



Delaware Health and Social Services
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**Delaware's Plan for
Managing the Health Care Needs of
Children with Medical Complexity**

May 15, 2018



I am pleased to present Delaware's Plan for Managing the Health Care Needs of Children with Medical Complexity. This plan reflects the collaboration of many stakeholders, including state agencies, payers, providers, and families. I was very impressed at the willingness of all involved to step outside their traditional roles and engage in open and meaningful dialogue in an effort to better understand the needs and challenges we face in effectively serving children with medical complexities.

Most importantly, I would like to express my respect and sincere appreciation to the parents who participated in this process. I realize that their time and contribution came at great personal sacrifice. They shared their personal stories and provided a window to their world that was not only educational, but also very impactful. They are quite extraordinary and we all learned from their experiences.

I am grateful for the opportunity over the last six months to learn more about our program and the services needed in the community. The information we shared and the lessons we learned are invaluable. We now have new insight into our system of care. We can see things that work well and areas where we need improvement.

From the outset we realized that our timeline would not permit a fully comprehensive analysis of such complex issues. We have identified some initial steps that can be taken in the short term. However, we agreed early on that we would continue this partnership to develop longer term strategies. Our work has just begun and I look forward to this ongoing discussion and collaboration.

Thank you,

A handwritten signature in blue ink, reading "Stephen M. Groff".

Stephen M. Groff
Medicaid Director

Acknowledgements

The Delaware Department of Health and Social Services would like to thank the following participants for their dedication and contributions to the development of this plan.

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Introduction: Setting the Stage

“An important mismatch has emerged between our current system of child health care and the current epidemiology of childhood need...the proportion of children with a chronic condition that interferes with daily activities has increased by >400% since the 1960s.”¹ “Children with medical complexity (CMC) are an extraordinary group of children—with the most extraordinary families—who are striving to live with the rarest and most severe, functionally limiting, complicated, and life-threatening health problems of all. CMC are one of the smallest, yet fastest growing, populations of children, and they have an enormous impact on the healthcare system.”²

In 2017, the State of Delaware’s Legislature, 149th Generally Assembly, passed an *Act making appropriations for the expense of the State Government for the fiscal year ending June 30, 2018; specifying certain procedures, conditions and limitations for the expenditure of such funds; and amending certain pertinent statutory requirements* [House Substitute No. 1 (HS1) for House Bill No. 275 (HB275)]. Within this Act, Budget Epilogue Section 141 addresses the needs of Children with Medical Complexity in the State of Delaware and gives specific instructions for the Department of Health and Social Services (DHSS) to develop and publish a comprehensive plan for managing the health care needs of Delaware’s children with medical complexity by May 15, 2018. (The full budget Epilogue language can be found in Appendix B)

Under guidance from Kara Odom Walker, MD, MPH, MSHS, Cabinet Secretary of DHSS, The Division of Medicaid and Medical Assistance (DMMA) came together with multiple community partners, sister divisions, parents, caregivers, and other advocates to develop a comprehensive plan for identifying and managing the health care needs of Delaware’s children with medical complexity. This document describes the planning process, a comprehensive analysis of the system of care for CMC, and the visions, goals, and strategies developed by the Children with Medical Complexity Steering Committee and its workgroups.

The CMC Steering Committee was launched in November 2017 with the desire 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. The CMC Steering Committee divided into four smaller workgroups that used four broad questions to guide their planning sessions which spanned approximately six months.

Delaware CMC Steering Committee Key Planning Questions
• What do we want to achieve?
• What are the visions and goals that drive our work?
• What barriers limit CMC’s ability to receive appropriate care?
• What are some possible solutions?

¹ Cohen, E., Berry, J. G., Sanders, L., Schor, E. L., & Wise, P. H. (2017). *Status Complexicus? The Emergence of Pediatric Complex Care*. American Academy of Pediatrics.

² Berry, J. G. (2015). *What Children with Medical Complexity, Their Families, and Healthcare Providers Deserve from an Ideal Healthcare System*. Lucile Packard Foundation for Children’s Health.

A Comprehensive Approach to Care for Children with Medical Complexity (CMC)

The CMC Steering Committee used a comprehensive approach with a range of goals and strategies to clearly identify the population, assess access to services, evaluate models of care, and analyze the relationships between insurance payers. The planning process was designed to take a systemic approach, focusing on how the current health care system is providing for Delaware’s children with medical complexity, identifying areas of which improvement can be made, and suggesting some strategies to strengthen the system so that Delaware can adequately meet the needs of this vulnerable population.

“Children with medical complexity have intense health care needs and their families often face real challenges in getting them what they need. I am really pleased that DHHS has convened patients and families, providers, payers, and other representatives to focus on how to best serve these kids. I am optimistic that we can all continue to work together to remove barriers so that children with medical complexity can benefit from the provision of optimal health care.”
 - Jonathan M. Miller, MD, FAAP, Interim Chief, Division of General Pediatrics, Nemours A.I. duPont Hospital for Children

The CMC Steering Committee met bi-weekly, for approximately six months. Additionally, there were five initial workgroups, comprised of steering committee members, as well as additional volunteers, that met weekly or bi-weekly to address specific areas, such as population, data, access, payers, and models of care. It became evident early on that there would not be enough time to perform an in-depth analysis of the full continuum of care for CMC. Therefore, the first recommendation made by the steering committee is to continue this process. We would suggest that the Steering Committee meet and outline a suggested path forward to continue the discussion, review the data and guide implementation strategies for system improvement.

The Population workgroup was established to aid in the development of a Delaware specific definition for Children with Medical Complexity. Once the steering committee approved the definition, the group disbanded.

Comprehensive Approach to Care for CMC
<p>Access: "The timely use of personal health services to achieve the best health outcomes. Attaining good access to care requires three discrete steps:</p> <ol style="list-style-type: none"> 1. Gaining entry into the health care system. 2. Getting access to sites of care where patients can receive needed services. 3. Finding providers who meet the needs of individual patients and with whom patients can develop a relationship based on mutual communication and trust.³
<p>Payers: Represents the coordination between Medicaid, private insurance agencies, other state agencies, and any other payers of care for a child with medical complexity.</p>
<p>Models of Care: “Broadly defines the way health services are delivered. It outlines best practice care and services for a person, population group or patient cohort as they progress through the stages of a condition, injury or event.⁴”</p>
<p>Data: Analysis of information to identify and support updated or new approaches to health care delivery and payment structure for children with medical complexity.</p>

³ Agency for Healthcare Research and Quality, U. D. (2011). *National Healthcare Disparities Report*. Rockville: AHQR Pub.

⁴ Agency for Clinical Innovation. (2013). *Understanding the Process to Develop a Model of Care - An ACI Framework*.

Identifying Children with Medical Complexity – A working definition

The CMC Steering Committee developed a broad definition of children with medical complexity to aid in the development of a Delaware’s Plan for Managing the Health Care Needs of Children with Medical Complexity. This definition is not intended to serve as the basis for denying or authorizing care and/or payment for care for children served through the Delaware Medicaid Program.

Definition

Children with medical complexity are a subset of children and youth with special health care needs because of their extensive health care utilization. For the purpose of this plan, a child is considered medically complex if she/he falls into two or more of the following categories:

- Having one or more chronic health condition(s) associated with significant morbidity or mortality;
- High risk or vulnerable populations with functional limitations impacting their ability to perform Activities of Daily Living (ADLs);
- Having high health care needs or utilization patterns, including requiring multiple (3 or more) sub-specialties, therapists, and/or surgeries;
- A continuous dependence on technology to overcome functional limitations and maintain a basic quality of life.

“Please don't dismiss our children. Please don't dismiss our families. We, like you, work very hard to make sure our children have everything they need to be successful in life. Our children just need a whole lot more to succeed. They need a whole lot more to be safe. They need a whole lot more to live and to live with quality of life. They are, in fact, children first; not in any way defined by their diseases. They are singers, dancers, huggers, flirts and pranksters. They are our hearts. – Maria Olivere, Franki’s Mom



Visions and Goals

In developing this comprehensive plan to identify and manage the health care needs of Delaware's children with medical complexity, the CMC Steering Committee members were asked to focus on the future and identify ways the group could make the process easier for families, parents, and other caregivers of children with medical complexity. Evaluating the system of care in this way helped to guide efforts to strengthen the system for children with medical complexity so that Delaware can adequately meet the needs of this vulnerable population.

