

# DELAWARE'S CHILDREN WITH MEDICAL COMPLEXITY ADVISORY COMMITTEE

April 13, 2021

9:30 -11:00

## Meeting Notes

<b>Welcome and Roll Call</b>	<ul style="list-style-type: none"> <li>• DMMA Director and CMCAC Chair, Stephen Groff welcomes everyone, and apologizes that the meeting had to be abbreviated due to a conflict with another meeting. Director Groff asked everyone for roll call to type their name and organization in the chat box.</li> </ul>
<b>Skilled Home Health Quarterly Report</b>	<ul style="list-style-type: none"> <li>• Lorene Reagan of Mercer gave an update on the following:             <ul style="list-style-type: none"> <li>○ Workgroup provided feedback to the University of Delaware regarding the Private Duty Nursing (PDN) Workforce Capacity Study.</li> <li>○ The PDN Workforce Capacity Study's protocol was submitted to and reviewed by DHSS Human Subject Review Board (HSRB).</li> <li>○ Provided assistance to Vital Research with encouraging families to respond to the Family Satisfaction Survey.</li> <li>○ The Workgroup provided feedback to the MCOs on the proposed changes needed to finalize the PDN Welcome and What to Expect Letters.</li> <li>○ Workgroup reviewed the priorities for 2021 and discussed effective strategies and resources needed to address these priorities.</li> <li>○ The workgroup updated the work plan to address the work and the tasks that need to be done in order to meet the different goals and priorities.</li> <li>○ Finalized the 2020 Year-End Report, which was shared with everyone.</li> <li>○ Posted material on the CMC website, including the 2020 Year-End Report and the 2021 Priorities Document.</li> <li>○ Upcoming activities                 <ul style="list-style-type: none"> <li>▪ Finalize and post the MCO PDN Welcome Letter and What to Expect Letter on the CMC Website.</li> <li>▪ Finalizing the work plan for 2021 based upon priorities.</li> <li>▪ Reviewing and analyzing responses to the Family Satisfaction Survey.</li> <li>▪ Moving forward with conducting the PDN Workforce Capacity Study.</li> </ul> </li> <li>○ Upcoming SHHN workgroup meeting are on 4/27/21 and 5/11/21.</li> </ul> </li> </ul>
<b>PDN Workforce Capacity Study Update</b>	<ul style="list-style-type: none"> <li>• Mary Culnane from the University of Delaware shared the following:             <ul style="list-style-type: none"> <li>○ Project purpose:                 <ul style="list-style-type: none"> <li>▪ To evaluate the capacity of Delaware's PDN workforce, and those nurses who serve Delaware families of Children with Medical Complexity.</li> </ul> </li> <li>○ The research team is using interview and surveys to evaluate.</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>▪ Gather data to evaluate the current capacity of the Home Health Nursing Workforce.</li> <li>▪ Collecting data to evaluate factors that contribute to the perceived workforce shortage.</li> <li>▪ Inform if the current workforce is sufficient to meet the needs of Children with Medical Complexity in Delaware.</li> <li>○ The Study will evaluate both Registered and Licensed Practical nurses who provide PDN services to children in the home.</li> <li>○ The team developed 7 data collections tools, which include interviews and surveys with a focus on: <ul style="list-style-type: none"> <li>▪ Agency providers</li> <li>▪ Surveying and interviewing the private duty nurses</li> <li>▪ Surveying and interviewing family caregivers</li> <li>▪ Surveying nurses who are not in the private duty work force</li> </ul> </li> <li>○ The team circulated the instruments to the Workgroup and worked closely with members of the Workgroup to review the tools; field testing of the tools has been completed.</li> <li>○ Last week the team received approval from DHSS HSRB to move forward with the study as well as approval from the University of Delaware’s Research Board.</li> <li>○ Next steps: <ul style="list-style-type: none"> <li>▪ Recruitment</li> <li>▪ Data collection</li> <li>▪ Further analyses</li> <li>▪ Collaborate with DNA for nurses not employed in private duty nursing</li> <li>▪ Projected timeline for study completion is the end of June 2021</li> </ul> </li> </ul>
<p><b>Family Satisfaction Survey Update</b></p>	<ul style="list-style-type: none"> <li>● Cathy Coddington of Vital Research shared the following: <ul style="list-style-type: none"> <li>○ Reminder to everyone that the Family Satisfaction Survey’s goal is to assess and understand families of Children with Medical Complexity experiences of acquiring and satisfaction with available services across the board in the State of Delaware.</li> <li>○ The team has been collecting data since January and is available in mail form or online via an access code. <ul style="list-style-type: none"> <li>▪ The access code is used for tracking purposes only</li> <li>▪ The responses are completely confidential</li> </ul> </li> <li>○ The team sent a series of two reminder postcards to families.