

Language Matters: Identifying Medically Complex Children in Foster Care

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An estimated 428 000 children are in foster care in the United States¹; half of those children experience chronic medical problems and unmet health care needs.² These ~200 000 children span a spectrum from low to high health care needs and utilization,² with the most complex having frequent hospitalizations and significant home care burdens.³ These children with medical complexity have multisystem, long-term diseases, and/or functional limitations that result in high care needs, high health care utilization, and often rely on medical technology.⁴ Although the majority of children enter foster care because of neglect or abuse, sometimes a child with medical complexity will enter foster care because his or her daily care needs outstrip their families' resources or capabilities.¹ They are often placed in medical foster care with foster parents who receive medical training, reimbursement at higher rates than typical foster parents, and special services (eg, respite, support groups) to match the needs of the medically complex foster child.

Children with medical complexity account for one-third of all pediatric health care spending and expectedly have some of the most expensive care needs among children in foster care.^{5,6} Medical foster care is typically the most expensive foster placement in terms of daily rates provided to foster parents, although payment incentives have not increased the number of medical foster parents to meet the current demand.⁷ Not much is known about the outcomes of children in medical foster care or about the value of the federal and state resources dedicated to this population. Most available data about medical foster care is from the child welfare system and focuses on placement status: whether children remain in foster care or exit via adoption or placement with a family member. Broader outcomes data related to the health, well-being, and associated expenses for this population are lacking because of a significant barrier: the absence of a common language to classify children in medical foster care.

Here we highlight the implications for children, the health care system, and the child welfare system of the lack of a universal language for designating children with medical complexity in medical foster care.

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CURRENT VARIABILITY IN MEDICAL FOSTER CARE DESIGNATION

The well-being of children with medical complexity in medical foster care is supervised by 2 separate but overlapping entities: the health care system and the child welfare system. Both oversee foster children well-being with the health care system emphasizing health-related outcomes and the child welfare system emphasizing safety and placement permanency. Both have distinct and insufficient approaches to naming and classifying foster children with significant medical needs, which undermines the foundation for tracking and thereby optimizing health outcomes for this population.

In 1998, the Maternal and Child Health Bureau defined children with special health care needs (CSHCN) as those children who have “chronic physical, developmental, behavioral, or emotional conditions” and who require an excess of health-related services.⁸ In 2015, the American Academy of Pediatrics declared all children in foster care as CSHCN because of their high rates of medical and mental health needs and their poor health care access.⁹ The clear benefit of including all foster children in the CSHCN category is that it brings attention to the excess health issues faced by this population. Yet by grouping all children with any type of health needs, it confounds outcomes data collection for those with medical complexity.

The child welfare system commonly utilizes a related term: “children with special needs.” In 1980, the Adoption Assistance and Child Welfare Act established federally sponsored state subsidies to families who adopt children with special needs. The act defines children with special needs as those who (1) the state determines cannot return home, (2) have had difficulty being placed successfully with adoptive parents, and (3) have a special condition (eg, medical, emotional, or behavioral issues;

ethnicity; older age; sibling in foster care) that complicates permanent placement.¹⁰ Again, although this broad term includes children in foster care with medical complexity, it groups them with children without medical needs. Medical complexity becomes merged with any child-related factor that makes them less likely to successfully exit foster care.

The designation of medical foster care also varies significantly by state and county. Each state determines their own foster care classification system and rates, eligibility for medical foster placement, and the extent of training that qualifies medical foster care providers to meet the daily care needs of individual children.⁷ Across the United States, variable terms designate medical foster care placements, including “intensive,” “exceptional,” “specialized,” “special needs,” “handicapped,” “therapeutic,” “medically complex,” and “medically fragile.”⁷ Some states do not distinguish children with medical needs but group them with children with mental or behavioral health needs into “therapeutic foster care.” A few states rank every child in foster care (including nonmedical) based on a point system,⁷ although children with medical needs (eg, feeding tube), social needs (eg, autism), and behavioral needs (eg, fire setting) could all be assigned equal points. Other states use a tiered system to connote severity of child’s illness.⁷ In Table 1, we present 3 test cases of children with increasing medical complexity that reveal variable medical complexity designation strategies, placement, and reimbursement within 3 state foster care systems. Of these, the state of Michigan, using the “medically fragile” designation, has a tiered system demarcating 4 levels of medical complexity and health care needs and is an example of a more nuanced approach for assessing the needs of and placement for children

with medical complexity. Yet even a tiered approach may not account for an individual child’s daily care needs because states often do not use independently developed and tested assessment tools. All of these factors contribute to inconsistent designations of children with medical complexity in foster care.

COMMON LANGUAGE TO IMPROVE OUTCOMES

When children with medical complexity in foster care cannot be identified by virtue of widely differing assignments, they and their health outcomes become invisible. Neither the child welfare nor the health care systems are consistently tracking how much health care these children need, how much they receive, how well they do, or how much it costs. Although multiple strategies will be required to track, assess, and optimize outcomes for this population, consistent language to designate these children is a fundamental component.

