

DELAWARE'S CHILDREN WITH MEDICAL COMPLEXITY ADVISORY COMMITTEE

January 12, 2021

9:00 -11:00

Meeting Notes

Welcome and Roll Call	<ul style="list-style-type: none"> • DMMA Director and CMCAC Chair, Stephen Groff welcomes everyone. Attendees announce their presence via the chat box.
Review of CMCAC Charter and Guiding Principles	<ul style="list-style-type: none"> • Kimberly Xavier gave a brief review of the CMCAC Charter and Guiding Principles.
Review of 2020 Accomplishments	<ul style="list-style-type: none"> • Kimberly Xavier reviewed the 2020 Year-End Report and asked for Committee members to review and provide feedback at a later date.
Skilled Home Health Quarterly Report	<ul style="list-style-type: none"> • Kimberly gave a summary on the following: <ul style="list-style-type: none"> ○ The workgroup continues to meet virtually due to the pandemic. ○ DMMA along with a parent representative of the CMCAC presented at the national ADvancing States Home and Community Based Services (HCBS) Conference, highlighting the work done on the Family Satisfaction Survey. ○ The Workgroup has collaborated with the University of Delaware on the PDN Workforce Capacity Study and members provided key input into the Study. ○ The Workgroup has finalized the Family Satisfaction Survey. ○ Workgroup members provided input into the Family Satisfaction Survey tool, which resulted in a reduction in overall survey items and changes in key areas. ○ Final Human Subject Review Board (HSRB) approval was received for the Family Satisfaction Survey tool. ○ Upcoming activities <ul style="list-style-type: none"> ▪ Finalize and post the MCO PDN Welcome Letter and What to Expect Letter on the CMC Website. ▪ Develop a 2021 work plan based upon CMCAC priorities. ▪ Distribute the Family Satisfaction Survey. ▪ Continue Work on the PDN Workforce Capacity Study. ○ Upcoming SHHN workgroup meeting are on 1/19/21 and 2/2/21.
Data Workgroup Quarterly Report	<ul style="list-style-type: none"> • Kimberly gave a summary on the following: <ul style="list-style-type: none"> ○ Workgroup remained on hiatus; however, work on the Family Satisfaction Survey continued under the purview of the Skill Home Health Nursing Workgroup. ○ Data workgroup will develop a work plan based upon CMCAC 2021 priorities.

<p>2020 End of Year Summary Report</p>	<ul style="list-style-type: none"> ● Kimberly gave a high-level overview of what the report will look like: <ul style="list-style-type: none"> ○ Discussed having a draft for this meeting, no draft was printed ○ Will be approximately 8 pages long with a table of contents ○ Will discuss how the work was organized for 2019, the objectives and a summary of each objective, and the progress made towards them ○ An overview of the objectives for 2020 will also be included in the report ○ Kimberly will share the draft with CMCAC and will ask for feedback by the end of January 2020
<p>PDN Workforce Capacity Study Update</p>	<ul style="list-style-type: none"> ● Mary Culnane from the University of Delaware shared the following: <ul style="list-style-type: none"> ○ Study design to look at nurses in home care. <ul style="list-style-type: none"> ▪ Survey tool will include interviews with stakeholders from various backgrounds i.e. nurses, PDN agencies and families. ▪ Will also include nurses who opted not to go into home care and find out why. ○ The research team will step-back the timeline for the family survey so that families do not confuse this study with the Family Satisfaction Survey study. ○ The survey questions for the Study were developed based upon input from the SHHN workgroup, literature reviews and websites. ○ The team has submitted the HSRB draft to DMMA for a preliminary review.
<p>Family Satisfaction Survey Update</p>	<ul style="list-style-type: none"> ● Cathy Coddington of Vital Research shared the following: <ul style="list-style-type: none"> ○ Research team has ensured language assistance for families who do not speak English or Spanish. ○ Family Satisfaction Survey reminder cards have been sent and are open until the end of February. ○ Warm introductions to the survey are needed to hear from as many families as possible.
<p>Review of 2021 Priorities</p>	<ul style="list-style-type: none"> ● Kimberly Xavier gave an overview of the 2021 CMCAC Priority List and will focus on accomplishing the following: <ul style="list-style-type: none"> ○ Strengthening the network of home health providers. ○ Evaluation of home-based therapies as it relates to physical therapy; speech therapy; occupational therapy etc. and determine what works and does not work. ○ Development of another workgroup that will work to improve the work of other home care providers i.e. speech language, occupation therapists, physical therapists etc. ○ Developing resources for families and children with medical complexity. ○ Looking for feedback and recommendation on the priority list from Advisory Committee.
<p>Covid-19 Update and Discussion</p>	<ul style="list-style-type: none"> ○ Olga Goncharova-Zapata stated that children are left behind and COVID shows all the cracks in the system. ○ Maria Olivero asked will family of CMC get the vaccine. <ul style="list-style-type: none"> ▪ Steve Groff responded stating that DMMA is working closely with the federal government and DPH on vaccine rollout measures. <ul style="list-style-type: none"> ✓ Currently includes healthcare workers, high-risk individuals and people 65 and older. ✓ Problem with the vaccine rollout is that many people are in need of the vaccine but cannot get it at the moment. ✓ May be unwise to vaccinate one person of a whole family. ○ Dr. Mpsai raise concerns that children are not being thought of for the vaccine; but home health care providers, even parents are moving up the list.

	<ul style="list-style-type: none"> ▪ Steve Groff responded stating that vaccines are not being developed for children and pediatric leaders are in the process for raising awareness of the needs of this population. ▪ Vaccine delivery for COVID is separate and different from other vaccine deliveries.
Public Comment	<ul style="list-style-type: none"> ○ Steve Groff welcomes families to share comments with Committee. <ul style="list-style-type: none"> ▪ Families commented on the impact of having a child with complex medical needs can have on families' livelihood. ○ Steve Groff acknowledges the challenges families face with caring for child with medical complexity and other life responsibilities. Thanks everyone for sharing and joining the meeting.

Future Meeting Dates:

<p>April 13, 2021 9:00 AM – 11:00 AM</p>	<p>July 13, 2021 9:00 AM – 11:00 AM</p>	<p>October 12, 2021 9:00 AM – 11:00 AM</p>
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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.