

Families of Children With Medical Complexity: A View From the Front Lines

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abstract

This article, written by a group of experienced parents of children with medical complexity (CMC), provides an overview of the demands of managing care from their unique perspective. The article articulates why attention to understanding the challenges that families of CMC face with a fragmented health care system, inadequate health insurance coverage, deficits in the delivery of medical care, and problems accessing other critical services (as well as lack of support for children and adolescents in developing and exercising self-management skills) are vital to efforts to improve the current system and positively impact the life course of vulnerable populations. The authors discuss the financial and intangible costs experienced by families of CMC and other stakeholders (including providers, payers, and others), as well as the benefits that can result when effective, flexible, comanaged team-based care coordination is provided within the environment that is the most natural locus of care for the family. The authors detail the role of policy strategies that provide protections for CMC and the importance of family-led advocacy and support organizations in helping families “on the front lines.” Throughout the article, the case is made that families authentically involved at every level of health care systems are critical partners in designing policies and systems that will improve care for CMC. The experiences of families of CMC should inform and guide efforts to improve systems of care, thus positively impacting the life course of this vulnerable population.

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The needs of children with medical complexity (CMC) and their families have recently become a topic of heightened interest and discussion among health care providers, policy makers, payers, and families. Families raising CMC often experience complex systems that are uncoordinated, inconsistent, and difficult to navigate. This article from the family perspective includes discussion of (1) the definition of CMC, (2) the history of policies and programs that provide supports to children and youth with special health care needs (CYSHCN) and CMC, (3) costs and challenges related to accessing high-quality, affordable care, and (4) opportunities to improve supports and services for families caring for their children and helping them transition to adult health care.

CMC are a subset of CYSHCN, a population defined as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”¹

There are a variety of terms and definitions used to describe CMC; for the purposes of this article, we use the following: CMC are those who are “clinically recognized by at least 1 chronic condition resulting in high family-identified service need, medical equipment addressing functional difficulties, multiple subspecialist involvement, and elevated health service use.”² Examples of CMC include those with cystic fibrosis, serious congenital heart defects, or complex metabolic disorders.

Meeting the individual and collective needs of CMC (who, by using the above definition, are estimated to constitute 3.2% of CYSHCN and ~0.4% of all children in the United States^{2,3}) should be a shared priority of health care delivery systems,

payers, the health policy research community, and society as a whole.

The experience of CMC in their homes, schools, and communities is unique, and each family sees their child with medical complexity as an individual first and foremost, which is why the authors promote and use person-first language. Families want providers, payers, and policy makers to remember that each child should always be seen as an individual person first and foremost.

The numbers of CMC have grown, with therapies and treatments for many life-threatening diseases and congenital abnormalities that once were universally fatal contributing to a new generation of children whose survival is often both ahead of the scientific evidence to guide their treatment and beyond the capacity of current medical and community systems.² Although their numbers remain small, each community pediatric care system, school, house of worship, and extended family likely includes CMC. CMC require tailored systems of care and community supports, yet often experience fragmentation, inadequate insurance coverage, a lack of infrastructure for home- and community-based care, an inadequacy of home care training and support for families, a lack of self-care training for children, and a lack of attention to overall health status and the impact of the social determinants of health. These deficits point to shortcomings in our health system, but often hit the CMC population first and hardest, making them the equivalent of canaries in the coal mine of America’s evolving health care landscape. Investing in better ways to meet the needs of the CMC population will provide opportunities to “trickle-up” lessons learned from clinical delivery innovations, caregiver support, improved partnerships, and community integration that will

benefit the health of CMC populations across their life course.

