Association
   - Pediatrician
   - Pediatric Residential Care Facility

## Meetings
A. Frequency
1. Delaware’s Children with Medical Complexity Advisory Committee will hold quarterly meetings.
2. All meeting dates, times, and locations will be posted on the State’s public meeting calendar at [https://publicmeetings.delaware.gov](https://publicmeetings.delaware.gov).

B. Participation
1. All meetings are open to the public and will have an opportunity for public comment.
2. Decisions at all meetings, regarding any action or future actions of the group or regarding the group’s philosophy or purpose, shall be reached following a consensus decision making process.
Guiding Principles

Children with Medical Complexity Advisory Committee
January 2019

Delaware Health and Social Services, Division of Medicaid and Medical Assistance (DMMA), is committed to addressing the recommendations made in the May 2018 Plan for Managing the Health Care Needs of Children with Medical Complexity, developed by the Children with Medical Complexity (CMC) Steering Committee. To achieve this, DMMA supports the continuation of the work of the CMC Advisory Committee and, where appropriate, associated work groups.

The Guiding Principles describe the beliefs and philosophy pertaining to the work of the Advisory Committee. These principles guide what the Advisory Committee does, why it does it and how.

Guiding Principle #1: The Advisory Committee acts as an advisory body to DMMA and is comprised of stakeholders including family members of children with medical complexity (and, potentially, youth with medical complexity), state agencies, advocates, payers and providers.

Guiding Principle #2: The outcome of the Advisory Committee’s work is to address the recommendations outlined in the Plan. Emerging issues will also be considered for inclusion in the Advisory Committee’s work plan, as agreed upon by the Committee.

Guiding Principle #3: Leadership, input and active participation by families is valued, encouraged and supported.

Guiding Principle #4: The Advisory Committee’s focus is on current systems and processes. The emphasis is on addressing system gaps and affecting future systems change.

Guiding Principle #5: A consensus driven decision making process is used.

Guiding Principle #6: The Advisory Committee strives to use available data, whenever possible, to inform decision making. Decision making will also be informed by emerging promising practices and new technology.

Guiding Principle #7: Measurable goals are established.

Guiding Principle #8: Progress toward achievement of agreed upon outcomes is measured based on specific timeframes.

References:

SKILLED HOME HEALTH NURSING WORK GROUP

QUARTER 4 ACTIVITIES

- Met bi-weekly
- Received scope of work from the University of Delaware Center for Disabilities Studies for the Workforce Capacity Study
- Training project renamed to Family-Centered training and launched
- Developed list of items for the Prior Authorization (PA) Toolkit
- Reviewed DE Medicaid Provider Manual content specific to PA process for PDN
- Reviewed and provided input into revisions of the DE Home Health Agency Regulations

KEY ISSUES TO NOTE

- Workforce Capacity Study is moving forward
- Obtained information on PA process from multiple perspectives
- Parking Lot Items

UPCOMING ACTIVITIES

- Finalize University of DE Workforce Capacity Study scope of work and complete study
- Develop toolkit for navigating the PA Process
- Continue work on Family-Centered Training Curriculum
- Upcoming meetings: 1/28, 2/11

2019 Q1
- Finalize work plan
- Present highlights to Advisory Committee

2019 Q2
- Design workforce study
- Review existing provider/provider agency PA process

2019 Q3
- Develop PDN Emergent Care definition and Decision tree
- Arrange for administration of Workforce Capacity Study
- Collect feedback regarding PA process from multiple stakeholder groups

2019 Q4
- Conduct Workforce Capacity Study
- Develop toolkit for PA process
- Continue work on competency training curriculum
**SKILLED HOME HEALTH NURSING**  
**WORK GROUP**

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<thead>
<tr>
<th>2020 Q1</th>
<th>2020 Q2</th>
<th>2020 Q3</th>
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<tr>
<td>• Distribute Emergent Care Decision Tree and place on CMC Webpage.</td>
<td>• Complete Workforce Capacity Study, evaluate results, and share results and next steps with CMCAC.</td>
<td>• Implement next steps of Workforce Capacity Study.</td>
<td>• Implement Family-Centered Training plan.</td>
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<tr>
<td>• Finalize University of Delaware SOW for Workforce Capacity Study.</td>
<td>• Present PDN Prior Auth Toolkit with CMCAC for consensus and then add as resource to CMC webpage.</td>
<td>• Share Family-Centered Training implementation plan with CMCAC.</td>
<td>• Share lessons learned with CMCAC to assist other work groups as other priorities move forward.</td>
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<tr>
<td>• Finalize PDN Prior Auth Toolkit.</td>
<td>• Develop Family-Centered Training implementation plan with CMCAC.</td>
<td>• TBD based on results of workforce study and other SHHN workgroup activities.</td>
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<td>• Continue work on Family-Centered Training.</td>
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PRIVATE DUTY NURSING GAPS IN CARE

STRENGTHEN THE NETWORK OF HOME HEALTH PROVIDERS FOR CHILDREN WITH MEDICAL COMPLEXITY.
EMERGENT CARE DECISION TREE

STRENGTHEN THE NETWORK OF HOME HEALTH PROVIDERS FOR CHILDREN WITH MEDICAL COMPLEXITY.
Private Duty Nursing Emergent Care Decision Tree

Emergent Private Duty Nursing (PDN) Need

1. Nurse/nursing agency conducts an evaluation with the family/guardian to determine health and safety needs of member.

2. Nurse/nursing agency notifies the member’s MCO care coordinator and physician (PCP) about the emergent PDN need/situation. MCO and nursing agency ensure provision of PDN services.

