

Children with Medical Complexity

Written Testimony

U.S. House Committee on Energy and Commerce, Subcommittee on Health

“Examining the Advancing Care for Exceptional Kids Act” Hearing

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Testimony Summary

- Children with medical complexity (CMC) represent a small, vulnerable population that has a large impact on the pediatric health care system; CMC are the “sickest of the sick” children.
- Most healthcare spending for CMC goes to hospital care. Small amounts of spending go to primary and home care. Large proportions of care provided to CMC are not reimbursed.
- The main goal of caring for CMC is to continuously strive to give the children the best life possible, under the unfortunate circumstance that their health will always be limited to a certain degree because of their chronic health problems.
- Very rarely is one provider or one clinic able to achieve this goal. Rather, this goal is more often achieved by all providers working in large geographic catchment areas (often across state lines) as a team.
- Major areas of deficiencies in care for CMC include (1) underfunded and understaffed primary and home care; (2) insufficient accountability and governance of the healthcare professionals involved in their care; (3) lack of access to high quality urgent care; (4) insufficient integration of care across the continuum; and (5) inadequate healthcare data (e.g., Medicaid claims) available to measure their quality of care and identify best practices.
- These deficiencies negatively affect the health and wellbeing of CMC, causing the children to have unmet healthcare needs, to get sick more often than they should, to require emergency and hospital care too frequently, and to have parents/family members struggle (emotionally, physically, and financially) to care for them.
- There are wonderful opportunities for healthcare policy and legislation to help CMC receive the quality of healthcare that they deserve. In my opinion, opportunities best positioned to help are those that (1) redirect healthcare spending and resources to primary and home care; (2) create accountability and governance across the children’s healthcare providers; (3) make it easier for CMC to receive out-of-state care when they need it; and (4) bolster the availability and integrity of Medicaid claims data.

Thank you to the Committee members and staff for making time to discuss legislation intended to better the health and lives of children with medical complexity (CMC). I offer this testimony to convey my perceptions and experiences of caring for these children.

A. My Clinical And Research Background On Children With Medical Complexity

I am a general pediatrician and hospitalist with a decade of experience providing healthcare and conducting research in the inpatient, outpatient, home, and rehabilitation settings exclusively for CMC. Clinically, I work for a clinical service (i.e., the Complex Care Service at Boston Children's Hospital) that is dedicated entirely to serving CMC throughout the greater New England area and beyond. Through my research, I have linked together healthcare providers across the U.S. of all types, practicing in a variety of settings to assess the prevalence, health services, and outcomes of CMC using large administrative health datasets, including those available from hospitals and state Medicaid programs.

B. Definition of Children with Medical Complexity

My colleagues and I think of the following clinical attributes when defining children with medical complexity (CMC):

1. A lifelong, often incurable, chronic disease that is so severe that it causes multiple organ systems of the body to function improperly.
2. Significant impairment in the ability to perform basic bodily functions, including - but not limited to - the ability to independently eat, drink, breathe, walk, talk, etc.
3. The need for myriad healthcare providers (e.g., specialists, therapists, home nurses, etc.) and treatments (e.g., multiple medications, durable medical equipment, etc.) to maintain health.
4. High health resource use, through numerous outpatient clinic visits, medication prescription fills, recurrent hospitalizations, and emergency department visits.

Although these attributes may seem non-specific, children's hospitals and other healthcare entities throughout the U.S. use themes and variations of the attributes to successfully identify and enroll CMC into clinical programs to optimize their health.

C. Example of a Child with Medical Complexity

Suzanne is a 14-year-old female with cerebral palsy that was caused by lack of oxygen to her brain during her birth. Cerebral palsy is Suzanne's underlying, lifelong chronic condition. Her organ systems affected by the cerebral palsy include:

Neuro/brain: she has seizures due directly to her brain injury, which require multiple medications to control.

Urinary: she can't adequately empty her bladder, which causes her to have multiple urinary tract and kidney infections.

Bones: her muscles in her back and abdomen are so tight that they have twisted and curved her spine, which causes chronic pain and impedes her ability to sit up in a straight position.

Lungs/airway: she sometimes is unable to protect her airway from saliva getting into it. When saliva gets into her airway and lungs, she develops pneumonia and lung damage.