"We are here so that no other families have to go through what we have been through." Olga Zapata, Victor's Mom

Each CMC workgroup developed individual visions and goals for access, models of care, and payers. These visions and goals helped to guide the members through the planning process and focus discussions. Throughout the planning process, the workgroups met either weekly or bi-weekly to discuss gaps in the system of care for children with medical complexity. Each workgroup focused on broad areas in which a variety of challenges were identified. Due to the complex nature of payer claims and data systems, the workgroups were not able to react to quantitative data and relied mostly on anecdotal feedback provided by parents. Throughout many long meetings, parents provided an invaluable perspective regarding their personal experiences with the system of care as it relates to their child with medical complexity. The workgroups then examined each area so as to identify actionable recommendations to address those challenges.

During this process many themes, challenges, and recommendations arose from various workgroups that impacted other workgroups, requiring collaboration and sharing of information. This was facilitated by an overarching repository of information shared at each steering committee meeting, as well as reports provided by each of the workgroups at steering committee meetings.



Data Workgroup

Children with medical complexity are becoming a priority population for the health care system with considerable attention from clinical providers, payers and policy makers on targeted approaches to reduce health care expenditures through improved care coordination and quality health care delivery.⁵ Children with medical complexity have intensive health problems and medical fragility that require extensive health care services and a coordinated care delivery system. The illness burden and chronic conditions lead to functional limitations and affect multiple organ systems that necessitate substantial medical needs to provide optimal care.⁶

Nearly 20 percent of all US children ages birth to 18 years have a chronic and/or complex health care need (e.g., asthma, diabetes, spina bifida, autism) requiring physical and behavioral health care services and supports beyond what children normally require. A smaller group of children, which is increasing in number, have complex health care needs, with about 4 percent estimated to be medically complex⁷.

It is imperative for the health care system, payers, and policy makers to understand the current health care utilization for children with medical complexity and identify specific areas to enhance health care service delivery. Data on health care utilization and Medicaid spending will provide insight into the unique and specific needs for this pediatric population to focus on resource utilization, networks, models of care and the potential for cost management and savings.⁵

Due to the complex nature of payer claims and data systems, the Data workgroup was not able to provide quantitative data for the other workgroups to consider in identifying gaps and developing recommendations. The workgroup was able to develop an “at-a-glance” analysis of the characteristics of children in Delaware (Appendix C). Additionally, the Data Workgroup met diligently to identify data parameters of which would be useful in analyzing the system of care for children with medical complexity, once the mechanism by which the data would be acquired was identified.

The data parameters identified by the workgroup will characterize patient demographics and evaluate both clinical services and home services utilization. For each data parameter, data statistics will be provided for all characterized health status groups in order for comparison of demographic and health services utilization between children classified as healthy vs. children classified as medically complex. Furthermore, the Data workgroup has provided recommendations for next steps in performing a comprehensive data analysis of State Medicaid claims data to enhance the work of the Steering Committee and health care delivery for children with medical complexity.

⁵ Berry JG, Hall M, Neff J, Goodman D, Cohen E, Agrawal R, Kuo D, Feudtner C. Children with medical complexity and Medicaid: spending and cost savings. *Health Aff (Millwood)*. 2014 Dec;33(12):2199-206

⁶ Murphy NA, Carbone PS; Council on Children with Disabilities; American Academy of Pediatrics. Parent-provider-community partnerships: optimizing outcomes for children with disabilities. *Pediatrics*. 2011 Oct;128(4):795-802

⁷ Honsberg, K., Normile, B., Schwalberg, R., & VanLandeghem, K. (2018). *How States Structure Medicaid Managed Care to Meet the Unique Needs of Children and Youth with Special Health Care Needs*. National Academy for State Health Policy.

Access Workgroup

Vision: Parents need the knowledge, skills, and ability to procure appropriate services for their children in a timely manner.

Goals of the Access workgroup:

- To identify barriers and challenges to accessing care for children with medical complexity.
- To identify person-centered solutions to access care using a team approach.

The Access workgroup identified five broad areas in which access to services for children with medical complexity posed challenges; these include Provider Capacity, Nursing and other Support Services, Transportation, Durable Medical Equipment and Supplies, and Pharmacy. The group then identified and prioritized challenges and recommendations based on overall need, availability of resources, and the feasibility of implementation.

Provider Capacity

Provider Capacity is one of the most important factors when considering access for any population. This is especially important for populations such as children with medical complexity, as there is a stronger need to access services that are not regularly provided. The Access workgroup identified the following five areas, explained below, in which Provider Capacity is the most challenging for this population: Primary Care Services; Specialists; Out-of-Network Providers; Speech, Occupational, and Physical Therapy; and Imaging and Labs.

The workgroup identified a need for Primary Care Providers (PCP) to be educated regarding the depth of care necessary for children with medical complexity, as well as resources available to both themselves and the child's parent/caregiver. When a knowledge or resource gap occurs, a child with medical complexity may not be referred to, or informed of, much needed services. Additionally, some parents/caregivers may not be aware of the role primary care physicians play in the care of a child with medical complexity. This can result in parents/caregivers not sharing all of the information with the PCP, resulting in fragmented care.

Additionally, due to the complex needs of children with medical complexity, they are often under the care of multiple specialists. Parents expressed that they have had to wait for extended periods of time for new patient appointments in some specialties. The group



also mentioned that it is especially difficult to see specialist in Kent and Sussex Counties in a timely manner, which results in children with medical complexity traveling to New Castle County to access services. Requiring children with medical complexity to wait to see certain specialists could result in severe complications that may end up requiring hospitalization. Additionally, traveling long distances with a child with medical complexity is very difficult, and at times, dangerous for the child. This is further exasperated in instances where parents/caregivers do not have adequate transportation and must rely on DMMA's non-emergency medical transportation provider, public transportation, or others. This adds an additional level of coordination for parents/caregivers.

Also due to these complex needs, there are times that a specialist may not be available in the child's insurance carrier's network. For example, children with medical complexity may have a rare condition that could require them to travel to specialty hospitals in other states. The process for approval to see an out-of-network provider can be a bit lengthy and cumbersome. Once the referring doctor provides the necessary medical information and the out-of-network doctor agrees to see the child, the out-of-network doctor must work with the payer to develop an agreement to provide services.

Home-based speech, occupational, and physical therapies are essential for children with medical complexity for multiple reasons: some children pick up illnesses when they travel to facilities for services; others have conditions that make it extremely difficult to travel at all. Families reported difficulty obtaining these services and described long waiting lists and overall lack of availability. Although some of these therapies are offered through the education system, they do not always adequately meet the child's medical needs. Speech therapy is an example of an educational service that also needs to be provided as a medical service. When a child receives speech therapy in school, the therapy is intended to address educational needs. Medical needs, such as oral feeding, are often not part of the therapy. Parents also reported that re-authorization of therapy services for children with medical complexity could be denied based on a lack of progress. However, the therapies are often required to maintain the child's current condition; stopping these therapies based on a lack of progress could result in a decline in health and functioning.

Additionally, coordination of lab and imaging appointments for children with medical complexity can be very difficult. In order to perform imaging, children with medical complexity can require anesthesia, a large care team, surgeons, and other critical staff on stand-by. Coordination of these imaging appointments is especially important for children with medical complexity that require regular imaging from multiple specialty areas. Care givers could benefit from assistance in coordinating imaging appointments.

Finally, parents shared that they have had difficulty getting specialty lab authorizations approved. For instance, some specialty testing can only be done in certain laboratories. There were experiences reported in which prior authorizations to go to specialty labs were denied and parents were told to use a preferred provider. However, the preferred provider was not able to provide the required test, which could have been determined prior to the denial if proper research was done. Additionally, parents share that some genetic and rare specialty tests doctors have requested for their child either were not approved or were very difficult to get approved. However, knowledge that these tests provide can often significantly improve

the care a child with medical complexity will receive, as well as the child’s quality of life. Furthermore, parents express that they don’t receive a clear reason for some denials, for instance, how the requested service or equipment was determined to not be medically necessary, although requested by the physician.



