

## What Families of Children With Medical Complexity Say About Their Family Well-Being

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### INTRODUCTION

Family well-being (FWB) is a paramount outcome for all families and should be facilitated by clinicians, especially those caring for children with medical complexity (CMC). The US Department of Health and Human Services defines FWB as being “when all family members are safe, healthy, and have chances for educational advancement and economic mobility.”<sup>1</sup> Distinct from family quality of life (perceived satisfaction with family life) and family functioning, coping, or resilience (being equipped to manage stress), FWB has been recognized as a critical outcome for system improvement efforts.<sup>2,3</sup> MacGregor and Goldsmith proposed a broader view of FWB, describing it as a state of thriving across multiple dimensions: economic, physical, social, emotional, political, spiritual, and environmental.<sup>4</sup>

Families of CMC—who have chronic conditions that affect multiple body systems—spend much of each day providing medical care for their child, and due largely to system shortcomings, they experience greater hardships and unmet needs.<sup>5,6</sup> Emerging evidence suggests that families of CMC question the validity of existing FWB definitions and measures, identifying them as too narrow, biased toward viewing CMC as a “burden,” and not reflective of the range of family experiences.<sup>7,8</sup> We present a conceptual framework for improving FWB, based on crowdsourcing the perspectives of families with CMC (Supplemental Material). Determinants of FWB related to (1) their family’s internal system (including the child, caregivers, and siblings), (2) their family’s external system (including health care, education, employment, community organizations, and government/policy), and (3) the interface between systems. In each domain, we highlight a call to action to improve FWB.

### THE FAMILY’S INTERNAL SYSTEM

FWB for CMC is influenced by the inner workings of the family unit—the family’s “internal system”—in multiple ways. Families noted FWB is possible when their family is healthy, at home together “*under one roof*,” and there is minimal disruption due to illness, for example:



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*“we’ve found routine and balance with the everyday things our daughter needs. It’s the new and unexpected that throws us off and leaves us scrambling.”* Family caregivers described achieving FWB when they have emotional, mental, and physical reserves, sufficient rest, and *“adequate downtime.”* Families emphasized that siblings of CMC need support and attention and that FWB is possible when all family members can do the things that are meaningful to them. Families noted that having time to connect with one another and engage in so-called typical activities, while often elusive, were integral to FWB: *“attending to regular activities as a family—spending unstructured time together, reading, going to the park, connecting with friends/families.”*

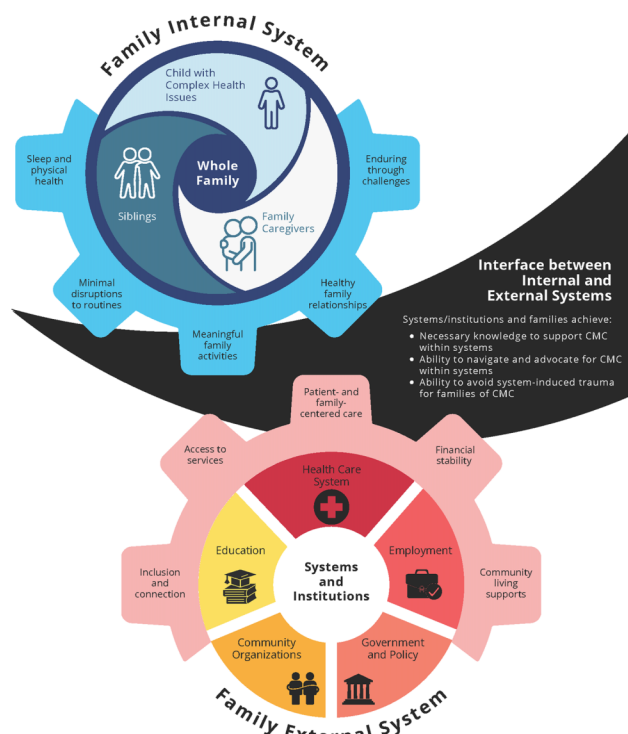
In the family’s internal system, sleep is described as vital to FWB for families of CMC, who are often awake throughout the night managing their child’s health-related needs.<sup>7</sup> The toll of sleep deprivation can increase burnout as well as interfere with decision-making and judgement. Families of CMC frequently have no alternative caregiving workforce and may experience sleep deprivation over years, in part due to home nursing shortages.<sup>5</sup> It is imperative that studies assess quality of sleep for family caregivers and initiate interventions to improve sleep—and by extension, the safety of care provided in the home—as an important condition for FWB.

## THE FAMILY’S EXTERNAL SYSTEM

FWB is also determined by institutions that provide necessary supports for CMC and their families—characterized here as the family’s external system. Families perceived their FWB as enabled when systems include and value their CMC; for example, when *“we belong,”* when the community asks, *“how to help or make it easier to participate in events,”* and is *“accepting and safe.”* FWB is possible when systems are sufficiently resourced and make services accessible. Healthcare-related examples include the following: *“supplies get shipped on time and we don’t run out of formula,”* and *“we aren’t fighting with insurance.”* Regarding education, families valued when their child has *“necessary supports”* to attend school, *“reliable and safe bus transportation,”* and *“a supportive school nurse who is not daunted by the health needs.”* Regarding employment, a family remarked that FWB occurs *“when I have a flexible job that allows me to attend doctor’s visits.”* Regarding government/policy, one family described receiving payment from her state for being a caregiver as *“life changing.”* When systems enable CMC to live safely in their community, families reported improved FWB.