Digestive: she is unable to drink and eat enough by mouth to stay hydrated and nourished; she requires a feeding tube (gastrostomy) in her stomach to receive water and formula.

Endocrine: her brain is unable to keep her sodium levels normal in her bloodstream and cells; major increases and decreases in her sodium levels require urgent care and hospitalization if not promptly treated.

Suzanne has 15 healthcare providers actively involved in her care, not including hospital and emergency care providers who are needed on an episodic basis. Her family thinks of her durable medical equipment vendor

as a “provider,” because Suzanne relies heavily on medical equipment to maintain her health.

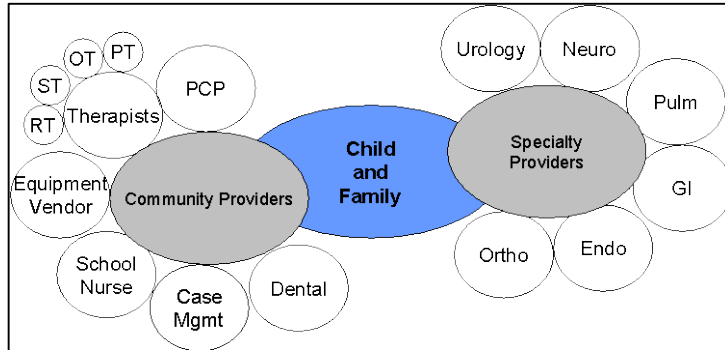
Suzanne recurrently engages the healthcare system on a monthly – and sometimes weekly or daily – basis.

Throughout her life, she’s experienced multiple hospitalizations and emergency department visits.

Her most frequent healthcare encounter occurs by phone, mostly from her parents

calling her providers for questions, advice, and for help meeting a healthcare need.

Suzanne’s Healthcare Providers



Suzanne’s Health Services Use

Health Service	N
Chronic medications	8
Elective surgeries	10
Acute hospitalizations	15
Emergency department visits	45
Outpatient clinic visits	150
Telephone calls to the clinic	600

D. Goals of Caring for Children with Medical Complexity

The main goal of caring for CMC is to continuously strive to give the children the best life possible, under the unfortunate circumstance that their health will always be limited to a certain degree because of their chronic health problems. Very rarely is one provider or one clinic able to achieve this goal. Rather, this goal is more often achieved by all providers working as a team.

E. Key Concepts of Care Activities for Children with Medical Complexity

Provided below are key concepts of care activities of CMC that influence the children's health and quality of life (taken from Berry JG et. al, Children with Medical Complexity and Medicaid: Spending and Cost Savings; *Health Affairs* 2015)

Understanding the Child's Health

Through recurrent communication with the child, their family, and care team, it is important that clinicians in care management achieve an on-going understanding of the child's acute and chronic health problems, healthcare needs, issues that could modify the child's health for better or worse, important physical examination findings, health trajectory, well-being, and quality of life.

Managing Health Information

CMC can accumulate a very large amount of health information. It is important to organize, update, validate, and share the child's health records as well as help the family and other health care team keep track of and actively use the child's health records when making treatment decisions.

Creating Care Plans

Care managers can help coordinate care with the child's healthcare team to create proactive care plans that will help 1) treat acute illnesses, 2) avoid chronic illness exacerbations, 3) meet all of the child's healthcare needs; 4) manage the roles and responsibilities of the child's health care team, and 5) optimize the child's well-being and quality of life.

Providing Urgent Care

Through rapid response in the outpatient, community, and home settings, care managers can help make possible the ability to deliver high quality urgent care to the children by executing care plans, mitigating the illness severity of urgent health problems, and shortening acute illness duration.

Empowering Families

Care managers can help assess family values and perceptions, teach caregiving skills, assist with home caregiving activities, support physical and emotional health, address financial and social issues, and encourage shared medical-decision making.

