

# Briefing Paper

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## What Children with Medical Complexity, Their Families, and Healthcare Providers Deserve from an Ideal Healthcare System

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### Introduction

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.<sup>1,2</sup> CMC are one of the smallest, yet fastest growing, populations of children, and they have an enormous impact on the healthcare system.<sup>3-8</sup>

With a prevalence of ~0.5% (n ~400,000) of all U.S. children,<sup>9</sup> it is suspected that CMC account for as much as one-third of health care spending for all children (i.e., ~\$100 billion).<sup>4</sup> Their rates of emergency department use are high, their hospitalizations are long, and their hospital readmissions are frequent.<sup>6,10-14</sup>

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Hospital readmission rates for CMC equal or exceed the rates of elderly Medicare beneficiaries (i.e., ~20% and higher), with many of the children experiencing  $\geq 5$  recurrent readmissions each year, a median of 38 days apart.<sup>5,6,8,10-17</sup> In children's hospitals, CMC account for 55% of hospital cost for all admissions and 85% of cost for 30-day unplanned hospital readmissions.<sup>3,15</sup>

Caregiving for CMC can be a very rewarding, yet herculean, strenuous, stressful, and time-consuming task.<sup>18,19</sup> CMC's medical complexity makes it difficult to meet their healthcare needs; consequently, of all children, they are the most likely to have unmet healthcare needs.<sup>9,20</sup> Even when their needs are identified, there is a paucity of scientific evidence to guide their medical management.<sup>13</sup> Also because of their complexity, CMC and their families depend on a variety of services from multiple disciplines (e.g., disability, in-home care, legal, special education, transportation, etc.). Their outpatient, community, and home care services generally are severely understaffed and underfunded.<sup>4</sup> As a result, their health services across the care continuum are rarely integrated, organized, or reliable.<sup>21</sup> These systemic shortcomings no doubt contribute to

CMC having the highest rates of adverse events, including medical errors, of all children.<sup>12,23-27</sup> There is no question that CMC and their families deserve better from our healthcare system.

Better care may be coming. A strong force of coalescing administrative, clinical, educational, policy, quality improvement, and research initiatives is briskly pushing forward the field of “complex care” to optimize healthcare delivery for CMC. From start-ups of outpatient complex

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care clinics in children’s hospitals,<sup>28,29</sup> to randomized trials of rapid-response systems for urgent healthcare problems endured by CMC,<sup>30</sup> to multi-centered quality improvement assessments of care coordination for CMC that involve innovative health informatics solutions,<sup>31</sup> to federal legislation calling for regional networks of care integration for CMC across the continuum,<sup>32</sup> to families of CMC leading amazing initiatives of empowerment and connectivity,<sup>33</sup> the multi-disciplinary, myriad

of people dedicating their time and effort to make things better for CMC is growing. As the field of complex care moves forward, a unique opportunity exists to determine how to best serve CMC and their families. This report describes what all those involved in the care of CMC deserve from the healthcare system.

## Care Management

### Body of Evidence

A growing body of evidence suggests that exposure to high-quality care management can have a major impact on the health and well-being of CMC and their families. For the child, care management reduces their unmet healthcare needs and improves their health and functional status.<sup>34</sup> For the family, care management increases knowledge of their child’s health problems, helps the family cope with their child’s health, reduces familial caregiving burden, and improves family satisfaction with care.<sup>34</sup> Care management for CMC also has an impact on health resource use. Exposure to high-quality care management has reportedly increased outpatient office visits by as much as 70% and has reduced hospital admissions by 26-59%, the number of days spent in the hospital by as much as 52%, and emergency department visits by 18-55%.<sup>28,34-37</sup>

A variety of approaches to effective care management for CMC have been described. Primary care medical homes in community and academic settings have begun to focus on CMC. Their approaches include assigning special staff to them (e.g., nurse practitioner, case manager, or parent consultant); offering extended office visits (e.g., 60-minute “well child check”); creating written individualized health plans; and expediting referrals and communication with specialists.<sup>35</sup> Some primary care practices have embedded pediatric subspecialists for enhanced co-management of CMC, helping the practices to respond rapidly to the children’s urgent health problems (e.g., chronic condition exacerbations that require assistance from specialty

providers).<sup>30</sup> Consultative outpatient and inpatient clinical programs dedicated entirely to CMC have emerged in children's hospitals across the U.S.<sup>11,28</sup> The care management they offer can be intensive. Some programs spend up to 20 hours monthly per child to manage their care.<sup>28</sup> The providers in the programs move ubiquitously with CMC across the care continuum to help them in the emergency department, hospital, subspecialty, and primary care clinics.<sup>28</sup> These providers also interface with a wide variety of community providers and entities upon which the children and families depend.<sup>28</sup>

