

# **Paid Family Caregiving for Children with Medical Complexity and Disabilities**

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# Moderator



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# 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<sup>1,2</sup>
- Insufficient hours covered, lead to extended hospitalizations & institutionalization<sup>3,4</sup>
- 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)<sup>5</sup>
  - \$18,000 in annual lost earnings per affected US household (2016–2017)<sup>6</sup>
  - Averaging \$14.3 to \$19.2 billion lost wages in US economy/year (2016–2017)<sup>6</sup>

1. Berry, *JAMA Pediatrics*, 2016
2. Rasooly, *Pediatrics*, 2020
3. Maynard *Pediatrics*, 2019
4. Sobotka *Clin Pediatr* 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

# 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*

# 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%**

Family CNA

**18-21%**

Traditional PDN

### Average Daily Costs

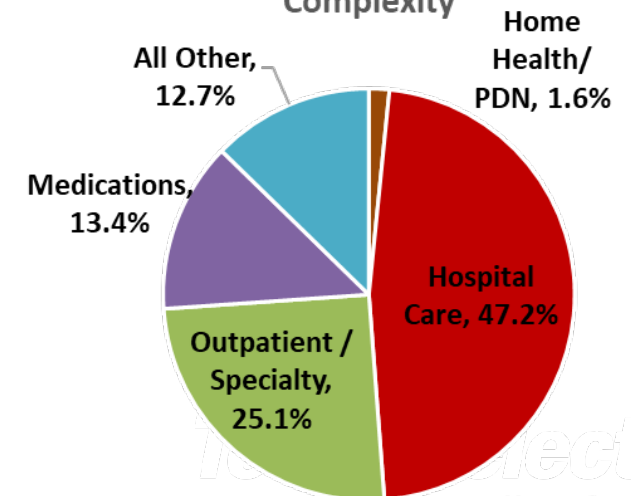
**\$800**

Private Duty  
Nursing

**\$4,264**

Hospital  
(Inpatient)