These care management activities help to:

- 1) Optimize the health of CMC who are at high risk for poor health outcomes and excessive healthcare utilization;
- 2) Prevent altogether or address early-on health problems that otherwise would require the need for expensive health services;
- 3) Rapidly and effectively respond to changes in patients' conditions to avoid use of unnecessary use of health services; and
- 4) Ensure efficient and successful transitions of hospitalized CMC at admission and hospital discharge

F. Example Approaches to Conduct Care Management Activities for Children with Medical Complexity

Community Case Management	Primary Care Clinic	Complex Care Clinic
<p>Example of care management services provided in the community, independent of a clinical practice:</p> <p>Medicaid contracts with community care management personnel (e.g., nurse or social worker) working independently of an outpatient or community clinic to integrate with the children's existing healthcare providers, school, hospitals, etc. to perform various care management activities. The nurses make home visits, attend clinic visits, and interact directly with hospital personnel when the children are admitted.</p>	<p>Example of enhancing care management for CMC in a primary care pediatric practice:</p> <p>Within a practice, CMC are distinguished to receive special care characterized by access to a designated pediatric nurse practitioner (8 hours per week), consultation from a local parent, modifications of office routines, implementation of an individualized health plan, regularly scheduled continuing medical and nursing education, and expedited referrals and communication with specialists and hospital-based personnel.</p> <p>Systems are developed to streamline the ordering of medications and supplies as well as coordinating patient appointments so that family burden was minimized. Care plans are created and maintained in Word and faxed to specialists, emergency departments, hospitals, etc.</p>	<p>Example of care management in a consultative, outpatient clinic dedicated entirely to CMC:</p> <p>Nurse care managers (NCM) serve as a single point of contact for patients and families, PCPs, and community resources. They prepare a plan of care, facilitate communication among specialists and PCPs, attend appointments, work with community agencies and insurers to make sure that the children had all needed services. They sometimes spend up to 20 hours per patient per month.</p> <p>Physicians are available 24 hours / 7 days a week. They perform detailed H&Ps, reviewed the medical record, and synthesize the child's many problems in a comprehensive summary provided to the family, PCP, and specialists. The physicians frequently arbitrate among competing diagnoses and therapies. They see patients electively in the clinic, urgently in the ED, and occasionally at home or in the PCPs' office. They facilitate admissions and coordinated care during the hospital stay.</p>

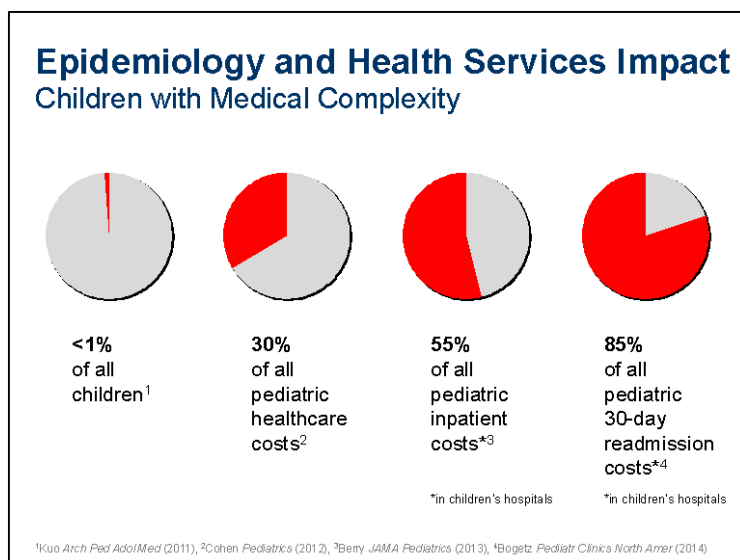
(taken from Berry JG et. al, Children with Medical Complexity and Medicaid: Spending and Cost Savings; *Health Affairs* 2015)

G. Distinguishing CMC For Policy, Research, And Clinical Initiatives

It is possible to distinguish CMC from populations of children. My research group has accomplished this through the use of both proprietary and open-source diagnosis classification systems that rely on ICD-9-CM diagnosis codes for use with health administrative data. My clinical service has distinguished CMC using “subjective” attributes that are not disease specific. The service continuously receives new referrals every week to enroll new CMC into our service based on the attributes.

H. CMC Prevalence and Impact on the Pediatric U.S. Healthcare System

The estimated prevalence of CMC ranges from <1% to 5% depending on the strictness of the definition used. My personal belief is that the true prevalence of these children resides on the lower side of that range. It is estimated that CMC account for as much as 30% of all healthcare spending on children.



