



*A White Paper prepared for
Centers for Medicare and Medicaid Services*

Children and Young Adults with Medical Complexity: Serving an Emerging Population

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ABOUT PEDIATRIC COMPLEX CARE ASSOCIATION

The Pediatric Complex Care Association (PCCA) is a national, non-profit organization whose mission is to create opportunities for professionals to advocate, educate, network, research and promote excellence in providing a continuum of care for children with medically complex needs and their families. We currently have thirty-seven Active members located across the United States that provide pediatric 24-hour post-acute care. We also have Affiliate members, professionals involved in serving this population of children, from around the country, Ireland and Qatar.

PCCA strongly supports the concept of a continuum of care. Every child whose family wants to care for their child at home should be provided the necessary supports including home care, respite care, durable medical equipment and case management. When a child cannot be cared for at home, parents should have residential options to choose from including medical foster care, medical group homes and post-acute facilities with specialized services for children. Which option is best for the child and their family must be a matter of parental choice and may change over time.

The Pediatric Complex Care Association has its roots in the Building Bridges Network that was founded by Sister Katherine Smith, PhD, RN of the Sisters of Providence in Portland Oregon in the early 1990's with the mission to link pediatric post-acute and residential facilities around the country. The Network, which benefited from a group of volunteer leaders gleaned from these organizations, provided opportunities for ongoing education and networking through a series of conferences. Building Bridges also collaborated with the Centers for Medicare & Medicaid Services (CMS) on the development of a Pediatric Minimum Data Set (MDS) tool. While this tool was developed, it never proceeded to the beta testing phase due to lack of CMS funding.

As educational conferences grew, a core group identified the need to develop a national organization to expand services and involve additional organizations serving children with complex medical needs. These leaders incorporated the not for profit entity Association of Providers for Children with Complex Medical Needs, Inc. in 2012. The organization hired a part time Executive Director. In early 2013, the Board voted to simplify the Association's name and now does business as the Pediatric Complex Care Association.

DESCRIPTION OF OUR POPULATION

While there is no universal definition, there is growing agreement that children with medical complexity (CMC) describes four main areas:

- 1) Chronic, severe health conditions
- 2) Substantial health service needs
- 3) Functional limitations, which are often severe
- 4) High health resource utilization

More technically, this chart from the Children's Hospital Association characterizes CMC as those who are classified within a Clinical Risk Group (CRG) of 5b or higher, including the following categories: Single Dominant Chronic Disease, Complex Chronic Disease and Malignancies. ¹ Most children served by members of PCCA are in CRG 6-9.

	NON-CHRONIC (CRGs 1, 2)	EPISODIC CHRONIC (CRGs 3, 4)	LIFELONG CHRONIC (CRG 5*)	COMPLEX CHRONIC (CRGs 6, 7, 9)	MALIGNANCIES (CRG 8)	
a	Brief Description	<ul style="list-style-type: none">• Acute conditions that will not last one year	<ul style="list-style-type: none">• Chronic conditions that will last one year and are likely to be episodic in manifestation• Potentially curable with adequate treatment• Not likely to last into adulthood	<ul style="list-style-type: none">• More severe primary condition in one body system that is more likely to cause significant long-lasting health impairment	<ul style="list-style-type: none">• Significant chronic condition in two or more body systems or• Progressive or life limiting chronic conditions or• Conditions requiring a dependency on technology	<ul style="list-style-type: none">• Malignancies requiring active treatment
b	Example Conditions	Fracture, pneumonia, appendicitis, trauma	Asthma, depression, conduct disorders	Type 1 diabetes, congenital heart disease	A child with diabetes, encephalopathy and chronic pulmonary disease. Down syndrome, cerebral palsy, cystic fibrosis	Leukemia, bone tumors, brain tumors

*CRG Category 5 is further broken into two subcategories by the Children's Hospital Association - 5a and 5b. The definition of Children with Medical Complexity includes 5b - Single Dominant Chronic Disease, such as those with Sickle Cell Disease or Congenital Heart Disease.

