



State Roles in Preventing and Improving Foster Care Placements for Children with Medical Complexity

By Catherine Hess

Children with medical complexity (CMC) generally require intensive family support and high-cost health care services – needs that may lead to out-of-home placement when they are not available or affordable. The Family First Prevention Services Act of 2018 offers resources to transform state foster care systems to emphasize prevention – and when necessary placement in a foster care home rather than an institution.¹ CMC could benefit if states applied its goals to improve foster care prevention and placement options for CMC. Medicaid and Title V services also can help keep CMC at home. This report explores how states can leverage federal and state policy tools to improve options for CMC in or at risk of foster care placement.

Background

Children with medical complexity have substantial needs for health care, which can have major impacts on their families' well-being.² Making up fewer than 1 percent of all US children,³ CMC are a subset of children and youth with special health care needs. CMC are generally defined as children who are medically fragile and have substantial functional limitations, as well as increased needs for and costs of health care services.⁴

Roughly two-thirds of CMC are enrolled in Medicaid,⁵ and according to one recent study, they account for over one-third of Medicaid costs for children's health care. Yet, services that CMC or their families need may not be covered or not covered adequately by private or public insurance.⁶ Families must devote considerable time and energy to caring for their CMC and coordinating the many services the children need. These demands can take a toll on families' finances, health, and well-being. For some families, the demands of caring for their CMC may be beyond their resources or capabilities, especially when community-based supports are inadequate, resulting in some CMC entering the foster care system.⁷ While the numbers of CMC that are placed in foster care is unknown, given their needs and the strain on their families, they appear to be a population at significant risk for out-of-home placements.

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State child welfare, Medicaid, and Title V Maternal and Child Health/Children and Youth with Special Health Care Needs (MCH/CYSHCN) officials have opportunities to collaborate to transform options for preventing out of home placement of CMC or for providing family-centered options when placement outside the home cannot be avoided. Title V CYSHCN

programs have expertise in the needs of CMC and working with their families, and Medicaid programs have a number of state options to help families care for children at home.

In the child welfare domain, consistent with the 1999 Supreme Court's Olmsted decision⁸ and subsequent deinstitutionalization movements, the Family First Prevention Services Act of 2018 provides impetus, requirements, and resources to transform state foster care systems to emphasize prevention and when necessary, placement in a foster care home rather than an institution.⁹ While not addressed explicitly in the law, CMC could benefit if its goals are applied to improve prevention and placement options for this unique population of children.

Overview of CMC in the Foster Care System

CMC in the foster care system have not received extensive research or policy attention, despite the intensity of their needs and their high health care and support costs for families and child welfare and health care systems. Data on CMC in the foster care system is quite limited. Nationally, an estimated 20,000 to 40,000, or about 5 to 10 percent, of all children in foster care have medical complexities.¹⁰ The national Adoption and Foster Care Analysis and Reporting System (AFCARS) requires state child welfare agencies to submit data on special needs status, but states vary on how they define this term – some states include such factors as race and age, and not just disability or medical condition.¹¹ The limited information about CMC and foster care includes a lack of data documenting the reasons and circumstances under which they are placed in foster care. Some CMC are placed in the system because their medical needs have outstripped their families' capabilities, resources, and the supports available to them. Some CMC are placed primarily for reasons of abuse or neglect, and some may result from a combination of these reasons.¹²

While the provision of comprehensive community-based systems, services, and supports could arguably better enable families to provide an appropriate level of care for their children, thereby allowing the children to remain in the home, these services are typically limited or may not be available preventively. CMC and foster care expert Rebecca Seltzer, assistant professor of pediatrics at Johns Hopkins School of Medicine, noted, "If the added layer of supports provided to [medical foster care] parents were offered to biological parents struggling to care for their child's medical needs, then perhaps placement into foster care could be avoided for some of these children. While state policies vary in regard to voluntary placement agreements, such provision of upfront resources and supports may be particularly relevant to assist families that feel the only way to adequately care for their child is to give them up voluntarily."¹³ In the context of very strained budgets in 2020 due to the effects of COVID-19, state resources to improve these services are expected to be even harder to come by.

