Testimony 3/29/2023 by Georges Nashan, RN, BSN, MS with additional documentation in support of:

LD346 - An Act to Clarify the Requirements for Family Caregivers, and LD874 - An Act to Address the Shortage of Direct Care Workers for Children with Disabilities in Maine

My name is Georges Nashan. I've been a registered nurse for over 40 years, working primarily in the state of Maine. I've worked across the state in a variety of clinical settings and consulting roles. I'm here as a proponent of LD346 and LD874 and I am hoping that it would also extend to parents with a PSS or a CNA, as has been identified. Availability of essential home health services for children with disabilities is just not adequate and the challenge of a parent becoming an RN after they have had a child with special needs is insurmountable.

For those who are less well informed than you folks obviously are, I want to say:

We are *not* talking about paying parents to babysit their kids.

Let me say that again.

We are *not* talking about paying parents to babysit their kids.

These children have *significant* physical and emotional needs. They have extensive therapeutic modalities that the parents need to be both trained in and good enough at that they can then train the staff that do come to their home. They must be case managers. They must be personnel managers, deciding whether the nurse or the person that's taking care of your precious child is doing a safe job, whether their calling out frequently is a reflection of not being able to trust this person with your child, interacting with the agency that they're paid by to try and manage these issues. These are all things that I as a nurse manager for several years had to do, and that now my step-daughter, Andrea Dole, must do without any of that training, or pay.

She must advocate with specialists, with various agencies, and with insurance companies that are maddening for everybody. She has had to travel to Portland and Boston multiple times a year for our grandson's specialist visits and surgical procedures. These trips are often done without nursing care, because of home care agencies' limitations on paying for shift hours and out of state travel. That leaves our daughter, without any clinical training, having to remember and interpret complex treatments and therapy recommendations for the nursing staff when she returns home.

If you haven't treated an infant having a seizure, knowing that you must do the right thing at the right time and with the right amount or that child might die, then I hope you never find yourself in that situation. And yet our daughter and many of these parents are in that situation all too frequently.

These bills would utilize existing infrastructure rather than creating a new infrastructure. I realize there may be some challenges for the agencies involved, but it would be much more efficient than creating a new program.

This model is not new. Maine would not have to start from scratch in getting the necessary Medicaid waiver or developing the supporting elements. Please review the many supporting documents submitted outlining the successes of others who have gone before us.

This is not meant as an alternative to other solutions like additional out of home care or residential care, although both are desperately needed. This is meant to address much more common needs that those programs do not meet.

Thank you very much for your attention to the desperate needs of our families.

Georges Nashan, RN, BSN, MS

Please see the three documents attached below regarding other states' programs that were referenced in Andrea Dole's testimony. They help provide a roadmap for implementation.

Family CNA Program Overview

The Family CNA Program leverages nurse aides for lower acuity children and tasks, driving down total cost of care

What is Private Duty Nursing (PDN)?

Private Duty Nursing is also referred to as Continuous Nursing; frequently for patients requiring medical technology and equipment. It is meant to achieve the same level of care a patient would receive in a skilled nursing facility or hospital but at a fraction of the cost. (Average cost of daily PDN of ~$250 vs $4,000+ for hospital or SNF)

Who are the typical PDN patients?

Medicaid in every state is entitled to provide PDN for Medically Fragile Pediatric patients (under 21). Some states also cover PDN for adults. Common diagnoses include Traumatic Brain Injury, Cerebral Palsy, Chronic Respiratory Failure, etc. Patients generally receive 4-24 hours of skilled nursing per day, with the national average being ~45 hours per week. The Family CNA Program currently focuses primarily on pediatric patients only.

The Family CNA Program is a subset of Private Duty Nursing (PDN) for low acuity tasks for Medically Fragile Children

How does the Family CNA Program help?

PDN Care Continuity in the home is the #1 driver of reduced hospital admissions. When these children have their care plan executed in the home every day without fail, hospitalizations and total cost of care plummet.

The Family CNA Program takes parents, relatives or family friends, and trainsthem for free to become CNAs. They are then hired by a Home Health Agency and are paid to take on the lower acuity duties of the care plan for their child. This helps the nursing shortage by freeing up nurses to work on higher acuity children and tasks while driving down hospitalizations and cost for lower acuity children.

What is the problem with PDN for Medically Fragile Children?

Medicaid is the payor for > 80% of national PDN claims. The national nursing shortage combined with the low nature of Medicaid PDN reimbursement rates, makes it extremely difficult or impossible, to find reliable nurses to work these PDN hours given the substantial salary discount they must accept vs working in a hospital (hospital nurses able to make 25% to > 100% higher wages in hospitals).

The result is that Medically Fragile Children and their families often go without the home nursing care that Medicaid is entitled to provide for them. This generally leads to one of two scenarios when PDN is not available:

1. Hospitals/Institutions

When PDN is not available, children often remain trapped in hospitals and skilled nursing facilities at ~16 X higher daily cost than PDN

2. Unemployment/Frequent Re-Hospitalizations

If parents don't want to put child back in hospital or SNF, they are forced to try to cover the missed nursing shifts (with no proper training / oversight). This has the effect of significantly increasing the patients overall total cost of care due to frequent re-hospitalizations.

