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The Family CNA Model:

Supporting Families and Improving Care for Children With Medical Complexity

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Analysis provided by Manatt Health

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Contributors

The following organizations provided the guidance and subject matter expertise that served as the foundation for this report.

Family Voices

Family Voices is a family-led organization that transforms systems of care to work better for all children and youth, especially those with special health care needs or disabilities. By putting families at the forefront and centering their leadership and lived expertise, we build a culture that includes everyone and fosters equitable outcomes.

Health Leads

An innovator in community-led health equity initiatives and advocacy for over 25 years, Health Leads drives toward a vision of "health, well-being, and dignity, for every person, in every community." Health Leads has a proven track record of working collaboratively with local and national partners to unearth and address the root causes of some of the most pressing and complex health equity challenges of today. From maternal health to vaccine access, to housing and food security, Health Leads initiatives are focused on removing systemic barriers to health and building a future where communities have the essential resources they need to thrive.

Lucile Packard Foundation for Children's Health

The Lucile Packard Foundation for Children's Health is here to unlock philanthropy to transform health for all kids and moms. The Program for Children and Youth with Special Health Care Needs (CYSHCN) uses grantmaking and advocacy to create a more efficient and equitable health care system.

Team Select Home Care

Team Select Home Care is a leading provider of in-home pediatric and adult private duty nursing and personal care services across the United States. They proudly advocate for the paid family caregiver model and lead with innovative, cost-effective solutions that prioritize both quality outcomes and family support. Team Select's mission is grounded in compassion, clinical excellence, and empowering those they serve.

Reviewers

The contributors wish to thank the following for their review of this paper and their thoughtful guidance:

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Table of Contents

Executive Summary

Children with medical complexity represent less than 1% of all children in the U.S., but have significant, specialized, and long-term health care needs, accounting for one-third of pediatrics costs in the U.S.[1] This group of children have one or more chronic and/or complex medical conditions—such as cerebral palsy, muscular dystrophy and seizure disorders—that result in functional limitations and/or dependence on in-home nursing support and medical devices like a ventilator. Care for children with medical complexity is not only costly but also too often difficult for families to access. Yet, without this care, children with medical complexity are at higher risk of emergency room visits, hospitalization, and even moving into an institutional setting, away from their homes, families, and communities.

The well-documented national home care workforce shortage is leaving families of children with medical complexity struggling to balance all of the challenges that come with caring for their child, chief among them finding the right care for their child in their homes.[i] Home health agencies, for example, reported turning away over 25% of referred patients due to staff shortages in 2023. When families can't find providers for their children, family members are often forced to leave the workforce to fill the gap, without compensation for the care they provide to their child.[2]

There is an urgent need to expand access to care delivery models that keep children with medical complexity in their homes and out of costly hospital or institutional settings, while supporting families' financial security. A small but growing number of state Medicaid programs[ii] are adopting the **Family Certified Nursing Assistant (CNA) model** to do just that.

The Family CNA model trains and reimburses family members—including parents, guardians, siblings, aunts, uncles, and grandparents—to provide certain types of home care for children with medical complexity that would otherwise be provided by a registered nurse (RN), a licensed practical nurse (LPN), or a non-family CNA. This care includes low acuity in-home nursing tasks, such as medication administration, gastronomy tube (G-tube) care, or catheter care. Family CNAs are licensed or certified health care professionals that work in concert with other providers on a child's care team, including RNs and LPNs who provide supervision and perform high-acuity tasks, to support their child's medical needs and activities of daily living at home. The unique benefits of the Family CNA model include:

1. Addressing critical home care workforce shortages by increasing the number of trained and compensated caregivers and freeing up RNs and LPNs to operate at the top of their credentials and serve more patients.
2. Improving the continuity and quality of care for children with medical complexity. Family CNAs receive, at minimum, the same training as non-family CNAs, and in some states receive additional training on skilled tasks such as feeding tube care and tracheostomy care. Additionally, as family members, they maintain a close and lifelong connection to their child.

[i] The home care workforce shortage is also impacting the ability of seniors and people with disabilities to find the care and support they need to remain in their homes and communities.

[ii] Medicaid is the largest payer of long-term services and supports (LTSS)—this paper uses the term "long-term care"—in the United States. In 2022, Medicaid paid for 61% of all LTSS spending in the U.S. and 69% of home and community-based services, a subset of LTSS. https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss.

3. Strengthening families' agency and supporting financial security. Giving family members the technical skills and support they need to provide person-centered care while compensating them for their time improves the well-being of the entire family.

The Family CNA model also has cost-saving potential for states, by preventing avoidable or prolonged hospitalizations and by freeing up RNs and LPNs to provide care at the top of their licenses. A recent analysis by the Oklahoma Medicaid agency found that implementing a Family CNA program could save more than $3 million annually.[3]

There is bipartisan support and momentum at both the federal and state levels to acknowledge the value of family caregivers and better support them as part of a multi-pronged strategy to address the national home care workforce shortage and, in turn, improve care for children with medical complexity. While Medicaid priorities and policies are in a dynamic state, there are actions federal and state policymakers can take to build on that momentum of support for family caregivers and expand access to the Family CNA model. These actions, discussed in more detail in this paper, include:

1. Building a coalition of key constituencies, including families and their advocates, providers, nursing boards, and policymakers, to support and design state Family CNA programs that meet the needs of children with medical complexity in their state, proactively address barriers to implementation, and produce positive outcomes.
2. Identifying appropriate Medicaid authorities available to states to implement the Family CNA model and collaborating with coalition partners to monitor and evaluate the model's impact.
3. Issuing federal guidance to states on a standardized definition, training, and coding and billing procedures for family CNAs.

