

# Status Complexicus? The Emergence of Pediatric Complex Care

Eyal Cohen, MD, MSc,<sup>a,b</sup> Jay G. Berry, MD, MPH,<sup>c</sup> Lee Sanders, MD, MPH,<sup>d,e</sup> Edward L. Schor, MD,<sup>f</sup> Paul H. Wise, MD<sup>d,e</sup>

**abstract** Discourse about childhood chronic conditions has transitioned in the last decade from focusing primarily on broad groups of children with special health care needs to concentrating in large part on smaller groups of children with medical complexity (CMC). Although a variety of definitions have been applied, the term CMC has most commonly been defined as children and youth with serious chronic conditions, substantial functional limitations, increased health and other service needs, and increased health care costs. The increasing attention paid to CMC has occurred because these children are growing in impact, represent a disproportionate share of health system costs, and require policy and programmatic interventions that differ in many ways from broader groups of children with special health care needs. But will this change in focus lead to meaningful changes in outcomes for children with serious chronic diseases, or is the pediatric community simply adopting terminology with resonance in adult-focused health systems? In this article, we will explore the implications of the rapid emergence of pediatric complex care in child health services practice and research. As an emerging field, pediatric care systems should thoughtfully and rapidly develop evidence-based solutions to the new challenges of caring for CMC, including (1) clearer definitions of the target population, (2) a more appropriate incorporation of components of care that occur outside of hospitals, and (3) a more comprehensive outcomes measurement framework, including the recognition of potential limitations of cost containment as a target for improved care for CMC.

<sup>a</sup>Department of Pediatrics, The Hospital for Sick Children, Toronto, Canada; <sup>b</sup>Department of Pediatrics and Institute of Health Policy, Management, and Evaluation, University of Toronto, Toronto, Canada; <sup>c</sup>Complex Care Service, Division of General Pediatrics, Boston Children's Hospital and Harvard Medical School, Harvard University, Boston, Massachusetts; <sup>d</sup>Center for Policy, Outcomes and Prevention (CPOP) and <sup>e</sup>Department of Pediatrics, School of Medicine, Stanford University, Stanford, California; and <sup>f</sup>Lucile Packard Foundation for Children's Health, Palo Alto, California

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Address correspondence to Eyal Cohen, MD, MSc, Department of Pediatrics, The Hospital for Sick Children, 555 University Ave, Toronto, ON M5G 1X8, Canada. E-mail: [eyal.cohen@sickkids.ca](mailto:eyal.cohen@sickkids.ca)

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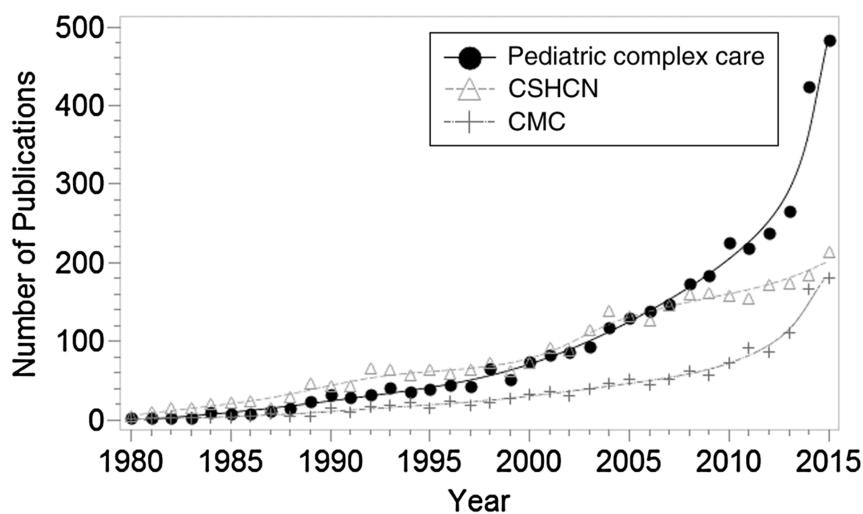
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An important mismatch has emerged between our current system of child health care and the current epidemiology of childhood need. This mismatch is as much a product of the successes of recent child health interventions as it is of the failure or functional obsolescence of past programs or legislation. Dramatic change in the prevalence and survival of childhood-onset diseases in the last half-century has led to an epidemiologic shift that is characterized by growing numbers of children with chronic conditions<sup>1</sup>; the proportion of children with a chronic condition that interferes with daily activities has increased by >400% since the 1960s.<sup>2</sup>