FWB depends on the smooth functioning of families’ external systems. We believe this requires accountability on institutions to measure, report on, and optimize FWB. Stakeholders including teachers, hospital administrators, and community leaders should identify alongside families

## What Determines Family Well-Being for Families of Children with Medical Complexity (CMC)



**FIGURE 1.**

Conceptual framework for achieving family well-being for children with medical complexity. The framework consists of three themes of determinants of family well-being identified by families of children with medical complexity: 1) the family’s internal system (the family unit including the child with complex health issues, family caregivers, siblings), 2) the family’s external system (institutions including the health care system, education, employment, community organizations, government and policy), and 3) the interface between internal and external systems. Each theme encompasses subthemes: 1) All members of the family’s internal system experiencing sleep and physical health, minimal disruptions to routines, meaningful family activities, healthy relationships and ability to endure through challenges; 2) All institutions in the family’s external system supporting inclusion and connection, access to services, patient- and family-centeredness, financial stability, and community living; 3) Institutions and families together ensuring necessary knowledge to care for children with medical complexity, ability to navigate and advocate within systems, and avoidance of trauma. Each subtheme encompasses individual determinants of family well-being (Supplementary Material). An interactive version of the conceptual framework can be found at [<https://sprnetwork.org/family-well-being-for-families-of-children-with-complex-health-issues/>].

Abbreviation: CMC, children with medical complexity.

context-specific practices that facilitate or detract from FWB and advocate for needed systems improvements. Families of CMC are beholden to the performance of system sectors that are interdependent—for example, policies that increase access to respite services enables employment and financial stability, which is necessary for FWB. We strongly

believe that FWB should be a key outcome for assessing and improving system functioning.

### THE INTERFACE BETWEEN A FAMILY'S INTERNAL AND EXTERNAL SYSTEMS

Achieving FWB requires mutual understanding and commitment between families and systems of care about meeting the unique needs of CMC and their families. Families reported FWB when *"We have an understanding of the health issues and needs and a plan and providers who partner continuously to support our family."* FWB is enabled when families advocate effectively within systems and experience responsiveness to their needs. For example, *"All systems and supports are transparent, and we are able to navigate them without excessive confusion or obstruction... My child's needs are met without my family needing to constantly and excessively justify each and every need."* Families described the trauma associated with navigating complex systems and encountering shortcomings and note that FWB is only possible when this trauma is addressed.

Given that the interface between families and systems is important to FWB, it should be the standard practice of clinicians—and personnel in other systems—to discuss FWB and help families to achieve it. To our knowledge, measurement of FWB has not been a central goal in the patient- and family-centered medical home. This is concerning because the caregiving required to implement care plans generated by the medical home influences several aspects of FWB, including employment, relationships, and health. Families and clinicians could explore determinants of FWB to personalize decision-making tools, a practice that could be reinforced via quality improvement methods. Trauma-informed care approaches should also be considered a means to support FWB.

### CONCLUSIONS AND RECOMMENDATIONS

This proposed framework encompasses diverse concepts that collectively portray actionable determinants of FWB drawn from lived experience (Figure 1). Although FWB, and the factors influencing it, may vary across families, we suspect that all determinants resonate with families to some degree, including those raising children with special health care needs as well as typically healthy children. We advocate for a broad conceptualization of FWB to capture what is meaningful to families—from having uninterrupted sleep to being able to partner fully across systems.

Eliciting the insights of families of CMC about FWB and honoring them by enacting clinical care, education, and policy change represents a needed cultural shift in current systems. First, collaborative efforts should be taken by families of CMC and systems to acknowledge the range of factors that affect FWB and to use this expansive understanding to advocate for necessary resources, programs, and policy reform. Second, measurement of FWB for CMC should be further investigated, including whether any existing measures validly assess determinants of FWB. Third, pediatric training should foster competency in assessment and optimization of FWB as an essential clinical activity. Fourth, administrators and policymakers should consider FWB as a key performance indicator of systems relied on by CMC and their families. Collectively, these actions will help position FWB as a paramount outcome that families deserve.

### ABBREVIATIONS

CMC: children with medical complexity  
FWB: family well-being

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### REFERENCES

1. U.S. Department of Health & Human Services. Family support and well-being. Updated April 18, 2024. Accessed February 20, 2025. <https://eclkc.ohs.acf.hhs.gov/family-support-well-being>
2. McLellan SE, Mann MY, Scott JA, Brown TW. A blueprint for change: guiding principles for a system of services for children and youth with special health care needs and their families. *Pediatrics*. 2022; 149(suppl 7):e2021056150C. PubMed doi: 10.1542/peds.2021-056150c
3. Coleman CL, Morrison M, Perkins SK, Brosco JP, Schor EL. Quality of life and well-being for children and youth with special health care needs and their families: a vision for the future. *Pediatrics*. 2022;149(suppl 7):e2021056150G. PubMed doi: 10.1542/peds.2021-056150g
4. McGregor SLT, Goldsmith E. Extending our understanding of quality of living, standard of living, and well-being. *J Fam Consum Sci*. 1998;90(2):2–6, 22.
5. Allshouse C, Comeau M, Rodgers R, Wells N. Families of children with medical complexity: a view from the front lines. *Pediatrics*. 2018;141(suppl 3):S195–S201. PubMed doi: 10.1542/peds.2017-1284d

6. Randolph G, Coleman C, Allshouse C, Plant B, Kuo DZ. Measuring what matters to children with medical complexity and their families. *Pediatrics*. 2024;153(suppl 1):e2023063424C. PubMed doi: 10.1542/peds.2023-063424c
7. Houlihan BV, Coleman C, Kuo DZ, Plant B, Comeau M. What families of children with medical complexity say they need: humanism in care delivery change. *Pediatrics*. 2024;153(suppl 1):e2023063424F. PubMed doi: 10.1542/peds.2023-063424f
8. Comeau M. *Family Burden and Medical Complexity: Wrestling with the Meaning and Impact of Commonly Used Terms*. Lucile Packard Foundation for Children's Health; 2019.