



State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs through Medicaid

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Executive Summary

States have implemented a variety of approaches to finance family caregivers through Medicaid for the services they provide to children and youth with special health care needs (CYSHCN). This report identifies special considerations for states in designing these policies to meet children's specific needs and highlights several approaches that states have taken in these efforts.

State Medicaid agencies have implemented policies that allow family caregivers to be reimbursed for the services they provide through Home and Community-Based Service (HCBS) authorities, including the:

- [1915\(c\) Home and Community-based Services waiver](#);
- [1915\(i\) Home and Community-based State Plan Option](#);
- [1915\(j\) Self-Directed Personal Assistance Services State Plan Option](#); and
- [1915\(k\) Community First Choice](#).

Through these authorities, states can enable enrollees to receive participant-directed (or self-directed) services so enrollees have decision-making authority over their Medicaid-funded services, which can include hiring and overseeing their service providers. States can design self-directed HCBS services to allow for reimbursement of family caregivers. Additionally, states can develop policies that enable family caregivers to become home health service providers who can then be reimbursed through the state home health benefit and the Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) benefit.

Family caregivers of CYSHCN face unique challenges, one of which is a lack of financial support.¹ The role of family caregivers has become more critical during COVID-19, which has created barriers for providers and licensed caregivers (e.g., home health nurses) due to social distancing requirements and infection rates. In response, Medicaid reimbursement of family caregivers has become more common as a result of emergency Medicaid waivers that strengthen home- and community-based services during a public health emergency. Policies that promote Medicaid reimbursement of family caregivers can also help alleviate home health provider workforce shortages while potentially reducing costs for the state, depending on how reimbursement rates for family caregivers are balanced against increased oversight costs. While many state Medicaid policies have focused on supporting family caregivers of adults, some states have also implemented policies to support family caregivers of CYSHCN through Medicaid. When states develop these policies to meet the needs of CYSHCN, there are additional factors to consider, including:

- Implementing multiple Medicaid authorities that allow for reimbursement of family caregivers for CYSHCN to support children with various needs who meet different eligibility criteria;
- Instituting oversight and training mechanisms to support program integrity;
- Clearly defining who is eligible for reimbursement as a family caregiver of a child;
- Tailoring the family caregivers' services available for reimbursement to the needs and conditions of CYSHCN;
- Adopting assessments that account for varying needs of CYSHCN;
- Aligning policies that allow for reimbursement of family caregivers of CYSHCN with training and support; and
- Forming collaborations with agencies that serve CYSHCN to strengthen policies that support their family caregivers.

Background

Family caregivers are an important source of home health services, though they are often not compensated for the skilled and non-skilled care that they provide.² These caregivers provide about 1.5 billion hours of health care to about 5.6 million CYSHCN annually in the United States.³ If these services were instead provided by a home health aide, they would cost an estimated \$11.6 to \$35.7 billion per year.⁴

Through the EPSDT benefit, state Medicaid agencies are required to provide children under age 21 with all Medicaid services that can be covered through federal Medicaid law.⁵ Yet, states face challenges in delivering personal care and home health services to CYSHCN due to workforce shortages of home health aides, personal care aides, nursing assistants, and other health providers.⁶ Reimbursement can be an incentive for family caregivers to provide more comprehensive services than they are otherwise able to deliver due to time and budget constraints, which can help to alleviate these challenges.⁷

State policies often reimburse family caregivers as individuals rather than through provider agencies. While this may be financially beneficial for states as the reimbursement rates for individuals can be lower than for agency-provided care due to reduced administrative costs, states may incur costs in implementing adequate oversight and quality assurance mechanisms for family caregivers.⁸ Still, these policies are an important service option to support family choice and quality care as Medicaid-funded family-provided care may reduce hospital utilization while also improving health outcomes.⁹

Methodology: The National Academy for State Health Policy conducted a literature scan, including national publications, journal articles, and state reports, Medicaid waivers, health plans, and legislation related to state funding of services provided by family caregivers to children. State health officials from Alabama, California, Connecticut, Idaho, and Texas provided guidance and insights on this topic during a project advisory committee meeting in May 2020.