Their impact is felt tremendously in children’s hospitals, where they account for over 50% of hospital costs and the vast majority of hospital readmission costs.

I. Healthcare Spending and Health Resource Use for CMC

From analyzing state Medicaid data, we have learned that hospital care accounts for a large percentage (i.e., nearly one-half) of healthcare spending for CMC. Conversely, primary care and home nursing care accounts for a small percentage (i.e., 2%) of healthcare spending for CMC. Many providers caring for CMC believe these percentages are imbalanced; they reflect

one of the biggest problems of the system: CMC are using the hospital too much and primary/community/home care too little.

J. Reimbursement for Care Management Activities for CMC

Outpatient and community healthcare providers often receive the same reimbursement for an office visit for a CMC as they do for a generally healthy child with an acute illness that takes much less time and effort to treat. Care management activities that involve extended time for an office visit, lots of telephone correspondence, lengthy review of medical records, large amounts of paperwork, multidisciplinary team meetings etc. are insufficiently reimbursed to cover the cost of the clinic personnel doing them, especially when the activities are not associated with an in-person patient encounter. This, in part, explains why many hospital-based clinics serving CMC are not financially self-sufficient. Some programs following ~250 CMC report annual deficits as large as ~\$400,000. Often, these clinics depend on philanthropy and hospital subsidies to operate. As long as reimbursement of care management services for CMC is insufficient or absent, providers may be reluctant to offer them. Absent adequate reimbursement, care management activities for CMC will continue to be viewed, in many practice settings, as peripheral - rather than a core - clinical activities that occur sporadically when time permits [e.g., during a lunch break or when another patient “no shows”].

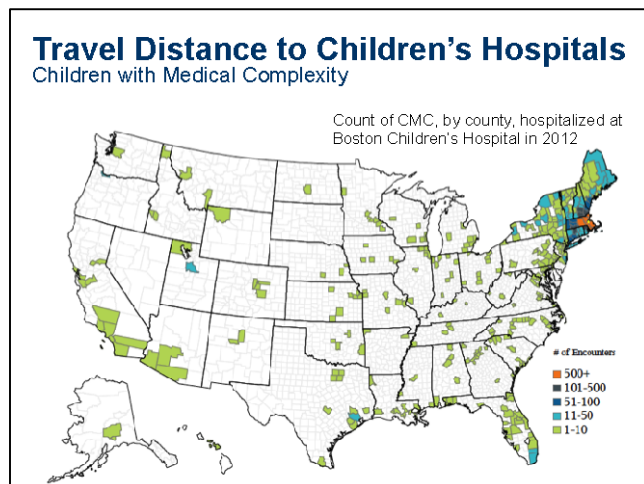
K. Dispersion of Healthcare Providers for CMC

From analyzing children’s hospital data, we’ve learned that healthcare for many CMC is dispersed across large geographic areas. CMC often rely on a children’s hospital for their specialty, surgical, and inpatient care. This is largely because children’s hospitals employ most of the clinical workforce who is proficient to care for CMC. Children’s hospitals are largely inaccessible to most CMC and their primary, community, and home care providers who do not

reside near the children's hospital. This is especially true for CMC and their providers who reside in rural / underserved medical areas or out-of-state from the children's hospital.

L. Experiences with Care Coordination for CMC

The term care coordination is used frequently when discussing optimal care delivery for CMC. Implied in the spirit of care coordination is that everyone involved in the children's care (i.e., the child's care team) should function together in an organized way, dividing and sharing responsibility. Care coordination for CMC works best when the coordination duties are explicitly articulated and agreed upon among the child's care team. That process can ensure that someone on the team takes ownership and accountability for each piece of the child's care, even if certain pieces are co-managed between two or more providers. Understanding who is on the team and knowing who is responsible for each aspect of care and care coordination will greatly benefit the team leader for each child, making it easier to monitor care and assure optimal outcomes. Throughout this process, the child and family should remain the focus. Family-centeredness will ensure that they are always a part of critical discussions, decisions, and planning as well as full partners in all care processes. Care coordination should not be limited to medical decisions at hand (e.g., a primary care physician, pulmonologist, and home nurse working together to treat pneumonia in a child with cerebral palsy and a tracheostomy). Rather, care coordination should involve the child's care team consistently thinking forward to create and execute plans that will (1) fulfill the child's healthcare needs; and (2) manage and treat future health problems that the child could experience.



