

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

July 15, 2020

9:00 am–11:00 am

Welcome and Roll Call	<ul style="list-style-type: none"> <li>• Delaware's Division of Medicaid &amp; Medical Assistance (DMMA) Director and CMCAC Chair, Stephen Groff welcomed CMCAC members and introductions were completed</li> </ul>
DMMA COVID-19 Update	<ul style="list-style-type: none"> <li>• Director Groff provided an update on Delaware (DE) COVID-19 statistics, including:             <ul style="list-style-type: none"> <li>○ Within the Medicaid membership                 <ul style="list-style-type: none"> <li>▪ 1,500 positive cases confirmed</li> <li>▪ Over 200 deaths</li> </ul> </li> <li>○ Hospitalizations have gone down dramatically over last month</li> <li>○ Currently around 50 Medicaid members hospitalized</li> <li>○ Approximately 400 members testing positive are in Nursing Facilities</li> <li>○ Of the COVID-19 positive population overall                 <ul style="list-style-type: none"> <li>▪ Approximately 17% are children under the age of 18                     <ul style="list-style-type: none"> <li>• To date, no deaths in this age group</li> </ul> </li> <li>▪ 55% cases 50+</li> <li>▪ 95% deaths 50+</li> </ul> </li> </ul> </li> <li>• The DE Public Health Emergency (PHE) was extended for another 30 days</li> <li>• The national PHE is set to expire July 24, 2020             <ul style="list-style-type: none"> <li>○ The Centers for Medicare &amp; Medicaid Services (CMS) indicates it will likely be extended</li> <li>○ Extension of the PHE allows DE to continue to work under emergency authority</li> </ul> </li> </ul>
COVID-19 Observations from Committee Members and Others	<ul style="list-style-type: none"> <li>• CMCAC members and others discussed the following:             <ul style="list-style-type: none"> <li>○ Some families are not allowing providers in the home but this is gradually resuming</li> <li>○ Nursing coverage for families when the child is COVID-19 positive</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>▪ To date, this has not been an issue for any of the members nor have others on the call have had this experience</li> <li>○ Nursing coverage for families when a household member of the child is COVID-19 positive <ul style="list-style-type: none"> <li>▪ If this occurs, one agency indicated the household member would likely quarantine in another part of the home</li> <li>▪ Personal Protective Equipment (PPE) kits are available in the home and the use of PPE is required</li> <li>▪ Agencies are monitoring providers/nurses who work elsewhere</li> <li>▪ Agencies receive frequent updates on COVID-19 guidelines <ul style="list-style-type: none"> <li>• One agency has a COVID-19 team that they outreach to for resources</li> </ul> </li> </ul> </li> <li>○ For families who have put nursing supports on hold, it is expected that nurses will be needed again in the near future as parents are called back to work outside the home</li> <li>○ Highmark Health Options indicated: <ul style="list-style-type: none"> <li>▪ To date, none of the children receiving Private Duty Nursing (PDN) have tested positive</li> <li>▪ The Managed Care Organizations (MCO) continues to communicate with families and agencies regarding family needs</li> <li>▪ Family stress is being monitored and resources are offered to families to address stress and ensure services for the child are in place</li> </ul> </li> <li>○ Family perspectives included: <ul style="list-style-type: none"> <li>▪ One family chose not to have providers coming in to the home during the first month of the pandemic because many nurses are working in different/other settings</li> <li>▪ Families may be working from home, overseeing schoolwork, therapies and medical care for their child with medical complexity</li> <li>▪ One family asked the nurse not to work in other facilities and to replace the hours working elsewhere with PDN for the child</li> <li>▪ Families are probably exhausted mentally and physically — they may not know what to do to get the support they need</li> <li>▪ Important for care coordinators to check on families to make sure they are doing well</li> <li>▪ The pandemic has also taken a toll on children specific to socialization and social skills</li> </ul> </li> </ul>
--	--

	<ul style="list-style-type: none"> <li>▪ Some of the challenges highlighted during the pandemic are present on an everyday basis for children with the highest level of medical complexity, such as the need for high level infection control practices and the need to address social isolation and home based educational supports</li> <li>○ Discussion regarding re-opening schools included the following: <ul style="list-style-type: none"> <li>▪ Questions about how the state workgroups were formed to provide recommendations for school re-opening, how they are informed about the needs of children with medical complexity and the importance of having CMCAC family representation on the groups</li> <li>▪ Questions about how school re-opening will be managed for children with medical complexity</li> <li>▪ Information about how schools and school nurses are approaching re-opening, including: <ul style="list-style-type: none"> <li>● Compiling a list of higher risk students</li> <li>● Following Centers for Disease Control and Prevention recommendations</li> </ul> </li> <li>▪ Requirements for face masks and social distancing <ul style="list-style-type: none"> <li>● Children with medical complexity may not be able to tolerate masks or other restrictions</li> <li>● Children with hearing impairment or those who rely on lip-reading or facial expressions for communication may struggle</li> </ul> </li> <li>▪ Supports for parents who choose to keep their children home from school <ul style="list-style-type: none"> <li>▪ Availability of respite providers</li> <li>▪ The provision of remote/online autism services</li> </ul> </li> </ul> </li> </ul>
<p>CMCAC 2019 Annual Report</p>	<ul style="list-style-type: none"> <li>• The CMCAC 2019 Annual Report <ul style="list-style-type: none"> <li>○ Has been shared in draft form with the workgroups</li> <li>○ The final report, including data appendix, will be sent out to the committee following the meeting <ul style="list-style-type: none"> <li>▪ Provide comments or questions to DMMA no later than August 21, 2020</li> </ul> </li> <li>○ The final report will be posted on the CMCAC website</li> </ul> </li> </ul>