States that newly adopt the model will have the advantage of learning from existing Family CNA programs as well as other national family caregiver initiatives under way. More families with access to the Family CNA model will mean more families are trained to care for their children with medical complexity while also receiving appropriate support and oversight to provide high-quality care. This, in turn, will mean fewer gaps in care and greater economic security for the entire family.

A Critical Member of the Care Team: Family Caregivers

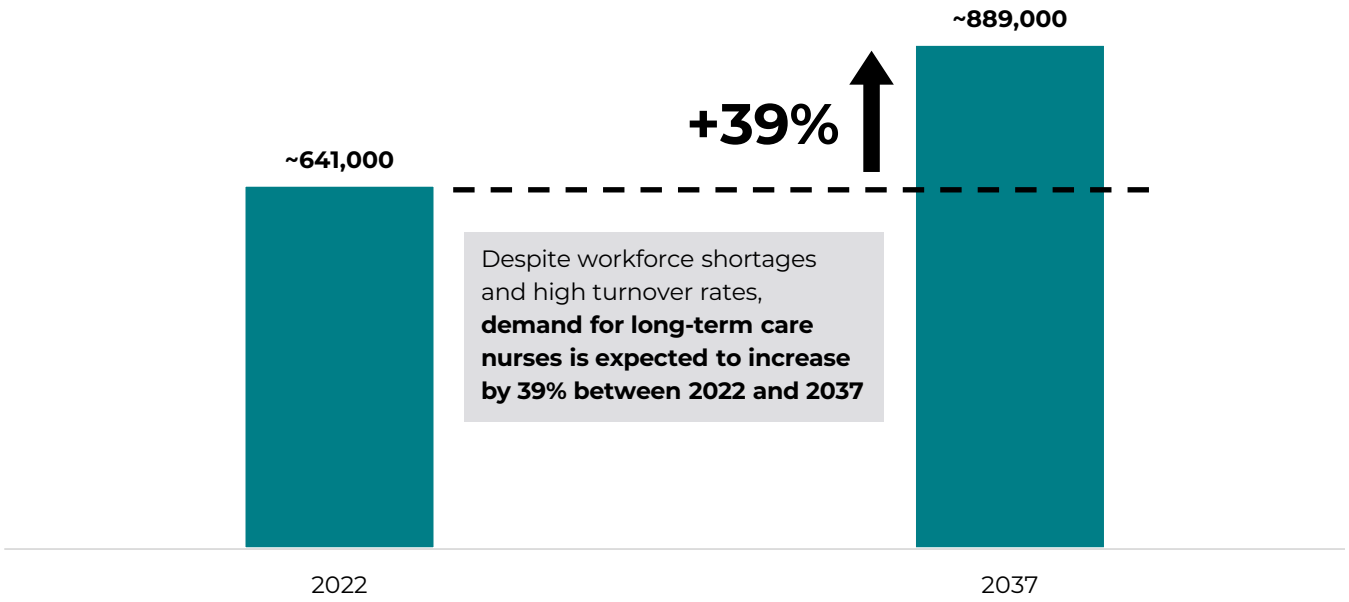
There are at least 53 million family caregivers in the United States providing informal and, most often, unpaid care to their loved ones.[4] Family caregivers provide supports for older adults and people of all ages with disabilities and/or complex medical conditions that are needed for those individuals to continue to live in their homes and communities. Supports from family caregivers can range from assistance with daily tasks, such as feeding, dressing, or bathing, to higher skilled low-acuity medical tasks, such as medication administration or cleaning and using a feeding tube. Often, family caregivers must learn these skills on their own without any formal training or ongoing oversight.[5]

Without family caregivers, many of the individuals they care for would be forced to seek care in institutional settings, such as nursing homes or inpatient hospitals (often not specifically designed to care for children), where the care is significantly more expensive and can lead to worsening health (e.g., exposure to hospital-acquired infections). In fact, evidence has shown that poor access to home care services increases the risk of prolonged hospitalization and increased costs.[6] Put more simply, services provided by family caregivers help keep people out of more expensive settings like hospitals.

Family caregivers can work in partnership with other in-home health care professionals such as nurses, physical, occupational, and speech therapists, non-family CNAs, home health aides, and personal care attendants. These workers are sometimes referred to as the "formal" home care workforce. Family caregivers can be a parent, spouse, child, or other close relative or even a friend or neighbor. What sets family caregivers apart from the "formal" workforce is their personal relationship to and intimate knowledge of the people they care for, which can positively impact an individual's care experiences and quality of care. Not only are family caregivers well positioned to advocate for the person they are caring for, but they may more intimately understand their condition, health status, or behaviors. This can help them to notice changes in their health or well-being earlier than other "formal" providers. Such early intervention can prevent or mitigate the need for higher, more costly levels of care in hospitals or other facility settings. Additionally, language and cultural barriers—which have been linked to rehospitalizations for home care patients—are likely rare between a family caregiver and the person they're caring for.[7]

Family caregivers can also provide a greater continuity of care to their loved ones compared to the formal home care workforce. For example, turnover rates for nursing assistants who provide home care was nearly 80% in 2024; turnover rates for RNs and LPNs who provide home care was 28% and 29%, respectively (2023).[8] Every time a new provider is hired, new training and new learning are required—on the part of the caregiver, the individual receiving services, and provider agencies. This creates gaps in access to services that can directly impact care quality and outcomes. On the contrary, individuals receiving home care services from a consistent provider are more likely to avoid hospitalization and emergency department care.[9]

Figure 1: Projected Demand for Long-Term Care Nurses[iii]



[iii] Health Resources and Services Administration Bureau of Health Workforce. Long-Term Services and Support: Demand Projections, 2022–2037. November 2024. https://bhw.hrsa.gov/sites/default/files/bureau-health-workforce/data-research/ltss-projections-factsheet.pdf. In this report, long-term care nurses refer to RNs and LPNs that work in both home- and community-based settings and facility-based settings.