Representative diagnoses of children with medically complex conditions include: chronic lung disease, genetic disorders, complications of prematurity, congenital heart disorders, cerebral palsy, neurologic, orthopedic and respiratory conditions, post-acute burn treatment, HIV/AIDS, feeding or metabolic disorders, spina bifida, traumatic brain injury, coma recovery, sickle cell disease, short bowel syndrome and congenital anatomical malformations. These diagnoses are often accompanied by one or several comorbidities, and many also present with some form of developmental delays and intellectual disabilities.

All children with medical complexity have long-term healthcare needs that require technology intensive, multidisciplinary—and often expensive—care plans. Most require at least one of the following: tracheostomies with oxygen and frequent suctioning, gastric feeding tubes, pumps and ventilators, or other high technology medical devices, as well as around-the-clock monitoring. Providing long-term care to children and young adults with medical complexity is a complicated exercise in medical care management—in quality of care, cost effectiveness, reimbursement, and in the provision of integrated care, which includes careful service coordination and transition planning.

We have seen ever increasing acuity in the level of care required by the children who are being admitted to our Member facilities. In years past, this level of care was provided only in intensive care units but is now provided routinely through our Members.

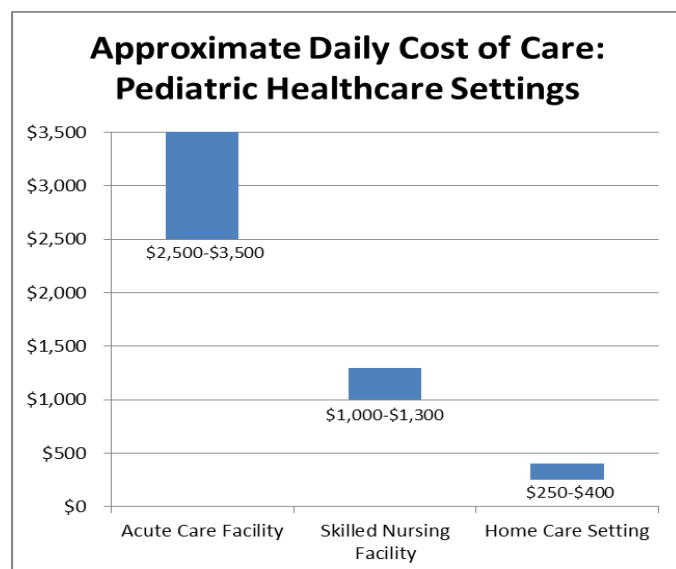
Commercial insurance frequently does not cover the highly intensive and long-term care these children require, considering it to be maintenance or custodial care. Consequently more than 90% of children in our facilities rely on Medicaid for funding of services. As states increasingly transition these populations to managed care, maintenance of the level of reimbursement required to provide access to needed services for these children becomes increasingly challenging.

DESCRIPTION OF ACTIVE MEMBER FACILITIES

There is no consistent national definition of the facilities that provide post-acute care to children with medical complexities. Licensing and definitions vary state by state, and the term “nursing home” doesn’t have a formal and generally accepted definition. Our member facilities include skilled nursing facilities, intermediate care facilities, sub-acute facilities, specialty hospitals, rehabilitation hospitals, residential schools and medical group homes. Our members provide a variety of services to children with medical complexity including transitional care, sub-acute care, rehabilitation, long-term care, respite, palliative care, and end of life care regardless of licensure category.

The long-term needs of this population are clearly unique yet the regulations that guide reimbursement for children with medical complexity for long-term, sub-acute and post-acute care are the same as those for the geriatric population in almost every state.

We provide specialized care to children over the course of weeks, months and often years – at a much lower cost to private insurance providers and Medicaid than acute care providers. Additionally, our facilities play a key role in avoiding re-hospitalizations.



This table reflects an example of costs in the New York City area using posted Medicaid rates.

FACILITY ISSUES

Lack of State Regulations

Most states do not have regulations specific to facilities that serve the pediatric post-acute care population. Rather, our members must comply with regulations that were developed to address the care and services required by the geriatric population. This results in facilities having to comply with rules that are not appropriate to the population served and a lack of rules that address the specific needs and services of the children we serve.