Nursing and other Support Services

Nursing and other support services are essential for children with medical complexity. It is important to understand that children with medical complexity are a subset of children with special health care needs; thus, the support required to care for them can be more intense. Due to the complex needs of this population, children with medical complexity need an extensive support team surrounding them at all times. The Access workgroup identified the following areas, explained below, in which support services are most essential for this population: Skilled Nursing Services, Support Services in Emergency Situations, Respite Services, and Comfort Care.

Parents described access to home nursing services as one of their most difficult problems, at times causing risks to their children’s medical stability as well as disruptions in their ability to maintain employment and manage other family needs. Parents noted that they were frequently unable to fill authorized home nursing shifts. Parents/caregivers also experience “call outs,” in which nursing agencies are unable to provide a substitute when the nurse assigned to a child’s care is unavailable. Professional-level nursing duties often fall to parents/caregivers, who are often functioning with little sleep and with responsibility for other family members.

“We need to improve access to nursing and therapy services in the home for medically complex children.”
– Patricia Watson RN, BSN, Division Director, Bayada Pediatrics & Alice Knott, Director, Delaware Pediatrics North, Bayada Pediatrics

Children with medical complexity require skilled home health providers to provide care consistently throughout the day. The majority of them need constant monitoring and care to ensure safety, health, and life. Due to the high acuity of children with medical complexity, many home health nurses choose other assignments, limiting the availability of skilled home health nurses for children with medical complexity. Finding adequate nursing coverage for children with medical complexity becomes even more difficult as the children age, because the care becomes more intense. Additionally, some of the things that children with medical complexity require may be outside of the scope of certain licenses, or beyond what nursing agencies may allow certain provider types to do. Parents/caregivers in this situation must either remain close at all times or risk an emergency situation that can be extremely dangerous for a child with medical complexity. The lack of available, skilled, home health nurses results in parents being unable to fill all approved nursing shifts for their child, resulting in parents filling these shifts and performing as skilled nurses. This can result in parents/caregivers losing time at work, and in some cases the ability to work at all; the deterioration of

parent/caregiver's health as a result of inadequate sleep and time to address their own needs; and an overall decrease in quality of life for the family.

Parents also expressed the need for a cultural shift regarding the way home health nursing hours are allocated for children with medical complexity. When children with medical complexity are denied the number of hours specified by the child's provider in the letter of medical necessity, parents/caregivers feel that it is because the focus is often shifted to their availability rather than the child's need. They are often asked personal things during the authorization process, such as how many hours they work and who else lives in the home that can help with the child's nursing needs. However, the needs of children with medical complexity are multifaceted and parents/caregivers feel that it is unreasonable to expect them, or other household members, to provide skilled nursing services; although some are capable, that cannot be said for all. It was suggested that nursing hours should be based on the child's need, not parents/caregiver availability. Additionally, parents express that there is a misconception regarding the need for nursing hours when a child returns home from a hospitalization. Nursing hours may not be approved with a reason that the child is returning home because they are better. Families state the inverse is true; the child is better because they are being monitored properly and sending them home without proper supports will cause them to deteriorate.



Payers approve nursing coverage for a specific number of hours. Parents report a cultural bias among providers, payers, and the general public. They feel there is a belief, expressed or not, that parents/caregivers should only be allowed to schedule nursing coverage for work outside the home or the child's schooling. Parents expressed that some home health nursing agencies are not very flexible in how they assign their nurses to cover shifts, which can result in a parent/caregiver having to call out of work, risking their job security. Parents state that this cultural bias can make things difficult for parents/caregivers that may have varied work schedules, a higher need during times when secondary parent/caregiver may be unexpectedly unavailable, etc. This also does not allow the parent/caregiver to do regular tasks, such as cooking, cleaning, basic daily life activities, and self-care.

"The opportunity to participate in the Children with Medical Complexity Steering Committee has truly been an enlightening and enriching journey that combines lived experience with evidenced-based practice, data, and policy. The work of this group will affect the approach to children with medical complexity in Delaware to ensure a family-centered model of care, to improve outcomes for children with medical complexity and their families." – Lenaye Lawyer, MD, Market Chief Medical Officer, Amerihealth Caritas DE

Respite and Comfort Care were additional areas that parents identified as lacking for children with medical complexity and their families. Respite care is noted as potentially one of the most underutilized services in pediatric care despite the potential to substantially help families and parents/caregivers of children with medical complexity.⁸ Respite is a service designed to give parents/caregivers a break from the stress of taking care

⁸ Berry, J. G. (2015). *What Children with Medical Complexity, Their Families, and Healthcare Providers Deserve from an Ideal Healthcare System*. Lucile Packard Foundation for Children's Health.

of an individual with special needs. This allows for parents/caregivers to have some quality of life to do things such as visit family or maintain their own health so as to continue to care for a child with medical complexity. Comfort care for children with medical complexities can be an essential component to ensuring quality of life for the child.

Transportation

Transportation is a major challenge for children with medical complexity. Due to the complex needs of this population, it can be difficult for children with medical complexity to acquire appropriate transportation, especially as children grow and age. Many families cannot afford vehicles, or modifications to existing vehicles, to accommodate the needs of a child with medical complexity, such as very large and bulky wheelchairs. For families that do own vehicles that have been modified, there are still many issues with reliability, availability, and cost of fixing and maintaining these vehicles.

Workgroup participants expressed concern over the reliability and availability of transportation for children with medical complexity. It was reported that this is especially apparent in Kent and Sussex Counties, as families must often travel to New Castle County to see specialists. Children with medical complexity often have a lot of equipment making transportation in regular vehicles difficult. As a result, parents/caregivers must either purchase a vehicle that can accommodate the child's needs, rely on non-emergency medical transportation, or rely on others that may have modified vehicles.

When using non-emergency transportation, providers often pick up multiple members that may be going in the same direction or area so as to make the most efficient use of the transportation provider's time and resources. This can add a significant amount of travel time onto what may already be a long trip. Furthermore, parents have expressed that families may wait extended amounts of time to be taken to or home from appointments, resulting in extra costs to families for meals and incidentals while waiting. Additionally, many children with medical complexity have a lot of equipment that requires electricity. When these children travel, they have to use battery packs that have limited time. Not knowing how long a trip may take, to and from an appointment, can be dangerous to those traveling with battery packs. Finally, DMMA's non-emergency transportation provider requires requests for transportation to be made within three-business days of an upcoming appointment. Although there is an exception that allows the non-emergency transportation provider to bypass the three day rule for sick patient appointments, it is not well known.



Durable Medical Equipment and Supplies

Children with medical complexity often require a multitude of durable medical equipment (DME) and other supplies, such as wheelchairs, lifts, diapers, etc. The approval, acquisition, and management of DME and supplies can be very overwhelming for parents/caregivers of children with medical complexity.

Children with medical complexity often have needs that are much different than those of the rest of the pediatric population. Therefore, there is a need for extensive, and at times specialized, DME and supplies. Parents shared that it seems as though DME and supplies are often approved with arbitrary numbers that do not reflect the child's needs. For instance, it was shared that one child with medical complexity was approved for a suction toothbrush. However, the approval only included enough supplies for the child to brush his teeth one time per day; it is customary for people to brush their teeth twice per day to maintain oral health. Parents also expressed that many of their requests for DME and supplies appear to be denied initially without considering the child's needs, resulting in appeals that would not need to occur had the initial request been more thoroughly reviewed. For example, some items, such as a nebulizer, could be denied based on a child's age. However, children with medical complexity are not able to do many age typical activities of daily living, so the same parameters that would be used for a typical child should not be applied when determining approval of services for children with medical complexity.