Most foster care placements are court-ordered. Overall, only about 3 percent of all foster care children are placed through voluntary agreements between child welfare agencies and parents. Voluntary placements are more likely than court-ordered placements to be among children with disabilities, with the majority of placements related to disabilities for behavioral health

issues. Voluntary placements also are more likely than court-ordered placements to be in group homes or institutions rather than in foster homes.¹⁴

Challenges in providing quality foster care homes can be multiplied for CMC, and there is limited information on children's outcomes. Fragmentation of care and financing, and lack of coordination across multiple agencies and providers are issues.¹⁵ Recruiting, training and supporting foster parents to meet the specialized care needs of CMC add to the general challenges of engaging foster families.¹⁶ Medical decision making can be more complex given the number of those involved – multiple public agencies, health care providers along with biological and foster parents – as well as regulations that may restrict information sharing. Compounding placement issues, transitioning CMC back to their biological homes or to an adoptive family is more of a challenge than for children without medical complexity.¹⁷ An analysis of 2014 AFCARs data found poorer placement outcomes for children with disabilities, with the number of disabilities increasing the odds of poor outcomes in areas such as length of stay, placement stability, and permanency.¹⁸

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State Approaches to Preventing and Providing Foster Care Placements for CMC

Many states and state-based organizations have developed tailored approaches to preventing or improving placements for CMC in foster care. Care coordination, case management, respite care, and home health services are among the prevention services provided by the health sector, which may be funded by Medicaid, Title V Children and Youth with Special Health Care Needs (CYSHCN), or exclusively state funded programs. When CMC are placed in foster care, placements tailored to their needs generally fall within the rubrics of therapeutic or treatment foster care (TFC), and more specifically medical foster care (MFC), although there are no standard definitions of these terms across states or at the federal level.

CMC researchers have noted that specialized foster homes serving CMC may encompass “variable terms [to] designate medical foster care placements, including ‘intensive,’ ‘exceptional,’ ‘specialized,’ ‘special needs,’ ‘handicapped,’ ‘therapeutic,’ ‘medically complex,’ and ‘medically fragile.’ Some states do not distinguish children with medical needs but group them with children with mental or behavioral health needs into ‘therapeutic foster care.’ ...When CMC in foster care cannot be identified by virtue of widely differing assignments, they and their health outcomes become invisible.”¹⁹ While the services rendered in these foster care settings may be similar, the absence of a standard definition or specific designation for those specifically serving CMC further compounds the challenges for understanding, surveilling, and adequately caring for CMC.

With federal Title IVE foster care funding support, states have the flexibility to determine their own classification systems for foster care categories. Given this flexibility, placements supporting the needs of CMC have different names, requirements, and program structures. There is no national compilation of these programs. Some states adopt distinct programs whereas other states incorporate a tiered framework, with each tier corresponding to a higher acuity and thus greater need and level of care. Other states group all children with high needs, including those with medical complexity, behavioral health, or severe trauma, into one classification. TFC and MFC are two common classifications. While many TFC programs are designed to serve children with severe mental, behavioral, or emotional needs, some also provide care for children with distinct or concurrent complex health conditions.

Funding for foster care generally and TFC or MFC more specifically is fairly complex and varies state by state. Foster care is administered at the state level by child welfare agencies which administer Title IVE federal foster care funds as well as state appropriated funds. Federal Title IVE financing is available for children who are in the custody of these agencies, and generally has paid for care and supervision. Treatment costs for children in the custody of child welfare agencies are generally paid by Medicaid, as these children automatically qualify. Other children not in state custody who receive services from child welfare agencies also may qualify for Medicaid on the basis of their income levels or their disability status. Although Medicaid's Early, Periodic, Screening, Diagnostic and Treatment program provides some consistency in benefits for children, there is some variation across states, in part due to varying definitions of medical necessity.²⁰ Other funding sources include other state agency funds, such as for behavioral health. That resources are often not sufficient is highlighted by a recent state level lawsuit seeking to improve public support for in-home services for CMC.²¹

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Given the variations in terminology for CMC and for their foster care placements, understanding how states across the country are approaching services for this small but growing population is challenging without more in depth research. Florida is featured here as an example of a coordinated interagency approach to CMC placement in foster family homes.