<p>Skilled Home Health Nursing (SHHN) Workgroup Quarterly Update</p>	<ul style="list-style-type: none"> <li>• The SHHN Workgroup quarterly report was presented <ul style="list-style-type: none"> <li>○ Refer to the quarterly report posted on the CMCAC website for details</li> </ul> </li> </ul>
<p>PDN Prior Authorization Toolkit</p>	<ul style="list-style-type: none"> <li>• The PDN Prior Authorization Toolkit <ul style="list-style-type: none"> <li>○ Is a living document that will be regularly updated with relevant information</li> <li>○ Will be posted on the CMCAC website</li> <li>○ Parent Welcome Letters developed by the MCOs are under review by the workgroup and will be added to the toolkit once they are finalized</li> <li>○ Refer to the CMCAC website for details on additional content</li> </ul> </li> </ul>
<p>Affidavit for Temporary Custodian’s Health Care Authorization</p>	<ul style="list-style-type: none"> <li>• Discussed the collaboration with the Delaware Community Legal Aid Society, Inc (DE CLASI) to develop an Affidavit for Temporary Custodian's Health Care Authorization <ul style="list-style-type: none"> <li>○ The affidavit and associated documents have been posted on the DE CLASI website at <a href="http://www.declasi.org/downloads/">http://www.declasi.org/downloads/</a></li> <li>○ DMMA will add a link from the CMCAC website to the documents on the DE CLASI website</li> </ul> </li> <li>• On a related note, the group discussed legislation being developed by Representative Krista Griffith specific to Surrogate Decision Making <ul style="list-style-type: none"> <li>○ Meetings are ongoing with DE CLASI, Representative Griffith and others</li> <li>○ Status updates will be provided when available</li> </ul> </li> </ul>
<p>Workforce Capacity Study Update: University of Delaware</p>	<ul style="list-style-type: none"> <li>• University of Delaware Center for Disabilities Studies provided an overview of the Workforce Capacity Study <ul style="list-style-type: none"> <li>○ The overall goal is to understand what is happening with the PDN workforce and to identify gaps <ul style="list-style-type: none"> <li>▪ The study will involve interviews and a survey</li> <li>▪ Project timeline is being finalized</li> <li>▪ Project kick-off meeting is being scheduled</li> <li>▪ There is a plan to establish a Steering Committee of key stakeholders to help guide the project <ul style="list-style-type: none"> <li>• Contact Brittany Powers at: <a href="mailto:bblument@udel.edu">bblument@udel.edu</a> at the University of Delaware to suggest Steering Committee members</li> </ul> </li> </ul> </li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>▪ Additional details and updates will be shared with the SHHN Workgroup and the CMCAC</li> </ul>
Data Workgroup Quarterly Update	<ul style="list-style-type: none"> <li>• The Data Workgroup quarterly report was presented <ul style="list-style-type: none"> <li>○ Refer to the quarterly report posted on the CMCAC website for details</li> </ul> </li> </ul>
Family Satisfaction Survey Update: Vital Research	<ul style="list-style-type: none"> <li>• Vital Research provided an update on the Family Satisfaction Survey <ul style="list-style-type: none"> <li>○ 11 family interviews conducted (in lieu of focus groups due to COVID-19) to elicit family input</li> <li>○ Next step is survey item/question development, informed by the input of the Children with Medical Complexity Report, the CMCAC, work groups, interviews, prior research and existing survey tools</li> <li>○ Survey items/questions will be submitted to DMMA and families for review</li> <li>○ Final survey items/questions will be submitted to the Human Subjects Review Board for approval</li> <li>○ Updates will be shared with the Data Work Group and the CMCAC</li> </ul> </li> </ul>

Future Meeting Dates:

October 21, 2020 — 9:00 am–11:00 am	January 20, 2021 — 9:00 am–11:00 am
-------------------------------------	-------------------------------------

**CMCAC meetings are being held via webinar/phone due to the COVID-19 PHE until further notice**