Recommendation: Develop federal pediatric regulations for both nursing and intermediate care facilities for the intellectually and developmentally disabled

Licensing Surveys

Because facilities are surveyed to ensure compliance with state and federal regulations designed for the geriatric population, these surveys do not bring the same value to the facility or its consumers in identifying deficits and opportunities for improvement. Additionally, many surveyors do not have experience working with the pediatric population and therefore have difficulty understanding how to apply the regulations to these specialized facilities. In some states, facilities have worked collaboratively with their state agency to educate, inform to meet the intent of the regulatory standards and have assigned pediatric acute care nurses to survey these facilities to enhance the process.

Recommendation: Provide federal surveyor training on surveying facilities that serve a pediatric population

Children Residing in Adult Nursing Facilities

As the demand for beds in adult nursing facilities has decreased, we have seen operators of adult facilities actively recruiting for the placement of children in their vacant beds. These facilities often do not have specialized programs for children, staff who are trained to care for children with medical complexity, and the resources and knowledge to support families. This has led to children not being appropriately served and parents being frustrated and taking legal action. Note: These facilities should not be confused with adult facilities that have served children for many years in specialized units, often in communities/geographic areas that do not have a sufficient population to support a solely pediatric facility.

Recommendation: Require adult nursing facilities that serve children to develop appropriate programs, hire staff qualified to care for this unique population and to develop necessary family support services.

Standards and Quality Indicators

Standards of care for the geriatric population are the basis of the federal regulations for nursing facilities and the MDS used for resident assessment. The regulations for intermediate care facilities for individuals with intellectual or developmental disabilities (ICF/IID) are oriented to adults. Components of ICF/IID regulations and the MDS are not appropriate to the pediatric population. They also do not address elements that are important in facilities serving children. Examples of this include the developmental age of the resident, specific pediatric medications, incontinence related to developmental age, restraints vs. postural supports and enabler, and behaviors related to pediatric diagnoses rather than Alzheimer's/dementia.

The Pediatric Complex Care Association has developed a Model Practices document that outlines standards for facilities serving children with medical complexity. We would welcome the opportunity to share this document with CMS.

Because quality indicators are taken from the MDS, as required by the IMPACT Act, some indicators are also not the best measure of the quality of care provided in pediatric nursing facilities. PCCA has developed clinical care indicators, which we would also welcome sharing with CMS. Other current work includes developing administrative quality indicators.

Recommendations:

- ***Develop pediatric quality indicators and reporting requirements***
- ***Develop a pediatric assessment tool to be utilized in facilities serving children with medical complexity***

Staffing

The medical complexity of many of the children served in pediatric facilities drives significant staffing differences. Higher staffing ratios for professionals including nurses and therapists are required to meet the needs of the children. In addition, a high level of clinical competence is required to assess and care for these children. These issues make staffing a challenge and add additional costs to the facilities that often go unrecognized by payers.

Recommendation: Maintain adequate reimbursement to facilities where higher staffing ratios for quality of care are needed, particularly as States move to an all Managed Care reimbursement model.

POPULATION ISSUES

Barriers to Access to Care and to Discharge

Barriers to Admission: While the proper setting for most children with complex medical needs is at home, sometimes more comprehensive care is required. Children and their families are almost always the best equipped to make this determination. Yet we continue to find that families face significant barriers to admission to pediatric nursing facilities. In light of the Americans with Disabilities Act and the subsequent Supreme Court decision in *Olmstead v. L.C.*, many states are refusing to allow admissions to pediatric nursing facilities even if the family has chosen that option as best meeting their child's and family's needs. Some states have set limiting criteria as to which children facilities may admit. Code of Massachusetts Regulation 105 (CMR 105) states facilities cannot admit a child without approval from the Department of Public Health's Medical Review Team (MRT). MRT guidelines as of June 2010 are not posted by the state, but can restrict admissions based on cognitive age.

This is particularly troubling as many areas lack adequate community based services to support the family in caring for their child at home and a lack of other residential resources such as medical foster homes and group homes.