Medicaid Spending for Children with Medical Complexity



# 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.

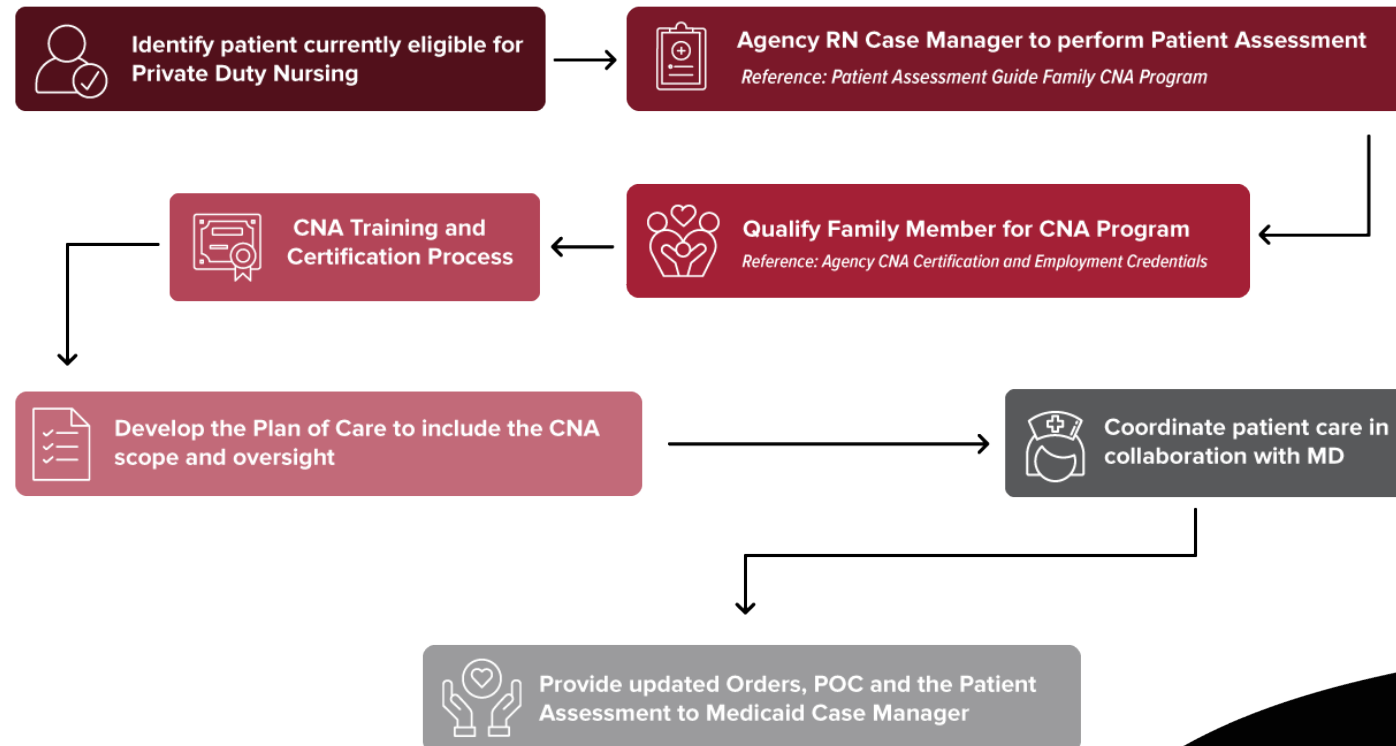


Win-Win for All Stakeholders

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.

# Ensuring top-quality outcomes with the Family CNA Model

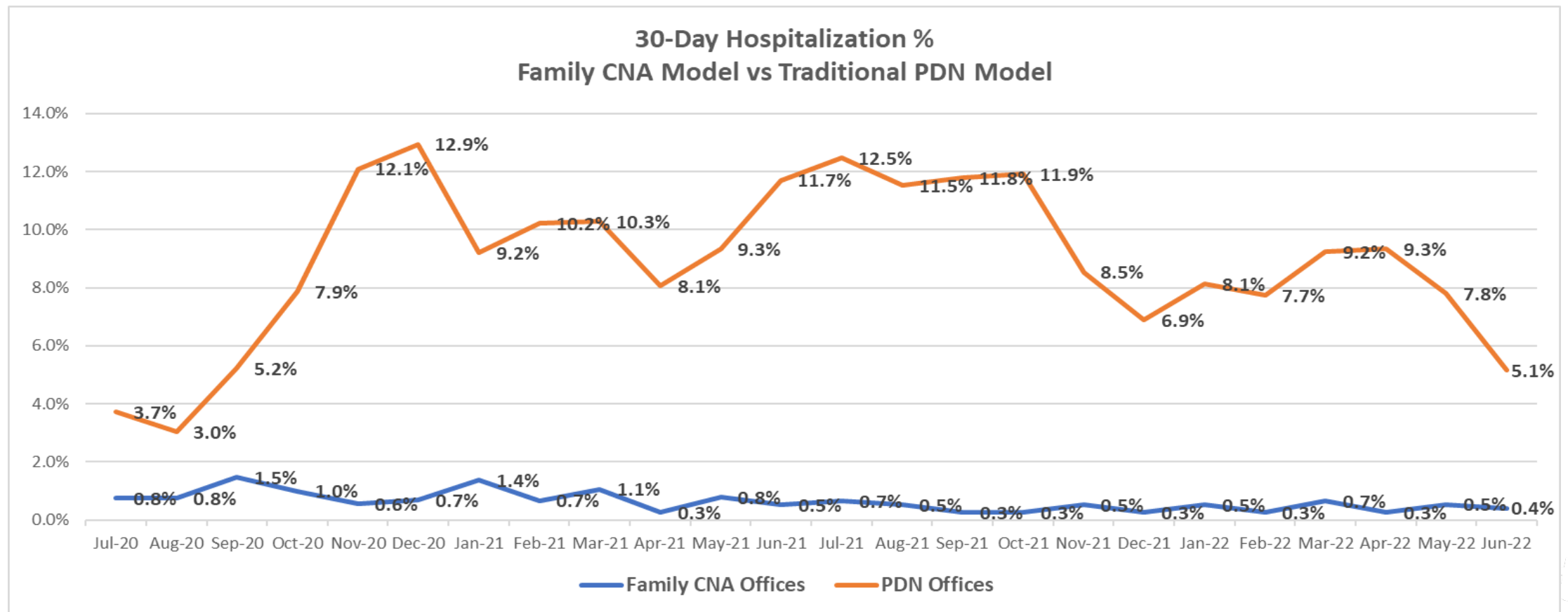
-  Background Screening
-  Certified CNA Training Program
-  I-9 and eVerify
-  Employee Training
-  Initial Skills Assessment
-  Competency Exam
-  Ongoing RN supervisory visits