Miscommunication between parents/caregivers, DME and supply companies, and payers, such as managed care organizations or private insurance companies, appears to be a driving force for many issues surrounding acquisition of DME and supplies. DME companies often require parents/caregivers to provide new prescriptions for equipment and supplies although the original has not yet expired. Also, many DME companies do not appear to be aware of payer's policies regarding ordering and reordering of equipment and supplies; this causes extra work for the parent/caregiver to coordinate communication between the two entities. The process required by payers to renew prescriptions is cumbersome and lengthy, and could likely be simplified in some instances. Finally, parents/caregivers often have to contact multiple supply companies as not all companies carry all of the items they need for the child; this adds yet another layer of complexity when coordinating the care of a child with medical complexity.

Pharmacy

Children with medical complexity are often on many medications, some more complex than others. Access to and management of prescription and over-the-counter medications can be very complex for parents/caregivers. Children with Medical Complexity often have a large number of prescriptions that must be filled regularly. Furthermore, some children with medical complexity have complex pharmacological needs which necessitate the parent/caregiver to receive medications from multiple pharmacies and make contact often weekly to order and then pick up medications. Many times these medications have different refill and pick-up dates adding an extra layer of coordination that is required for parents/caregivers.

Some children with medical complexity have specially formulated and compounded medications that cannot be filled at the regular neighborhood pharmacy. Compounding medication requires specific processing and can often take 24 hours or more to prepare. Therefore, parents/caregivers must go to the regular pharmacy for basic medications and to specialty pharmacies to receive compounded medications. This can create transportation and coordination challenges for families, as well as require them to be away from other responsibilities. Although there is an option to receive some specialty medications via home-delivery, some parents/caregivers live in areas that make medication delivery unsafe as there is a high risk of having it

stolen. Although the complex needs of this population may not allow them to receive all of their medications from one pharmacy, parents/caregivers expressed a desire to limit the number of pharmacies they must use whenever possible.

Access to medication in a solution format is an area in which many children with medical complexity struggle. Some children with medical complexity, such as those with jejunal tubes, require medications be administered in “solution” form to prevent clogging the tube. Receiving all of a patient’s medication in “solution” form from any one pharmacy in Delaware is unlikely. Additionally, complex prescriptions cannot be sent through an electronic prescription system, requiring parents/caregivers to physically take scripts to the pharmacy and return to pick them up as compounding solution medication takes much more time than filling a typical prescription. Furthermore, there is a lack of knowledge as it relates to solution formatted medication that applies to providers, parents/caregivers, and in some cases pharmacies.



Over-the-counter (OTC) medications are another area that some children with medical complexity have difficulty with. It is difficult to find pharmacies that carry the quantity of an OTC medication that is needed for older children with medical complexity. For example, many children with medical complexity must have liquid medications; however, a typical bottle of liquid Tylenol may only provide two doses of medications for a teenage child. For a child that takes Tylenol regularly, that would be very expensive for parents/caregivers. When parents/caregivers attempt to get these OTC medications through a prescription at the pharmacy, they are often denied at point of sale with the reason that the medication is available over-the-counter. This is an education issue on the pharmacy side as the pharmacist can request approval based on circumstance such as that of a child with medical complexity.

Finally, medications sometimes require prior-authorization requests accompanied by medical necessity documentation, even in instances in which a child has previously been approved for the same medication. This leaves parents/caregivers and providers guessing as to the next steps they need to take to get the appropriate medication for the child. Parents also expressed that many medications are initially denied without considering the child’s needs, resulting in appeals that would not need to occur had the initial request been more thoroughly reviewed. For example, a solution antibiotic may be denied with the reason that the preferred drugs were not tried first. However, the preferred drugs may not be appropriate for that child. Furthermore, a parent/caregiver that has already gone through the process to prove this, and received approval for the same medication, must go through the appeal process each time. This would be similar to requiring a parent/caregiver to prove their child has an allergy to Penicillin each time they request an antibiotic. Payers have access to prior claims and medical necessity information that reviewers should be referring to prior to making decisions regarding denials or approvals of medications.

Payers Workgroup

Vision: Optimizing the health of Children with Medical Complexities by empowering strong partnerships between parents/caregivers, medical providers and payers through building trust, cooperation, effective communication and knowledge.

Goals of the Payers workgroup:

- Standardize medical necessity documentation and review the MCO authorization processes so as to reduce redundancy of information, avoid delays in care and/or services, streamline the authorization process, and decrease confusion among providers, payers, and parents/caregivers.
- Empower parents/caregivers to navigate the appeals process by making it more transparent and less intimidating.

The Payers workgroup identified three broad areas within the payers roll that pose challenges for children with medical complexity; these include Redundant Documentation, Appeals and Fair Hearings, and Coordination between Payers. The group then identified and prioritized challenges and recommendations based on overall need, availability of resources, and the feasibility of implementation.

Redundant Documentation

Parents shared that redundant documentation is one of the most frustrating aspects of coordinating care for children with medical complexity. Medical Necessity documentation is required for almost all services provided to children with medical complexity. Additionally, some services, medications, DME, and supplies require authorization every six months to a year, in addition to when the child's needs may necessitate change. Since these children have such high needs, this means that providers are tasked with providing the same information multiple times for different prior authorization or re-authorization requests. The need for medical necessity to be documented is valid, and in most cases necessary. However, children with medical complexity have conditions that are life-long and progressive. Most services that this population receives are required to maintain care, and if they are stopped, the child's condition can decline. Payers have access to prior claims and medical necessity information that reviewers could be referring to prior to making decisions regarding denials or approvals of services, medications, DME, and supplies. Further complicating this process, many children with medical complexity have more than one insurance provider; many of these children have private primary insurance with Medicaid as a secondary payer. Each payer has their own forms and documents that must be submitted each time a request is made or medical necessity is required to be provided. This is very time consuming and a large burden for parents/caregivers and providers of children with medical complexity.

Appeals and Fair Hearings

The Payers workgroup identified the appeal and fair hearing processes as a large challenge for parents/caregivers of children with medical complexity. Parents expressed that the appeal process is very lengthy and often requires that they take time off work and away from other duties. With the high acuity of children with medical complexity, parents/caregivers feel that they have to file appeals for a large majority of services their children need. Not only can the process be time consuming, but it can also be very overwhelming and confusing for parents/caregivers. Parents in all of the workgroups shared that it feels as if the onus is put on parents/caregivers to prove why a service is needed for their child despite letters of medical necessity from ordering physicians.



They feel that the process should be a collaborative one in which all players work together to come up with the best solution for the child. In most cases, payers have access to prior claims and medical necessity information that reviewers should be referring to prior to making decisions regarding prior authorization. Payers do face a barrier in that they do not have access to the full medical record when determining authorization for a service. However, the workgroup identified a gap in which active collaboration among payers, providers, and parents/caregivers does not seem to be taking place prior to making a final determination.

Parents also shared that the State Fair Hearing Process can be very intimidating. It was expressed that they did not feel prepared and would have benefited more from education around the fair hearing process prior to attending. Additionally, the workgroup noted that Managed Care Organizations always bring an attorney to all State Fair Hearings. Parents expressed that this increases the intimidation factor and also makes them feel as though they are at an unfair disadvantage. Although notices that parents/caregivers receive regarding the appeals and fair hearing processes include information for community law agencies, these agencies do not accept all cases, and parents/caregivers are often required to represent themselves at these hearings.

Coordination between Payers

In many cases, children with medical complexity have more than one insurance company, with Medicaid being the payer of last resort. Parents expressed that private insurance companies appear to have many barriers that often lead children with medical complexity to rely on Medicaid. Additionally, private payers and Medicaid are challenged to communicate. This can slow down the process of getting services approved for many children with medical complexity for a variety of reasons. For example, Medicaid requires a denial from the primary insurance company before covering any services; however, many services are explicitly not covered under private insurance plans. A review of what the plan covers, versus waiting for a child with medical complexity to go through the prior authorization and denial process, could save a lot of time and ease the burden on parents/caregivers.

Models of Care Workgroup

Vision: Maximize the health, functioning, development, and quality of life for children with medical complexity and their families, by providing proactive care and services, through coordinated patient and family-centered care.