Is the backup/secondary caregiver able and available to provide and/or direct care?

- **YES**
- **NO**

Emergent PDN Need = Parent/primary caregiver is unexpectedly unable to provide or direct care for the member with complex medical needs.
Private Duty Nursing Emergent Care Decision Tree

YES

1. Backup plan is activated.
2. Backup/secondary caregiver assumes primary caregiver role and responsibilities.

Nurse/nursing agency works with backup/secondary caregiver.

Physician and MCO re-evaluate PDN services/authorizations based on nursing agency/family evaluation to determine if increased hours or services are needed and available.

Increased hours needed

1. Nursing agency notifies PCP and obtains feedback regarding next steps and care plan orders.
2. MCO completes prior authorization.
3. MCO care coordinator supports as needed.
4. Effectiveness of backup plan re-evaluated every 24-48 hours to ensure member’s safety and health are maintained.

No need to increase hours

Effectiveness of backup plan re-evaluated every 24-48 hours to ensure member’s safety and health are maintained.

If re-evaluation results indicate it is unsafe to maintain member in home, the nurse/nursing agency, MCO coordinator, PCP and family/guardian discuss different options and possible arrangements for transferring the member to a facility appropriate for the member’s level of care.

See page 2
Private Duty Nursing Emergent Care Decision Tree

See page 1

Nurse/nursing agency assesses and evaluates health and safety needs of the member to determine if needs can be met at home. Assessment includes communication with any relative caregivers or temporary custodians of the child.

1. Nurse/nursing agency notifies PCP and requests order for increased PDN hours.
2. MCO completes prior authorization.
3. MCO coordinates supports as needed.

PDN services are evaluated every 24-48 hours.

YES

The need for PDN services can be met.
Maintain member in the home and re-assess health and re-evaluate safety as needed.

NO

The need for PDN services cannot be met.
Not safe to maintain member in home.

Nurse/nursing agency, MCO coordinator, PCP and family/guardian discuss different options and possible arrangements for transferring the member to a facility appropriate for the member’s level of care.
QUARTER 4 ACTIVITIES
- Met bi-weekly
- Met with MCOs regarding PDN gaps in care analysis results
- Continued trend analysis of demographic data and utilization data for CY 2014-2017
- Submitted Human Subjects Research Board (HSRB) application for family focus groups and survey

KEY ISSUES TO NOTE
- Findings from demographic and utilization data trend analysis

UPCOMING ACTIVITIES
- Implement family focus groups and survey
- Report findings of PDN gaps in care analysis
- Report findings of demographic and utilization data for CY 2014-2017
- Upcoming meetings: 1/28, 2/11

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<tr>
<td>Identify CMC population</td>
<td>MCOs complete PDN gaps in care analysis. Workgroup reviews results</td>
<td>Secure resource for family focus groups and survey</td>
<td>Continue analysis of MCO PDN gaps in care data</td>
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<td>Present initial data to Advisory Committee</td>
<td>Present initial summary to Advisory Committee</td>
<td>Continue analysis of MCO PDN gaps in care data</td>
<td>Develop family focus groups and survey</td>
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<td>Draft elements for MCO PDN gaps in care analysis</td>
<td>Analysis of CY 2017 demographic and utilization data</td>
<td>Continue analysis of demographic and utilization data</td>
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<td>Present updates</td>
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<td>• Complete Population, Hospital Admission, Length of Stay, and Emergency Department Visits utilization data analysis for inclusion in annual summary report.</td>
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<td>• Implement Family Focus Groups and Surveys.</td>
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<td>• Determine next steps for Provider Survey.</td>
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<td>• Continue to provide support to CMCAC and work groups.</td>
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<td>• Present findings of Family Focus Groups and Surveys to CMCAC.</td>
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I. Background
II. Organizing the Work for 2019 and Developing 2019 Objectives
III. Summary of 2019 Objectives and Progress
   1. Keep the Children with Medical Complexity Steering Committee in place.
   2. Uniformly circulate the Delaware Specific Definition of Children with Medical Complexity through DMMA and MCO provider quarterly bulletins.
   3. Develop CMC web page on DMMA site with links to resources and information.
   4. Perform a comprehensive data analysis as it relates to children with medical complexity.
   5. Strengthen the network of skilled home health nursing providers for children with medical complexity.
IV. Overview of 2020 Objectives
# PRIORITIES FOR 2020