In response, those in pediatric health care practice and policy have made chronic conditions an important focus. In 1998, after an extensive and comprehensive process of consultation, the Maternal and Child Health Bureau advanced a definition of children with special health care needs (CSHCN). This definition included those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type and/or amount beyond that required by children generally.<sup>3</sup>

The CSHCN definition was purposively constructed to be broad and inclusive to enable comprehensive policies and planning as well as new child health promotion and prevention programs to address the at-risk population. As a result, ~15% of US children are categorized as CSHCN, and ~23% of US households have  $\geq 1$  child who fits this definition<sup>4</sup> not including those children deemed at risk, who are difficult to quantify.

In more recent years, however, many health care providers, policy makers, and child health services researchers have shifted their focus from all CSHCN to a subgroup of chronically ill children, defined as children



**FIGURE 1**

A plot of PubMed-indexed publications over time with different search terms. The searches were conducted by using PubMed on May 25, 2016, and encompass January 1, 1980, to December 31, 2015. Search terms included the following: (1) “pediatric complex care” = (“pediatrics”[MeSH Terms] OR “pediatrics”[All Fields] OR “pediatric”[All Fields]) AND complex[All Fields] AND care[All Fields]; (2) “children with special health care needs” = (“child”[MeSH Terms] OR “child”[All Fields] OR “children”[All Fields]) AND special[All Fields] AND (“delivery of health care”[MeSH Terms] OR (“delivery”[All Fields] AND “health”[All Fields] AND “care”[All Fields]) OR “delivery of health care”[All Fields] OR (“health”[All Fields] AND “care”[All Fields]) OR “health care”[All Fields] OR “healthcare”[All Fields]) AND (“health services needs and demand”[MeSH Terms] OR (“health”[All Fields] AND “services”[All Fields] AND “needs”[All Fields] AND “demand”[All Fields]) OR “health services needs and demand”[All Fields] OR “needs”[All Fields]) OR “children with special healthcare needs”; and (3) “children with medical complexity” = (“child”[MeSH Terms] OR “child”[All Fields] OR “children”[All Fields]) AND medical[All Fields] AND (“Complexity”[Journal] OR “complexity”[All Fields]).

with medical complexity (CMC). Although a variety of definitions have been applied, the term CMC has most commonly been applied to children and youth with chronic conditions associated with medical fragility, substantial functional limitations, increased health and other service needs, and increased health care costs.<sup>5</sup> Although the definition of this term has only been in wide use for a few years and the 2 terms (CMC and CSHCN) are still often used interchangeably, CMC (and variations of this term) is now frequently used in the discourse of child health services research. Figure 1 demonstrates the growth in publications using terminologies focused on complex care in recent years. Pediatric complex care is now a common topic discussed in major pediatric meetings, a priority in funding calls, and a target for major legislative efforts.

In this article, we explore the rapidly growing attention that has been paid to CMC within the child health community, particularly as it relates to child health services research. The aim is to provide insights into 2 important questions: (1) why has attention shifted from CSHCN to CMC, and (2) what are the potential implications for pediatric practice and research?