State Medical Foster Care Programs: Florida's Interagency Approach

Florida has a Medical Foster Care (MFC) program coordinated by the state's Medicaid agency (Agency for Health Care Administration – AHCA), the Department of Health Office of Children's Medical Services Managed Care Plan and Specialty Programs (DOH-CMS), which includes its Title V Children and Youth with Special Health Care Needs program, the Child Welfare (Department of Children and Families-DCF) state agency, and the local non-profit community-based care (CBC) programs with which DCF contracts. The CBC lead agencies work to manage and deliver child welfare services in Florida.

To be eligible for Florida's MFC program, children must be younger than age 21, in the foster care system, and have complex medical needs. Medical necessity for program eligibility and medical stability – capable of receiving care in a home setting – is determined by a Children's Multidisciplinary Assessment Team (CMAT) facilitated by DOH-CMS. The CMAT is comprised of a medical director, registered nurse, a social worker, and representatives from the DOH-CMS Early Steps program (for children under age 3), the Agency for Persons with Disabilities (APD), the child's Managed Medical Assistance (MMA) plan, as well as the child's CBC and legal guardian.

Children in Florida's MFC program may have conditions such as:

- Complications of prematurity (respiratory problems, feeding problems, apnea);
- Chronic problems, such as asthma or diabetes, that require stabilization, monitoring or medication maintenance;
- G-tubes with little or no nutrition by mouth;
- Potential life-threatening illnesses such as HIV/AIDS, cancer, cystic fibrosis, or sickle cell anemia;
- Medical problems resulting from abuse or neglect (burns, fractures, shaken baby syndrome); and,
- Newborn drug exposure and requirements for medication or treatment.²²

In 2018, Medicaid services for the 300 children in Florida's Medical Foster Care Program were transitioned from fee-for-service to statewide Medicaid managed care, with the health plans taking on some roles previously carried out by DOH-CMS. Health plans now are responsible for the children's plans of care, care coordination, and medical services. The DOH-CMS MFC team provides oversight of the medical foster parents to ensure quality and safety, child-specific training, meeting annual education requirements, home and community visits as well as reviews of care and documentation. DOH-CMS notes that the transition to Medicaid managed care required significant attention to determining the roles of DOH-CMS and the MMA plans, and a solid change management plan. State and local agency partners now have regular calls for ongoing communication and coordination.²³

MFC foster parents must meet a number of conditions to be eligible for enrollment in the program. They must be licensed by DCF, complete competency-based training through DOH-CMS, enroll as Medicaid providers, and be credentialed through the MMA plans. These foster parents receive rates through DCF for board and care of the children, and daily rates from MMA plans for medical services provided. The rates vary by the level of care (1-3) that the children require, as determined by the CMAT.

What Services Do Florida Medical Foster Care Parents Provide?

- Implement the child's individualized plan of care, including administration of medications and interventions, and attendance at all medical, developmental and therapeutic appointments.

- Provide a home environment.
- Monitor or complete usual activities of daily living including:
 - Personal hygiene: Assist the child with bathing, grooming, oral, nail and hair care;
 - Contenance management: Assist a child who may not be mentally and physically able to properly use the bathroom;
 - Dressing: Assist the child in selecting and putting on clothes;
 - Feeding: Assist with self-feeding or other feeding needs as ordered; and
 - Ambulating: Assist a child’s ability to change from one position to the other and to walk independently.
- Provide transportation and shopping.
- Plan and prepare meals.
- Manage medications: Keep medications up to date and assure taking meds on time and in the right dosages.
- Advocacy: Make dependency court appearances as necessary to address the status of the child.²⁴

State Programs that Support Families in Keeping CMC at Home

While the research for this brief did not identify state-level policies or programs explicitly designed to prevent out-of-home foster care placement for CMC, there are state policies and programs in place designed to provide or finance services that support families to keep their CYSHCN at home. Such services, especially where they reach families of CMC, presumably would help prevent the need for out-of-home placement for many of these children.