Recommendation: Federal clarification of the right of parental choice in decisions regarding care and services for children with medical complexity

Barriers to Discharge: Facilities identify a number of factors that are barriers to discharge that are non-medical including social issues, housing issues, lack of other nursing and other services at home, lack of transportation, inadequate number of medical foster care homes capable of caring for this population and a lack of alternative residential options. This suggests that proper care for children with medical complexity must extend to proper support for their families as well. In a Clinical Report published in *Pediatrics*, it was noted

that while parents prefer to have their medically complex children at home, the “lack of adequate community-based disability or family support services to meet their particular needs was associated with out-of-home placement.”² While community placement may fail due to lack of local resources, PCCA Members continue to provide quality care and reduce hospitalizations (2015 PCCA Clinical Practice Benchmark data).

A family or guardian responsible for the care of a child with medical complexity faces a maze of decentralized regulatory agencies and bewildering options that are contingent on the child’s diagnosis, as well as physical, cognitive and functional abilities. Parents are challenged to learn and navigate the complex and varied standards and requirements of these different agencies, which lead to delays in obtaining proper care, and often result in securing less than optimal care.

While stable and educated parents have trouble navigating care, low-income parents, who comprise a majority of the children we serve, face more daunting obstacles. Practical barriers for these families include lower levels of educational attainment to navigate complicated healthcare documentation, language differences, transportation costs to and from a hospital, and not being able to afford missing work to tend to the processes involved in caring for a CMC.

Families experience substantial emotional and personal strain when caring for a child with medical complexity. Add to this the economic, logistical and bureaucratic concerns detailed above, and it is clear that familial stress can become a complicating factor. For caregivers providing home care who do not receive proper reimbursement, nursing care, and/or respite, studies suggest that CMC caregiving may contribute to financial, marital, mental, and physical health difficulties.³

Recommendations:

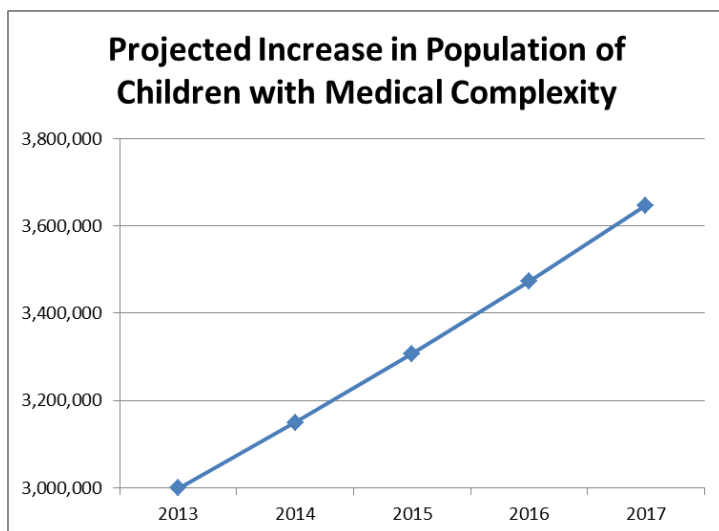
- ***Provide appropriate funding for family support including housing, transportation, home services and respite***
- ***Adequately fund and support pediatric case management and home care services including private duty nursing***

EMERGING ISSUES

Growing population of children with medical complexity: It is estimated that children with medical complexity comprise approximately 3 million of the nation’s 76 million children, and that this population is increasing at approximately 5% annually, outpacing the rate of

growth of typically developing children ¹, which, in recent years, was estimated to be between 1% and 2%. ⁴

According to the Children's Hospital Association, children with medical complexity represent only 6% of all children enrolled in Medicaid, but they account for over 40% of all Medicaid spending on children. ¹ At the current trajectory, the costs to Medicaid will continue to grow as more and more children survive serious illness and injury.



This dramatic increase in population can be linked to advances in medicine and technology, which are enabling children with medical complexity to live longer than ever. According to a recent literature review, “medical successes in survivorship have likely also resulted in rising rates of complications and childhood disability, with subsequent increases in intensive medical technology use, medical and nursing care and coordination needs.” ⁵ As this population ages into adolescence and young adulthood, we expect Medicaid spending to increase dramatically. This trend is supported by abundant evidence in recent medical literature, which correlates dramatic improvements in acute and post-acute pediatric care to reductions in mortality and prolonged survival of children with complex chronic medical conditions. ⁶