## WHY GREATER ATTENTION TO CMC?

### The Limitations of a Broad Definition for Children With Chronic Conditions

The considerable variation in needs, functional limitations, and medical complexity of CSHCN presents the child health community with both an opportunity and a challenge. For some health policy efforts, the broad CSHCN definition has been logical, important, and effective. For instance,

initiatives to improve access to health care in the United States that have been aimed at CSHCN (eg, via health insurance coverage)<sup>6</sup> are logical because these are the children who most need health care. However, for other purposes, the definition is too broad. Programs and policies often need tailoring to those subgroups that require more specific and/or more intensive models of service provision. Systems that are well designed to care for most CSHCN (eg, children with isolated speech delay) may be insufficient to meet the needs of CMC (eg, children with spastic quadriplegia and complex seizure disorder); complex needs require intensive support and care coordination.

## The Dramatic Health System and Family Impact of CMC Care

### The Health System Impact

CMC have a disproportionate impact on the pediatric health care system. Although CMC account for a small portion of children, they consume approximately one-third of all child health expenditures,<sup>7</sup> use approximately one-fourth of all hospital days, and account for >40% of all hospital deaths.<sup>8</sup> Although there are no known population-level surveillance data that have been used to track trends over time, researchers in multiple studies of the hospital sector suggest that the overall health system impact of CMC is growing.<sup>9–11</sup> For instance, from 1997 to 2006, the proportion of inpatient pediatric admissions, days, and charges in the United States increased among children with complex chronic conditions.<sup>8</sup> Patterns of CMC hospital use have also demonstrated substantial vulnerabilities, such as a high risk of hospital readmission,<sup>12</sup> total and preventable adverse events,<sup>13</sup> and unnecessary variation in hospital care.<sup>14</sup>

### The Impact on Families

The care of CMC rests primarily on the children's parents and families, and there are profound negative effects when these family caregivers are inadequately supported.<sup>15</sup> Frequent (and often extensive) travel to receive specialized health care can create enormous stress.<sup>16</sup> Financial problems are common; more than half of CMC parents report a family member stopping work to care for the child,<sup>17</sup> and relative poverty occurs over time.<sup>18</sup> The effects of chronic stress of caregiving can have serious, lifelong impacts on the health of primary caregivers, who are most frequently the children's mothers.<sup>19–21</sup>

## The Emphasis on Bending the Cost Curve

The development of the CMC category is a logical step in any strategy to control health care spending on children. Although overall child health spending is relatively small, this focus aligns well with a new emphasis on the need to cut costs for the high-using patients and across the entire (adult-centered) health care system. The rationale is based on a few observations that are driving current health policy debate: (1) health care expenditures are outpacing economic growth<sup>22</sup>; (2) such expenditures are concentrated among a relatively small number of people<sup>23</sup> with characteristic clinical features (eg, older adults with multiple chronic conditions)<sup>24</sup>; and (3) much of the spending is on avoidable or even harmful care (eg, repeated and prolonged hospitalizations), and hence targeted efforts to better manage such patients can lead to substantial improvements in health system functioning and sustainability.<sup>25,26</sup> This logic has particular relevance when payment models reimburse providers through contracts that hold them accountable for population-level costs of care

(eg, Medicare's accountable care organization contracts)<sup>27</sup>; such models can create strong incentives to focus on preventive care and avoidable health care use in high-cost populations.

Key differences exist between pediatric and adult complex care. Pediatric complex diseases are comparatively rare, and there are differences in the type of services children need.<sup>28</sup> They are also heterogeneous, making standard quality measurement difficult. Nevertheless, in a cost-containment environment, CMC are a logical choice for targeting because the cost of their care is disproportionate even in relation to other CSHCN.

## WHAT ARE THE IMPLICATIONS OF THE GROWING FOCUS ON CMC?

The emergence of CMC and, in particular, the conflation with advocacy efforts that have historically focused on larger CSHCN populations introduce several challenges for child health systems. First, CMC attention has occurred rapidly, without adequate time to create a body of knowledge to inform the development of meaningful definitions and evidence-based models of care. Second, the focus on a small subpopulation of CSHCN has key implications and potential tensions for policy and practice directions. Each of these issues will be addressed separately.