From my position in my clinical program for CMC, I have had a vantage point of care coordination the entire care continuum. This point exists because my colleagues and I are recurrently communicating with, collaborating with, and relying on with healthcare professionals practicing in the children's communities and homes to help CMC. For example, we're constantly on the phone with (a) *primary care physicians* trying to help them decide what to do to help a CMC that shows up in their office for an acute health problem or healthcare need; (b) *home nurses* troubleshooting issues in the children's homes, (c) *durable medical equipment vendors* attempting to deliver and maintain medical treatments (e.g., home ventilator, feeding tube supplies, etc.) that are critical to maintain the children's health, (d) *specialists* trying to manage a particular comorbidity; (e) *surgeons* needing assistance to keep the children safe during and after an operation; (f) *community case managers* assigned to a CMC who are stuck trying to meet a healthcare need (e.g., obtain a referral, adjudicate differing opinions in a treatment plan); and (g) *emergency department clinicians* unfamiliar with a CMC trying to determine the best way to promptly treat the child's critical, urgent health problem. Of course, communication lines are constantly open with CMC and their families when helping with these situations.

M. Experiences with Primary, Community, and Home Care for CMC

Unfortunately, many CMC and their families report a non-optimal experience with primary, community, and home nursing care. They report that their primary care clinicians do not (1) take the time to understand and take charge of their child's health problems; (2) help CMC when they are facing urgent health problems; or (3) sufficiently coordinate care with the children's specialty physicians and therapists. This may explain why a large proportion (up to 40%) of CMC do not visit annually with their primary care physician. Regarding home nursing care, many families of CMC report that they are unable to obtain a sufficient amount of home care; that is they are unable to fill the number of home nursing hours that are approved to their

children by Medicaid. Families of CMC feel that the insufficient supply of pediatric trained home nurses is largely responsible for this.

Primary, community, and home care clinicians also report non-optimal experiences caring for CMC. Primary care clinicians report that Medicaid does not sufficiently reimburse them for the lengthy office visits (e.g., 1 hour or longer), multiple phone calls, administrative paper work (e.g., letters of medical necessity to obtain Medicaid approval for durable medical equipment), and other domains of care that are needed to keep CMC healthy. As a result, they are reluctant to provide care to CMC; rather, they are incentivized to take care of healthier children (e.g., a healthy child with an ear infection) in a shorter amount of time and with better reimbursement. Similarly, home nursing companies report that Medicaid reimbursement for their pediatric home nurses is insufficient to recruit and maintain high quality personnel. These companies often rely on financial margins (when they exist) generated from adult patients to underwrite the financial losses accrued from payment for their pediatric patients.

N. Overall Challenges of Caring for Children with Medical Complexity

In my experience, caring for CMC is very difficult and time consuming. Lengthy office visits (sometimes lasting an hour or longer) are required to meet the children's healthcare needs. Often, lots more work with follow-up phone calls, emails, paperwork, etc., is required after a visit when trying to communicate and coordinate care with all of the children's healthcare providers. It's often a laborious process to meet some of the children's health care needs (e.g., obtain insurance approval for more home nursing hours). During this process, it's common to rely on other healthcare providers for help, which can be tricky depending on how willing they are to engage.

Providing urgent care, in particular, to CMC is very hard. The health of many CMC is so tenuous that minor delays in assessment and treatment can lead to major effects. In the setting of pneumonia in a child with cerebral palsy, for example, minute to hour delays in administration of respiratory therapies (e.g., nebulized medications, suctioning, oxygen, chest physical therapy, positioning, etc.) can lead to substantial, protracted worsening in respiratory function that may require hospital admission and may take days or weeks to resolve. Failure to provide adequate attention to the child's routine needs (e.g., punctual administration of anti-epileptic and gastrointestinal motility drugs) while addressing new, acute illness may inadvertently induce exacerbations of existing, chronic conditions. It is imperative, then, that CMC have - as best as possible - immediate access to a site of urgent care that is equipped with clinicians, medical supplies, etc., that can rapidly assess, accommodate, and treat them. Unfortunately, many CMC do not have such access to high quality urgent care.