Team Select Home Care

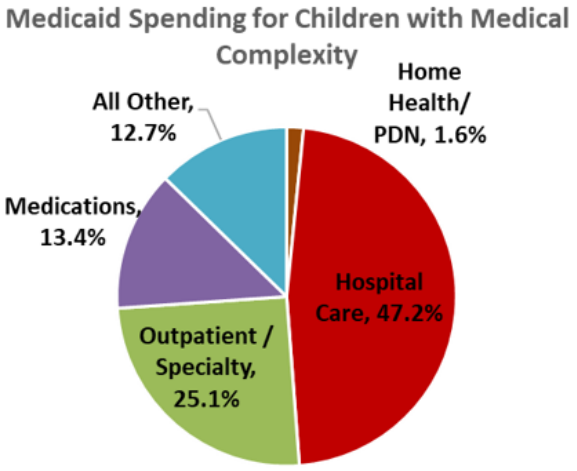
Benefits of the CNA Model

Improve Access to Care & Combat Nursing Shortage	Overcome the nursing shortage and reimbursement rate challenges by leveraging CNAs to take on lower acuity tasks delegated and overseen by an RN.
Improve Quality of Care and Outcomes	Valuable and scarce nurses are freed up to work in more supervisory roles or higher-acuity cases at top end of their licenses. Leveraging Family CNA's drives continuity of care, therefore improved quality and outcomes.
Significant Reductions in Total Cost of Care	Replacing RN/LPN hours with CNA hours drives ~30-50% savings per hour, plus data shows unplanned hospitalizations go down by ~90% due to continuity of care driven by Family CNA's vs traditional PDN.
Job Creation	Train parents and family members for free to become CNAs (with no strings attached) to fill these delegated low-acuity tasks. Full benefits package for > 30 hours per week.
Innovating the Home Health Space	Providing a program that brings a solution to areas of challenge within the home health space to ensure continuous care coordination through innovation and technology.
Making the World a Better Place for Children & Families	This program keeps families together, children safe at home, and generates income and health benefits for parents and family members.
Win-Win for All Stakeholders	Hospitals win by freeing up beds. Payors win from significant cost reductions. Parents and Families win by taking back control of their lives and generating an income. Children especially win by having consistent care from a loved one who knows them best and cares the most.

How does the Family CNA Program save money?

States that adopt the Family CNA Program will see savings of ~30-50% on every hour of PDN billed. Data also shows a > 90% reduction in unplanned hospitalizations for patients cared for under the Family CNA model vs the Traditional PDN model.

This is because Traditional PDN is plagued by the nursing shortage, making it difficult or impossible to drive consisten PDN every day. Family CNA succeeds at reducing hospitalizations because the family member never misses a shift, and that child remains stable by having their care plan executed every day.



Average Daily Costs

$800 Private Duty Nursing

$4,264 Hospital (Inpatient)

30-Day Hospitalization

0.6% Family CNA

18-21% Traditional PDN

Team Select Home Care

Lucile Packard Foundation
Children's Health

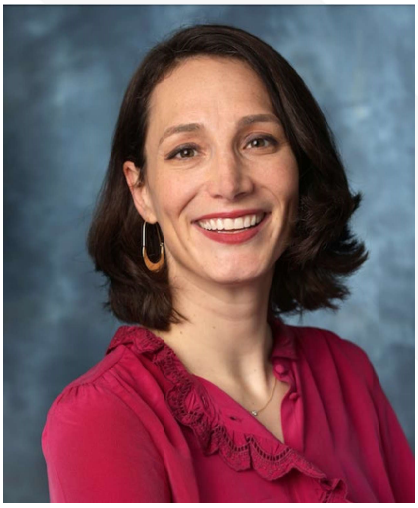
Paid Family Caregiving for Children with Medical Complexity and Disabilities

March 8, 2023

Moderator

Cara Coleman, JD, MPH
Family Voices, Policy Consultant
Bluebird Consulting, LLC.

Moderator



Carolyn Foster, MD, MS

Assistant Professor of Pediatrics at Northwestern University Feinberg School of Medicine
Attending Physician, Ann & Robert H. Lurie Children's Hospital of Chicago
@CarolynFosterMD
fosterhealthlab.com
ccfoster@luriechildrens.org

Speakers

Bill Sczepanski

VP, Government Relations
Team Select Home Care

Nannette Salasek

Health Care Systems Administrator
Raising Special Kids

Live Captioning

Select CC CLOSED CAPTIONING in Zoom **or**
Click the link in the chat to view captions

Ask Questions!

We look forward to a lively discussion with our audience.
Submit your questions through the Q&A

Welcome

Additional Information

- Recording and slides will be available.
- Submit questions in “Question & Answer” box.
- Please minimize jargon, including use of acronyms.

Overview

Pediatric home health care

Services & supplies delivered in the community setting for individuals with chronic conditions and disabilities to support independent living

Example services for activities of daily living (ADLs) and clinical tasks

- Personal care
- Home health aide
- Certified nursing assistant (CNA)
- Visiting nurse
- Shift nursing

Pediatric home health care

Medicaid Act 1967

- Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) provisions
- < 21 years entitled to medically necessary home health care services
- Obligations to provide and help arrange with reasonable promptness

Americans with Disabilities Act 1990

- Olmstead Decision 1999
- Integration mandate
- Disabled persons should have option of health care provided in the community
- Institutionalization is form of discrimination

Overview

Pediatric Home Health Care Challenges

- Wide variation in public and privately covered home health care service access[1,2]
- Insufficient hours covered, lead to extended hospitalizations & institutionalization[3,4]
- Financial cost born by families when services not provided
  - 5.6 million children received 1.5 billion hours/year of family-provided health care (2009-2010)[5]
  - $18,000 in annual lost earnings per affected US household (2016–2017)[6]
  - Averaging $14.3 to $19.2 billion lost wages in US economy/year (2016–2017)[6]

1. Berry, *JAMA Pediatrics*, 2016
2. Rasooly, *Pediatrics*, 2020
3. Mayndard *Pediatrics*, 2019
4. Sobotka *Clin Pediatri* 2019
5. Romley et al *Pediatrics*, 2017
6. Foster et al *Pediatrics*, 2021

Paid Family Caregiving

Policy option to meet patient health care needs and improve family wellbeing

- Some states have had longstanding programs, typically limited.
- Data from CO CNA program shows increased retention & equivalent care.
- Public health emergency provided flexibility to programs.
- Active legislation in some states now, varied roles and scope.
- Next step to expand programs that work for patients and families.