### Critical Knowledge Gaps: Why Do They Matter?

#### Incomplete and Imprecise Definitions of CMC

Despite the existence of a broad conceptual definition of CMC, precise operational definitions are critical yet remain elusive.<sup>29</sup> Reliable and acceptable definitions are important to a variety of stakeholders who can use them to guide inclusion

criteria for clinical interventions (eg, structured complex-care programs and/or clinics), policy interventions (eg, financial and/or taxation benefits to caregivers), and population-level monitoring of the size of the population and unmet needs of CMC. Part of the challenge stems from the facility of collecting data on medical conditions and health care use and the difficulty of collecting information on other core domains. Diagnostic code lists and health care use tend to be captured readily in administrative databases. Not surprisingly, the most widely used systems for ascertaining the presence of CMC<sup>30–32</sup> or other meaningful subgroups of CSHCN (eg, children with disabilities)<sup>33</sup> focus on such data sets. The limitation of such systems is that they may overemphasize medical diagnoses at the expense of other key contributors to complexity (eg, mental health, family dynamics, health literacy, poverty, and other social determinants of health). Two key domains of medical complexity relate to unmet need and the degree of functional limitation. These issues are not captured routinely in health systems and so are rarely used in population health. Studies in which researchers use anonymized survey data seem to reveal that CMC can be meaningfully ascertained from questionnaires,<sup>34,35</sup> but their clinical application has been limited. Integrative approaches in which researchers use population-based screening with administrative data in combination with prospectively administered questionnaires hold promise, but these have yet to be widely incorporated.<sup>29</sup> Those who use such systems must be able to incorporate dynamic ascertainment because the complexity of a particular chronic condition can vary over time because of factors such as the development of comorbidities, transitions in the life course, and psychosocial stressors.

### *Insufficient Evidence-Based Models of Care for CMC*

There has been a rapid proliferation of a variety of structured complex-care programs,<sup>36–41</sup> with a burgeoning body of evidence supporting their development, but well-controlled studies in which researchers compare the effectiveness of alternative models of care are lacking.

A common thread in virtually all of these models is a focus on care coordination, but they can otherwise vary dramatically in terms of their target populations, health care team compositions, organizational structures, and processes of care. Among the different models, hospital-based complex-care programs have received the most attention recently. These programs have grown in popularity, particularly in children's hospitals, where CMC are highly prevalent.<sup>42</sup> Many large children's hospitals in the United States have developed structured complex-care programs in recent years. Evidence for the efficacy of such programs is limited primarily to before-and-after studies,<sup>43</sup> but a recent single-center randomized controlled trial of a hospital-based clinic in which researchers focused on a narrow group of CMC in Texas (80% of whom had respiratory disorders) seems to reveal improved health outcomes at lower cost.<sup>44</sup> Evaluations for a variety of complex-care–management interventions (eg, through the Center for Medicare and Medicaid Innovation) likely will be completed in the next few years, which will help researchers assess the effectiveness of such programs for more clinically diverse populations of CMC. Future studies in which researchers focus on the comparative effectiveness of differing models of care and on differing reimbursement strategies are necessary as well.

### **What Are the Policy and Practice Implications of a Focus on CMC?**

#### *The Issue of Scoping: Who Is in and Who Is out?*

Incomplete operational definitions have led to potentially orphaned subpopulations and incoherent policies. For instance, in an application of 1 particular software system algorithm, diabetes mellitus is considered a complex condition,<sup>45</sup> whereas in another, it is not.<sup>46</sup> Such inconsistency can lead to a 10-fold difference in the estimates of CMC prevalence, ranging from as low as 0.4%<sup>47</sup> to as high as 6% of all children.<sup>48,49</sup> It also can lead to confusion when developing potential policy solutions to problems that are most applicable to broad groups of CSHCN compared with those that are best focused on just CMC. Recognizing that complexity is a continuum of attributes, >1 threshold may be necessary for different purposes. For example, a state Medicaid program assigning care managers to CMC among a large population of beneficiaries may use a different threshold than a hospital assigning patients to an inpatient complex-care service.