Population growth can also be linked to advances in neonatal care and corresponding increases in survival rates of premature infants and those with chronic lung disease, cardiac anomalies, birth defects, and genetic disorders. ⁷ Furthermore, medical treatments, surgical interventions, and post-acute care modalities have improved outcome and survival rates, as evidenced by reports tracking the increase in prevalence of infants born with spina bifida and children with cystic fibrosis who survived to adulthood. ⁸ And new developments in infant and child nutrition, including increased use of gastrostomy tubes, have improved the survival rate of children with cerebral palsy. ^{9, 10}

There is a lack of adequate community based services to meet the needs of these children, but resistance on the part of the states to serving children in facilities continues resulting in children receiving far less than optimal care. Additionally, many states lack the high acuity subacute care needed to serve children who require ventilator care and total parenteral nutrition.

Recommendations:

- ***Develop medical foster care homes with appropriate standards and services across the country***
- ***Develop alternative residential models for children with medical complexity***
- ***Encourage states to develop a level of care within post-acute facilities or new facilities that provides ventilator care and total parenteral nutrition when families need this for their child***
- ***Adequately fund and support pediatric case management, home care services, and family supports including housing, transportation and respite***

Children with Medical Complexity Aging into Adulthood: As noted above, children with medical complexity are increasingly surviving into adulthood because of the improved care that they receive.

Almost all community programs and pediatric providers (primary and subspecialty physicians, nurses, physical, occupational and speech therapists, home health aides) function and are reimbursed under age-specific limits. At age 18 or 21, eligibility changes dramatically for young adults with medical complexity. After aging out of pediatric care, they are defined as adults in terms of state and federal benefits, and parents and caregivers must learn an almost entirely new set of procedures and regulations. The age at which a pediatric program or service terminates varies, and with children with medical fragility relying on a variety of different programs and services, the transition from pediatric to adult care can be confusing and hugely labor intensive for parents.

Though there has been some progress in recent years, the transition from pediatric care to adult care is often overlooked by healthcare providers, as indicated by the fact that only 40% of Children with Special Healthcare Needs receive transition services.¹¹ Consequently, they and their caregivers often have little guidance when transitioning, and those who do receive transitional guidance often express dissatisfaction with the thoroughness and quality of services.

In addition to the challenges young adults face in accessing community programs and providers, there is a lack of alternative residential options. While pediatric skilled nursing facilities specialize in long-term care for children, no such facilities exist for young adults who age out of pediatric care. Parents of young adults with medical complexity often must

turn to geriatric nursing facilities. With missions dedicated solely to caring for elderly populations, even the most accommodating geriatric nursing facilities tend to be ill prepared to provide proper plans of care and residential life programs for young adults with medical complexity. Quality of care can suffer as a result, placing young adults at risk. Furthermore, many reports have chronicled the dramatically decreased quality of life that children and their caregivers experience in geriatric facilities, with very limited access to mental or physical stimulation, infrequent visits from parents who often live far away, and virtually no engagement with their community.^{12,13,14} There are few medical foster homes or group homes for young adults with medical complexity.

Recommendation: Develop alternative community based residential alternatives for young adults with medical complexity

GAPS IN SERVICES

In addition to the issues outlined in this paper, the Pediatric Complex Care Association has also identified the following gaps in services to this population:

- State by state disparities in home care services and in Early and Periodic Screening, Diagnostic and Treatment (EPSDT) service provision¹⁵
- Lack of community based programs such as Prescribed Pediatric Extended Care Centers (PPECC)

Recommendations:

- ***Standard enforcement of EPSDT across the country***
- ***Develop other community based services such as PPECCs nationwide***

CONCLUSION

We recognize that we have identified broad and long-range activities to address the challenges and opportunities we jointly face in serving children with medical complexity and their families. It is clear that post-acute care is a central component of a cost effective, well-functioning Accountable Care Organization or a vertical health system. Addressing the concerns outlined here and strengthening facilities and organizations that provide Pediatric Post-Acute Care will benefit the country's entire health system, not to mention the special children that are served by these providers. We would welcome the opportunity to work with CMS on these issues and suggest the creation of an ongoing work group consisting of representatives from CMS, PCCA and other stakeholders.

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