Family CNA Program Overview

Team Select Home Care

Private Duty Nursing (PDN)

What is Private Duty Nursing (PDN)?

Continuous care for medically fragile patients by a registered nurse or licensed vocational nurse, often delivered in the home and meant to achieve the same level of care a patient would receive in a skilled nursing facility or hospital but at a fraction of the cost. *(Average cost of daily PDN of ~$250 vs $4,000+ for hospital or SNF)*

Who are the typical PDN patients?

- Medically fragile pediatric patients (under 21) who are eligible for Medicaid
- Patients requiring medical technology and equipment
  - Common diagnoses: Traumatic Brain Injury, Cerebral Palsy, Chronic Respiratory Failure, etc.

What is the problem with PDN for medically fragile children?

- National nursing shortage
- Low Medicaid PDN reimbursement rates

The results for medically fragile children and their families:

- *Extended stays in hospitals and institutions*
- *Caregiver unemployment / Frequent re-hospitalizations*

Team Select Home Care

The Family Certified Nurse Assistant (CNA) Program

What is the Family CNA Program?

The Family CNA Program is a subset of PDN for low acuity tasks for medically fragile children.

How does the Family CNA Program help?

The Family CNA Program leverages nurse aides for lower acuity children and tasks, driving down total cost of care.

How does the Family CNA Program save money?

- Replacing Registered Nurses (RN) and Licensed Practice Nurses (LPN) with CNAs
- Reducing unplanned hospitalizations for medically fragile children

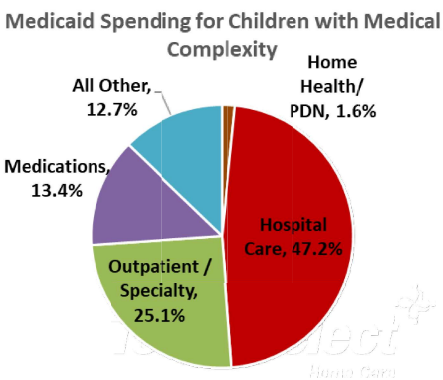
PDN Care Continuity in the home is the **#1 driver of reduced hospital admissions**.

30-Day Hospitalization

0.6%	18-21%
Family CNA	Traditional PDN

Average Daily Costs

$800	$4,264
Private Duty Nursing	Hospital (Inpatient)



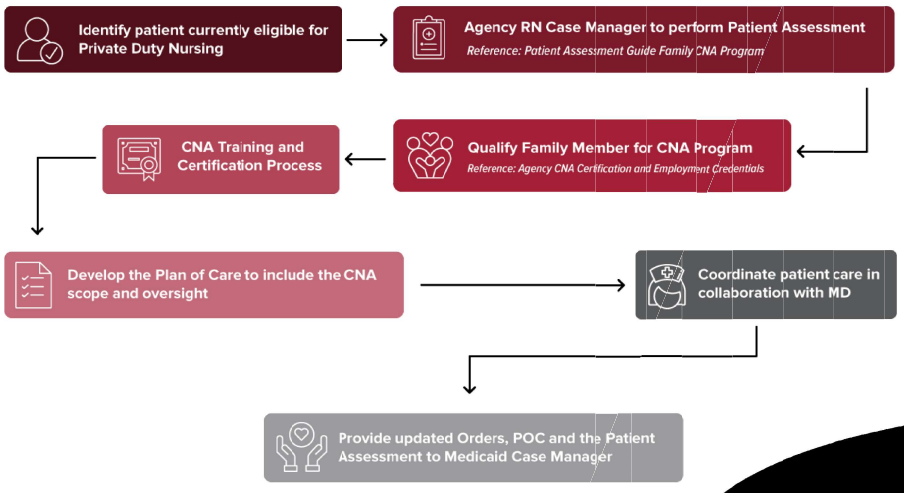
Benefits of the Family CNA Model

Improve Access to Care & Combat Nursing Shortage	Overcome the nursing shortage and reimbursement rate challenges by leveraging CNAs to take on lower acuity tasks delegated and overseen by an RN.
Improve Quality of Care and Outcomes	Valuable and scarce nurses are freed up to work in more supervisory roles or higher-acuity cases at top end of their licenses. Leveraging Family CNA's drives continuity of care, therefore improved quality and outcomes.
Significant Reductions in Total Cost of Care	Replacing RN/LPN hours with CNA hours drives ~30-50% savings per hour, plus data shows unplanned hospitalizations go down by ~90% due to continuity of care driven by Family CNA's vs traditional PDN.
Job Creation	Train parents and family members for free to become CNAs (with no strings attached) to fill these delegated low-acuity tasks. Full benefits package for > 30 hours per week.
Innovating the Home Health Space	Providing a program that brings a solution to areas of challenge within the home health space to ensure continuous care coordination through innovation and technology.
Making the World a Better Place for Children & Families	This program keeps families together, children safe at home, and generates income and health benefits for parents and family members.
Win-Win for All Stakeholders	Hospitals win by freeing up beds. Payors win from significant cost reductions. Parents and Families win by taking back control of their lives and generating an income. Children especially win by having consistent care from a loved one who knows them best and cares the most.