Medicaid finances many of the services that help support families of CYSHCN to keep their children at home.

Through a number of state options or waivers, Medicaid finances many of the services that help support families of CYSHCN in keeping their children at home. All but one state (Tennessee) have adopted the “Katie Beckett” Medicaid waiver or state plan option to cover care at home for children who would otherwise need an institutional level of care.²⁵ Eligibility is based solely on the child’s – not the family’s – income. Comparable coverage also is being provided by five states through the Family Opportunity Act state plan option, which requires Supplemental Security Income eligibility, but not institutional-level of care requirements.²⁶ Eighteen states have Medicaid Home- and Community-Based Waivers that target children who are medically fragile or technology dependent and cover medical and other services, such as respite care. These programs serve state-determined numbers of people in need, and often have waiting lists.²⁷ Fourteen states provide long-term services and supports to qualifying CYSHCN through their Medicaid managed care programs.²⁸

A new State Plan option for Health Homes designed specifically for medically complex children was added by the Medicaid Services Investment and Accountability Act of 2019 (MSIA).

The Affordable Care Act included a state option for Medicaid Health Homes benefits for individuals with chronic conditions, including mental illness, although many states have targeted this benefit to conditions primarily affecting adults.²⁹ A new state plan option for health homes designed specifically for medically complex children was added by the Medicaid Services Investment and Accountability Act of 2019 (MSIA), but is not effective until Oct. 1, 2022.³⁰

In addition to providing expertise regarding CMC, state Title V MCH and CYSHCN programs offer resources and services to support family-centered care, care coordination, and address social determinants of health (SDOH). Social determinants, such as housing, food and social needs, may be factors affecting whether CMC may need an out-of-home placement.

Georgia’s Childkind Prevention Services, Part of the State’s Child Welfare System

Childkind’s prevention program surfaced in NASHP’s research as an example of child welfare services specifically designed to prevent out-of-home placement – other programs like it may exist in other states as well. Childkind, a nonprofit agency founded in 1988 to serve children with HIV/AIDs, later expanded to serve all children with complex medical challenges, and in 2010 implemented its Home-Based Services with the “goal of preventing avoidable medical neglect and keeping children out of the foster care system.” Childkind provides in-home training and supports for families, in addition to providing placement services.³¹

Childkind reports that most of the families it works with are living well below the poverty line. They are most often referred by pediatric specialists or by the state Division of Family and Child Services (DFCS). The agency works with them for four-to-six months, or sometimes longer. The program focuses not just on “the ability to handle g-tube feedings, trach suctioning, equipment, medications, and the like, we also want to make sure they understand the diagnosis itself and the impact it has on all aspects of family life. From there we look at all of the barriers to success - lack of bonding, no community or personal support, and service navigation, eventually teaching the parents to become their own case managers and care coordinators.”³²

Childkind is funded by a mix of federal and state programs and private sources. These include federal Promoting Safe and Stable Families (Title IV-B) grant funds, which Childkind matches with private donations, a DFCS contract for placement services, and a DFCS grant for prevention services. Childkind’s executive director notes that managing the various funding sources is challenging given differing requirements and restrictions.