Goals of the Models of Care workgroup:

- Prospective identification of Children with Medical Complexity.
- Patient and family-centered care (PFCC) as the main focus across all levels of care and services.
- Proper and timely management of care delivery.
- Appropriate resource identification and allocation.

The Models of Care Workgroup has leveraged the Standards for Systems of Care for Children and Youth with Special Health Care Needs from the Association of Maternal and Child Health Programs⁹ to develop a framework upon which to build a model of care. Unlike other sections of this report, this section focuses on what could be, rather than what is now. Instead of documenting barriers, this section describes an ideal framework for a model of care that could satisfy some of the needs identified in the planning process.

Patient and Family-Centered Models of Care

An effective model of care must have the values of Patient and family-centered care (PFCC) at its core. PFCC is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care by placing an emphasis on collaborating with people of all ages, at all levels of care, and in all health care settings. In patient and family-centered care, patients and families define their “family” and determine how they will participate in care and decision-making with the goal to promote the health and well-being of individuals and families. Additionally, a family-to-family/peer-to-peer approach to assisting families through diagnosis and procurement of services is encouraged across all systems of care. A PFCC model of care can lead to better health outcomes, improved patient and family experience of care, better clinician and staff satisfaction, and wiser allocation of resources¹⁰. Additionally, an effective model of care for children with medical complexity must include a plan of care for the child that respects family and parents/caregiver strengths and goals and is jointly developed, shared, and implemented by the child’s family, primary care provider (PCP), specialists, and other’s as appropriate, that spans across systems.

⁹ Association of Maternal & Child Health Programs and National Academy for State Health Policy. (2017). *Standards for Systems of Care for Children and Youth with Special Health Care Needs Version 2.0*. DC.

¹⁰ PFCC Institute for Patient- and Family-Centered Care. (n.d.). *Best Practices: Patient- and Family-Centered Care*. Retrieved from <http://ipfcc.org/about/pfcc.html>



PFCC is also crucial in providing good care coordination within a model of care. Care coordination is the deliberate organization of child/family care activities between two or more participants (including the child/family) involved in a child's care to facilitate the appropriate delivery of health care and other services. Organizing care involves the allocation of personnel and other resources needed to carry out all required child/family care activities and is often managed by the exchange of information among participants responsible for different aspects of care. Care coordination for individuals with a medical complexity can be very time intensive.¹¹

Care Coordination

It is important to distinguish between care coordination as a task-oriented process supported by systems-level infrastructure, and care coordination as relationship-based approach to address complex problem solving with families of children with medical complexity. Pediatric care coordination is a patient and family-centered, assessment driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs in order to achieve optimal health and wellness outcomes. Care coordination for pediatric populations includes the ability to develop and sustain caring relationships among children, youth, families, and community providers as well as ensure seamless delivery of care for the child across the continuum of care, in various settings including primary care, subspecialty, emergency department, or the community. It is imperative that these concepts and values are held by all individuals on the care coordination team including, but not limited to, physicians, nurses, therapist, parents/caregivers, children, and any non-health professionals who may provide care coordination services. High-quality care coordination may enable children, youth, and families to access services that support their health, developmental, behavioral/mental health, and wellness needs. Delivery of care coordination should

Medically fragile children are magical and unique. They are unicorns in a world of too many unknown outcomes. Together we must provide the most appropriate coordinated care. Care that keeps their hearts beating and their smiles leaving a trail of glitter. They are forever in the heart and minds of their parents/caregivers. This is how I see my sweet Christopher. - NANCY AND CHRISTOPHER, PARENT AND CHILD ADVOCATES

be flexible and responsive to these needs, although it may vary by location, encounter type, timing, intensity, and duration. Accommodations should be made for interpreters and/or other

forms of communication preferred by the family. A family-to-family liaison from the cultural community, preferably identified by the child/family, would be key in crossing over systems with families to facilitate cultural awareness.¹² Care providers must take into account the cultural preferences of each family and strive for effectiveness in different circumstances and environments.

¹¹ Berry, J. G. (2015). *What Children with Medical Complexity, Their Families, and Healthcare Providers Deserve from an Ideal Healthcare System*. Lucile Packard Foundation for Children's Health.

¹² Kuo, Dennis Z; Houtrow, Amy J; Council on Children with Disabilities. (2016). Recognition and Management of Medical Complexity. *Official Journal of the American Academy of Pediatrics*, e1-e13.

The Care Coordinator for a child with medical complexity is the individual who is the identified point of contact for the child/family. Although care coordinators may exist in a variety of agencies each child with medical complexity should have one main care coordinator. This care coordinator must be able to communicate and coordinate across systems, such as but not limited to primary care providers, specialists, hospitals, educational systems, and durable medical equipment providers, in order to effectively coordinate care and needs for the child/family. The care coordinator must be able to proactively identify appropriate resources and services for families and assist in the procurement process. This should include assisting parents/caregivers with getting approvals from payers; a working knowledge of the benefit structure of the covering insurer(s); full understanding of how to initiate requests for medically necessary services that are not covered benefits under the child's insurance carrier;¹³ and coordinating services and communication between payers.

Essential Competencies for Providing Pediatric Care Coordination

- Building partnerships that foster family-centered, culturally effective care;
- Proficiency in interpersonal, cross-sector, and interdisciplinary communication;
- Use of team-based, patient and family-centered assessments that identify strengths and needs of the families;
- Care-planning skills promoting shared decision-making and patient/family self-management, with thorough follow-up;
- Integration and shared use of accumulated medical, educational, and community resource information;
- Efforts and attitudes that are goal- and outcome-oriented;
- Flexibility and adaptability to the fluctuating needs of children, youth, and families in the context of a changing health care environment;
- Continuous learning skills and team leadership sharing new knowledge;
- Capacity to participate in organizational quality improvement activities; and
- Resourcefulness in the use of information technologies for optimal care coordination.

A model of care for children with medical complexity should provide parents/caregivers with a choice of where to receive their primary care coordination services. A strong suggestion that came from workgroup participants is that parents/caregivers of children with medical complexity should identify a Medical Home for their child. A Patient-Centered Medical Home (PCMH) is defined by the following, five core attributes¹⁴:

- **Patient-Centered:** Supports patients in learning to manage and organize their own care based on their preferences, and ensures that patients, families, and parents/caregivers are fully included in the development of their care plans. It also encourages them to participate in quality improvement, research, and health policy efforts.
- **Comprehensive:** Offers whole-person care from a team of providers that is accountable for the patient's physical and behavioral/mental health needs, including prevention and wellness, acute care, and chronic care.
- **Coordinated:** Ensures that care is organized across all elements of the broader health care system, including specialty care, hospitals, home health care, community services, and long-term care supports.
- **Accessible:** Delivers accessible services with shorter waiting times, enhanced in-person hours, 24/7 electronic or telephone access, and alternative methods of communication through health information technology (HIT).
- **Quality and Safety:** Demonstrates commitment to quality improvement and the use of data and (HIT) and other tools to assist patients and families in making informed decisions about their health.

¹³ U.S. Department of Health and Human Services (2014). *Making Connections: Strengthening Care Coordination in the Medicaid Benefit for Children & Adolescents*. Retrieved <https://www.medicaid.gov/medicaid/benefits/downloads/epsdt-care-coordination-strategy-guide.pdf>.

¹⁴ U.S. Department of Health & Human Services, Agency for Healthcare Research and Quality (2018). *Defining the PCMH*. Retrieved from <https://pcmh.ahrq.gov/page/defining-pcmh>.

A Medical Home can be very beneficial to the centralization of coordination; therefore, one should be identified as soon as the child is recognized with complex medical needs. Parents/caregivers always have a choice on the Medical Home identification; they may choose the child's PCP or a sub-specialist as the Medical Home Provider. However, because prevention of illness is key in optimal health and functioning, the Medical Home Provider must be able to communicate and coordinate care with the Primary Care Provider, as well as all others on the care coordination team.