Workforce Shortages Are Putting Children With Medical Complexity at Risk and Increasing Health Care Costs

Worker burnout tied to low wages and the high demands of caregiving is driving a nationwide shortage of nurses, home health aides, personal care attendants, and other in-home care providers.[10] This shortage is the most significant challenge facing individuals needing long-term care and their families, particularly in rural and frontier states, and it is also driving the increased reliance on family caregivers.[11] For families of children with medical complexity, the risks associated with worker shortages are severe.

Children with medical complexity are a small population with specialized, intensive, and long-term health care needs.[12] While there is no standardized definition for children with medical complexity, they are children who have one or more complex and/or chronic medical conditions—including cerebral palsy, muscular dystrophy and seizure disorders—that result in functional limitations and/or dependence on in-home nursing support and medical devices like a ventilator. Unsurprisingly, children with medical complexity have high health care costs. They make up 1% of children but account for approximately one-third of total pediatric health care costs.[13]

Table 1: Common Conditions and In-Home Medical Needs of Children With Medical Complexity

Who are children with medical complexity and what does their care look like?	
Common Conditions	**Common In-Home Medical Needs**
• Cerebral palsy • Muscular dystrophy • Epilepsy or other seizure disorders • Respiratory conditions • Traumatic brain injury (TBI) • Quadriplegia • Cystic fibrosis • Gastrointestinal conditions	• Managing medical equipment (e.g., g-tubes, ventilators, and tracheostomy care) • Administering medication • Assistance with the activities of daily living (e.g., feeding, bathing, and dressing)

Much of the care that children with medical complexity rely on is considered "skilled" care, which puts an added burden on families when providers are not available due to shortages. Family caregivers are often forced to step in or expand their roles to include providing highly technical clinical and non-clinical services and supports to their children, without training, support, or compensation. As a result, family caregivers of children with medical complexity experience particularly high levels of stress, burnout, behavioral health needs, and—if they've had to leave the workforce—financial instability, compared to other family caregivers.[14]

Nearly half of all children with special health care needs—children at risk of chronic physical, developmental, behavioral, or emotional conditions—have at least some Medicaid coverage to pay for needed services (children with medical complexity are a subset of children with special health care needs; insurance rates for children with medical complexity specifically are unclear). However, this does not insulate them from worker shortages that leave children with medical complexity at risk for worsening health and poor outcomes, particularly emergency department visits and hospitalizations. Many of those children find their hospital stay extended unnecessarily, with poor access to nursing care in the home cited as the top reason for a delay in discharge.[15] When children do return home, nursing care may not be available at sufficient levels, forcing family

members to step in and try to cover missed nursing care. To do that, family members may need to temporarily take time off from their jobs or leave the workforce altogether (either voluntarily or by being terminated for taking too much time off), which increases financial instability for the family. Family caregivers assuming these tasks without appropriate training and support can lead to a deterioration in the health of the child and readmission to the hospital. It is a traumatizing cycle for children with medical complexity and their families of multiple hospitalizations, disjointed care, and avoidable costs (which are also borne by state Medicaid agencies and other payers).

The Family CNA Model: Improving Care and Supporting Families of Children With Medical Complexity

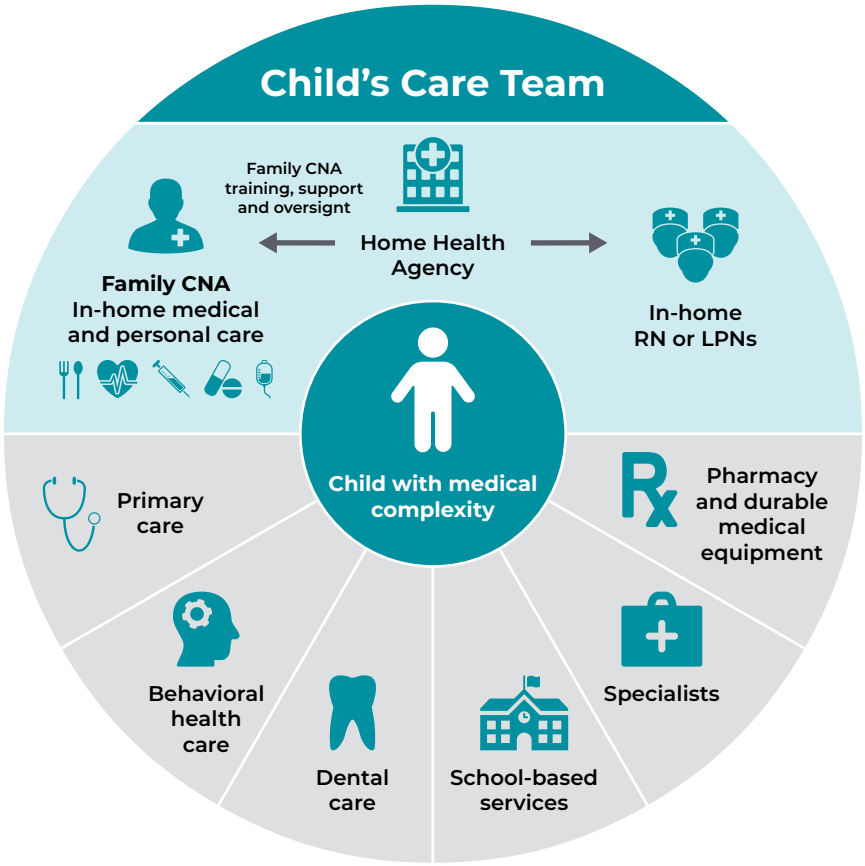
While family caregivers have always cared for loved ones, including children with medical complexity, the COVID-19 pandemic accelerated the development and expansion of care models that recognize and support the critical role of family caregivers. These models—which generally have bipartisan support—pay, train, and offer other supports (such as counseling and peer-to-peer networking) to people who provide or want to provide in-home services to their loved one.[16]