Childkind is a Medicaid provider for some disability-related services for children aging out of foster care, but its home-based services are not Medicaid reimbursable. At Childkind’s request, Georgia Medicaid analyzed claims data for 56 home-based services program participants selected by Childkind and determined that, “Childkind achieved a significant impact on the total Medicaid claims paid for these children from FY13 to FY15. The average per member per month

(PMPM) cost (on an incurred basis) for FY13 was \$4,880.37, while the PMPM for FY15 is \$2,508.78. This represents a decrease of 49 percent.” This decline compared to a 22 percent drop in the same time period for a comparison group matched on age and aid category, but not condition.³³

Two other evaluations were conducted to assess outcomes for children who graduated from the program:

- One evaluation found that for 40 technology-dependent children referred by pediatric hospitals, post discharge inpatient days were down 70 percent and patient charges were down 69 percent.
- Another study of 135 children who were referred to Childkind by DFCS found that one year after program graduation, 77 percent of families participating in Childkind’s Take Charge model of home-based services did not require DFCS intervention, compared with 46 percent of non-participating families. Just 3 percent of children whose families participated in the program were placed in foster care, while 12 percent of children whose families did not participate were placed in foster care.³⁴

The Family First Prevention Services Act: Moving Child Welfare Systems toward Home- and Community-Based Care

Enacted in 2018, the Family First Prevention Services Act (Family First) was designed to transform state foster care systems by shifting federal funding to prevention of out-of-home placement, or when necessary, to foster family homes over congregate care. In recognition of the state work in preparing for implementation of the new law, the Family First Transition Act was passed at the end of 2019, providing \$500 million in grants to assist states in implementation, as well as some modifications in the law’s requirements. Importantly, the law phases in the evidence based requirements that states have found challenging.³⁵

Family First focuses strongly on the needs of children with behavioral health issues, and particularly at this early point in implementation, it is unclear how much the shift in funding and services will address the specific needs of CMC. Once states have a plan approved by the federal Children’s Bureau in the Administration for Children and Families, they can use Title IVE funds for mental health and substance abuse prevention and treatment services, and for in-home, parent skill-based programs to prevent placement in the foster care system. Family First also seeks to move children who are placed in the foster care system from congregate or group care settings to foster family homes. With some exceptions that generally are not relevant to CMC, states will be reimbursed only for two-week stays in group care. As of publication, 15 jurisdictions had submitted plans, and six had been approved.³⁶

Prevention services funded through Title IVE pursuant to Family First must meet several conditions. Children must be “candidates for foster care” as defined by states and within federal guidelines. Importantly, the services must be evidence based, as reviewed and approved by the Title IVE Prevention Services Clearinghouse established through Family First.

As of April 1, 2020, 25 programs have been reviewed and the results published by the clearinghouse. Federal reimbursement is available for up to 12 months of prevention services.³⁷

Georgia may incorporate Childkind’s Take Charge! Medically-Based Parenting program in its Family First Title IVE plan if the program is included in the federal Title IVE Prevention Services Clearinghouse. Following its public call for submissions, Georgia’s DFCS submitted this Childkind program to the clearinghouse for review and inclusion as an in-home, parent skill-based program. As of publication, Childkind’s program had not yet been reviewed. Georgia was developing its plan for submission with a planned implementation date of October 2021.

Considerations and Strategies for States

CMC have received inadequate attention in research and policy, especially given their growing numbers, unique and intense needs, and costs to their families and child welfare and health care systems. National attention, particularly to the need for better data on CMC and foster care, is needed.

As states focus on health care, and now, foster care transformation, this population of children and families – who have substantial needs that may lead to out-of-home placement – calls for attention. Federal resources are available to support improved care for CMC. While state budget constraints make further state investments challenging, supporting families in caring for CMC at home, or if not possible in specialized foster care families, also can help reduce state costs in areas such as nursing home care and hospital readmissions. According to one study, “Hospitalized children with CCCs [chronic complex conditions] discharged to HH [home health] experienced fewer short-term readmissions, subsequent hospitalizations, and lower hospital costs over a 12-month period than matched controls of children with similar attributes who were not discharged to HH.”³⁸

Supporting families in caring for CMC at home, or if not possible, in specialized foster care families, also can help reduce state costs in areas such as nursing home care and hospital readmissions.

With supports, many families of CMC can successfully care for their children at home and for those unable to do so, placement in medical or therapeutic foster care can be an option but requires specialized training and support for foster families. Given the high costs of CMC care and state responsibility for much of those costs, it is important for states to assure cost-effective care that optimizes outcomes for CMC and their families.