</li> <li>○ As a result of the outreach efforts to families, there has been a nice uptick in survey responses; thanks to everyone for your outreach efforts. <ul style="list-style-type: none"> <li>▪ Currently received 272 survey responses</li> <li>▪ 217 surveys were received for children under age 18</li> <li>▪ 55 survey were received for children ages 18 – 21 years old</li> </ul> </li> <li>○ There was a screener in the survey that asked families about defining their children as medically complex needs and based upon that screeners there were families who did not meet the criteria bringing the total eligible survey responses down to 234. <ul style="list-style-type: none"> <li>▪ Of the 234 eligible results – 188 children under 18 were received</li> <li>▪ And 46 are in the 18 – 21-year old age range</li> </ul> </li> <li>○ If anyone knows a friend of a child with medical complexity, or a group you can reach out to there is still time to complete surveys. <ul style="list-style-type: none"> <li>▪ Data will close at the end of the month</li> </ul> </li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>▪ Then will move into analysis and reporting</li> <li>▪ Analysis will span the month of May</li> <li>▪ Will share results with the Advisory Committee at the July meeting</li> </ul>
<b>Discussion of New Workgroup</b>	<ul style="list-style-type: none"> <li>• Kimberly Xavier shared the following: <ul style="list-style-type: none"> <li>○ .</li> <li>○ The workgroup is Durable Medical Equipment (DME) and Supplies and has come about as a result of the planning process in 2018/2019.</li> <li>○ Resources for the workgroup are needed. <ul style="list-style-type: none"> <li>▪ We discussed with the Skilled Home Health Nursing (SHHN) Workgroup members and some individuals would like to participate.</li> <li>▪ We will definitely need participation from the DME &amp; Supplies providers.</li> <li>▪ Asking for help from our MCO partners if you can assist with reaching out to those DME &amp; Supplies providers that you work with.</li> <li>▪ We would like participation from the Home Health Agencies as they have been very involved.</li> <li>▪ Looking for the MCOs to participate, as well as anyone that could benefit the group.</li> </ul> </li> <li>○ The work of this group will be similar to that being done in the SHHN Workgroup.</li> <li>○ The meetings will be biweekly and we're hoping to launch the first meeting in May.</li> <li>○ As you think of people that are willing to help please email myself or Yalanda Thomas so we can start gathering their information.</li> </ul> </li> </ul>
<b>Covid-19 Update and Discussion</b>	<ul style="list-style-type: none"> <li>• Steve Groff gave an update on the following: <ul style="list-style-type: none"> <li>○ The CDC/FDA announced this morning the halting of the Johnson &amp; Johnson vaccine while they do further investigation into very rare and concerning medical complications as a result of the vaccine.</li> <li>○ Delaware Division of Public Health (DPH) issued a statement recognizing that announcement: <p style="margin-left: 40px;">“We are unaware of any issues of blood clots in Delaware that may be related to the vaccine, but out of an abundance of caution we are recommending that our Delaware vaccine partners hold off on using the J&amp;J vaccine until the situation has been further assessed.” The State will not use the J&amp;J vaccine at its vaccination sites until we receive further federal guidance.”</p> </li> <li>○ The good news is that the overall Covid-19 vaccine distribution has been pretty robust.</li> <li>○ The opportunity for people to get vaccinated has been opened up to anyone age 16 and over. <ul style="list-style-type: none"> <li>▪ Children 16 to 18 can only receive the Pfizer vaccine.</li> <li>▪ Children as young as 12 may be able to receive the Pfizer vaccine soon.</li> </ul> </li> </ul> </li> </ul>
<b>Public Comment</b>	<ul style="list-style-type: none"> <li>○ Jean Mullin asked about homebound vaccine access. <ul style="list-style-type: none"> <li>▪ Steve Groff responded saying that DMMA asked the MCOs to outreach to not only reach out to members about the new vaccine eligibility criteria, but also to those individuals who have transportation and mobility issues such as our LTSS population so that we may be better able to know how we can ensure they get vaccinated.</li> </ul> </li> <li>○ Maria Olivere announced the Delaware Family Voices/MCO call is today at 11 am for anyone is interested.</li> <li>○ Steve Groff announced that Ann Phillips will be retiring from DE Family Voices and we will certainly be sad to see her go; but wish her well in her retirement. <ul style="list-style-type: none"> <li>▪ Maria Olivere stated that Ann will be retiring but still very active in advocacy for Children with Medical Complexity.</li> </ul> </li> </ul>

**Future Meeting Dates:**

July 13, 2021 9:00 AM – 11:00 AM	October 12, 2021 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.