States have taken several approaches to paying family caregivers. Among the most innovative models for families of children with medical complexity is the Family CNA model. Under the model, parents or family members of children with medical complexity who qualify for PDN services are trained as a CNA, licensed health aide, or complex care assistant (the title of the role varies state to state). The training is, at minimum, equivalent to the training that other CNAs receive and can include training specifically on the needs of children with medical complexity and on more advanced skills depending on state requirements, such as feeding tube care and medication administration. This approach ensures that care provided by the family CNA is of the highest quality and that family caregivers aren't left to teach themselves how to perform the intensive types of medical services upon which children with medical complexities depend.[17]

Family CNAs are employed and paid by home health agencies (which may also pay for the training and compensate family CNAs during their training time) so the family CNA isn't forced to forego income in order to care for their loved one. The home health agency is responsible for clinical oversight of the family CNA and quality assurance, which includes regular performance evaluations and monitoring for adherence to care plans. The home health agency also provides family CNAs with dedicated resources for when they have questions about their child's care needs. This infrastructure ensures that care provided by family CNAs complies with state and federal program and regulatory requirements. The home health agency also facilitates billing and payment processes for the services provided, ensuring transparency and accuracy of payment for delivered services.

Family CNAs work closely with other home care professionals, supplementing the specialized nursing services provided by RNs or LPNs. When family CNAs manage lower acuity medical tasks, RNs and LPNs are freed up to operate at the top of their license and can provide care for more higher-acuity patients.

Figure 2: Family CNA Care Model



"A Blessing" for Brittany's Family

Before becoming a family CNA, Brittany always struggled to find high-quality nursing care for her daughter. Brittany had struggled to hold a job due to her daughter's significant medical needs, saying that "having a medically complex child is a 24-hour job." The Family CNA model allowed her to get certified and provide skilled care for her daughter, growing her professional skill set and helping provide financial stability for her family. Even more important, it has allowed her daughter to be cared for by the person that loves her most, eliminated the gaps in state-approved care her daughter experienced due to worker shortages, and reduced her daughter's hospitalizations. Brittany now describes herself as an advocate for the model, sharing information about this opportunity as often as she can with other families who have children with medical complexity.

The Case for Expanding Access to the Family CNA Model

The Family CNA model predates the COVID-19 pandemic but, like other family caregiving models, it is getting a fresh look as families, providers, and states seek improved care options for children with medical complexity. The American Academy of Pediatrics has endorsed family caregiver programs for children with medical complexity like the Family CNA model, highlighting benefits for parents, children, and state Medicaid agencies including improved child health and well-being, better continuity of care, and enhanced family financial stability.[18] Additionally, the Centers for Medicare and Medicaid Services (CMS) issued guidance at the end of the pandemic encouraging states to continue to use available authorities, such as certain Medicaid state plan benefits and home- and community-based service (HCBS) waivers, to pay family caregivers, which extends to home health agency models like Family CNA.[19] In 2022, the National Strategy to Support Family Caregivers was published, implementing the Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregivers Act which was signed into law in 2018, during the first Trump Administration.[20]

> "Research shows that when states enable parents and caregivers of [children with special health care needs] to be paid for the extraordinary care they provide to their children, there can be numerous potential benefits to the parents, child, and state."
>
> American Academy of Pediatrics

The Family CNA model has been fully implemented in seven state Medicaid programs—with some variation in the services the family CNA can provide, the populations that are eligible for family CNA services, and how they title the program and the family caregiver position (see table 2); several additional states have a limited version of the model or are working to implement the model (see figure 2).