Team Select
Home Care

Ensuring top-quality outcomes with the Family CNA Model

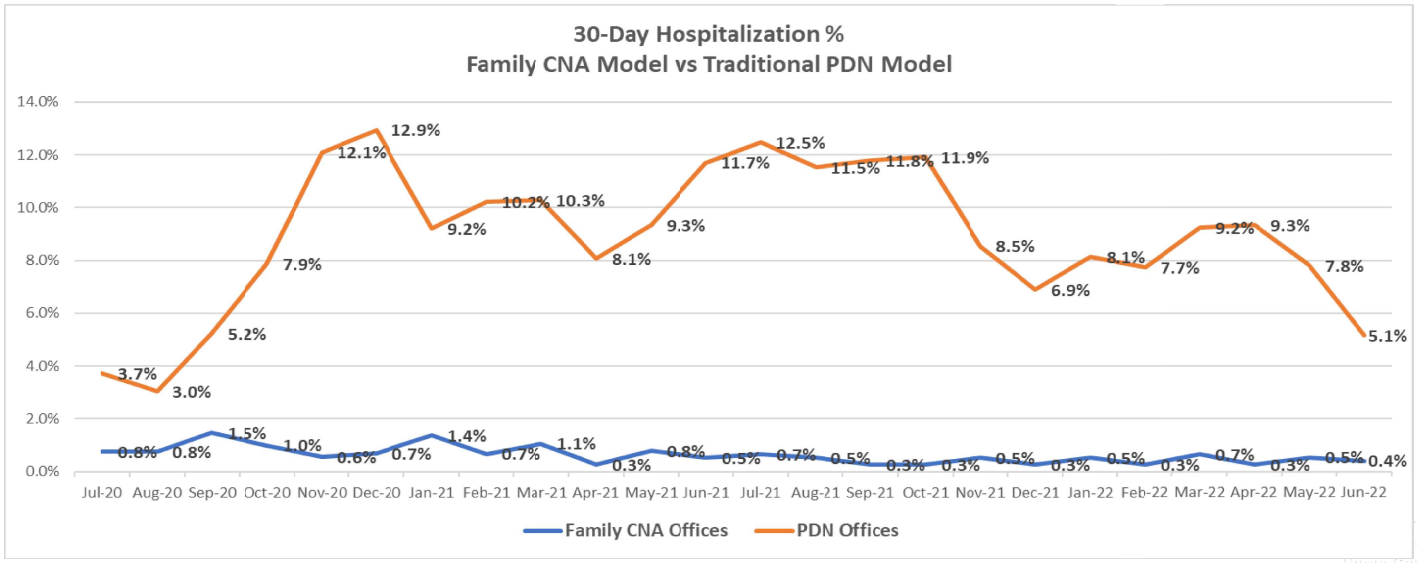
- Background Screening
- Certified CNA Training Program
- I-9 and eVerify
- Employee Training
- Initial Skills Assessment
- Competency Exam
- Ongoing RN supervisory visits



Team Select
Home Care

Team Select's Family CNA Program drives >90% lower hospitalizations than traditional PDN

A two-year-long analysis (July 2020 to June 2022) of the average monthly census 1,221 Medically Fragile Children within Team Select shows over a 90% reduction in 30-day hospitalization on average for children cared for by "Family CNA" model vs Traditional PDN (0.6% vs 8.9%)



Arizona Family Licensed Health Aide Program compared to the Pennsylvania Family Home Health Aide Program

Questions	PA	AZ
What is the name of the model?	Family Home Health Aide	Family License Health Aide
When was did this model start?	2020	May of 2022
How was this model established?	Allowed under the Public Health Emergency	Allowed under Legislation
Who can be a paid caregiver?	Anyone that the Family Choses	Parents, guardians, and family members
What benefit is this model under?	Home Health	Home Health
Any limitations?	Does not allow for delegation of skilled tasks	Limited on who can be a LHA
Challenges?	PA Medicaid believes this model Provides Personal Care. PA Medicaid believes that one the PHE is over this model must stop.	The limit on who can be a LHA. Not having a public assessment tool. Not having a standardize training.

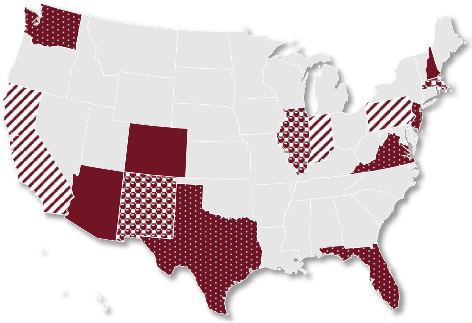
Team Select
Home Care

What do you call an aide?

