

## Medicaid Paid Family Caregiving for Children

This document was created in response to an overwhelming demand for resources on paid family caregiving. State laws, policies, and regulations vary greatly across the country. The information provided here reflects paid family caregiving options that are currently available or under consideration.

### Home Health Benefit and EPSDT:

States can create policies that pay families of children and youth with special health care needs (CYSHCN) as home health service providers through the home health benefit and the Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) benefit.

- Home health service provider tasks include medical assistance, like medications or g-tube feedings, in addition to activities of daily living (ADLs).
- Federal law allows for legally responsible relatives, guardians, and family members for children under 18 to provide home health services.
- Family members must get professional certification [such as Certified Nursing Assistant (CNA) or Home Health Aide (HHA)] and be employed by a home health agency.
- States may need to change or create policies to delegate nursing tasks and help families get training for certification.

**Examples:** [Colorado Family Certified Nursing Assistant](#) or [Arizona Licensed Home Health Aide](#)

### Home and Community-Based Services (HCBS) Waivers:

States can use Medicaid funds to pay families of CYSHCN for the personal care assistance they provide for ADLs through state plan options and federal Medicaid waiver authorities that allow for self-directed services.

- Family members must show that personal care provided by the legally responsible family member is deemed “extraordinary care” (such as lifting and bathing a child who does not walk), and that it is in the best interest of the child that the services are provided by the family.
- HCBS Waiver authorities:
  - [1915\(c\) Home and Community-Based Services Waiver](#)
  - [1915\(k\) Community First Choice](#)
  - [1915\(i\) Home and Community-Based State Plan Option](#)
  - [1915\(j\) Self-Directed Personal Assistance Services State Plan Option](#)
  - Also see: <http://www.hcbs-ta.org/authority-comparison-chart>

**Examples:** [Colorado Children's HCBS Waiver](#) is for children needing institutional level care, and allows legally responsible persons to be paid for “health maintenance care”; [Texas Star Kids](#) Medically Dependent Children's Program allows for payment of guardians or relatives for flexible family support while the legally responsible person is working, training, or in school.

**Note:** During the COVID-19 Public Health Emergency, the federal Centers for Medicare and Medicaid Services (CMS) gave states additional flexibilities for paid family caregiving on a temporary basis. Although the public health emergency ended May 11, 2023, in a [June 6, 2023 CMS All State Call](#), CMS officials specifically stated “We are calling on states to take advantage of these opportunities and continue these flexibilities for family caregivers.” Slides 7-13 from the call discuss paid family caregiving.

## Advocacy

How do I find out about options in my state and connect with others for advocacy?

1. Visit your state Medicaid website by clicking on this [map](#).
2. Connect with other families and family-led organizations, such as [Family Voices Affiliates](#) or [family-to-family health information centers](#) or the [National Federation of Families](#).
3. Connect with the [State Council on Developmental Disabilities](#) or [University Centers for Excellence in Developmental Disability](#) in your state.

## Legislation

Examples of current legislation for Family CNA/HHA programs:

Florida: [Senate](#) and [House](#)

Montana: [House](#)

Washington: [House](#) ([A Legislative Study on the Model](#))

Texas: [Senate](#) and [House](#)

Examples of current legislation for HCBS waiver:

Oregon: [SB646](#) and [SB91](#)  
Allow payment of parent or guardian to provide personal care to minor

## Frequently Asked Questions

Many of these answers apply regardless of where you live. Please use them as a guide and seek further information specific to your state, as variations may occur.

- 1. Are Paid Family Caregiving Programs only for biological parents of a child?**  
Depending on the program in your state, a guardian, other family members, or trusted friend/ally may be eligible to be paid to provide care.
- 2. Is money earned as a paid family caregiver taxable income?**  
Yes. Money earned is subject to federal and state taxes. If paid family caregiving is through an HCBS Waiver, however, it may not be subject to federal income tax. For more information, consult a tax or legal professional and the IRS page, [Certain Medicaid Waiver Payments May Be Excludable From Income](#).
- 3. Could earning income as a paid family caregiver for my child affect SSI and other benefits?**  
Yes. Talk with your caseworker about income and eligibility.
- 4. Do I need to have lawful immigration status and employment authorization to be a paid family caregiver?**  
Yes. Lawful status and employment authorization are required.
- 5. Once I get certification, can I provide care for children other than my own?**  
Depending on the program in your state, you may be eligible to provide care for others if/when you are no longer working to provide care for your child.
- 6. If I am already, for example, a registered nurse (RN), licensed practical nurse (LPN), licensed vocational nurse (LVN), certified nursing assistant (CNA), or home health aide (HHA), can I work as my child's provider?**  
It depends on your state and its rules. For example, [California's State Plan Amendment](#) allows relatives and legal guardians who are nurses (RN or LVN) to provide care.
- 7. Do private or commercial insurance through an employer or the marketplace have paid family caregiving programs?**  
No.
- 8. Does paying a family cost more for a state?**  
No. Studies show that it does not cost more, and it has other benefits such as continuity of care and well-being of families.
- 9. Are there limits on the number of hours I can work as a paid family caregiver?**  
Yes. Hours are determined by medical necessity of the child and labor laws in your state.
- 10. What about burnout? Families provide care 24/7 whether paid or not. Are there options for respite?**  
Use this link to help locate information about respite options where you live: [ARCH National Respite Center](#).

## Key Terms

**A legally responsible individual** is a person who has a legal obligation under the provisions of state law to care for another person, and generally includes the parents (natural or adoptive) of minor children and legally assigned caretaker relatives of minor children. A **guardian** is appointed by a court to provide care and a **legally liable relative** has duty under state law to provide care. **Relatives** are those related by blood or marriage. *All of these terms can be defined by state law.*

**Extraordinary care** exceeds ordinary care that would be provided to a child without a disability or special health care need of the same age. States must define and clearly distinguish between ordinary and extraordinary.

**Delegation of nursing tasks** is the process for a nurse to direct another (e.g., a paid family CNA) to do skilled nursing tasks (e.g., tracheostomy care or feeding tubes) that are not usually part of their role. States do this through legislation and with State Board of Nursing.

## Resources

[State Approaches to Reimbursing Family Caregivers of CYSHCN](#) | [National Academy of State Health Policy](#)

[Voices of Paid and Family Caregivers for Medicaid Enrollees Receiving HCBS](#) | [Kaiser Family Foundation](#)

[State Policy Choices About Medicaid Home and Community-Based Services Amid the Pandemic](#) | [Kaiser Family Foundation](#)