State Medicaid and Children’s Health Insurance Programs (CHIP) play important roles in covering health care services and supports for CYSHCN. As of 2017, Medicaid and CHIP completely or partially covered about 47 percent of CYSHCN. Medicaid and CHIP-covered CYSHCN are disproportionately Black or Latinx,* 27 percent and 30 percent, respectively. CYSHCN who are White are more likely to have private insurance (65 percent) or both private insurance and Medicaid/CHIP (45 percent).¹⁴

Over the past several decades, Medicaid policy has shifted to prioritize providing services for CYSHCN in the home rather than in facilities whenever possible. In the 1980s, Katie Beckett, a child with encephalitis who was hospitalized for several years, drew attention to CYSHCN who were required to remain in institutional care or risk losing their Medicaid eligibility. The resulting Tax Equity and Fiscal Responsibility Act (TEFRA) state plan option was a first step toward expanding Medicaid reimbursement for home-based care for CYSHCN.¹⁵ All 50 states have implemented a TEFRA state plan option or a comparable waiver.¹⁶ As a result of the 1999 Supreme Court *Olmstead vs. L.C.* decision, Medicaid programs are now required to cover services for people with disabilities in the community rather than institutions when it is appropriate, the person does not oppose it, and when it can be reasonably accommodated.¹⁷ While this shift has improved the quality of care for many children, families have become increasingly relied upon to provide services, often without adequate support or reimbursement.¹⁸

The Impact of Family Caregivers

Nearly half of CYSHCN receive family-provided health care at home. CYSHCN who are Black or Latinx* are more likely to receive family-provided care at home (51 percent and 52 percent, respectively), while 48 percent of CYSHCN who are White reported receiving this type of care.¹⁹ Family caregivers of CYSHCN tend to face financial challenges due to reduced or lost employment, and forego an estimated total of \$17.6 billion in earnings per year.²⁰ Those most likely to receive a significant amount of care, defined as 21 hours per week or more, “were Hispanic, lived below the federal poverty level, had no parents/guardians who had finished high school, had both public and private insurance, and had severe conditions/problems,”²¹ according to a 2017 report published in the journal *Pediatrics*.

Children who have more than one special health care need are more likely to receive family-provided care.²² Family caregivers of children with medical complexity (CMC), a subset of CYSHCN who have significant needs beyond those of other CYSHCN and comprise 0.4 percent of children in the United States, are more likely to provide a significant amount of care than

Children and Youth with Special Health Care Needs (CYSHCN): CYSHCN are those who “have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”¹⁰ These children account for nearly 20 percent (13.8 million) of children under the age of 17.¹¹ In comparison to other racial and ethnic groups, special health care needs are most prevalent among children who are Black and children who are American Indian or Alaskan Native, with prevalence rates of 25 percent and 24 percent, respectively. Children who are Black represent 18 percent of CYSHCN, while accounting for 12 percent of all children.¹² These children, as well as those who are Latinx,* are more likely to have unmet health care needs and to receive lower quality primary care than CYSHCN who are White.¹³

caregivers for other CYSHCN.²³ Nearly 80 percent of families of CMC spend five or more hours per week providing medical care at home, and this is more than twice as common for families who are non-White and Latinx.*²⁴

In comparison to caregivers of adults, family caregivers of CYSHCN face unique challenges. Caregiving for CYSHCN often involves complex medical care, including technical medical equipment tasks (e.g., adjusting feeding tubes), occupational therapy, and symptom monitoring and management.²⁵ These caregivers tend to rate their health more poorly, more frequently report enduring physical strain, and are more likely to face financial hardship.²⁶ Many caregivers of CYSHCN have reported a need for information related to managing stress, finding time for oneself, and balancing work and family responsibilities, among other topics.²⁷ There are a number of ways that states can support family caregivers. Training, education, and respite services are important supports that are often lacking in availability and quality.²⁸ However, family caregivers of CYSHCN have reported that policies that offer financial support for the caregiving they provide are their most crucial need.²⁹