#### *Incorporating Mental Health Into Operational Definitions of Complexity*

One particularly relevant group is children with complex mental health conditions, either as a primary diagnosis (eg, schizophrenia) or as a comorbidity in children with underlying medical conditions (eg, anxiety disorder in a child with epilepsy). Most complex-care programs focus on children with medical conditions (eg, those that are associated with medical technology assistance and/or those that are associated with severe neurodevelopmental disabilities). Interventions that are designed to improve care coordination in medical settings (eg, among many subspecialists) differ in the type of coordination of care needed in



mental or behavioral health, which frequently require community-based service provisions with separate funding streams (eg, county-based funding in the United States and funding from nonhealth ministries in other countries).

Some have preferred to use more inclusive terminologies (eg, children with health complexity)<sup>50</sup> to acknowledge a broader, more holistic definition of complexity that incorporates mental health and other broader, nonmedical issues, such as psychosocial complexity. Even in the absence of mental health problems, CMC frequently require diverse and fragmented community-based services, such as special education, therapists, and social services. Whichever term is used, the incorporation of a broad definition of health is clearly important in scoping CMC initiatives, but it creates challenges in terms of the current definitions of the health care system and payment mechanisms.

#### *Consideration of the Needs of Broader Populations of “Non-CMC” CSHCN*

If so much attention is now placed on CMC, where does this leave other CSHCN? Even with coherent CMC definitions, there will always be a much larger, residual group of non-CMC CSHCN that warrants a different but still enhanced level of care. Such children who do not fit into the category of CMC include those with more common conditions, such as asthma, and common behavioral conditions, such as attention-deficit/hyperactivity disorder.<sup>2</sup> For these children, the bulk of general- and condition-specific care will be delivered in community-based settings, especially in primary-care practices. They also need care coordination and other supports but with approaches that differ from those needed by CMC. For instance, many CSHCN benefit from the development of a disease-management plan (eg,

an asthma action plan)<sup>51</sup>; CMC require an integrated, multifaceted care plan.<sup>52</sup> Enhanced support for primary-care practices to provide patient-centered medical homes with access to coordinated specialist and community services is essential for all CSHCN, and this may be lost if policies and programs focus solely on CMC.

#### **Weighting the Components of Care: Is There an Overemphasis on Hospital-Based Care for CMC?**

A major target of CMC policy and advocacy has been care within hospitals, especially children’s hospitals. For instance, the authors of the Advancing Care for Exceptional Kids Act of 2015 that was promoted before Congress endorsed the creation of Medicaid CMC care-coordination programs in nationally designated children’s hospital networks.<sup>45</sup> Similarly, in Canada, Complex Care for Kids Ontario,<sup>53</sup> a network of complex care providers centered around children’s hospitals, was launched in 2016.

#### **Rationale for a Hospital-Based Focus in Pediatric Complex Care**

There are certainly several good reasons to anchor CMC initiatives around children’s hospitals, and many hospitals have developed formal complex-care programs. Children’s hospitals are key hubs for the specialized providers who are needed to care for CMC, including those that cross state lines. Such organizations also often develop networks of affiliated primary-care practices, providing opportunities for more integrated care, including transitions to and from inpatient care. Another attractive feature of a focus on pediatric hospital care is that it can adapt popular frameworks in adult health care quality-improvement initiatives, such as reductions in preventable readmissions<sup>54</sup> and decreased emergency department (ED) use. Much of this attention is justifiable by

the growth of the population within hospitals<sup>10,11</sup> and the enormous cost both to the health care system and families as well as the elevated risk of error<sup>55,56</sup> from hospital encounters for CMC. Decreasing avoidable hospital use (eg, inpatient stays, long length of stay, readmissions, ED use) is frequently used as a key outcome for CMC. Not surprisingly, much of the wording of complex-care interventions (eg, ambulatory ICU)<sup>57</sup> borrows from hospital terminology.