<table>
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<tr>
<th>Priority Level</th>
<th>Action Item</th>
<th>Anticipated Completion Date</th>
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| 1              | Keep the Children with Medical Complexity Steering Committee in place.  
|                | - Continue meeting with the CMC Steering Committee. Meetings are held quarterly.                                                          | On-going                                                                                  |
| 1              | Uniformly circulate the Delaware Specific Definition of Children with Medical Complexity through DMMA and MCO provider quarterly bulletins (Q1 2019, On the DMMA CMC webpage, DHSS Facebook page, and any other means the Advisory Committee has access too). | Complete - March 2019                                                                      |
| 1              | Develop CMC web page on DMMA site with links to resources and information                                                                    | Complete - January 2019                                                                   |
| 2              | Perform a comprehensive data analysis as it relates to children with medical complexity.                                                    | • Population data analysis completed; to be included in annual summary report as appendix. |
|                | - Analyze data to identify the population of children with medical complexity in the state of Delaware.                                      | • Hospital Admission, Length of Stay, and Emergency Department Visits utilization data analysis complete; to be included in annual summary report. |
|                | - Analyze data to review potential service gaps identified by the workgroups, as well as identify any additional service gaps, that impact the care coordination and health care delivery for children with medical complexity. | • Support for other initiatives is on-going; next steps for 2020 have been identified.     |
| 3a             | Strengthen the network of home health providers for children with medical complexity.                                                           | • Many aspects of work plan completed and summarize in annual summary report.              |
|                | - Evaluate provider capacity, of both FFS and Managed Care Networks, of Skilled Home Health Nurses.                                            | • Next steps for 2020 have been identified.                                                |
|                | - Review and make transparent the Prior Authorization and approval process.                                                                    |                                            |
|                | - Work with MCOs to expand provider capacity where needed.                                                                                   |                                            |
|                | - Develop Competency/Training for home health providers regarding CMC – People first language, Family-Centered Care, multi-lingual (Including ASL). |                                            |
|                | - Assess and/or develop mechanisms for children with medical complexity when parents/caregiver is presented with emergent situation and unable to provide care.  
|                |     o Include nursing call out, not just family emergency.                                                                                   |                                            |
## PRIORITIES FOR 2020

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| 3b             | Strengthen the network of home health providers for children with medical complexity.  
- Evaluate provider capacity, of both FFS and Managed Care Networks, of home-based physical, occupational, and speech therapy.  
- Review and make transparent the Prior Authorization and approval process.  
- Work with MCOs to expand provider capacity where needed.  
- Develop Competency/Training for home health providers regarding CMC – People first language; Family-Centered Care; multi-lingual (including ASL) | - Plan to begin work on this priority upon completion of, and using lessons learned from, priority 3a.  
- This will require a new work group. |
| 3c             | Strengthen systems of care for children with medical complexity.  
- Review and revise, as appropriate, policies and processes for the Children’s Community Alternative Disability Program (CCADP) including, but not limited to redetermination of medical eligibility requirements and Provider Policies.  
- Publish informational fact sheets for the Children’s Community Alternative Disability Program (CCADP) as a resource for parents/caregivers, providers, staff, and other stakeholders.  
- Ensure that entry point staff (call center/SWers/etc.) are aware of CCADP  
- Consider including a flyer in enrollment paperwork | - Plan to begin work on this priority in 2020.  
- This will be an internal DMMA work group, but materials and information will be brought to the CMCAC for feedback. |
| 4              | Be clear in contracts about the role of managed care organizations in identifying and providing services to children with medical complexity.  
- Work with the managed care organizations (MCOs) to develop a mechanism to identify and flag all children with medical complexity in their systems.  
- Work with MCOs to streamline, simplify, and make transparent the prior authorization process for children with medical complexity as it relates to durable medical equipment, supplies, and pharmaceuticals.  
  - Review DME Reimbursement.  
  - Review Letter of Medical Necessity requirements.  
- Provide Competency/Training regarding CMC to MCO staff at all levels – People first language; Family-Centered Care; multi-lingual (including ASL) | - Some formal updates have been made to contracts.  
- MCOs have voluntarily made other informal changes.  
- This priority item to be looked at by DMMA more closely in 2020. |
# PRIORITIES FOR 2020

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| 5              | **Strengthen systems of care for children with medical complexity.**  
  - Work with the Non-Emergency Medical Transportation Provider to clarify, enforce, and revise policies as appropriate  
  - Conversations between NEMT Provider and DMMA are on-going.  
  - Further work for this item needs to be prioritized. | |
| 6              | **Develop and/or strengthen existing resources for parents/caregivers, providers, and the larger community involved in the care of children with medical complexity.**  
  - Develop a handbook with replaceable sheets for parents/caregivers of children with medical complexity.  
  - Publish policies and educational materials specific to children with medical complexity on DMMA’s Delaware Medical Assistance Provider Portal.  
  - Strongly influenced by results of previous priorities.  
  - On-hold until completion of other priorities. | |
| 7              | **Strengthen systems of care for children with medical complexity.**  
  - Develop care coordination standards specifically for this population.  
  - Considerations innovative care delivery models and appropriate payment structures to address identified gaps.  
  - Strongly influenced by results of previous priorities.  
  - MCO have been informally revising internal procedures as this process evolves.  
  - On-hold until completion of other priorities. | |
PUBLIC COMMENT