# Team Select'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.

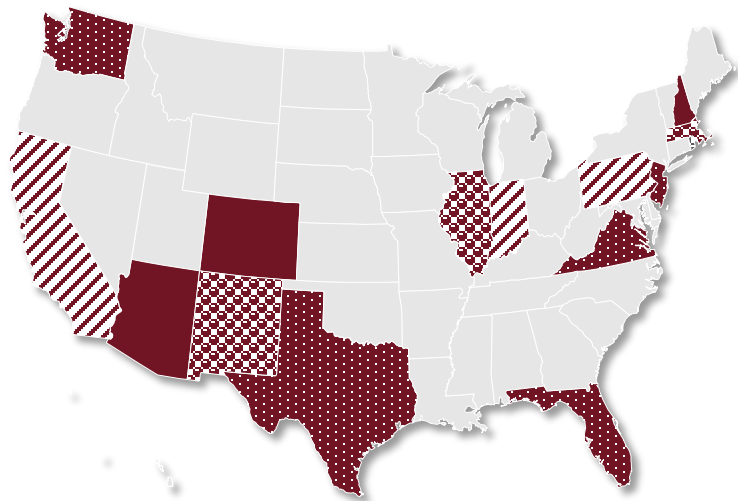





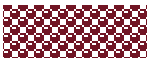


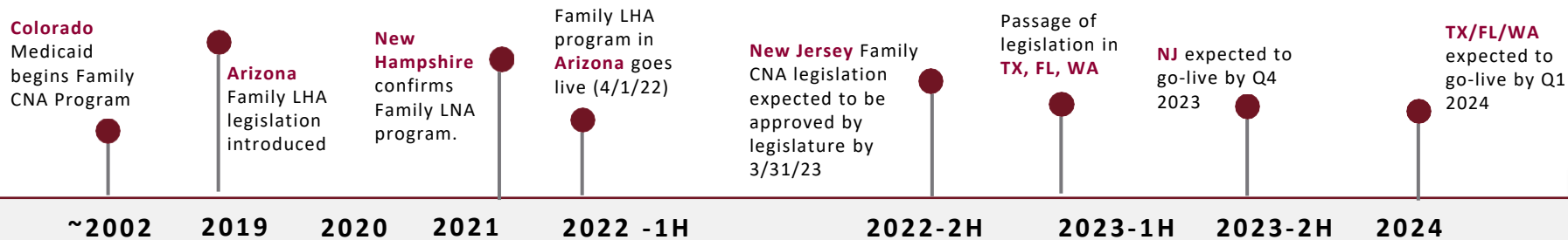
## What do you call an aide?