I believe that the main challenges that emerge when caring for CMC include:

- 1) Empowering primary, community, and home care providers to engage in their care
- 2) Empowering specialty and hospital providers to integrate with primary, community, and home care providers – especially those providers practicing in distant locations.
- 3) Incentivizing providers to work on the children during non in-person healthcare encounters for which they are not typically reimbursed
- 4) Incentivizing providers to deliver high quality urgent care to CMC
- 5) Convincing providers to be accountable for the care they provide to CMC
- 6) Making care accessible for CMC who need to cross state lines to get it

I can affirm that these challenges are not exclusive to my local area of clinical practice; they are present throughout the U.S.

O. Illustrative Cases of Substandard Care for CMC

Described below are three real world cases that, in my opinion, indicate substandard care delivery to CMC.

- A primary care provider declines to help a CMC with an urgent health problem because it's easier for the provider to send the child to the emergency department for help. In the emergency department, it's easier for the clinicians there to admit the child to the hospital rather than watch and wait to see if the child's health improves. Once in the hospital, it's easier for the hospital providers to discharge the child back to the primary care physician without substantive communication rather than to work with and help the physician improve their urgent care capability and responsibility to the child.
- A child travels out of state to undergo a highly specialized surgery to better align their hips and spine in the hopes that the surgery will improve their mobility. Intensive rehabilitation, including physical therapy, is recommended to make sure that the surgery has long-lasting effects. The child's home state Medicaid program does not approve the frequency of therapy prescribed by the surgical team. There is no inpatient option for rehabilitation in the child's state. A rehabilitation facility outside of the child's state is available to help the child, but the child's home-state Medicaid program denies approval to receive care from the out-of-state rehab facility. The child does not receive the needed rehabilitation and physical therapy, which significantly impedes the affect of the surgery.
- Healthcare providers in some states are advising families of CMC to move to a different state because the Medicaid funding for and the supply of home nurses are insufficient in the child's home state; without sufficient home nursing, it is anticipated that the health of the child will decline and recurrent emergency and hospital care will be required. In these same states,

some hospitals have blocked investment of clinical resources and personnel to help CMC because their state legislators are proposing substantial cuts to the Medicaid budget that threaten the hospitals' capability, in general, to provide care for children in Medicaid.

P. Illustrative Cases of Optimized Care for CMC

It is important for the Committee members and staff to understand that not all is dire regarding healthcare for CMC. Described below are additional real world cases of state Medicaid programs instituting novel initiatives to optimize care delivery for CMC. I believe that standardization of these initiatives, and others like them, across states could have a profound impact on the health and wellbeing of CMC.

- Some state Medicaid programs are reimbursing outpatient, community, and home care providers of CMC for non in-person healthcare encounters with the children and families. That is, they are reimbursing providers directly when coordinating care by phone and email, and when holding multi-disciplinary team meetings, etc. As a result, providers are expanding the amount of time to care for CMC by billing for these activities.
- Some state Medicaid programs are embedding case managers directly into primary care practices to help coordinate care for CMC. There are some phenomenal success stories of how these case managers have optimized the health and well being of the children. On-site and in-person, the care managers assist the primary care providers with activities that, in particular, involve interaction with insurance personnel (e.g., prior authorizations for medications, approval for durable medical equipment, etc.). The care managers facilitate treatment adherence by accessing Medicaid claims data for medication refills. They make home visits to educate families and ensure the safety and stability of the children's home environment. They help communicate with the children's subspecialty providers who may be

distant from the child's home. Such efforts can increase the use, capacity, and value of primary care for CMC.

Q. Healthcare Policy and Legislation That Could Help Children with Medical Complexity

I truly believe that healthcare policy and legislation can help optimize care delivery for children with medical complexity and improve health for these vulnerable children. To me, policy and legislation that affects the following attributes will have the highest likelihood of success.

- Healthcare spending: redirect it toward primary, community, and home care; use financial incentives to bolster and engage this clinical workforce
- Accountability and governance: make all providers on the hook for care quality; call them out explicitly as part of a formal team (e.g., “health home” or “care network”)
- Accessibility: make it easier for patients to get the care they need cross state lines
- Medicaid data: make it reliable and standardized across states; make it usable to distinguish best practices of care delivery for CMC across states

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S. Suggested References for Additional Information Related to CMC

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