Although all of these care management approaches have reported effectiveness, it is clear that one of them will not "fit" as a health system's solution to help all CMC. For example, despite decades of research, quality improvement, and policy promoting the use of the primary care medical home,<sup>38-43</sup> emerging evidence suggests that many CMC are not using primary care health services at all.<sup>44,45</sup> One recent study reported that 40% of CMC in Medicaid did not have an annual primary care visit.<sup>4</sup> There are substantial barriers to CMC receiving high-quality care management in the primary care setting, including time pressures, lack of adequate staff, and difficulty making referrals and inadequate reimbursement. These barriers hamper primary care providers who would like to provide a medical home for CMC, ensuring that the children's needs are planned for and met in a timely fashion.<sup>9,44,46,47</sup> Outpatient consultative clinics dedicated entirely to CMC can be a useful alternative or complement to the primary care medical home.<sup>28</sup> However, these clinics reside predominately in urban children's hospitals that may not be convenient to many CMC and their families.

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## Home and Community Services

More exploration is needed to augment and support efforts of community health care providers to CMC.<sup>48,49</sup> Some state Medicaid programs (e.g., Alabama) are embedding community care managers into primary care practices to help serve CMC.<sup>50</sup> 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.

More emphasis on self-management supports at home and in the community is needed to help families with their CMC caregiving activities. Many families provide caregiving activities in their homes that are equivalent, in some aspects, to the level of hospital care.<sup>18,19</sup> Unfortunately, families' efforts, out-of-pocket expenses, and missed days of work providing extensive home care can become both a financial and emotional burden. This is especially true for recently

hospitalized CMC who sometimes need weeks—or even months—of sustained, intense, daily caregiving to recover from their illness or injury.

Although pediatric home care, respite care, and post-acute hospital care are rarely studied and are potentially underutilized options in pediatric health care, they have the potential to substantially help CMC and their families.<sup>4</sup> Only 2% of hospitalized CMC with Medicaid receive post-acute care or home-care, compared with nearly 40% of high-cost, complex hospitalized Medicare beneficiaries.<sup>4,51</sup> This difference in utilization between children and adults is likely due to insufficient supply and payment for these services in children, in combination with expectations of parents as ready caregivers for CMC after discharge. From 2001 to 2011, Medicare beneficiaries experienced a remarkable reduction in spending on hospital care (38% to 24%) as spending increased for home health care and post-acute care.<sup>52</sup> Further assessment is needed of the child and family benefits that could result from increased access and use of home health care and post-acute care.

## **Taking Charge of Care Management**

The increasing attention to the different approaches to care management has failed to address what is arguably the most important aspect of it for CMC: having a pediatric healthcare professional assume responsibility with the family for managing the child's overall health and well-being. Many families of CMC report that they do not have a usual source of care, nor do they have clinicians who (1) listen to parents' concerns; (2) take ownership of their child's health and well-being; or (3) take the time to plan for health problems that the children are likely to encounter.<sup>9,44,46,47,53-55</sup> Many families take on their child's care management activities because their child's providers are not adequately doing so.<sup>56,57</sup> There are remedies for this less-than-ideal situation.

All CMC deserve healthcare professionals who will (1) explicitly lead the members of the child's care team (i.e., every provider and caregiver involved in the child's health); (2) function as the prime partner with the child and the family; (3) take responsibility for troubleshooting and solving problems and issues with the child's health; and (4) be the "backstop" to prevent omissions and delays in care. A variety of professionals (e.g., a physician, nurse, social worker, case manager, patient navigator, etc.) in a myriad of practice settings (e.g., primary care clinic, specialty care clinic, children's hospital, community-based practice, home care organization, etc.) can be a team leader. More important than the type of professional or their practice setting is simply having a professional who will take charge.