#### **Limitations of a Hospital-Based Focus**

##### *Hospital-Based Outcomes for CMC May Not Be Consistently Changeable*

Conventional hospital-based targets for improvement may not be amenable to large changes with CMC initiatives. For instance, the preventability of unnecessary hospital-based use (eg, hospitalizations, inpatient days, and/or ED visits), although frequently noted as a key target for CMC, is not actually known.<sup>58,59</sup> In EDs, although some use may be potentially preventable, the overall contribution of ED use to overall health care use (and costs) for CMC is small.<sup>60</sup> Pediatric adaptations of condition lists that have been designated as ambulatory sensitive (ie, for which high-quality primary care may reduce the need for inpatient or emergency care) include chronic conditions, such as asthma,<sup>61,62</sup> but lack many conditions that are common to CMC, who are frequent users of hospital care (eg, children with neuromuscular conditions who use a gastrostomy tube).

##### *The Underemphasized Role of Nonhospital Components of Care*

The other challenge in a children’s hospital-based focus for children with complexity is that an underappreciated proportion of CMC health care use occurs in community-based settings, especially home health, outpatient pharmaceuticals, and mental

health.<sup>7,60</sup> Within the community, attention to social determinants of health, such as poverty, housing, education, and support networks, becomes particularly important. Improved equity and quality of home health care delivery has received relatively little policy attention, with virtually no focus on children.<sup>63</sup> There are some interesting policies being described (eg, families self-directing how to use home health funding),<sup>64,65</sup> but these have not been widely adopted. Another key driver of health care use is high-cost pharmaceuticals,<sup>66</sup> whose affordability for the many rare, complex pediatric conditions likely will continue to be a policy challenge, particularly in the emerging era of personalized medicine.<sup>67</sup> Mental health, as previously alluded to, remains an important issue in this population and also a major component of health care use<sup>60</sup>; any organization that leads care delivery for CMC needs to be attuned to the importance of improving access and integration with other sectors of care (eg, with primary care and school-based behavioral services) for these children.

### *Geographic Challenges*

Lastly, centering care within children's hospitals creates challenges in delivery for populations that reside far away in travel time or distance from specialized centers, such as those in rural areas. A more widespread uptake of telehealth can help provide outreach and reduce the need for travel. One promising model is the Project Extension for Community Healthcare Outcomes (ECHO) model, in which providers use telehealth interfaces to conduct virtual clinics and deliver educational curricula to community providers.<sup>68</sup> The American Academy of Pediatrics has partnered to pilot Project ECHO for pediatric epilepsy. The model has potential applicability for a multitude of complex conditions. One potential advantage of Project ECHO

is that it can potentially be used to improve community-based capacity over time by increasing the comfort level of primary care providers in delivering high-quality care for CMC in community-based settings when they are well supported by specialists and specialized centers.

### **Financial Risk: A (Perhaps Elusive) Focus on Cost Savings**

#### *Targeting Cost Savings Has (Some) Appeal*

Business models used to support the development of structured complex-care-management programs often rely on predictions of savings to payers and/or reductions in correlates of costly care (eg, acute-care use). Despite this, potential savings in pediatric complex care have garnered much less attention in policy circles than in adult complex care. Although the cost of care for CMC is much higher than for other children, there are fewer CMC than adults with complex conditions, and the overall costs of child health are small (~13% of US health care spending).<sup>69</sup>