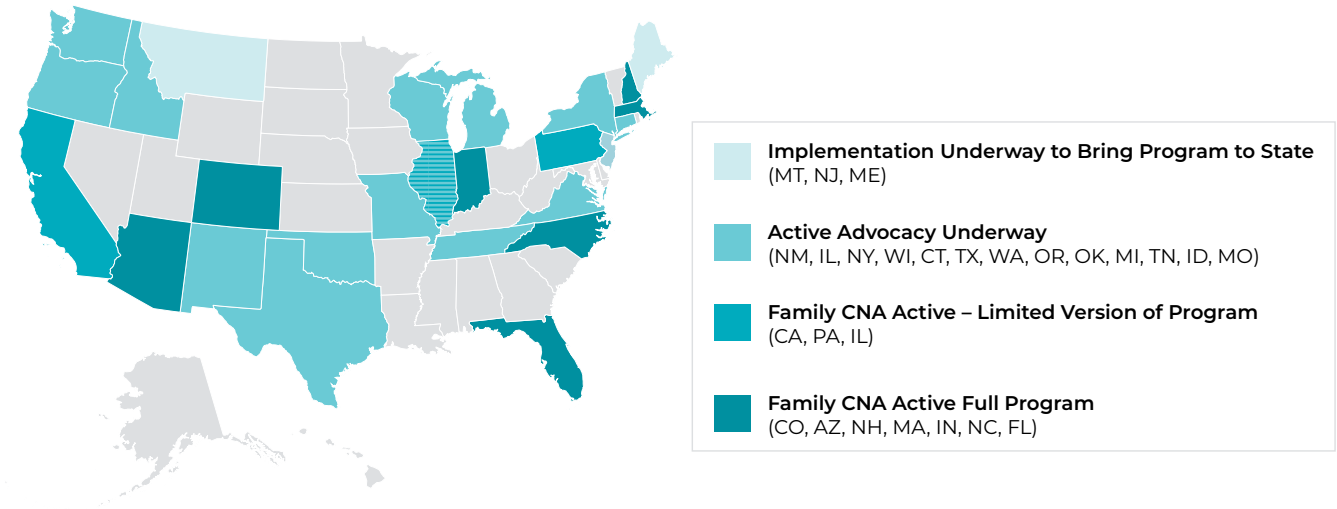
Table 2: State Family CNA Programs

State	Family CNA Position	Scope of Practice	Eligible Populations	Year Established
Arizona	Licensed Health Aide	• Same as a Licensed Nursing Assistant (basic nursing and personal care tasks, restorative services) • Tracheostomy care • Tube feeding • Routine ventilator care and therapy • Medication administration	Individuals under 21 years old enrolled in Medicaid's Arizona Long Term Care System, Developmental Disabilities, or Elderly and Physical Disabilities programs	2022

State	Family CNA Position	Scope of Practice	Eligible Populations	Year Established
Colorado	Family Certified Nurse Aide	• Basic nursing tasks (vital signs, recording symptoms) • Personal care tasks (bathing, feeding, dressing) • Supporting psychosocial and mental health needs • Restorative services • Tube feeding, oral medication administration (if deemed competent by an RN)	Children and adults enrolled in Medicaid who qualify for CNA services as assessed by a home health agency	1999
Indiana	Home Health Aide	• Basic nursing tasks, personal care tasks, restorative services • Tube feeding (with additional training)	Children enrolled in Medicaid eligible for home health services	2022
Massachusetts	Complex Care Assistant	• Basic nursing tasks, personal care tasks, restorative services • Tube feeding (not changing or replacing) • Oxygen therapy (cleaning/ monitoring) • Oral suction • Catheter care	Children enrolled in Medicaid eligible for continuous skilled nursing services	2023
New Hampshire	Licensed Nursing Assistant	• Basic nursing tasks, personal care tasks, restorative services • Feeding tube care • Medication administration (requires additional training)	Individuals eligible for home health Medicaid benefit	2009

State	Family CNA Position	Scope of Practice	Eligible Populations	Year Established
North Carolina	Certified Nursing Assistant I or II	Nurse Aide I • Basic nursing tasks, personal care tasks, restorative services Nurse Aide II (additional skills) • Oxygen therapy • Tracheostomy care • Feeding tube care • Catheters • Suctioning	Individuals enrolled in Community Alternatives Program for Children (CAP/C) who meet specific requirements for their parent to be paid for care[21]	2023
Florida	Home health aide for medically fragile children	• Basic nursing tasks, personal care tasks, restorative services • Oxygen therapy • Tracheostomy care • Feeding tube care	Medically fragile children eligible for Private Duty Nursing services	2025

Figure 3: Map of States with Family CNA Models



Regardless of the distinctions in services, eligible populations, and job title, the Family CNA model in the states where it has been fully implemented is improving care experiences for children with medical complexity and their families by:

1. Addressing workforce shortages;
2. Improving access to, and the continuity and quality of care;
3. Strengthening families' agency and supporting financial security.

Each of these benefits is explored in more detail below, followed by a discussion on steps that can be taken at the state and federal levels to expand access to the model into new states and beyond the Medicaid program.

Table 3: Common "Myths" About the Family CNA Model

Myth	Fact
✗ **The Family CNA model pays parents to be parents**	✓ Family CNAs provide extraordinary care, defined by CMS as care that a parent wouldn't typically provide as part of a household routine.
✗ **The Family CNA model increases the number of hours of home care Medicaid agencies must pay for**	✓ The number of authorized hours of care for a child with medical complexity is based only on medical necessity. Family CNAs can help ensure a child receives all the care they need (and their doctor orders), which may otherwise go unfilled due to workforce shortages. This also ensures care is compliant with Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) requirements.
✗ **Implementing the Family CNA model will increase a state's Medicaid enrollment, and thereby increase costs**	✓ Only children currently covered by Medicaid and eligible for State Plan private duty nursing or home health services can participate in Family CNA models (exact eligibility rules vary by state).
✗ **Home health agencies take on increased liability when they hire family caregivers**	✓ There is no evidence that providers who have hired family CNAs have seen their liability insurance increase.
✗ **Paying a family member to take care of their child is a conflict of interest**	✓ Home health agencies and Medicaid agencies provide oversight of family CNAs to make sure children are receiving appropriate care.

1. The Family CNA Model Can Help Address Long-Term Care Workforce Shortages

Federal law requires states to provide robust coverage and access to services for children enrolled in the Medicaid program through the EPSDT benefit, regardless of whether the service is included under a state plan.[22] However, workforce shortages, driven in part by low reimbursement for long-term care roles, can make it difficult for states to comply with this requirement, leaving children with medical complexity at risk for not receiving needed and federally-required care. Not only is this an EPSDT compliance risk for states but, as described above, gaps in care can lead to

+54 hospital days

Due to challenges finding needed home care, children with medical complexity who didn't have an existing home nurse relationship stayed in the hospital an average of 54 additional days.

