

# DELAWARE'S CHILDREN WITH MEDICAL COMPLEXITY ADVISORY COMMITTEE

JANUARY 16.2019

9:00 -11:00

## Meeting Notes


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| <b>Welcome and Introductions</b>              | <ul style="list-style-type: none"> <li>DMMA Director and CMCAC Chair, Stephen Groff welcomed CMCAC members and all had a chance to introduce themselves.</li> </ul>  |
| <b>Review notes from October 2018 meeting</b> | <ul style="list-style-type: none"> <li>Kimberly Xavier spoke regarding the agenda and updated notes; resource groups that have been added.</li> </ul>  |
| <b>Updates</b>                                | <ul style="list-style-type: none"> <li>A webpage has been added to the DMMA website with information regarding Children with Medical Complexity. Links can be added to resources or information developed by or identified through this work.</li> <li></li> <li>The official definition for Children with Medical Complexity is included on the CMC webpage. The definition will also be published in the next quarterly DMAP provider bulletin, which will be published in March, 2019. Both MCOs have agreed to share the information in their upcoming quarterly bulletins as well.</li> <li></li> <li>The Data Workgroup's work is ongoing, and we will update their progress.</li> </ul> |
| <b>Consensus Decision Making</b>              | <ul style="list-style-type: none"> <li>Mercer gave presentation on the Consensus decision making as a process in which the group members seek to make decisions by agreement rather than by a formal voting procedure.</li> <li></li> </ul>  |
| <b>CMCAC Charter</b>                          | <ul style="list-style-type: none"> <li>The Advisory Committee agreed with the updated CMCAC Charter and it is now the working Charter.</li> </ul>  |
| <b>Guiding Principles Discussion</b>          | <ul style="list-style-type: none"> <li>Mercer provided an developing and implementing guiding principles and how they are used to drive decision making.</li> <li></li> <li>Kimberly reviewed the draft CMCAC Guiding Principles with the CMCAC, documented suggestions, and asked for additional feedback to be emailed to her. Once all feedback is received, she will revise the Guiding Principles for review and agreement at the April CMCAC meeting.</li> </ul>   |

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| <b>Parent Presentation</b>       | <p>Parents shared concerns regarding Private Duty Nursing. Some of these concerns shared included:</p> <ul style="list-style-type: none"> <li>• Inappropriate demeanor of home health agency staff.</li> <li>• Issues around fatigue and safety issues that can arise from a lack of nursing coverage.</li> <li>• Issues regarding nurses accompanying patients to outpatient procedures, or accompanying them when parents are driving them to appointments were discussed.</li> <li>• Inconsistencies between home health agencies.</li> <li>• Lack of coordination between home health agencies that share members.</li> <li>• LPN vs RN and what they can do.</li> <li>• Training for nurses providing care to CMC.</li> </ul> |
| <b>Recommended Priorities</b>    | <ul style="list-style-type: none"> <li>• Kimberly reviewed the recommended priorities that the Planning Sub-Committee put forward to the Advisory Committee. There was not sufficient time to discuss, so Kimberly said she would send out a request for comments via email.</li> </ul>  |
| <b>Next Steps / Action Items</b> | <ul style="list-style-type: none"> <li>• Kimberly to send out Recommended Priorities for feedback.</li> <li>• Develop work group(s) based off feedback.</li> <li>• Committee members were asked to share contact information for a listserv to ensure all stakeholders are receiving information regarding the CMCAC activities and meetings.</li> </ul>   |
| <b>Public Comment</b>            | <ul style="list-style-type: none"> <li>• The public was given an opportunity to comment.</li> <li>• No comments.</li> </ul>  |

CMC Meeting Attendance: Stephen Groff, DMMA; Lisa Zimmerman, DMMA; Ellen McCleary, HHO; Eric Gonzalez, HHO; Tracie Martin, ECC; Annette Moore, ECC; Brenda Harrell, Brandywine SD; Maria Olivere, Parent; Dr. Lenae Lawyer, ACDE; Dr. Marie Petrini, Nemours; Jodie Puzio- Bungard, Nemours; Lee Lucas, Nemours; Dr. Elizabeth Brown, DMMA; Heather Courtney, DDDS; Ann Phillips, DE Family Voices; Meredith Tavani, DSCYF/PBH; Christine Sowinski, Christiana; Laura Waterland, DLP/CLASI; Judith Rodriguez, ACDE; Glyne Williams, DMMA; Olga Zapata, Parent; Nancy Agnes Rutkowski, Bayada; Thomas Hall, DSS; Pat Redmond, Nemours; Kimberly Xavier, DMMA; Yalanda Thomas, DMMA; Maggie Smith, DSS; Crystal Sherman, DPH; Jennifer Albano, Parent

**Future Meeting Dates:**

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| April 17, 2019<br>9:00 AM – 11:00 AM | July 17, 2019<br>9:00 AM – 11:00 AM | October 16, 2019<br>9:00 AM – 11:00 AM |
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 All CMCAC meetings are held at the DHSS Chapel, located in the Herman Holloway Campus at 1901 N DuPont Hwy / New Castle DE 19720.