#### *But Substantial Cost Savings May Not Be Realistic*

Although pediatric complex-care-management programs are relatively inexpensive to run compared with the overall cost of CMC care, a consistent financial return on investment may not be realistic. High-resource users in a given period of time may not be high-resource users in a subsequent year.<sup>70</sup> The probability of persistent use is smaller with longer time trajectories and higher thresholds for defining high use.<sup>71</sup> Therefore, poorly controlled studies that demonstrate improvements in health care use may be biased by the natural history of high resource use in child health (ie, regression to the mean). They may also selectively enroll the most medically fragile CMC (eg, those at the highest risk of prolonged hospital admissions)

to demonstrate financial return on investment. The generalizability of these findings to broader groups of CMC, whose use patterns may be less driven by inpatient use, may be poor. Given what is known about the impact on the health and well-being of those raising CMC,<sup>19,72–74</sup> efforts to incorporate costs from a family perspective, including the potential positive effects of improved child health and improved caregiver experience with the costs and health care use of the entire family unit, are underused yet critical.

### **Focusing on the Key Outcomes**

#### *Beyond Cost and Health Care Use: The Importance of Comprehensive Outcome Measures*

Although cost reductions are important in contemporary health policy, there are other important outcomes that have not been delineated for CMC. A clear enumeration of such outcomes is essential to guiding pathways of care, complex-care program development, and quality improvement, and also to furthering policy development. Improved health outcomes and improved patient experience, the noncost arms of the Institute for Healthcare Improvement's Triple Aim, may be the most achievable for CMC with health system improvement. For instance, for the many CMC with unmet needs,<sup>75</sup> improved coordination could potentially lead to facilitating access to durable medical equipment, transportation, home health care, and other key community-based supports that lead to improved child health and functioning without necessarily reducing costs. Family and caregiver health are other key outcome targets that are potentially amenable to improvement and are not consistently measured. Lastly, other important outcomes that are potentially sensitive to change in improved health care delivery for CMC exist entirely outside the health

care system. In the short-term, such outcomes include child school attendance, parental caregiver ability to work, and the family's financial well-being. Key long-term outcomes can include independence and societal integration as CMC enter adulthood.

### *An Opportunity for Child Health Services Research*

Measurement science and implementation is an area in which child health services researchers can play a leading role. Efforts to create, validate, and standardize the reporting of an appropriately broad set of measures, including those that are patient- and family-reported and are reflective of the health (and cost) impacts on the entire family unit, are starting to be developed (eg, Seattle's Center of Excellence on Quality of Care Measures for Children with Complex Needs). It is essential that these new measures continue to be developed, broadly applied, and prioritized to really determine the value of complex-care interventions.

## CONCLUSIONS

The shift in child health system discourse about the full spectrum of chronic disease from CSHCN to CMC is occurring rapidly, without much time to confront the implications for health system change. This begs a critical question for child-health advocates: will this change in focus lead to meaningful changes in outcomes for children with serious chronic diseases, or is the pediatric community simply adopting terminology that echoes that of adult-oriented health systems?

The focus on CMC has merits. To thrive, these children require policy and programmatic interventions that differ in many ways from those of broader groups of children with chronic conditions as well as adults with serious chronic diseases, including regionalized care models

that cross disciplines, organizations, and funders. However, advocates for CMC are faced with a key challenge to move pediatric complex care forward. Clinicians, researchers, educators, and other advocates for CMC need to develop and disseminate evidence-based solutions to the new challenges that this shift has created. This work needs to occur thoughtfully and include the differentiation of interventions targeting CMC from those aimed at broader groups of CSHCN. Definitional issues need to be reconciled to best tailor interventions effectively and efficiently. The incorporation of different components of care needs to be carefully considered and targeted accordingly even if care models are ultimately led by children's hospitals. Effective efforts to improve health care value for CMC in an increasingly value-based purchasing environment<sup>76</sup> cannot be aimed primarily at containing costs, which may not be consistently modifiable. Instead, they should be aimed at improving measurable health and health care outcomes for CMC in ways that most meaningfully impact their lives and those of their families. These goals are challenging to meet but are essential to ensuring that the growing focus on CMC leads to positive change.

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## ABBREVIATIONS

CMC: children with medical complexity  
CSHCN: children with special health care needs  
ECHO: Extension for Community Healthcare Outcomes  
ED: emergency department

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