declines in a child's health, unnecessary trips to emergency rooms, and prolonged stays in the hospital.[23] One study found that children with medical complexity who did not have an existing home care nurse relationship stayed in the hospital an average of 54 additional days due to challenges finding needed home care.[24] Other evidence shows that, when children with medical complexity are discharged from the hospital to appropriate home care nursing services, they are less likely to end up back in the hospital, and if they do, their hospital stays are shorter compared to children with medical complexity who do not have services upon return home.[25]

Training family caregivers to become family CNAs extends the workforce by creating more appropriately trained and compensated caregivers and frees up existing workforce to operate at the top of their credentials and serve more patients. For example, if a child being discharged from the hospital requires 30 hours of various types of care at home, including non-skilled, skilled, and higher acuity medical tasks, a family CNA can fulfill some of those needed hours with an RN or LPN taking on only the highest skilled tasks. That RN or LPN then has hours freed up to care for other higher acuity patients. The Family CNA model can also help reduce the number of nurses who are leaving the caregiving workforce. In a 2022 survey, 32% of RNs reported they are considering leaving their direct care role with many citing limited opportunities to operate at the top of their license as a key reason.[26]

The Family CNA model could also benefit families of older adults, adults with disabilities (including adult children of family CNAs), and children with medical complexity enrolled in employer-sponsored or other non-Medicaid coverage.

In sum, the Family CNA model is a practical and cost-effective way for states to fulfill their EPSDT obligations, keep children with medical complexities out of the hospital, and help slow the exodus from the nursing profession. Training more family CNAs means having more home care workers overall who can complete low-acuity medical tasks that would otherwise be performed by a nurse (who can then spend their time in high-acuity medical tasks), in turn lowering the total cost of care for states due, in part, to the lower reimbursement rate for family CNAs versus RNs or LPNs. Further, the skills acquired by family CNAs can be transferable beyond care for their own child to other populations who need long-term care.

2. The Family CNA Model Can Improve Continuity and Quality of Care

High turnover rates in the caregiving workforce disrupt the relationship between providers and children with medical complexities and their families. It requires both families and providers to invest time and money in searching for, hiring, retraining, and onboarding new staff. That is time and resources diverted away from care. Worse still, it takes time to build trust and knowledge between a caregiver and the child, and that process must start anew every time a caregiver leaves the job. Family caregivers, on the other hand, are among the most consistently present people in a child's life. They are experts in the child's medical history and personal preferences. The Family CNA model recognizes this and builds advanced skills on top of that intimate, long-term relationship, leading to high-quality person-centered care from a person the child with medical complexities (and the rest of their family) knows and trusts.[27] In Colorado, for example, retention rates for family CNAs from 2017 to 2019 was 82%, compared to 9% for non-family CNAs.[28] When operating under a hybrid model of Family CNA and Non-Family CNA care, having a qualified family CNA ensures a smooth transition and eliminates dangerous and expensive gaps in skilled care. Continuity of care is a key indicator

of quality across all health settings and in-home care has been tied to improvements in health.[29,30] Additionally, as discussed above, the continuity of care built into the Family CNA model is a top driver of reduced hospital visits and delayed discharges.

A Closer Look: Colorado's Family CNA Program

Colorado launched the first-in-the-nation Family CNA program for Medicaid-enrolled children and adults in 1999. Colorado utilizes family CNAs for lower acuity medical tasks for children and adults needing in-home care. Family CNAs in Colorado's program cannot perform intravenous medication administration or respiratory care (e.g., ventilator care), unlike family CNAs in states that have more recently adopted the model that allow for additional delegated skilled tasks such as tracheostomy care. Adoption of the program has been widespread across Colorado—approximately 90% of pediatric home CNA care for Medicaid-enrolled children with medical complexity is now provided by a family member, and there is widespread support of the model among families, home health providers, and primary care providers. The success of the Colorado model highlights several of the core reasons it should be expanded nationwide.

Lowering Total Cost of Care Through the Family CNA Model

High-quality, consistent care at home, like the type provided through the Family CNA model, is a key component to preventing unnecessary and prolonged hospitalizations. Nearly half of all Medicaid spending for children with medical complexity goes towards hospital care. Providing care in the home is not only the right thing for a child's care and quality of life, but also one of the greatest opportunities for cost savings for states and families. For example, the Oklahoma Health Care Authority found that **implementing a family CNA program would result in over $3 million in savings each year** based on a bill proposed in the state legislature.

Additionally, utilizing family CNAs to support low-acuity medical tasks frees up RNs and LPNs to operate at the top of their license and saves states money because family CNA reimbursement rates are lower than skilled nurses. As adoption of the Family CNA model grows, it will be important for states to collect and analyze data demonstrating the fiscal impact of the model.[31]

3. The Family CNA Model Can Strengthen Families' Agency and Supports Financial Security

Family caregivers of children with special health care needs (of which children with medical complexities are a subset) report significant financial hardship related to caring for their children, often due to lost employment or foregone wages (totaling $17.6 billion in earnings annually).[32] In a national survey of family caregivers of children with medical complexity, 54% reported that a family member stopped working because of their child's health, and nearly half reported needing additional income to pay for medical expenses.[33] These financial strains are compounded by physical and emotional strains associated with the workforce shortages discussed above. When a home

health nurse or worker calls out or is unavailable, it falls to the family caregiver to ensure their child receives the services and medical care they need, regardless of whether the family member has the appropriate training. The result is caregivers often feel like their loved one is suffering and that they are unable to support them.[34] Family caregiving, without the proper supports and training, can lead to chronic stress and higher levels of depression and anxiety.[35]

The Family CNA model relieves some of these stressors by giving family members the technical skills, knowledge, and resources needed to support their child's health while providing the caregiver with a family-sustaining wage that reflects their skill level and the critical nature of the care they provide. In Colorado, family CNAs described the financial benefits of the program as "indispensable" and "life-changing."[36] The model allowed family members to maintain financial security and avoid relying on public assistance programs without having to sacrifice caring for their child. The same study of the Colorado model found that family CNAs felt positively about their ability to provide high-quality care for their child, which in turn supported the emotional well-being of the parent and the entire family. However, the Family CNA model alone may not relieve all of the mental and emotional burdens of family caregiving, including exhaustion and social isolation. Additional investments in family caregiving are needed to expand caregiver supports such as respite, increased pay, and access to behavioral health services.