This is not to say that the pediatric health care system should be redesigned exclusively on the basis of the clinical needs of CMC. Not every child requires in-depth care coordination for their health care needs or access to complex medical technology. But every child needs primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. This model of care, known as the medical home and promoted by the American Academy of Pediatrics, was originally designed to meet the needs of CYSHCN but is recognized as essential for all children. Addressing current deficiencies impacting CMC can result in a similar impact on the pediatric population as a whole. Designing, testing, and operationalizing systems that work for CMC have the power to transform our larger care systems, especially those concerned with long-term services and supports. This is the next critical breakthrough in pediatrics. We must move beyond bench and clinical science, which has given CMC a better chance at a longer life, and create the means by which quality and success are supported and maximized in the lives of CMC and their families.

CONTEXT OF POLICIES AND PROGRAMS

Current care for CMC has been shaped by law, policy, financing, and social realities. The legislative and policy underpinnings of fundamental changes in care for CMC include the following:

- 1965: Medicaid was enacted as Title XIX of the Social Security Act, providing states with the option of receiving federal funding for providing health care services to low-income children, the blind, and individuals with disabilities of all ages;

- 1975: The Education for All Handicapped Children Act (PL 94-142) guaranteed a free appropriate public education to each child with a disability, including CMC, and supported both children with disabilities who had been excluded entirely from the education system and those who had had limited or inappropriate access to public education;
- 1981: The Omnibus Budget Reconciliation Act of 1981 (PL 97-35): As an amendment to the Social Security Act, the Home and Community Based Services Medicaid waiver program allows states to fund a broad array of home and community services. This statute represented a first step toward recognizing that many CMC can be supported in their homes and communities at reduced cost to Medicaid, resulting in improved quality of life for children;
- 1989: The Omnibus Budget Reconciliation Act of 1989 (PL 101-239) amended Title V (Maternal and Child Health Services) of the Social Security Act to promote the provision of family-centered, community-based, coordinated care for CYSHCN;
- 1998: The definition of CYSHCN, published in *Pediatrics*, defines a broad pediatric health population on the basis of the impact of their special health needs and their needs for health and related services, rather than their diagnoses;
- 1999: *OLMSTEAD v L. C.* (98-536) 527 US 581: The Supreme Court rules that individuals who have disabilities have the right to live in their communities rather than in institutions, thus affirming a right to community-based services for CMC; and
- March 23, 2010: The Patient Protection and Affordable Care Act (ACA) (PL 111-148) expands access to insurance for CMC by

ending exclusions for preexisting conditions, ending annual and lifetime caps for coverage, and creating marketplaces to purchase plans at market rates, regardless of health status.

These changes have in large part been instigated, driven, and implemented by individual family leaders and organizations representing them, partnering with policymakers and other professionals. This history of family leadership must be recognized and embraced as we consider what comes next for CMC. The transformative power of family advocacy matters at both the micro and macro levels, as illustrated by the experience of 1 family in the Heartland, beginning nearly 2 decades ago:

In the long days following the birth of my son with complex medical needs, I found myself in the library at our children's hospital trying to understand this new world which we had been thrust into. And because we all benefit from those who have gone before, it was a bit more than luck that led me to the story of Katie Beckett of Iowa, whose family had spearheaded a profound change in the way Medicaid pays for home and community-based services and supports. I learned by reading about Katie and her parents that I would be able to take my son home, even if medical devices were required to do so. And I learned that if I ran into problems with the systems in place to support him I, too, could work to change the law to support his needs. Thank goodness for those lessons, because the reality of health policy 19 years ago when my son was born – and of health policy today – is that it does not meet the needs of families who are raising children who have medical complexity.

The past 35 years have seen the development of important family-run programs that help families of CYSHCN access appropriate services, including Parent Training and Information Centers that help families of CYSHCN negotiate the education system, Family-to-Family Health Information Centers that help families access and navigate health and community services, and Parent-to-Parent programs, which provide emotional support

through individualized matching of parents to other parents with similar experiences. Each of these parent-led programs are designed to use the expertise of experienced parents to offer peer support, information, and training in how to navigate systems and understand rights. Research has shown that connecting families of CYSHCN with other families who share similar experiences can have many benefits.⁴ Peer support provides emotional and social supports that lead to a decrease in the levels of stress, anxiety, and feelings of isolation. These supports also lead to increases in engagement and confidence, access to more community resources, and access to better health care.⁵ Family-run programs in every state are sustained through federal grants, which also attract other sources of funding, but more investment in these programs is needed to meet parent needs. A connected national network of family organizations providing this peer support and training to families is a critical element in improving health care for CMC.