Taking charge of comprehensive care for CMC is not easy. It requires a deep understanding of a child's medical, familial, and social history; this takes time and organized processes to gather and process the information. Although this understanding is difficult to achieve, it will enable a healthcare professional to leverage the information well enough to foresee and proactively plan

for future health and life challenges (e.g., acute health demise, development of new comorbid conditions, difficult treatment decisions, etc.) that each child is likely to encounter.

Taking charge of care for CMC can be a daunting task, given the breadth and variety of health issues endured by many of these children, who typically have problems involving multiple body systems. Taking responsibility to help direct care and treatments that are beyond the usual knowledge and skills of primary healthcare professionals requires learning when and how to approach others to help manage and coordinate the care.

## **Care Coordination and Care Planning**

### **Care Coordination**

Implied in the spirit of care coordination is that everyone involved in the child'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.

### **Care Planning to Fulfill Healthcare Needs**

Care planning for CMC, at its core, involves the care team working closely together to (1) make a blueprint of the foundation and structural components that each child needs to optimize their health and quality of life; and (2) execute activities to get those components for the child. The extensive, multi-disciplinary needs that must be addressed to optimize CMC's health and quality of life define their medical complexity.<sup>2,13</sup> The list of possible healthcare and other needs of CMC is extensive. Needs might include medical treatments (e.g., special diet, medications,

durable medical equipment, therapies, etc.), diagnostic tests (e.g., medication levels, radiographic imaging, etc.), and health services (e.g., pediatric specialty care, home nursing care, care management, etc.). Social services, family support, and educational programming, transportation, etc., are also central to the functioning of children and families, and thus can greatly contribute to and heavily influence the health and lives of CMC.<sup>2,13</sup>

Healthcare needs for CMC often require extensive care planning to meet them because the needs (1) require multiple providers to meet them; (2) require a hefty amount of planning and paperwork to be obtained; and (3) are interrupted often because of health events experienced by the child.

It's not uncommon for a child to have as many as 25 ongoing healthcare needs that are met among 10 or more different pediatric providers. The needs with the largest impact on the health of CMC are often the most difficult to meet. For example, consider the time and effort needed to increase the number of weekly hours for home health nursing in a child with spinal muscular atrophy requiring continuous mechanical ventilation; or to arrange a brain magnetic resonance imaging (MRI) study with anesthesia for a child who will need, ahead of time, prior authorization from an insurance company. Because weeks and sometimes months of work can be required to meet the healthcare needs of CMC, the progress made is often interrupted when the children get sick and cannot attend planned tests or scheduled appointments.

CMC deserve health care providers who will relentlessly meet their health care needs. Regardless of the hefty work required to meet the needs—multiple phone calls, faxes, and emails; paragraphs and pages of documentation and forms; and other activities typically not reimbursable in traditional fee-for-service healthcare payment arrangements—CMC require providers who will continue to push forward through the administrative, financial, and other barriers that preclude the need from being met. Absent someone observing and managing the fulfillment of needs across providers, the likelihood of an omitted, overlooked, or delayed need is high. Of course, many providers may not perceive themselves as positioned to take on meeting the healthcare needs for CMC at this lofty level. Nevertheless, efforts involving health system reform for CMC should remove barriers and better enable providers of CMC to do it.

## **Care Planning for Future Health Problems**

Beyond organizing care to meet current healthcare needs, care planning for CMC also involves the proactive creation of instructions and guidelines to manage and treat future health problems that are likely to arise. Answering the following 10 questions throughout the course of caring for the child might help to do this:

1. Which aspects of the child's health and life are likely to get better or worse?
2. What acute illnesses is the child likely to experience?
3. What exacerbations of their existing chronic conditions is the child likely to experience?
4. What new comorbid conditions is this child likely to develop?

5. How can those illnesses and conditions be avoided altogether?
6. If unavoidable, then how can one mitigate their severity should they occur?
7. What major medical needs (e.g., medications, subspecialty consultation, equipment, etc.) is the child likely to need in the future to help treat the illnesses and conditions?
8. What decisions about major medical interventions (e.g., major surgery) are the child and family likely to face?
9. What is the likely impact on the family (e.g., marriage, employment, etc.)?
10. What will life be like for this child in one, five, ten, or more years?