The COVID-19 pandemic has underscored the important role that family caregivers play in providing home- and community-based services to CYSHCN. One way that states have addressed the increase in provider shortages during the pandemic due to social distancing requirements and infection rates is through policies that implement or expand Medicaid reimbursement for family caregivers.³² These policies may provide important mechanisms to increase the home health provider workforce and support continuity of care for CYSHCN while reducing costs for the state. They may also serve as an important financial support for families of CYSHCN, even more of whom may face employment insecurity due to a lack of provider availability. Given that children who are Black and/or Latinx* are more likely to receive unpaid family-provided care, be enrolled in public health insurance, and have been impacted by the COVID-19 pandemic, Medicaid programs have a unique opportunity to support children's health by considering policies that cover services provided by family caregivers.³³

The Recognize, Assist, Include, Support, and Engage Family Caregivers (RAISE) Act: The RAISE Act (42 USC 3030s), passed in 2018, requires the US Department of Health and Human Services (HHS) to develop a national strategy to support family caregivers of children and adults.³⁰ The act also formed the RAISE Family Caregiving Advisory Council to develop recommendations to inform the strategy developed by HHS, including a report that identifies effective models to support family caregivers.³¹ Support for family caregivers is clearly a federal priority, as demonstrated by the development of a national strategy and the formation of this advisory council. The national strategy may result in further opportunities for states to increase support for family caregivers based on best practices.

Medicaid Options for Funding Family Caregiver Services for CYSHCN

Historically, researchers and policymakers consider family caregivers to be those who help with activities of daily living (ADL), such as bathing, dressing, transferring and instrumental activities of daily living (IADL), such as shopping, cooking, and laundry.³⁴ ADLs and IADLs are often covered by personal care services, a state plan benefit under Medicaid.³⁵ However, federal

regulations prohibit legally responsible relatives from being paid family caregivers for state plan personal care services.³⁶

Instead, states can use Medicaid funds to pay family caregivers of CYSHCN for the assistance they provide with ADLs and IADLs through state plan options and federal Medicaid waiver authorities that allow for participant-directed (also referred to as self-directed) services. Through these options, Medicaid enrollees or their representatives have “employer authority” and are able to choose who provides their Medicaid-funded services, which may include a family caregiver. States have the option to allow or prohibit services to be provided by legally responsible persons, legally liable relatives, legal guardians, and/or relatives. However, to be eligible for reimbursement, a state must establish that personal care or similar services provided by legally responsible persons are deemed “extraordinary care” and that it is in the best interest of the child that the services are provided by a legally responsible person.³⁷ States may also grant “budget authority,” through which children or their representatives can allocate funds for services provided by family caregivers.³⁸

Policymakers increasingly recognize that family caregivers also provide services beyond ADLs and IADLs, including medical assistance tasks such as administering medications and injections.³⁹ When provided in the home, these services may be considered home health services, which are federally defined to include nursing services, medical supplies and equipment, and home health aide services, physical and occupational therapy, speech pathology and audiology services provided by a home health agency.⁴⁰ These services may be covered by states’ mandatory Medicaid State Plan Home Health benefit and by the EPSDT benefit if the services are deemed medically necessary.⁴¹ Federal regulations do not prohibit legally responsible relatives from providing home health services for family members. However, it is uncommon for family caregivers to be reimbursed under this benefit because most states do not allow participant direction for this benefit, and because these services often require providers to have professional qualifications and to be employed by a home health agency.⁴²

Participant-Directed Service Terms and Policy Considerations

The following terms are frequently used within participant-directed services, and are important for states to understand when developing policies to reimburse family caregivers of CYSHCN.

- **Participant-directed (or self-directed) services** are those that provide Medicaid enrollees or their legal representatives with “decision-making authority over certain services” and grants them “direct responsibility to manage their services with the assistance of a system of available supports.”⁴³
- **Employer authority** is granted to all Medicaid enrollees who self-direct their services. This makes consumers the employers, and they or their representatives have decision-making authority over those who provide services, including the ability to “recruit, hire, train, and supervise” the employee.⁴⁴ Through some Medicaid authorities, states can choose to grant authority over specific employer functions. For example, some states may choose to allow participants to recruit and supervise staff, but not to hire or train staff.
- **Budget authority** can be granted to Medicaid consumers who enroll in participant-directed services at the state’s option. This authority provides enrollees with a specified

amount of Medicaid funds that children or their representatives can use for approved goods and services.