Given different but complementary knowledge, resources, and authorities, it is important that state agencies and programs collaborate to develop, finance, maintain, and improve services that prevent and provide out of home placements for CMC.

State agencies responsible for Medicaid, Child Welfare, and Title V Maternal and Child Health/Children with Special Health Care Needs programs each have something they could contribute to address these needs. There are multiple Medicaid options and waivers that can support families in providing care for CMC at home, including the new Health Homes 1945A option to establish Health Homes for CMC specifically. State Title V CYSHCN programs may offer or help to arrange services, including for children who are not eligible for Medicaid. Title V MCH programs may be able to assist with strategies to address social determinants of health for these children and families, such as adequate housing that can be adapted to meet the needs of the child with medical complexity. These agencies and programs individually and together could review the options and consider which to modify, adopt and deploy to prevent, or when still needed, provide out-of-home placements for CMC. Florida provides one model of interagency collaboration in placements tailored to the specialized needs of CMC.

State Strategies to Prevent and Improve Foster Care for CMC:

- Promote collaboration between child welfare, Medicaid and Title V programs to leverage, coordinate, and maximize respective resources in addressing CMC and foster care.
- Exchange information and ideas across states to help foster improved policies and practices, especially given the wide variation in terminology, definitions, and data systems.
- Utilize the Family First Prevention Services Act’s new opportunities for preventing out-of-home placement of CMC through in-home parent training programs.
- Collaborate with private-sector agencies to develop and evaluate promising approaches to prevent and improve out-of-home placements for CMC.

In working together to address the needs of CMC and their families, state officials could benefit in learning from and exchanging ideas with other states. Forums such as state associations and interagency convenings could support state learning and exchange in this area. An important barrier to effective exchange is the lack of common nomenclature, definitions, and data collection systems, a barrier that might be addressed by states coming together and working with federal agencies around data, as progress has already been made in areas such as quality measurement.

The Family First Prevention Services Act opens the door to more focus on preventing out-of-home placement of CMC. While much of the focus in the law is on addressing the behavioral health needs of children, it can create momentum for examining and improving how all children, including CMC, can be better served by the system. A starting point is interagency consultation on the state-developed definition of “candidate for foster care,” to ensure that it enables, if not specifies, inclusion of CMC. This definition is one of the conditions for receipt of prevention services. Particularly relevant to CMC is the prevention services option of in-home parent training. Programs that offer parent training tailored to the needs of CMC might be

incorporated in state Family First plans, if not now, then later, as more programs are evaluated to create the necessary evidence base, and as states' attention shifts from immediate implementation challenges to how to use the federal goals and funding to achieve systemic improvements that benefit all of the children served.

Additional collaboration with the private sector, including health care providers, health plans, and nonprofit community agencies, can help to develop, evaluate, and sustain successful and innovative approaches to home-based and foster care services for CMC. Childkind is one example of a local nonprofit that has developed and worked, within its resources, to evaluate its effectiveness in preventing and providing out of home placements for CMC. There also are nonprofits working to address the challenges in providing high quality foster care for CMC. For example, *Angels in Waiting* in California recruits and trains nurses to serve as foster parents for CMC.³⁹ State agencies are in position to encourage, identify, support, and evaluate innovative approaches that might be identified as evidenced based practices and brought to scale.

Conclusion

Children with medical complexity are a particularly vulnerable group of children who have unique, specialized needs, including for high cost health care services, and whose families require supports to care for their children at home and in the community. In the absence of such supports, some children who could otherwise be cared for at home are at-risk of out-of-home placement. State programs have current and newly available options and federal financing to support families in caring for CMC at home, or when that still may not be possible, in specialized foster family homes. While variation in state terminology and approaches make sharing best practices challenging, state child welfare, Medicaid, and Title V CYSHCN program officials can gain from working within and across states and with the private sector to learn from each other and improve services to prevent and to improve foster care for CMC and their families.

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