COST

There have been significant changes in the past 6 years that have meant that the majority of children living with complex health care needs are now insurable, thanks to the patient protection provisions in the ACA. The ACA marked the moment when a childhood condition could no longer lead to denial of insurance coverage. It was a transformative moment for many families, opening a whole new range of coverage and care options. There are threats to eliminate these guarantees in health care reform discussion. Many of those now insured remain significantly underinsured. The new realities of health care financing, reimbursement, and the growing dynamic of population-based managed care will direct the future.

We must push the unique needs of CMC to the forefront in designing and implementing the next iterations of local, state, and national health care system changes. At each level, the individualized services and supports conducted by dedicated families, clinicians, and partners must be systematized, measured, and evaluated to ensure effectiveness for this growing, vulnerable population. At the same time, we must take the best components of care delivery and extend them to the broader population of CYSHCN, as well as to the care of all children.

Fragmentation of payment is a critical element in the escalating costs of care for CMC. CMC account for over one-third of all pediatric health care spending, with the bills paid by a combination of public and private insurers and families through deductibles, co-pays, and other cost sharing, as well as through uncovered services.⁶ Direct medical care generates spending related to hospitalizations, emergency department visits, home nursing care, outpatient specialty care provider visits, primary care and preventive care visits, over the counter and prescription medications, and durable medical equipment, among others.

Families are the primary providers of skilled and unskilled care for the majority of most children's lives outside the formal health care system. Families incur out-of-pocket costs including adapted clothing, modified tools for activities of daily living, utilities, and specialized food preparation. Although tied to a child's medical needs, such expenditures are generally not reimbursed by payers. Expenses related to home modifications, accessible transportation, and assistive technology are often primarily borne by families. The impact of these costs on families is not insignificant; a 2011 study through the National Institutes of

Health found that nearly half of families of CMC (46%) reported more than \$1000 in out-of-pocket health care expenses annually, whereas even more (49%) needed additional income for medical expenses. Moreover, a majority of the study's families reported members having to quit work because of a child's health care issues (54%) or reported that the family had suffered health care-related financial difficulties (57%).² Although changes implemented under the ACA have positively impacted many families of CMC since the National Institutes of Health study, the lived experience of families tells us that financial difficulties continue to present major challenges in meeting their children's needs. Treatment of complex health care situations can mean massive out-of-pocket expenses for a family, even for a family with the best of private insurance plans. State-specific eligibility limits and Medicaid waiver wait lists represent significant barriers to coverage and, by extension, to care. The state and federal partnership design of Medicaid can limit the ability of families to cross state lines to receive specialized health care or to respond to circumstances such as parental employment opportunities. The story of 1 family illustrates the financial impact stemming from the limits of our fragmented coverage systems:

Having a child with special health care needs was certainly not in my plan, but as a mother of 3 – 2 of whom have multiple diagnoses – I have had to adapt to many unexpected challenges. Of these challenges, financial strain on my family is the most stressful. I just didn't see it coming: my family went from being a dual-income family with minimal medical expenses to a single-income family with significant medical expenses. Deductibles, uncovered medications, frequent transport to specialists hundreds of miles away, annual therapy coverage limits, excluded medical supplies and equipment (orthopedic, feeding, wound care, etc), and other costs added up to tens of thousands of dollars. It remains a day-to-day struggle of seeking coverage for ongoing medical issues,

as my children's health care needs are continually changing.