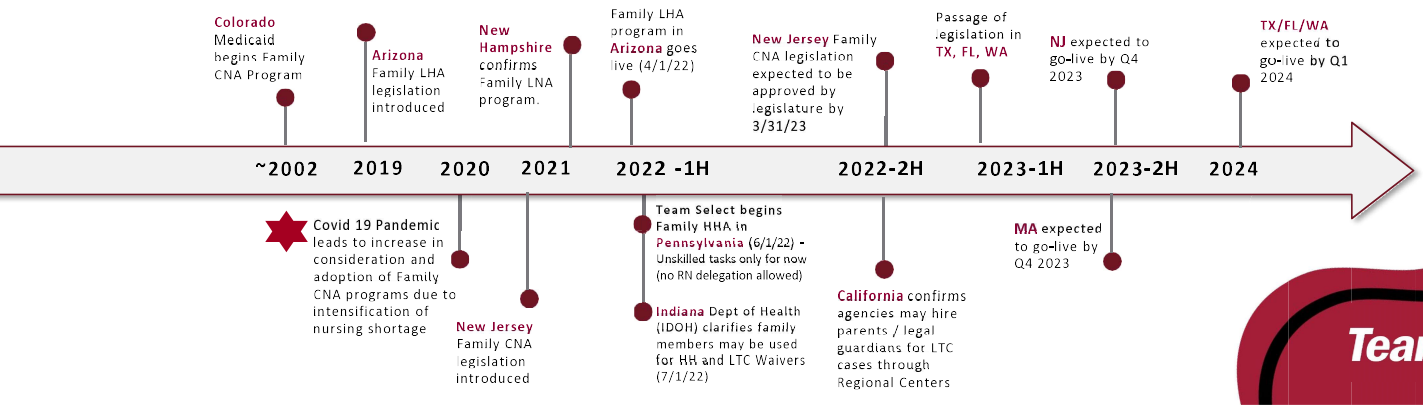
State	What Does the State Call the Model?	Active Model
CA	Certified Home Health Aide	Yes, partially
AZ	License Health Aide	Yes
CO	Certified Nursing Assistant	Yes
TX	Certified Health Aide	Legislation Pending
MT	Complex Care Assistant	Legislation Pending
IN	Home Health Aide	Yes, partially
PA	Home Health Aide	Yes, partially
NJ	Home Health Aide	Legislation Pending
FL	Home Health Aide	Legislation Pending
MA	Complex Care Assistant	Schedule to start 7/1/23
NH	License Nurse Aide	Yes

Team Select Home Care

Family CNA is gaining popularity across the country in response to the nursing shortage and pandemic



- Family CNA Active – Full Program (CO/AZ/NH)
- Family CNA Active – Limited Version of Program (CA/IN/PA)
- Legislation pending to bring program to state (WA, TX, FL, NJ, VA)
- Active lobbying underway



Team Select Home Care

Steps to Determine Adoption of the Family CNA Program in a State's Medicaid Program

Team Select Home Care

Step 1: Is there a prohibition that does not allow parents, guardians, or family members to be a paid caregiver under the Private Duty Nursing (PDN) benefit?

If yes

Go to **Step 2** to look under the home health benefit.

If no

Is the PDN a **state plan** or a **waiver plan?**

If it is a state plan, the Family CNA model will not be permitted under this PDN benefit because CMS legal opinion defines care under a state plan that can only be given by a Registered Nurse (RN) or Licensed Practical Nurse (LPN)/Licensed Vocational Nurse (LVN).

Go to the home health benefit.

If it is a waiver plan, check the provider rates to see if they're viable. If they are viable, then with the consent of Medicaid, the Family CNA Program can be implemented. If the rates are not viable, it will be necessary to work with Medicaid to ask for a rate increase from the legislature.

Team Select Home Care

Step 2: Is there a prohibition that does not allow parents, guardians, or family members to be a paid caregiver under Medicaid's home health benefit?

If yes

- Legislation will be needed to change the regulations.

If no

- Check licensing requirements for PDNs and home health providers in your state.
- Verify provider rates are financially viable.
- Obtain consent from Medicaid and potentially seek legislative approval.

****Please note accreditation by a body like CHAP, ACHC, or the Joint Commission is not a barrier for this model to work in a state.****

Team Select Home Care

Step 3: Does the state Board of Nursing (BON) allow for the delegation of skilled tasks from a Registered Nurse (RN) to a Certified Nurse Assistant (CNA)/Licensed Nurse Assistant (LNA)/Home Health Aide (HHA)?

If yes

Confirm approval for implementation of the Family CNA model with the BON.

If no

Legislation will be required to allow for the delegation of skilled tasks.

Team Select Home Care

Step 4: Does the Board of Nursing (BON) or Department of Health (DOH) allow under the scope of practice of a CNA/LNA/HHA to be delegated skilled tasks by a RN?

If yes

Confirm approval for implementation of the Family CNA model with the BON or DOH.

If no

Legislation will be needed to allow for the delegation of skilled tasks under the scope of practice for a CNA/LNA/HHA.

Team Select Home Care

Raising Special Kids

Paid Family Caregiving for Children with Medical Complexity and Disabilities

MY FAMILY STORY

RAISING SPECIAL KIDS' STATEWIDE SERVICES

Connections with a trained Parent Mentor skilled at providing information and support.

Accurate, authoritative information related to your child's disability or special health condition.

Special education consultations, training, and problem-resolution services.

Education and coaching for parents to learn the most effective methods in managing challenging behavior.

HISTORY OF LICENSED HEALTH AIDE (LHA) SERVICE IN AZ

- Collaborative effort among state agencies (Medicaid, dept. of developmental disabilities, dept. of health), the Board of Nursing, providers and other stakeholders
- Statewide nursing shortage as a motivator for home health agencies
- COVID-19 pandemic and urgency around patient safety
- LHA program not temporary or tied to the pandemic
- Approval of home health agencies' LHA training modules

LHA SERVICE

Purpose:

The program supports a path for qualified family caregivers, once licensed, to be paid to provide some skilled care to their minor children and improve access to care.

WHO CAN BE TRAINED & LICENSED

1. guardian
2. children/stepchildren
3. son/daughter-in-law
4. grandchildren
5. siblings/step-siblings
6. parents /step-parents/adoptive parents
7. grandparents
8. mother/father-in-law
9. brother/sister-in-law

LHA TRAINING PROCESS FOR FAMILY MEMBERS

- Verify child's nursing hours with state agencies.
- Contact a home health agency that offers the LHA training (typically 2-day training).
- Confirm agency's LHA training has Arizona Board of Nursing approval.
- Provide requirements: Article 9, CPR/First Aid, L1 Fingerprint Clearance, TB test.
- Submit state licensing exam fee of $50. (Fees typically covered by agency and licensure lasts two years.)

