

# The Moral Imperative of Home Health Care for Children: Beyond the Financial Case

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Children with medical complexity (CMC) are defined as those children with medical fragility, technology dependence, functional impairment, and intensive care needs that are not easily met by existing care models.<sup>1</sup> Common underlying syndromes include congenital or acquired neurologic diseases with manifestations over several organ systems, often resulting in the need for life support devices, such as tracheostomies, home ventilation, enteral feeding tubes, or home intravenous therapies. The services that allow for these children to be cared for at home have been the standard of care since the creation of the "Katie Beckett" waiver in 1986.<sup>2</sup>

CMC typically acquire the need for home care services during acute hospitalization, and arranging home care services is a vital part of discharge planning. In their article "Home Health Care Availability and Discharge Delays in Children With Medical Complexity," Maynard et al<sup>3</sup> report the extent to which discharges of CMC were delayed primarily because of the unavailability of home care nursing (HCN). Among 185 CMC discharged from 4 children's hospitals in Minnesota, discharge was delayed 1582 days, the majority of which (>90%) were attributable to the unavailability of HCN, at an additional cost estimated at \$5.72 million. Discharge delays were likely to be longer for patients <2 years of age, those newly prescribed home health care, and patients with tracheostomies.

What are the reasons for the unavailability of HCN, which caused these 185 patients to spend an additional 4.3 years admitted to the hospital? This has not been well studied, but a number of factors likely contribute to a shortage of personnel, all of which lead to home care services being an undervalued and thus underused medical service. As described by Maynard et al,<sup>3</sup> there is a shortage of qualified nurses with appropriate pediatric experience. The typical salary of a home care nurse is significantly lower than that of a nurse working in the inpatient setting. Home care workers have described the job as socially isolating and physically and emotionally difficult. Turnover is high. In addition, home care workers do not work while a patient is hospitalized, which is a frequent occurrence for CMC, which leads to uncertainty and potential disruption of income.

As the technology and experience to support CMC long-term have improved, a great need has emerged for systems to care for them, and the vast majority of parents prefer to do this in a home setting. The American Academy of Pediatrics considers in-home, community placement to be the most desirable option, although there are circumstances in which out-of-home placement is more appropriate.<sup>4</sup> For in-home care to succeed, families need myriad services to sustain the children and allow the families to thrive. Home care services provided by nurses and other caregivers are vital. The hours covered by HCN can allow family

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caregivers to maintain employment outside the home as well as maintain the physical and emotional health of the family unit, which is often strained by the need to care for CMC at home.<sup>5</sup> Although parents of CMC will always perform nursing duties, their primary role in the life of their children should be as parents first.

The magnitude of the delayed discharges described by Maynard et al<sup>3</sup> is unacceptable. Children and families thrive in home environments with access to community resources and activities. Hospitals have attempted to improve the developmental milieu for inpatients,<sup>6</sup> but this does not mitigate the need to get children home as soon as is medically safe. Continued admission to the hospital increases the likelihood of a nosocomial infection or a medical error, which is a particular problem for these vulnerable children.<sup>7</sup>

Many private insurance policies specifically exclude HCN services, but they are federally mandated for Medicaid enrollees <21 years of age under the Early and Periodic Screening Diagnosis and Treatment benefit. Despite this, it is often difficult to get these services

approved, particularly with the quantity of hours needed to sustain a patient receiving home ventilation: 16 hours per day.

However, it is not enough for Medicaid or an insurance company to approve hours. If a service is medically necessary, the insurance company must ensure network adequacy and availability of the service. If salaries for home care nurses are inadequate to attract enough skilled personnel, they must be increased. If working conditions for nurses are unpleasant or unsafe, they must be improved. Medicaid managed care organizations and other insurers should work with home care agencies to augment and improve the home care workforce. This will keep children out of the hospital and in their homes with their families where they belong. This is better, safer, and cheaper. As usual, doing the right thing for children also makes good financial sense.

#### ABBREVIATIONS

CMC: children with medical complexity  
HCN: home care nursing

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