C. Johnson

Often families must make hard choices and real sacrifices to ensure adequate care for their children, but for other families, the resources to pay for care are simply not available. Children and youth who are uninsured or whose insurance does not pay for critical components of care may experience adverse outcomes in relation to health, development, and capacity to function.⁷

There are also costs to providers and payers when CMC are at risk for hospitalization and readmissions as the result of conditions that, for other children, are routinely treated in ambulatory care settings.⁶ In these situations, unmeasured costs to children and families are significant and include costs such as those incurred by absences from school, missed work, and extra child care and transportation needed to juggle the care needs of children at home with those in the hospital. Too often, medical providers are unable to see the true costs of care in all its forms, because of the siloed nature of the health care delivery and financing systems. But many providers, like families of CMC, know there currently is not enough money to pay for what is needed without fundamental reform. Keeping all children and families at the heart of our health care financing policy decisions at all levels is the only way to have an American health care system that works for both the healthy and the most vulnerable.

CHALLENGES OF COMPLEX CARE

System fragmentation also impacts access to care. The specialists representing disciplines most needed by CMC are limited in number and primarily practice at children's hospitals that are not equally distributed geographically.⁸

Where a child lives greatly impacts access to care and state options to address access have important cost implications.⁹ Hospital and specialty services are not currently organized to integrate care across a child's team of providers, leaving families of CMC to traverse a complex referral pathway to access needed care. Fragmentation creates gaps and challenges for families, providers, and under-resourced care coordinators.

As a result of this fragmentation, the critical unmet need related to accessing clinical care is often coordination. CMC under the care of multiple specialty physicians may be supported with more than 1 home health care provider, have rehabilitative treatment plans created by multiple therapists, and be covered by payers who may operate at cross-purposes. For these children, it is real care coordination (coordination jointly designed with families to be authentically family-centered, assessment-driven, continuous, and team-based, which is designed to meet the bio-psychosocial needs of children, youth, and their families while enhancing caregiving skills and capabilities) that can ensure their legitimate access to the care they need.¹⁰ Care coordination is not a solution in and of itself to addressing enrollment in adequate health care coverage, reducing family stressors, and improving access to treatment and care, but such team-based comanagement of the complex needs of CMC is critical to achieving true family-centered care. The limits of time and the inefficient design of systems often mean that the complexities of fragmentation are only fully understood by families, who see across boundaries and silos. This experience is remarkably universal among families; the following story of 1 family rings true for many others.

The reality is that no one really understands the hoops we jump through, the time and energy required to follow up on her medical needs, and all we do to continue the best quality of life for our kids. In the last few weeks, we have:

- *been interviewed separately by the county and the provider company for assessment of home services;*
- *written a Behavior Plan for home services;*
- *applied for a grant to send my child to camp;*
- *oriented a substitute at school because her regular case manager is out;*
- *completed the 6-page form for state Health Care Programs Renewal packet to hire an additional home health provider;*
- *scheduled 4 follow-up appointments with specialists to conflict as little as possible with my child's school schedule and play practice; and*
- *all while she has been on the waiting list for 12 years for a Medicaid waiver.*

This is what it takes to assure our child is integrated, and functions well in our community!

R. Schlough

Although efforts to address the needs of CYSHCN via primary care medical homes are important and have made substantial differences in the lives of many children and families, the reality is that most CYSHCN (and, by extension, CMC) are not cared for under a medical home model. Care in a medical home setting is simply not available in most communities. For most CMC, the locus of care coordination resides with fragmented specialty and subspecialty providers. Coordination among specialty care and primary care is not systemized and reimbursed under current payment systems, and many primary care settings are inadequate to meet the clinical needs of CMC alone. Flexibility is key in meeting the needs of the heterogeneous CMC population. Care coordination for CMC needs to move with the child and family across service settings, agencies, and the life course, as well as across care neighborhoods, as primary goals and needs change. The key instrument in coordination is an

effective, team-based, shared plan of care, which includes a continuously updated portable medical summary that reflects the goals and needs of the child, the clinical team, and the family.¹¹ Effective care coordination only exists when the efforts are truly shared. The development and use of a shared plan of care must happen in partnership with the child and family and must be in a format that can be shared with all involved parties. In all its aspects, effective care coordination meets families where they are, recognizes the family as the most important constant in the child's care, and supports partnership in all aspects of that care. Increased funding opportunities for electronic health records that can provide shared plans of care for all CMC are needed.