AZ LHA PROGRAM PROS

- Improves access to quality care for the child
- Presents opportunity for family members to earn a living by providing skilled care for their loved one
- Helps alleviate the nursing shortage by adding an influx of LHAs to the workforce; More RNs and LPNs available to care for higher acuity patients
- Results in significant cost savings for Arizona Medicaid and taxpayers:
  - ✓ 30-50% savings for every hour of nursing care replaced with LHA
  - ✓ Estimated average of $4264 savings per day resulting from reductions in unplanned hospitalizations of medically fragile children

AZ LHA RESTRICTIONS

- Service is limited to an Arizona Long Term Care System (ALTCS) members under the age of 21 years old.
- Members receiving services must be eligible to receive private duty nursing or skilled nursing respite care services, consistent with their plan of care.
- An LHA may only provide care to an ALTCS member who is under 21 years of age and for whom they are a parent, guardian, or family member and only consistent with that member's plan of care.

ADDRESSING CONCERNS

Objections:

- "Should parents get "paid" to care for their own children?"
- "Care is just part of being a parent."

Responses:

- Caring for a medically fragile child is not a 'typical' parenting situation. Family members are providing **nursing-level care** for their child.
- Continuity of care helps decrease hospitalizations and ultimately reduce costs to the state and other insurance providers.
- Reimbursement rates for a parent LHA are lower than private duty nursing, resulting in overall cost savings to the state.

THANK YOU!

To Refer: https://raisingspecialkids.org/refer-a-family/

Raising Special Kids

602-242-4366

800-237-3007

www.raisingspecialkids.org

Thank you

Resources

- Employing Family Caregivers: An Innovative Health Care Model
- Paying Family Medical Caregivers for Children's Home Healthcare in Colorado: A Working Medicaid Model
- Paying Family Caregivers through Medicaid Consumer-Directed Programs: State Opportunities and Innovations
- Links to examples of active state legislation and regulation:
  - OR SB 91
  - OR SB 646
  - MT HB 449
  - MA draft regulation

HHS Public Access

Author manuscript

Pediatrics. Author manuscript; available in PMC 2022 July 01.

Published in final edited form as:

Pediatrics. 2022 June 01; 149(6): . doi:10.1542/peds.2021-054273.

Employing Family Caregivers: An Innovative Health Care Model

Kristin Carter, MD, MSCS[a], **Christy Blakely, MEd**[b], **Jeannie Zuk, PhD, RN**[c], **Mark Brittan, MD, MPH**[a,c], **Carolyn Foster, MD, MSHS**[d,e]

[a]Section of Pediatric Hospital Medicine, Department of Pediatrics, University of Colorado School of Medicine, Aurora, Colorado

[b]Family Voices Colorado, Centennial, Colorado

[c]Adult and Child Consortium for Health Outcomes Research and Delivery Science, University of Colorado, Aurora, Colorado

[d]Division of Advanced General Pediatrics and Primary Care, Department of Pediatrics, Northwestern University Feinberg School of Medicine, Chicago, Illinois

[e]Mary Ann & J. Milburn Smith Child Health Outcomes, Research, and Evaluation Center, Ann & Robert H. Lurie Children's Hospital of Chicago, Chicago, Illinois

Providing high-quality care to children with medical complexity (CMC) requires more than a team of skilled physicians, nurses, and therapists. Family members also play a vital role in health care delivery. Through the considerable amount of complex health care that they provide in the home daily, family members are critical to the achievement of good health outcomes. Yet, family caregivers are not systematically valued in their role as providers of essential health care, which has significant consequences for families and society.

We describe an innovative health care model of paid family caregiving in Colorado and its effects on Ms Christy Blakely, a parent of a child with complex health needs. Ms Blakely is a professional advocate for CMC who partners on research grants with the remaining authors, all pediatric health care providers. Together, we work to evaluate how health care delivery models can achieve better patient health outcomes and support family wellness. Here, we aim to highlight Colorado's paid family caregiving model as one worthy of wider national consideration to improve the lives of children and their families.

Address correspondence to Kristin Carter, MD, MSCS, Division of Palliative Care, Ann and Robert H. Lurie Children's Hospital of Chicago, 225 E. Chicago Ave, Chicago, IL 60611. kristin.carter@northwestern.edu.
Dr Carter's current affiliation is Division of Palliative Care, Department of Pediatrics, Northwestern University Feinberg School of Medicine, Chicago, Illinois

CONFLICT OF INTEREST DISCLAIMER: Dr Brittan receives

Dr Carter and Ms Blakely conceptualized the work and drafted the initial manuscript; Drs Zuk, Brittan, and Foster conceptualized the work; and all authors reviewed and revised the manuscript, approved the final manuscript as submitted, and agree to be accountable for all aspects of the work.

LIFE AS A PARENT OF A CHILD WITH MEDICAL COMPLEXITY

Ms Blakely

Our daughter was born in 1982 at 36 weeks' gestation. She developed what was then called hyaline membrane disease and suffered oxygen deprivation, which led to cerebral palsy. She was beautiful and demonstrated high cognitive intelligence early in life but met no physical developmental milestones throughout her childhood. She required full physical care, which meant that she needed assistance with all of the activities of daily living, including feeding, bathing, dressing, toileting, transferring, and mobility.