A Win-Win for Families and States: Brandi's Experience as a Family CNA

Thanks to the Family CNA model, Brandi now has the flexibility to care for her son's nursing needs in the way that works best for her family. Brandi's son has a complex neurological disorder that results in seizures and requires palliative care. This condition can be frightening and intimidating for the family—they don't know if on a given night he may experience Sudden Death in Epilepsy (SUDEP). To provide round-the-clock care for her son, Brandi had to give up her career. With her husband as the sole financial provider, they were barely making ends meet trying to care for their son's medical needs while supporting the rest of their family. With the Family CNA model, Brandi is now paid to conduct nursing tasks for her son (many of which she previously had to do unsupported due to the extreme nursing shortage in her area), while being supported by a nursing supervisor and home health team to address any questions or concerns she may have.

Brandi has seen an extremely positive impact on her son's continuity of care, and the support of her supervisor and broader care team has helped her avoid taking her son to the emergency department and reduced his hospitalizations. Additionally, it has given her the flexibility to financially contribute to her household again, while saving state dollars by reimbursing her for care instead of a more expensive RN or LPN. The family works closely with their home health agency to determine how many hours Brandi will work, while also hiring an outside provider to give Brandi respite as needed. Brandi hopes that the Family CNA program is available in every state across the country at some point.

Meeting the Moment: State and Federal Opportunities for Action

Efforts to support family caregivers and promote high-quality, cost-effective care in the home for children with medical complexity have received bipartisan support. There is also broad support for improving access to home- and community-based services (HCBS) for older adults and people with disabilities.[37] Further, a diverse array of states ranging from Indiana to Massachusetts have implemented or are in the process of implementing the Family CNA model, showing that it is broadly suited to families across different states and Medicaid programs.

This section explores opportunities for state and federal policymakers to maintain and build on this momentum to expand access to family CNA services. Though implementation of the Family CNA model happens at the state level through state Medicaid programs, federal policymakers are well-positioned to support states through guidance, funding, and rulemaking. Recognizing that federal and state Medicaid priorities, policies, and programs are dynamic and often change with new administrations, these action items are foundational to advancing the Family CNA model. States should consider the current state of their Medicaid programs, including workforce dynamics, home health/home care benefits, and family caregiver policies when considering these opportunities.

State Opportunities for Action

1. **Build a coalition of key constituencies including families and their advocates, provider communities (including hospitals), nursing boards, and policymakers to support and design Family CNA programs that meet the needs of children with medical complexity in their state.** These constituencies would each play an important role in implementing the Family CNA model in their states. Bringing them together to help design the program provides an opportunity to proactively identify and address potential implementation challenges (see below for more detail on state implementation considerations), align on delegated skills and training for family CNAs, and build awareness among families that would be eligible for the model. States can convene these constituencies by highlighting their shared goals, including delivering high-quality care to children with medical complexity, addressing challenges faced by family caregivers, lowering health care costs, and mitigating the broader long-term care workforce crisis that is also impacting older adults and people with disabilities.
2. **Partner with the state nursing board to establish a defined provider type, with clear delegated skills.** In the absence of federal guidance on a definition and standards for family CNAs (see the section below on federal opportunities), states should work closely with their boards of nursing to define family CNAs as a new provider type, with specific training standards and delegated skills they can provide to patients. Distinguishing family CNAs as a provider type that is distinct from other CNAs and home health aides allows the state to better monitor and evaluate care delivered through the model and recognizes the unique role a family CNA can play in a child's care.
3. **Identify the preferred Medicaid authority under which to implement the Family CNA model.** Most states that have implemented a Family CNA model, or are in the process of doing so, have done so under Medicaid's home health or private duty nursing state plan benefit. A handful of states, including North Carolina, have implemented a Family CNA model through a 1915(c) HCBS waiver. States can also explore implementing the Family CNA model through an 1115 Demonstration, where there is some precedent for paying family caregivers. Given that every state Medicaid program is

different, each state should evaluate its existing authorities and benefits for children with medical complexity and aim to implement the Family CNA model in a way that maximizes access and quality while balancing cost considerations.

4. **Once implemented, continue working with a coalition of partners to support adoption of the Family CNA model, monitor implementation and quality outcomes, and conduct evaluations to demonstrate the model's value to families and the state.** Working with the same coalition that was convened to advise on design and implementation of the Family CNA model, state coalitions can support efforts to train family caregivers and promote awareness of the model. Each constituency can play a role in this effort. Family-led organizations can educate families on the model and help them determine if it's the right fit for their child and family. Provider communities and state Medicaid programs can lead efforts to collect data to monitor and evaluate the efficacy of the model and support changes where needed. And families can provide critical feedback to state leaders on opportunities to improve the model to support better outcomes for their children. Widespread adoption of the model and continued investments in evaluation and improvement will support the long-term sustainability of the model and create a pathway to expanding the model to additional populations (e.g., adults with disabilities, children with medical complexity enrolled in commercial health insurance).