Proactive care planning for CMC remains a difficult task. Because the combinations of health problems endured by many CMC can be rare and unique, there may be little evidence-based guidance. Thoughtful, prudent creativity, in combination with a trial-and-error approach, may be necessary to craft and implement safe and effective care plans.

For example, a provider may anticipate that a child with neurologic impairment from a congenital brain malformation is likely to develop aspiration pneumonia due to worsening oromotor dysfunction and oral secretion management. The child tends to aspirate at the beginning of every winter. Although there are no published guidelines on early, outpatient treatment for suspected aspiration pneumonia, the provider may elect to partner with the family to create an aspiration pneumonia treatment plan that includes initiation of a regularly scheduled bronchodilator and inflammation antagonist as well as chest physical therapy, use of a small amount of oxygen, close monitoring for suctioning of secretions, initiation of an oral antibiotic, and one outpatient office visit daily for three days when symptoms of aspiration pneumonia appear.

## **Rapid Response and Urgent Care**

Care coordination and care planning efforts will often be insufficient when CMC experience acute changes in their health. In those circumstances plans should exist for rapid, timely access to care. 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. For best results, the site should be (or have characteristics congruent with) a medical home. Ideally, the child and family should be familiar with the site

and should have ready access to the child’s usual health care provider or, at least, their medical records.<sup>30</sup> The site should also possess the capability to efficiently contact pertinent members of the child’s healthcare team to consult on the urgent care assessment and approach.

## Financing, Payment, and Risk Assessment

### Reimbursement for Care Management Activities

Outpatient and community healthcare providers often receive the same reimbursement for an office visit for CMC as they do for generally healthy children with acute illnesses.<sup>58</sup> 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.<sup>28</sup> Often, these clinics depend on philanthropy and hospital subsidies to operate. On the other hand, some such clinics have achieved financial stability.

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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 core—clinical activities that occur sporadically when time permits (e.g., during a lunch break or when another patient “no shows”).

Fortunately, efforts to optimize payments to providers for care management of CMC are under way. Certain payers (e.g., Michigan’s Medicaid program) are beginning to offer reimbursement for care management activities for CMC in fee-for-service arrangements (e.g., \$100 monthly for CMC) based on individually submitted billing claims.<sup>58</sup> Accountable care organizations (ACO) are including payment rewards to outpatient and community clinics that minimize their patients’ hospital and emergency department (ED) use. Federal legislation for CMC in Medicaid is proposed to help allocate spending toward providers performing care management activities.<sup>32</sup> Federal Medicare programs now offer reimbursement for chronic care management services, although this generally applies to adults. Although these initiatives are promising, their sufficiency remains unknown. It may be that the current fee-for-service payment model will need to be replaced or augmented with an alternative (e.g., capitated) model.

### Predicting Risk of Future Healthcare Cost and Utilization

In theory, improving care management for CMC will result in tangible cost savings for the healthcare system by reducing future, expensive healthcare encounters. Although many prior studies of care management for CMC report cost savings,<sup>28,34-37</sup> quantifying and verifying this aim is not trivial. Most knowledge about projecting future health resource use and cost for CMC is derived from retrospective studies that assess statistical correlations between patient characteristics and healthcare experiences. These studies report findings such as the adjusted odds of a child with vs. without a complex chronic condition experiencing  $\geq 5$  hospital admissions to a children's hospital in one year [OR 5.6 (5.5-5.8),  $p < .001$ ].<sup>13</sup> Reporting the increased odds is important, but that doesn't convey the true predictive risk of future hospital use for a particular child.

Currently, predicting which CMC will have substantial future expenditures is not particularly accurate. Little is known about when, how long, and which CMC incur sustained high healthcare resource use and spending. One multi-payer study reported that nearly half of children in the top 10% of healthcare spending in one year did not maintain the same magnitude of spending in the subsequent year.<sup>59</sup> If it is found that half of the population of CMC experience a significant regression in spending from one year to the next, and it remains difficult to distinguish which children will experience this regression, then payers, ACOs, health plans, and others may find it difficult to set meaningful targets and derive valid estimates of projected cost savings from care management.