Doing my daughter's daily care was a struggle. Though I had a master's degree in special education, I often felt as though I was certified in everything but the care of my own daughter. Our days started at 4 AM, and nearly every minute was filled with medical tasks, phone calls, or appointments. I had no option but to stop working because I could no longer commit to the requirements of a classroom teacher. Our second daughter, born 1 year later, became independent faster than most because my attention was always focused on her sister. For example, she learned to French braid her own hair at a very young age, and I found myself embarrassed when others would comment on how beautifully I had done her hair.

At age 5 years, our oldest daughter began using a wheelchair and an augmentative communication device. When she entered elementary school, we received the Medicaid Home and Community-Based Services Waiver, which allowed access to home health care that our private insurance did not cover. We were able to hire a certified nursing assistant (CNA) to come to our home in the morning to get my daughter up, showered, dressed, fed, and onto the bus. The idea was that I would then have time to prepare her sibling and myself for the day and that I could return to work. However, like other families relying on traditional, nonfamily caregiver CNAs, we struggled with frustrating gaps in services because of no-shows and overall staffing shortages that often left us without the help that we needed on short notice, such as a snow day that you don't expect.

CHALLENGES FACING FAMILY CAREGIVERS OF CHILDREN WITH MEDICAL COMPLEXITY

Dr Carter

Though Ms Blakely's story is uniquely her own, it is representative of the stories of many other families who must care for their CMC while also earning a living. CMC are children with 1 or more complex chronic conditions that result in functional limitations and/or medical technology dependence.[1] CMC typically use large amounts of health resources through long hospitalizations, complex surgeries, and the need for multiple subspecialists. Although CMC comprise only 3 in 50 children with Medicaid, they account for 1 in 3 dollars of Medicaid spending for children nationally, a massive proportion that represented US $1.6 billion in 2011.[2]

Despite this price tag, the current calculated spending on health care for CMC does not account for the substantial, daily, unpaid medical care provided by their family members,

particularly for children with neurologic impairment and medical technology dependence. For example, at least half of US family caregivers like Ms Blakely who have children with cerebral palsy spend ≥21 hours per week providing health care at home for their children.[3] Exacerbating this trend is a chronically understaffed, underfunded, and undertrained pediatric home health workforce, leading to haphazard and sometimes poor-quality home care for this underserved population.[4]

As Ms Blakely's story highlights, the need for family caregivers to provide such large amounts of complicated health care has significant consequences. Family caregivers often are not able to make time for their own health care needs and may face emotional stress and physical strain.[5] Many family caregivers must stop working outside of the home or decrease their employment hours to provide this sort of care for their children,[6] which frequently causes financial hardships for the families and detracts from the overall US workforce.

While the United States has some government policies related to unemployment, family and children, and disability and caregiver financial supports, many of those benefits are not available to parents of children with chronic conditions who are not currently employed or seeking employment.[7] Thus, there is a critical need for our health care system to:

1. value family caregivers for the crucial role they play in keeping their children well each day and achieving good patient outcomes; and
2. devise creative solutions to the simultaneous problems of family caregiver under- and unemployment and home health care workforce shortages.

COLORADO'S PAID FAMILY CNA MODEL

Ms Blakely and Dr Carter

In 2001, families, community advocates, and Colorado lawmakers collaborated to establish a program within Medicaid that would allow family members, including parents, to be paid as CNAs for their own CMC.[8] Though the program requires additional commitment and effort from the family caregiver, it values families' work and has the potential to lessen their financial hardships and decrease the time their children are hospitalized.

To participate, the child must first qualify for CNA services through an agency-administered standardized assessment tool that identifies needs for activities of daily living assistance and medical tasks. Examples of medical needs relevant to eligibility include supplemental oxygen, secretion management, tube feedings, and repositioning to prevent skin breakdown.

The family caregiver must then become a licensed CNA in Colorado by completing an approved nurse assistant training program and must also pass a written and clinical exam. After achieving licensure, the family caregiver needs to be hired by a home health care agency that provides oversight and quality assurance. Many home health agencies seeking to hire the family caregiver will assist with the cost of training and testing. The pay for family members who serve as their child's CNA is no different from traditional CNAs, typically between $13 and $17 per hour. Currently, there is no maximum number of hours that a parent can serve in this role.

Despite the expressed popularity of the program among parent-led networks, little has been published about this model, and many health care providers and eligible families are still unaware of its existence.

EXPERIENCE AS A PARENT CNA

Ms Blakely

When our daughter was born, I was taught how to place a nasogastric tube before she was discharged. Over the years, I acquired additional medical skills to meet her needs by piecing together knowledge from isolated, hospital-based skill trainings and conversations with medical equipment companies or other parents. However, I wished that I could have received more formal training to do all that I needed to do.

A friend of mine was one of the first advocates for Colorado's paid family caregiver model, and she introduced me to the program. I was amazed that I could be trained as a CNA and could then be paid to meet my daughter's health care needs, eliminating the unpredictability of traditional CNA services.

The 4-week class that I took through the home health care agency was geared toward parents becoming CNAs. It was scheduled at "family-friendly" hours, and the only costs were for the testing and licensure. The class included practical components, with several days of field experience. The field experience was somewhat scary because it mainly involved learning tasks by caring for adults, even though I really was learning so that I could care for my own child.

Despite the challenge, the CNA training was invaluable. It improved my ability to direct my daughter's care, eased the financial burden of both under- and unemployment, and decreased my overall stress. Additionally, the CNA skills were transferable to situations outside of our home. For example, I was able to share my knowledge with friends who were caring for loved ones with complex medical conditions, and I felt more prepared to care for my mother when she entered hospice.