State Considerations for Implementing the Family CNA Model

There are several key components of program design that states should carefully consider when they are implementing a Family CNA program. Addressing these issues will help states realize the model's full potential to improve the lives of children with medical complexity and their families. Specific steps that states should take include the following:

- **Continue addressing the long-term care workforce crisis.** To support access to the full continuum of home care services, states must continue to address broader home care workforce shortages (e.g., providing family-sustaining wages, employment benefits, and supports such as respite for *all* long-term care workers) in parallel with implementing programs like Family CNA.
- **Maintain traditional CNA and PDN options.** Family CNA programs should not replace traditional CNA or PDN services for families that wish to use those services.
- **Clearly define eligible populations and provide oversight of the program.** To best direct resources to intended population(s), states should clearly define who is eligible for family CNA services when designing the program. Strong oversight of the model, including appropriate prior authorization requirements and utilization management, is also critical.
- **Provide a family-sustaining wage and employment benefits.** Adequate compensation for family CNAs will help support overall family well-being. States should also ensure that income earned from being a family CNA does not impact the child's eligibility for Medicaid coverage. States can engage caregivers directly when defining what a family-sustaining wage is.

State Considerations for Implementing the Family CNA Model

- **Support access for families across a state's populations.** States should conduct outreach and develop informational materials to build awareness of the model. Outreach should aim to address potential language and cultural barriers. States can consider leveraging partnerships with community-based organizations and existing family CNAs to reach communities.
- **Reduce barriers to family CNA training opportunities.** States can work with home health agencies and hospitals to deliver training that is free to families and available in multiple languages and multiple modalities (e.g., remote/online training, stipends for family members to travel and take time off from work to attend training).
- **Continue to support family CNAs once they are on the job.** Ensure family CNAs have the resources and assistance they need to provide high quality care by providing adequate, accessible, and consistent clinical supervision; continuing education opportunities; and help with administrative tasks such as billing for services.

Federal Opportunities for Action

1. **CMS can establish an intra-agency workgroup to develop a standardized definition, training requirements, set of billing codes for the family CNA role and services, as well as appropriate safety and quality standards.** The intra-agency workgroup could include representatives from different offices within the Department of Health and Human Services (HHS), representing public health, older adults and people with disabilities, children's health and the health care workforce, in addition to family members, providers (including children's hospitals), and representatives from states that have implemented the model. The workgroup would be tasked with developing recommendations that could inform sub-regulatory guidance (like the guidance discussed above in state opportunity #1) on how states should define a family CNA, what skills can be delegated to a family CNA, training standards for certification or licensure, procedures for billing and quality data collection for family CNA services, and quality and safety best practices.

   Standardizing these components of the model, which currently vary state-to-state, would ease the implementation pathway for new states to adopt the Family CNA model, and support quality oversight and evaluations. Standardization across states could also prevent parents from having to retrain and recertify if they move to a new state.
2. **CMS can provide technical assistance and other supports to states in implementing and evaluating the impact of the Family CNA model on quality and cost-savings.** CMS support could take the form of a CMS facilitated state learning collaborative workgroup, which CMS has used in the past to address a range of topics, including value-based purchasing and data analytics. The collaborative could bring together states that have implemented the model with states that are in the process of or are interested in implementing the model. Experienced states would share best practices and lessons learned. The collaborative could also centralize efforts to establish an evidence base for the Family CNA model.

3. **Congress can fulfill the unrealized promises of the 21st Century Cures Act to invest in family caregiver trainings.** The Cures Act authorized the Secretary of HHS to award up to $75 million in grants, across three years, to support the education and training of family caregivers to "learn skills to empower them to be a member of a care team and compliment a clinical visit."[38] Training could include "specialized training in medication adherence and injections, complementary strategies to ensure adherence to [therapeutic] regimens and "other services provided in the home." However, the funding was not administered and has since expired.[39] Congress can reauthorize this funding and direct the HHS Secretary to fund training and credentialing of family CNAs as well as other family caregiver types.
4. **CMS can adopt the recommendation of the National Strategy to Support Family Caregivers to encourage state Medicaid programs and other insurance programs to expand community-based long-term care options that allow for the hiring of family caregivers.** As part of CMS's adoption of the National Strategy recommendation, CMS can issue guidance (e.g., through a State Medicaid Director Letter or CMCS Informational Bulletin) on state options for expanding paid family caregiving that includes the Family CNA model as one option. The guidance can also include information and recommendations for how states can operationalize the model, such as which skills to delegate to family CNAs, how to use billing code modifiers and which ones to use, templates for requesting federal authority for the model, and best practices for monitoring and evaluation of the model.

Conclusion

The United States is facing surging demand for home- and community-based long-term care, but staffing for these services cannot keep pace. This is leaving many families of children with medical complexity in a bind, forced to either utilize expensive inpatient services while they wait for an in-home nurse or CNA to be available, or to provide services to their child themselves without training and oversight and at the expense of their employment and other obligations. These do not have to be the only options for families of children with medical complexity.

Evidence shows that training, paying, and supporting family caregivers benefits children and their families, as well as the broader health care system. It ensures children receive high-quality care at home from a trained professional who is deeply committed to their well-being and can support the entire family's financial security. This is why federal support for family caregivers and efforts to strengthen home and community-based systems for older adults and people with disabilities is bipartisan and growing. States like Colorado and Arizona led the way in implementing the Family CNA model in their Medicaid programs, offering a roadmap for other states to incorporate family CNAs into their continuum of home- and community-based services available to children with medical complexity. Legislators and state Medicaid officials should seize upon this opportunity of growing bipartisan support for long-term care workforce solutions to expand access to the Family CNA model, utilizing the policy tools outlined in the "State and Federal Opportunities for Action" section above, to implement a model that works best for residents in their state.

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