Transitioning to the Adult System of Care

Finally, a strong model of care must address the child's transition to adulthood. The transition to adulthood is a gradual process that should begin at age 12 with the introduction of the transition policy. By age 14, the child and parent/caregiver begin transition planning with those involved in the child's care. By age 16, the child, parent/caregiver, and team begin to prepare for an adult approach to care; there is also discussion of preferences and timing for transfer to adult health care. At age 18, the transition to an adult approach to health care is started, and by age 22, the care of the child is effectively and efficiently transferred to an adult medical home and specialists. Throughout this transition, there should be continuous discussion and education regarding rights and choices¹⁵.



"Our task to strengthen the way that we deliver care to children with medical complexity and their families is more important and timelier than we could have imagined at the outset. The participation of Delaware families caring for their medically fragile children was both impactful and humbling, bringing to light the opportunity to incorporate a more family-centered model of care. Working together with so many professionals invested in the common goal of improving healthcare delivery and care coordination to medically complex children has been inspiring. I look forward to seeing this project come to life in our work with our members at Health Options."

*- Ellen McClary, LCSW, CCM,
Manager, Care Coordination, Highmark Health Options*



¹⁵ American Academy of Pediatrics (2011). Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home. *Pediatrics*, 128(11). Retrieved from <http://pediatrics.aappublications.org/content/128/1/182>.

Recommendations from the CMC Steering Committee

It became evident early in the planning process that there would not be enough time to perform an in-depth analysis of the full continuum of care for children with medical complexity. The data needed to perform a quantitative analysis is very detailed and complex. Therefore, the first recommendation made by the Children with Medical Complexity Steering Committee is to continue this process. DMMA will continue to meet with stakeholders to address the system of care as it relates to children with medical complexity.

The CMC Steering Committee requests the Department of Health and Social Services, Division of Medicaid and Medical Assistance to take the committee's recommendations into consideration when developing Delaware's Plan for Managing the Health Care Needs of Children with Medical Complexity. These recommendations are summarized below and described in detail in Appendix A.

- **Keep the Children with Medical Complexity Steering Committee in place** to assist the state in strengthening Delaware's ability to adequately meet the healthcare needs of children with medical complexity.
- **Perform a comprehensive data analysis as it relates to children with medical complexity** so as to identify the population of children with medical complexity in the state of Delaware; determine important clinical and service utilization parameters to help identify service gaps that impact the care coordination and health care delivery for children with medical complexity; guide considerations for innovative care delivery models and appropriate payment structures; facilitate the creation of quality metrics and health outcome deliverables to monitor the successful implementation and effectiveness of new health care strategies; and consider areas for cost reductions.
- **Strengthen systems of care for children with medical complexity** by supporting models of care that are patient and family-centered, clearly defining requirements and qualifications of care coordination standards, and revising and create new policies and/or services for children with medical complexity to address identified gaps.
- **Be clear in contracts about the role of managed care organizations in identifying and providing services to children with medical complexity.** By consistently identifying children with medical complexity, and flagging them in payers systems, MCOs are able to provide needed services quickly. MCOs should identify opportunities to make processes more collaborative and ensure that all players work together in the best interest of the child. Additionally, by establishing specific network requirements for providers of children with medical complexity, the MCOs can monitor the capacity of its providers of children with medical complexity. DMMA can work with MCOs to expand provider capacity where needed.

Recommendations from the CMC Steering Committee

- **Develop and/or strengthen existing resources for parents/caregivers, providers, and the larger community involved in the care of children with medical complexity.** It is important that individuals are aware of and able to access available resources for children with medical complexity. Additionally, it is important to develop a network of care for children with medical complexity, as well as their parents/caregivers, in the areas that resources are lacking.
- **Strengthen the network of home health providers for children with medical complexity** by researching and investigating solutions for what appears to be a shortage in skilled, home health nurses, as well as providers of home-based physical, occupational, and speech therapy. Data must be reviewed and evaluated to clearly identify the shortage, and research must be performed to identify possible solutions.

The Plan

Delaware's Department of Health and Social Services (DHSS), Division of Medicaid and Medical Assistance (DMMA), is committed to continue our work with the Children with Medical Complexity (CMC) Steering Committee. Although the CMC Steering Committee was unable to access quantifiable, Delaware specific data during this initial process, a solution has been identified that will allow the committee to dive deeper into some of the broader recommendations listed in Appendix A, such as establishing separate network requirements for children with medical complexity. Furthermore, DMMA recognizes that there are areas in which collaboration with additional partners would be useful, such as partnering with the Department of Education to analyze the role of the educational system in the care of children with medical complexity.

Though there are many areas of the steering committee's recommendations that require more in-depth analysis, DMMA confidently believes that we can implement some of these recommendations immediately. While DMMA is committed to this long-range strategy to improve the care for this vulnerable population, there are some things that the division plans to put in place sooner. In keeping with the overall recommendations of the steering committee, DMMA commits to the following items over the next 18 to 24 months.

- **Keep the Children with Medical Complexity Steering Committee in place**
 - Continue meeting with the CMC Steering Committee. Meetings will be held bi-monthly.
- **Perform a comprehensive data analysis as it relates to children with medical complexity**
 - Analyze data acquired through the use of an episode grouper to identify the population of children with medical complexity in the state of Delaware.
 - Analyze the same 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.
 - Considerations innovative care delivery models and appropriate payment structures to address identified gaps.
- **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.
 - Work with the Non-Emergency Medical Transportation Provider to clarify, enforce, and revise policies as appropriate.
 - Develop care coordination standards specifically for this population.

The Plan

- **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 and simplify the prior authorization process for children with medical complexity as it relates to durable medical equipment, supplies, and pharmaceuticals.

- **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 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.
 - Publish an informational booklet for the Children's Community Alternative Disability Program (CCADP) as a resource for parents/caregivers, providers, staff, and other stakeholders.

- **Strengthen the network of home health providers for children with medical complexity**
 - Evaluate provider capacity of DMMA's providers of home-based physical, occupational, and speech therapy.
 - Work with MCOs to expand provider capacity where needed.
 - Assess and/or develop mechanisms for children with medical complexity when parents/caregiver is presented with emergent situation and unable to provide care.

Appendix A – Detailed Recommendations from the CMC Steering Committee

Evaluate and implement, as appropriate, Patient and Family-Centered Models of Care that include the following core values.

- Collaborative identification of child/caregiver needs and strengths around health and functioning, including, but not limited to, items such as respite care, family support groups, educational support and advocacy for resources.
- Multidisciplinary care that is child/family-centered and allows for family choice, leading to a collaborative partnership with shared decision-making that directly addresses child/family needs.
- A plan of care that is based on the review completed, and is developed by incorporating shared decision-making to define the goals and solve problems. The core of the decision-making is a child/family-provider partnership.

Strengthen systems of care coordination for children with medical complexity.

- Ensure that all children with Medical Complexity have a care plan.
 - The care plan respects family and parent/caregiver strengths and goals, and is jointly developed, shared, and implemented by the child’s family, primary care provider (PCP), and specialists, and other’s across systems as appropriate.
 - The care plan should be reviewed and revised, at a minimum of every six months or more frequently if the child has a major change, positive or negative, impacting the health condition or the status of the child and/or family.
 - If a Care Map is developed, it should be included with the Care Plan.
- Ensure that all children with Medical Complexity have a primary care coordinator. A primary care coordinator serves as the main point of contact with the parent/caregiver as it relates to care coordination. This person is chosen by the family and should tailor his or her role to reflect the needs of the child’s care plan. A primary care coordinator should:
 - Identify and address barriers to the achievement of the goals of the care plan with providers and the family.
 - Coordinate family-centered team meetings (across organizations and in person, as needed, including attendance at clinic meetings or home and inpatient visits, as appropriate for the child’s specific situation).
 - Engage in regular communication with the family.
 - Use health information technology to effectively deliver and continually monitor care coordination and the effectiveness of service delivery.
 - Assist parents/caregivers in navigating processes such as prior authorizations for services; prescription renewals and refills for medications, durable medical equipment (DME), and supplies; and other processes as they arise.
 - Identify liaisons at each DME company to ensure seamless acquisition of DME and supplies.
 - Support and facilitate all care transitions, including but not limited to, within the hospital setting, hospital to home, practice to practice, and pediatric to adult systems of care.
 - Serve as a bridge between the multiple payers, where applicable. This may include open communication with private insurance, DMMA, and/or other agencies. The coordination of care will involve a degree of understanding of the coordination of benefits provided by each.