Through my work as a professional advocate, I have also witnessed the significant benefit of Colorado's paid family CNA program for many other participants, particularly for single parents who can then stay home and care for their children. The program gives families options and flexibility.

Those options and flexibility allowed our family to successfully care for our daughter. Today, she lives in a home of her own with a partner who also has cerebral palsy. She is thriving and manages most of her own scheduling and appointments. Her physical care has become more complex, but we all take pride in her achievements.

PROGRAM CHALLENGES AND FUTURE NEEDS

Ms Blakely and Drs Carter, Zuk, Brittan, and Foster

To date, very few states have implemented models of paid family caregiving, which greatly limits the potential impact that wider adoption could have on children and families. Many

states have been slow to adopt similar models on the basis of the assumption that they require budgetary increases. In actuality, such programs represent budget-neutral options because the states' legal obligation to provide home health care benefits to eligible children does not change on the basis of whether family members or others are reimbursed for CNA services. Through the information described here and through our greater research efforts, we hope to contribute to a future in which every state has established a model of paid family caregiving.

However, parents without traditional CNA support may find themselves more isolated with little or no respite.[9] Thus, incorporating options for respite services into paid family caregiver models is essential. Furthermore, as families come to rely on the income, they may face financial insecurity with a loss of that income as the child ages or dies. Interested participating family members who acquire skills and licensure though the program should be proactively supported in leveraging future employment opportunities as CNAs elsewhere.

ADDITIONAL WAYS TO SUPPORT FAMILY CAREGIVERS OF CMC

Ms Blakely and Drs Carter, Zuk, Brittan, and Foster

We encourage all health care providers of CMC to dedicate time with their patients and families to ask about life at home. Too often, we do not step back to have the important, if difficult, conversation about what day-to-day life entails when caring for a child with high medical needs and how that might be impacting the family financially, emotionally, and physically. When those conversations do happen, we often learn that caregivers are suffering, and challenges that were already immense have only been further exacerbated by the coronavirus disease 2019 pandemic. Those conversations are the first steps in valuing family caregivers and assisting them in determining what programs might best support them.

Parent-led organizations and networks are also invaluable resources for helping families to find the combination of services that is right for them. Organizations such as Family Voices, Family-to-Family Health Information Centers, Parent-to-Parent, and Federation of Families can assist families and providers in navigating complicated Medicaid waiver information and have extensive knowledge of health care service eligibility and coverage. They are also among the strongest advocates for health care system change for CMC, including the expansion of paid family caregiver programs. We encourage all providers and the families they care for to become connected to these organizations.

CONCLUSIONS

There is a crucial need to address family caregiver under- and unemployment and home health care workforce shortages for CMC. Policy makers, advocates, providers, and health care systems should become familiar with Colorado's paid family CNA model for potential adoption locally and nationally as a budget-neutral way to address those critical issues.

To learn whether your state has or is creating a paid family caregiver program, contact your local family-driven organizations or your local American Academy of Pediatrics chapter. You also can visit the National Academy for State Health Policy for suggestions about how

to develop programs and policies that support family caregivers.[10] Together, we can work to keep children out of the hospital by supporting them and their families in the fullest ways possible.

FUNDING:

Ms Blakely's and Dr Brittan's time was supported by the Health Resources and Services Administration of the US Department of Health and Human Services under #UA6MC31101 Children and Youth with Special Health Care Needs Research Network. Dr Foster is supported under #1K23HL149829-01A1 for research related to health care of children with medical complexity. Dr Foster is supported by the National Institutes of Health under grant #1K23HL149829-01A1 for research related to health care of children with medical complexity.

ABBREVIATIONS

CNA	certified nursing assistant
CMC	children with medical complexity

REFERENCES

1. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. Pediatrics. 2011; 127(3):529–538 [PubMed: 21339266]
2. Berry JG, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings. Health Aff (Millwood). 2014;33(12):2199–2206 [PubMed: 25489039]
3. Romley JA, Shah AK, Chung PJ, Elliott MN, Vestal KD, Schuster MA. Family-provided health care for children with special health care needs. Pediatrics. 2017; 139(1):e20161287 [PubMed: 28028202]
4. Foster CC, Agrawal RK, Davis MM. Home health care for children with medical complexity: workforce gaps, policy, and future directions. Health Aff (Millwood). 2019;38(6):987–993 [PubMed: 31158008]
5. National Alliance for Caregiving and AARP. Caregivers of children: a focused look at those caring for a child with special needs under the age of 18. Available at: https://www.caregiving.org/wp-content/uploads/2020/05/Report_Caregivers_of_Children_11-12-09.pdf. 2009. Accessed May 25, 2021
6. Thomson J, Shah SS, Simmons JM, et al. Financial and social hardships in families of children with medical complexity. J Pediatr. 2016;172: 187–193.e1 [PubMed: 26897040]
7. Chua C, Bull C, Callander EJ. Income support for parents of children with chronic conditions and disability: where do we draw the line? A policy review. [Published online ahead of print November 22, 2021]. Arch Dis Child. doi: 10.1136/archdischild-2021-322663
8. Colorado Department of Health Care Policy & Financing. Parents as their child's Certified Nursing Aid (CNA). Available at: https://cdphe.colorado.gov/chronic-disease-prevention/parents-as-their-childs-certified-nursing-aide-cna. Accessed May 25, 2021
9. Sobotka SA, Lynch E, Quinn MT, Awadalla SS, Agrawal RK, Peek ME. Unmet respite needs of children with medical technology dependence. Clin Pediatr (Phila). 2019;58(11–12):1175–1186 [PubMed: 31502488]
10. Randi O, Girmash E, Honsberger K. State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid. Washington, DC: National Academy for State Health Policy; 2021