Nationally, the Department of Health and Human Services is the umbrella department for both Social Services (ie, child welfare and foster care services) and Health Insurance (eg, Medicaid and the Children’s Health Insurance Program).¹¹ This existing relationship within the Department of Health and Human Services could lay the groundwork for unified national guidelines to designate children in medical foster care and track related health outcomes and expenditures. At the state and local levels, dedicated information technology and personnel would coordinate joint collection of relevant data by social service and health insurance departments. Because almost all children in foster care are eligible for Medicaid and are assigned a foster care code when they enter Medicaid, their associated *International Classification of Diseases* codes could form the basis for

TABLE 1 Placement and Daily Care Rates of 3 Cases of Increasing Medical Complexity into 3 States' Foster Care Systems

Case	Florida ^a	Michigan ^b	Minnesota ^c
9-y-old boy with well-controlled type 1 diabetes who requires daily blood glucose monitoring and insulin injections	Medical foster care	Medically fragile: level 1	Level A
	Daily care rate: \$16.57 Additional daily Medicaid reimbursement rate: \$67.90 (Level III)	Daily Care rate: \$25.54	Daily care rate: \$28.76
9-y-old boy with severe Crohn disease resulting in colectomy with ileostomy. Treatment includes infliximab infusions and supplemental nutrition via gastrostomy tube	Medical foster care	Medically fragile: level 2	Level D
	Daily care rate: \$16.57 Additional daily Medicaid reimbursement rate: \$38.80 (Level I)	Daily care rate: \$30.24	Daily care rate: \$51.86
9-y-old boy with history of extreme prematurity, chronic lung disease, spastic quadriplegia, uncontrolled seizures, and severe cognitive and developmental delays. Requires wheelchair, tracheostomy with mechanical ventilation, gastrostomy tube, and multiple daily medications and respiratory treatments	Medical foster care	Medically fragile: level 4	Level E
	Daily care rate: \$16.57 Additional daily Medicaid reimbursement rate: \$67.90 (Level III)	Daily care rate: \$80.00	Daily care rate: \$59.56

Daily care rates are those reimbursed to foster parents for caring for a particular child in foster care. All daily care rates are estimated and based on max daily care rate reimbursed by foster care agency.⁷

^a In Florida, all children in foster care are placed into basic foster care, unless the child qualifies for medical foster care. The use of medical foster care is determined by a multidisciplinary assessment team and uses the State Plan and Medicaid Handbook to determine levels of Medicaid reimbursement based on care needs of child. Certified medical foster homes under the Department of Health are eligible to claim additional reimbursements from Medicaid: Level I (\$38.80/d); Level II (\$48.50/d); Level III (\$67.90/d). Medical foster care placement is determined by the Department of Health/Children's Medical Services in conjunction with the Department of Children and Families.⁷

^b In Michigan, all children in foster care are designated as basic, with the possibility of supplements for difficulty of care, or as medically fragile. This medically fragile designation is reserved for a child with "...a documented medical condition that threatens health, life, or independent functioning."⁷ Appropriate rate reimbursement (Levels 1–4) is determined by the child welfare agency using the Assessment for Determination of Care for Medically Fragile Children in Foster Care.⁷

^c In Minnesota, each child that enters foster care is assigned points by using the Minnesota Department of Human Services Difficulty of Care Assessment. Points range from 0 to 225. On the basis of number of points earned, each child qualifies for level of reimbursement from Level A (0–35 points) to Level F (176–225) points. Level G is reserved for children who require 24-h care in a residential treatment facility.⁷

determining medical complexity.^{12,13} For example, specific *International Classification of Diseases* codes, or constellations of codes, could trigger the designation of complex chronic conditions.¹⁴ In addition, universal use of the same validated care needs assessment tool would distinguish level of medical complexity by virtue of daily care needs. This systematic approach would streamline language to identify and support these children, as much as the Individuals with Disabilities Education Act provided a unified, national framework for identifying children with disabilities so as to connect them with appropriate special education services at the local level and allow for state and national tracking of outcomes.¹⁵

Improving the well-being of children with medical complexity in foster care requires intentional collaborations between the health care and child welfare systems to direct resources to those children who need them most. Such collaborations are encouraged by the 2016 federal report of the Commission to Eliminate Abuse and Neglect Fatalities, which recommended increased data sharing and linkage across agencies.¹⁶ To maximize meaningful assessment of health care utilization and outcomes for medically complex children in foster care, categorization of children with highly variable health needs must be consistent and relevant. By developing standardized national guidelines for designating children with medical complexity within foster care, we can begin to track health outcomes and identify ways to optimize placement for these children and appropriately allocate resources and federal and state funds to provide cost-effective quality care.

ABBREVIATION

CSHCN: children with special health care needs

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