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

# 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



 Covid 19 Pandemic leads to increase in consideration and adoption of Family CNA programs due to intensification of nursing shortage

**New Jersey** Family CNA legislation introduced

Team Select begins Family HHA in **Pennsylvania** (6/1/22) - Unskilled tasks only for now (no RN delegation allowed)

**Indiana** Dept of Health (IDOH) clarifies family members may be used for HH and LTC Waivers (7/1/22)

**California** confirms agencies may hire parents / legal guardians for LTC cases through Regional Centers

**MA** expected to go-live by Q4 2023

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

**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 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 no

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

**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.

**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.\*\***



**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.



**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.



Raising  
Special  
Kids

Paid Family Caregiving for Children with  
Medical Complexity and Disabilities



# MY FAMILY STORY

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# RAISING SPECIAL KIDS' STATEWIDE SERVICES

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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

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- 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

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## 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

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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

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- 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.)

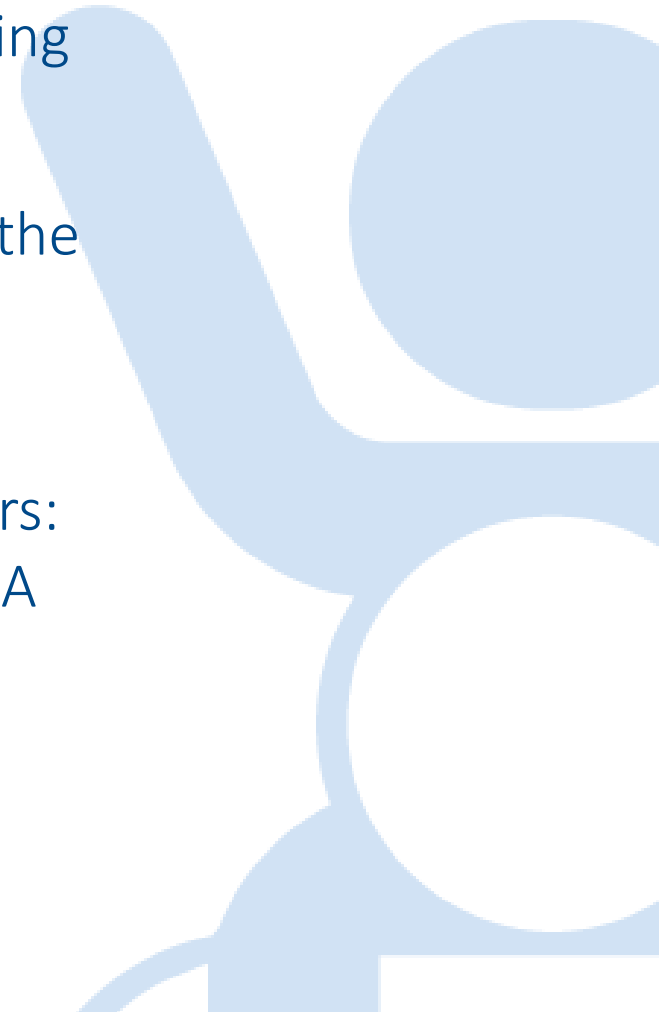




# AZ LHA PROGRAM PROS

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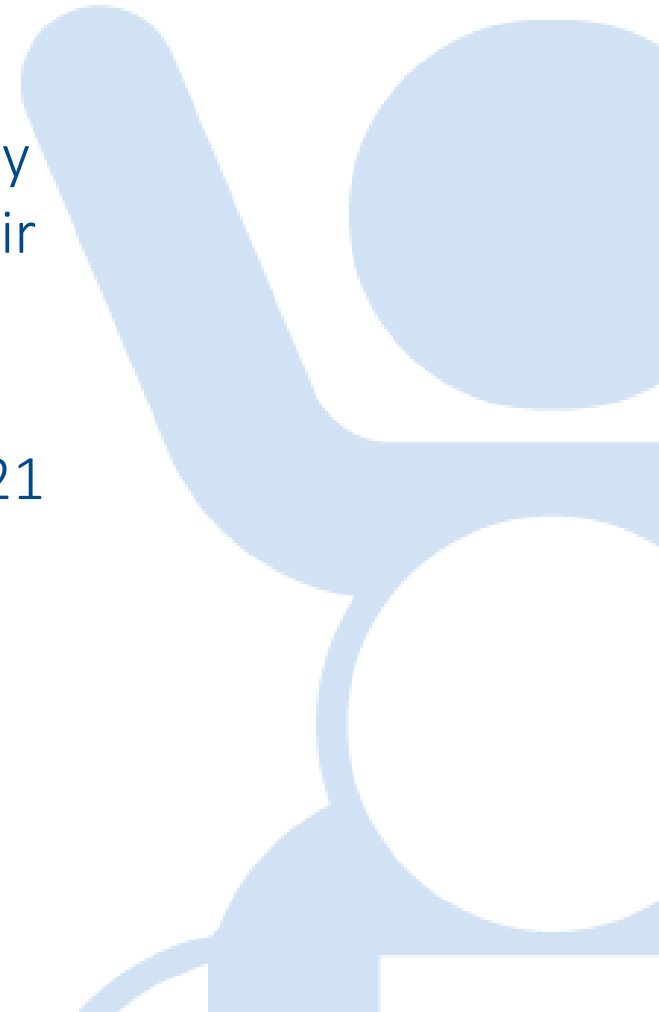
- Improves access to quality care for the child
- Presents opportunity for family members to earn a living by providing skilled care for their loved one
- Helps alleviate the nursing shortage by adding an influx of LHAs to the workforce; More RNs and LPNs available to care for higher acuity patients
- 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

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- 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

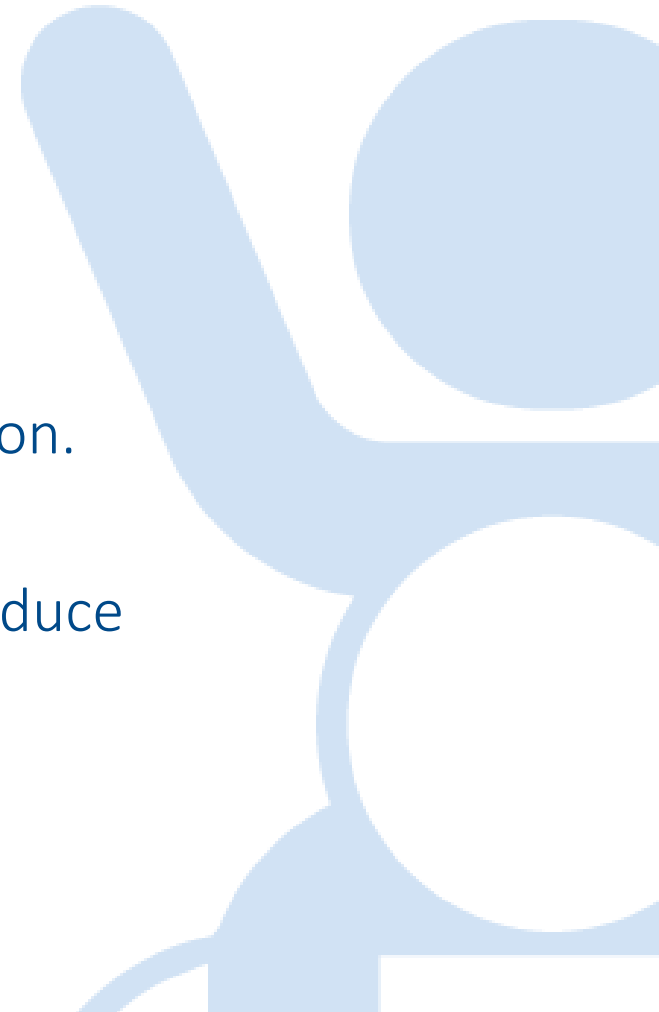
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## Objections:

- “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](http://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](#)