Care Mapping

“Care maps are visual diagrams that depict the complexity of caring for children with medical complexity. A care map illustrates all of the resources (people and places) needed to support a child with medical complexity and their family. Health care Practitioners may be able to use care maps to help families avoid duplications or gaps in services and prioritize and coordinate care.”

(Adams, S., Mahant, S., Kanani, R., Wesiser, N., Nicholas, D., Boydell, K., & Cohen, E. (2015, September 30). *An exploration of care mapping among families of children with medical complexity (CMC)*. Retrieved from Wiley Online Library: <https://onlinelibrary.wiley.com/doi/full/10.1111/dmnc.12886>)

Be clear in contracts about the role of managed care organizations in identifying and providing services to children with medical complexity. Consider requiring MCOs to:

- Identify children with medical complexity early and create a mechanism to flag them in their systems.
- Review the process used to determine medical necessity.
- Develop separate authorization processes for services, home health nursing hours, pharmaceuticals, DME, and supplies for children with medical complexity.
 - Consider models from other states.
 - Consider using an objective tool, such as a point system based on diagnosis, which corresponds to the number of nursing hours.
 - Look at the needs of the child with medical complexity separate from the parents/caregiver's availability.
 - Identify opportunities to make the process more collaborative where all players work together in the best interest of the CMC.
 - Ensure that the process is transparent and clear for providers, as well as parents/caregivers.
- Explore ways to gain access to electronic medical records for children with medical complexity to aid in the authorization of services.
- Work to ensure that denials/approvals are timely and transparent. Denials should include a clear explanation as to why services have been denied and provide options for parents/caregivers.
- Review services, medications, DME and supplies that require bi-annual or annual medical necessity documentation and, where permissible and appropriate, revise requirements to be less frequent.

Establish separate network requirements for providers who serve children with medical complexity.

- Identify primary care physicians that are willing to become a Medical Home and/or are willing to work with children with medical complexity.
 - Consider a model that supports PCPs, who may not have the resources, to consult with specialist to handle some of the complex issues of this population.
- Identify what specialty and therapy areas have the longest wait times. Consider:
 - Home health services vs. those provided in an office or facility setting, and
 - Geographical differences.
- Consider a sub-network of specialists that may be willing to give priority scheduling to children with medical complexity.
- Develop a plan to increase enrollment for areas that are lacking in specialist and therapists.
- Consider requesting organizations that have satellite offices, in which specialists are available once or twice per week, to make them available more often, especially in Kent and Sussex Counties.
- Explore uses for telemedicine to reduce wait times and exposure of CMC to unnecessary illnesses.
- Consider requirements that certain providers must be included in provider networks if they are the only available source of their services.
- Consider outreaching to pharmacy community to try and identify a possible chain that is willing to handle solution medications and evaluate what pharmacies can manage carrying large quantity medications.

Identify opportunities to make the appeals and state fair hearing process more collaborative where all players work together in the best interest of the child with medical complexity.

- Consider expediting all appeals for CMC.
- Develop a step-by-step guide about what to expect during each process.
- Consider a peer to peer process in which parents/caregivers can receive support from other parents/caregivers that have gone through the process.
- Consider conducting pre-hearing conferences prior to state fair hearings.
- Investigate resources for parents/caregivers of CMC that need representation at state fair hearings.

Consider expanding coverage of some specialty services to children with medical complexity.

- Respite services
- Comfort care
- Support and therapy services for parents/caregivers.
- Stipends or special programs for utility services for parents/caregivers of CMC with high wattage caused by medical equipment.
- Home modifications
- Vehicle modifications
- Medical day care or similar programs specific to CMC to support integrations and quality of life of CMC.
- Explore the possibility of a onetime benefit in which parents/caregivers can purchase an organizational system and have an agency or individual come to their home to assist in setting up a child with medical complexities supply system.

Identify opportunities to address identified gaps as it relates to transportation issues.

- Research transportation programs in other states.
- Re-evaluate the 72 hour requirement for non-emergency transportation.
- Consider service recovery requirements for NEMT.
- Consider providing members a stipend for transportation, rather than reimbursement after the fact; they can then contract out or request assistance from other parents/caregivers that may have reliable transportation.
- Implement a feedback/survey system for transportation providers and institute a performance-based reimbursement system.
- Explore the possibility of covering specialized durable medical equipment, such as specialized strollers and larger car seats that could fit in most vehicles. This would allow some CMC to be transported without having to bring a bulky/heavy wheelchair in many instances.
- Explore the possibility of offering vehicle modifications and repair of modified vehicles, similar to existing programs such as the Diamond State Health Plan Plus or Division of Developmental Disabilities Lifespan Waiver, to children with medical complexity.

Conduct a workforce study to determine provider capacity of skilled, home health nurses in the Medicaid program.

- Determine if there is a shortage of skilled home health nurses in Delaware.
- If a shortage is identified, investigate reasons and possible solutions.
- Include home health nurses and experts in pediatrics and home-based services in the discussion.
- Evaluate local solutions that could be implemented in the next two years.

Assess and/or develop mechanisms for children with medical complexity when parent/caregiver is presented with emergent situation and unable to provide care.

- Consider mechanisms, in which parents/caregivers can either pay other individuals, of their choosing, or be reimbursed directly, when tasked with providing emergency coverage.
- Consider options such as, but not limited to attendant care and Community Health Workers.

Perform research to clearly define gaps as children with medical complexity transition into the adult system in Delaware and identify solutions to address the findings.

- Consider continuing to provide dental coverage.
- Consider continuing to provide vision services.
- Planning for transitions from pediatric physicians and hospitals to the adult system of care.

Develop a handbook for parents/caregivers of children with medical complexity. Consider including information on:

- The role and importance of the primary care physician in the care coordination of CMC.
- What a Medical Home can provide for CMC.
- Pharmacy, DME and supply information issues that might arise for CMC; tips around managing supplies; the pharmacy benefit line; the benefits of having a home pharmacy; and define terminology, such as solution vs liquid medication.
- The availability of care coordinators to assist in things such as scheduling imaging appointments, scheduling appointments with specialists, managing DME and supply orders, etc.
- The ability of the provider relations coordinator at MCOs to assist with DME provider issues.
- The availability of interpreters, including American Sign Language, to assist in fully understanding all aspects of CMC's medical issues and required care.
- The appeals process and option to request an expedited appeal.
- Fair hearing process and resources available to parents/caregivers of CMC to assist in this process.

Develop resources for providers of children with medical complexity.

- DMMA to publish CMC specific information on the Provider Portal and make applicable policy changes to the Children's Community Alternative Disability Program (CCADP) Provider policy manual, Home Health Provider Policy manual, and other applicable policy manuals.
- Provide educational resources and/or instructions for providers regarding:
 - The role and importance of the primary care physicians in the care coordination of CMC.
 - How to clearly document the need for children with medical complexity when requesting specialized services or appointments, such as specific lab test that must be performed at a specific clinic/lab, specialized durable medical equipment, etc.
 - The benefits of faxing or emailing prescriptions to pharmacies that may be too complex to be sent through an electronic prescription system.
 - The importance of providing parents/caregivers with interpreters, including American Sign Language, to be sure that they fully understand all aspects of CMC's medical issues and required care.

Develop resources for the larger community involved in the care of children with medical complexity.

- DMMA to publish an informational booklet for the Children's Community Alternative Disability Program (CCADP) with updates as needed for parents/caregivers, providers, staff, and other stakeholders. This can be similar to what is provided to the Long-Term Care population.
- Consider developing an on-line repository of available services for CMC.

Appendix B – Budget Epilogue Section 141 of House Substitute No. 1 (HS1) for House Bill No. 275 (HB275).

Section 141. (a) Section 1 of this Act provides an appropriation to the Department of Health and Social Services, Medicaid and Medical Assistance (35-02-01). Children with medical complexity have intensive needs not easily met by existing health care models. This population is comprised of very high utilizers of health care services, with approximately 6 percent of all children with Medicaid benefits accounting for 40 percent of the costs. Moreover, this population is increasing as a proportion of the total Medicaid population, with approximately two thirds of all children with medical complexities now covered under Medicaid.