When projecting future healthcare resource use and cost of CMC, it is important to remember that their costs are chiefly due to hospital care. Nationally, CMC account for roughly one-half of Medicaid spending on hospital care for all children, and this proportion is increasing over time.<sup>4</sup> Compared with hospital care spending, the percentage of total spending on CMC for primary care is small: 47% vs. 2%.<sup>4</sup> The percentage of total spending on CMC for emergency department care is also small (3%).<sup>4</sup> Therefore, when focusing on potential cost savings from reducing different forms of care, a given percentage reduction in hospital use would yield much larger cost savings than from reductions in ED visits. The absolute dollar amount of the cost savings from a 10% reduction of overall hospital days could underwrite a substantial (i.e., doubling) investment in primary care that could be used to fund activities of care management for CMC.<sup>4</sup>

## **Cost Savings as a Measure of Effective Care Management**

Containing healthcare cost for CMC is extremely important to the health system. There is no doubt that some of the children's healthcare utilization (e.g., hospital and ED use) is excessive because of substandard quality of care.<sup>4</sup> Reducing this utilization through improved care and management could lead to overall cost savings for CMC. As noted above, a variety of studies have reported this outcome.<sup>34</sup> Because CMC account for a large proportion of healthcare spending on pediatric care (i.e., up to one-third<sup>4,5</sup>), cost savings for CMC could impact total healthcare spending for children. Consequently, many clinic, hospital, state, and federal

initiatives prioritize (directly or indirectly) cost savings as a primary goal of care management interventions for CMC.<sup>32</sup>

However, there are several issues that challenge the use of cost savings as a prioritized outcome for CMC. First, as described above, a substantial body of literature suggests that a large proportion (i.e., up to 40%<sup>4</sup>) of CMC have unmet health care needs. Many of these unmet needs (e.g., medications, equipment, home nursing, etc.) are expensive to meet.<sup>9,20</sup> Improving care management for CMC will result in meeting many of these needs on a population level and

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increasing costs.<sup>37</sup> Second, improved care management for CMC often results in a dramatic increase in outpatient clinic visits (e.g., 70% increase<sup>28</sup>). Third, exposure to high-quality care management often uncovers the need for major medical interventions (e.g., operations) for comorbid conditions whose high severity was previously unrecognized. Fourth, payment for care management activities for CMC—currently under-reimbursed or not reimbursed at all—will likely ensue with future health care reform.<sup>58</sup> All of these situations will likely increase the cost of care for CMC at an amount that has not yet been quantified.

The effectiveness of initiatives to improve care management for CMC should not be judged by whether they result in cost savings. The vast majority of care management programs for adult patients with medical complexity have incurred costs that have exceeded the cost savings achieved from corresponding reductions in hospital and ED use.<sup>60</sup> Reducing the children's unmet healthcare needs, improving their health and functional status, improving their families' ability to cope, and reducing the burden of caregiving experienced by the families are sufficient achievements to demonstrate effectiveness and to support care management despite questions about cost savings.<sup>34</sup>

## Management and Treatment of Specific Health Problems

Team-based care management activities have great potential to optimize the health and well-being of CMC, particularly when coupled with evidenced-based treatment. Unfortunately, in general there is a paucity of scientific evidence to help guide treatments for the health conditions of CMC. The severity, rarity, and heterogeneity of the children's health problems preclude advancement of scientific knowledge; these attributes often exclude CMC from randomized clinical trials and limit interest from federal agencies in funding research to study CMC. More basic, clinical, and translational research on diseases and health problems of CMC is needed, and it should be accompanied by additional health services research on implementing and disseminating the treatments and approaches to care that work best for this population. While awaiting increased research opportunities, those caring for CMC need to develop collaborative approaches to identify and share effective approaches to their care.

## Conclusions

To achieve an ideal health system of care for CMC, it is clear that much work is needed in a variety of areas, including care management, care coordination, care planning, financing, payment, risk assessment, and the treatment and management of specific healthcare problems. It is promising that initiatives to make things better in all of these areas are under way. I eagerly await future reports similar to this one documenting many meaningful gains toward an ideal system. With both sprint-like and ultra-iron-man-like endeavors (and everything in between), the field of complex care must keep striving to perform at the highest level for CMC. Along the way, I hope that CMC, their families, and their providers forcefully lead the field of complex care down the paths that will offer the greatest chance of helping these children and their families.

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