OPPORTUNITIES FOR PARTNERSHIP IN THE COMMUNITY AND TRANSITION

Mandated shorter hospital stays, limits on home nursing support, and shortages of providers mean that many families are managing complex health care needs outside of the hospital and with minimal supports. Carrying out health care in the community is time-consuming, taxing, and often physically, mentally, and emotionally exhausting for families and adolescents with complex care needs. Families must be included as colleagues in their child's care and accepted as essential members and leaders of the health care team. However, we must work together (families, children, clinicians, and payers) to support and strengthen families and their children to enhance their unique capacities and expertise. We must redesign how families are prepared to provide care for their children at home, help children and youth learn self-care, and eliminate barriers that may make these tasks difficult. Families and children benefit from different learning and support modalities to build these skills:

in-person “see 1 do 1” sessions, visual and written instruction, on-call contacts for troubleshooting home care, improving communication and access to the child’s providers, and more. Life’s complexity may also require greater levels of support at some periods across the life course, so flexibility is vital. Small investments in individual support at the needed time can transform children’s and families’ capacity for self-management:

Beginning with my earliest memories, I’ve always known that my medical needs are complex, so I never thought of learning how to manage them as an insurmountable obstacle – it’s always been a part of my life, evolving as I’ve grown up into a teenager who is in charge of her health in most every way. My parents have always been committed to letting us live with as few restrictions as possible; my mom has learned to do everything we needed, from accessing my port to dropping ng tubes to managing oxygen and apnea monitors. Life-saving medical interventions have been performed at the county fair, school, and church, activities that wouldn’t be possible without the ability to self-manage our conditions; home nursing and health aides don’t allow for flexibility or independence, and gaps in coverage are unpredictable and limit access to the community. It’s not perfect – we self-manage our conditions because we don’t have a viable alternative. The system is disjointed, with providers that don’t fit together, leaving lots of legwork for which our family is responsible. Self-management can be a great aspect of independence and allow for community involvement, but it should not mean that patients and families are responsible for coordinating all care or doing it without supports.

Because my care team has helped to teach me these skills as I was able, I am independent and will be able to transition into adulthood with the supports I need. Soon I will be an adult with medical complexity, and the skills of self-management I’ve learned will allow me to meet my medical needs and reach my goals.

L. Rodgers

As with all children, the care of CMC must begin with the end goal in mind, building the skills, team, financing resources, and knowledge to

successfully transition to adulthood. It must start with an understanding of diagnosis and health status, and it must be continuous. Those who create adult care models have much to learn from CMC, and acknowledging that CMC will become adults with medical complexity is an important lesson for our entire health care system. Care challenges faced by CMC are often the same challenges faced by all populations with long-term service and support needs, and extending the lessons learned in pediatrics regarding patient- and family-centered practices can mean critical improvements to care across the life course.

CONCLUSIONS

The important family perspectives discussed in this article, along with the perspectives provided in the other articles of this supplement, provide a potential framework for future planning and identify areas to address in an agenda to improve a system of care for CMC. The use of family expertise is foundational to design, improve, implement, and evaluate systems. Successful integration of the family perspective at all levels can be achieved by building on lessons learned in demonstration projects and initiatives. True systemic integration may require meaningful institutional supports, such as federal mandates and payment incentives. Families have extensive experience in partnering with professionals to improve systems of care, are organized and connected across the country, and stand ready to assist at every level of next efforts for improvement.

ABBREVIATIONS

- ACA: The Patient Protection and Affordable Care Act
- CMC: children with medical complexity
- CYSHCN: children and youth with special health care needs

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