(b) In recognition of the importance of managing the care of children with medical complexity who have significant, chronic health problems requiring extensive and coordinated medical care, the Department shall establish a comprehensive plan for managing the health care needs of Delaware's children with medical complexity.

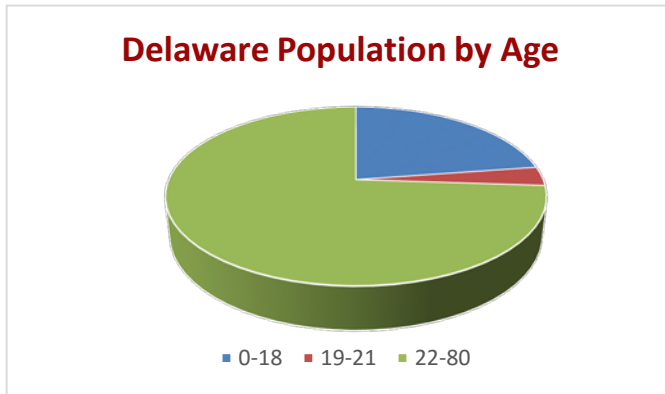
(c) In developing such plan, the Department shall seek input from health care providers, hospitals and health systems, payers, managed care organizations, social service agencies, consumer advocacy organizations representing children with medical complexity and parent advocates, and any other such organizations as may be necessary.

(d) The Department shall publish the comprehensive plan for children with medical complexities on or before May 15, 2018.

Appendix C – Delaware Child Population Baseline Data

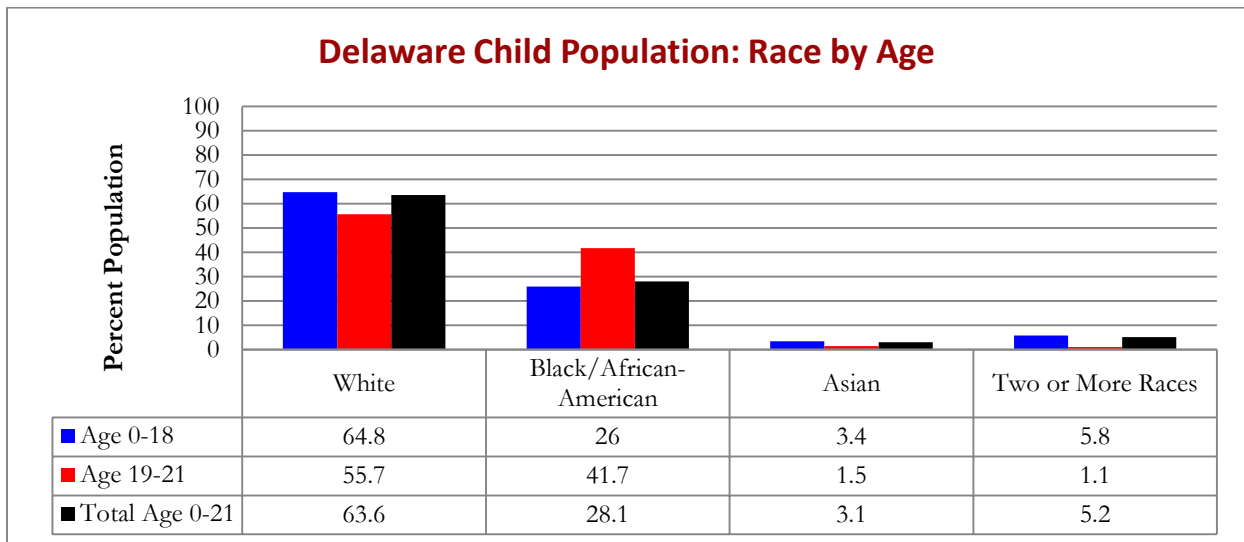
United States Census Bureau - Current Population Survey 2017

Delaware Population by Age		
Age	Count	Percentage of Total Population
0-18	214,772	22.65%
19-21	32,400	3.42%
22-80	701,068	73.93%



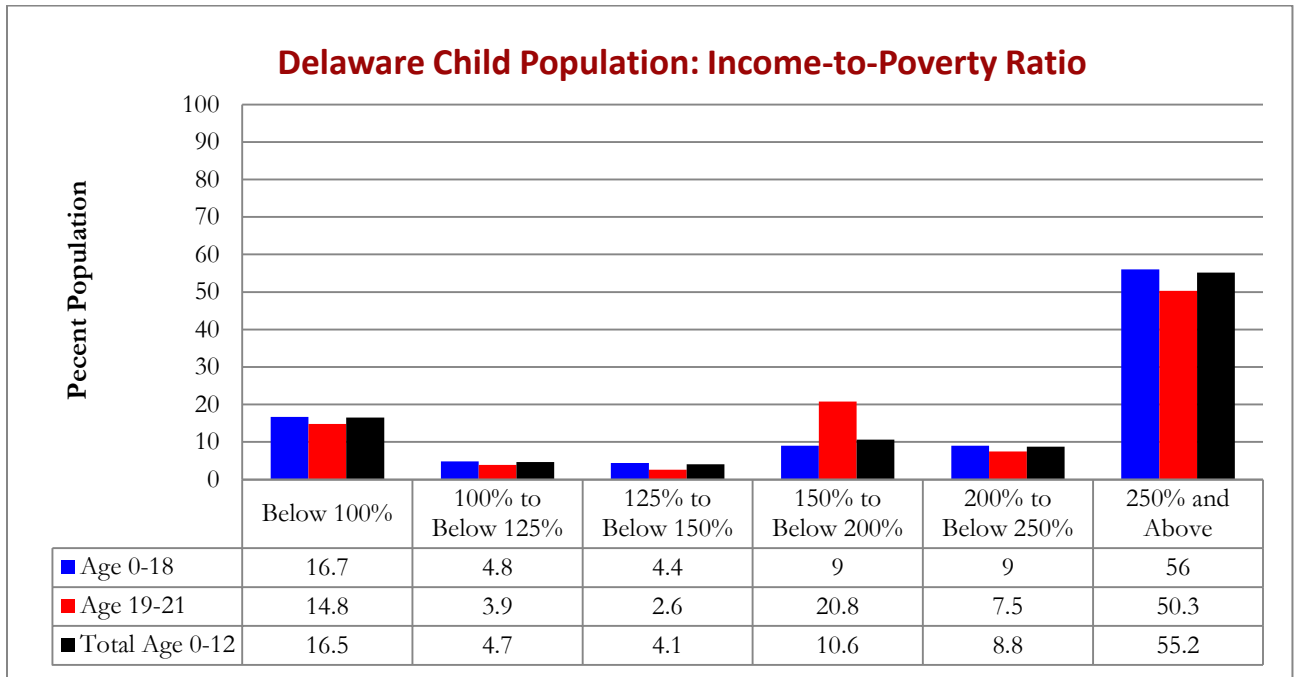
As of the most recent United States Census Bureau Current Population Survey, there is a total of 247,172 children ages 0-21 in the state of Delaware. This accounts for 26% of the state's population.

Delaware Child Population: Race by Age			
Race	Percent Age 0-18	Percent Age 19-21	Percent Total Age 0-21
White	64.8%	55.7%	63.6%
Black/ African American	26.0%	41.7%	28.1%
Asian	3.4%	1.5%	3.1%
Two or more races	5.8%	1.1%	5.2%
Total	100%	100%	100%



Delaware Child Population: Income to Poverty Ratio by Age

Income-to-Poverty Ratio	Percent Age 0-18	Percent Age 19-21	Percent Total Age 0-21
Below 100%	16.7%	14.8%	16.5%
100% to Below 125%	4.8%	3.9%	4.7%
125% to Below 150%	4.4%	2.6%	4.1%
150% to Below 200%	9.0%	20.8%	10.6%
200% to Below 250%	9.0%	7.5%	8.8%
250% and Above	56.0%	50.3%	55.2%



Appendix D – Care Map

