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.
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.

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.

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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.

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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