- **Legally responsible person or individual** is defined as “a person who has a legal obligation under the provisions of state law to care for another person. Legal responsibility is defined by state law, and generally includes the parents (natural or adoptive) of minor children, legally assigned caretaker relatives of minor children, and sometimes spouses.”⁴⁵
- **Extraordinary care** is defined as care that exceeds ordinary care that would be provided to a person without a disability of the same age.⁴⁶ States that choose to reimburse legally responsible persons for personal care or similar services they provide to CYSHCN must develop criteria and specify their method for distinguishing between extraordinary and ordinary care.⁴⁷
- **Legally liable relative** is defined as “persons who have a duty under the provisions of state law to care for another person.”⁴⁸ This group is similar to the “legally responsible person” category of family caregivers.
- **Legal guardian** is defined as “a person who has been appointed by a judge to take care of a minor child or incompetent adult (both called ‘wards’) personally and/or manage that person’s affairs.”⁴⁹
- A **relative** is any individual related by blood or marriage. States may choose to more narrowly define this term within their Medicaid state plans or waivers.⁵⁰ This is generally the broadest category of family caregivers that states can prohibit from reimbursement.
- A **legal representative** is “a person who has legal standing to make decisions on behalf of another person (e.g., a guardian who has been appointed by the court or an individual who has power of attorney granted by the person).”⁵¹ A legal representative will often be designated as a decision-making authority for a child’s self-directed services.

There are multiple Medicaid authorities that states can pursue to reimburse family caregivers for services they provide to CYSHCN. Most of these options are through the Home and Community-based Services authorities including the:

- [1915\(c\) Home and Community-based Services waiver](#);
- [1915\(i\) Home and Community-based State Plan Option](#);
- [1915\(j\) Self-Directed Personal Assistance Services State Plan Option](#); and
- [1915\(k\) Community First Choice](#) option.

These authorities require services to be provided to Medicaid enrollees in accordance with a plan of care and informed by an assessment. States are allowed to set individual budget limits and are required to offer financial management services to all participants who self-direct their services.

States have also obtained 1115 Research and Demonstration waivers, as well as emergency waivers in response to COVID-19, that allow for the reimbursement of family caregivers of CYSHCN or modify the provisions of existing policies. Additionally, states have developed policies to facilitate reimbursement of family caregivers through their Medicaid State Plan Home Health benefit. While some features are common across Medicaid options, such as the ability for states to choose whether to allow the participant to employ family members, they differ in several key ways (see **Chart: Medicaid Authorities that Fund Family Caregiver Services for Children and Youth with Special Health Care Needs** for a summary of features of Medicaid authorities that allow for reimbursement of family caregivers). In addition to determining the

appropriate federal waiver authority, states must also make programmatic decisions about the services that are reimbursable, how eligibility is determined, provider requirements, and other features that shape the policies that reimburse family caregivers of CYSHCN.

Medicaid Authorities that Reimburse Family Caregivers of CYSHCN

1915(c) Home and Community-based Services (HCBS) Waiver

The 1915(c) HCBS waiver is the most common authority that states use to offer participant direction for home and community-based services.⁵² Forty-seven states and Washington, DC have implemented one or more HCBS waivers, and most of these states offer participant-directed services through at least one of these authorities.⁵³ States can use HCBS waivers to reimburse family caregivers for selected medical and non-medical services provided to CYSHCN, including case management, homemaker services, personal care, habilitation to support individuals with disabilities to develop and maintain skills and functioning for daily living, and respite.⁵⁴ To be eligible for HCBS waiver services, including those provided by family caregivers, federal law requires children to qualify for an institutional level of care and meet other requirements that the state has designated in the waiver's target population. States have used the HCBS waiver more frequently because it allows for more control over the cost of services by permitting states to limit the number of people who receive services, the geographic area served, and the amount and scope of services.⁵⁵

- In **Colorado**, children can receive services from paid family caregivers through the 1915(c) Children's Home and Community-based Services (CHCBS) waiver. Case managers determine children's eligibility for CHCBS waiver services using the [Uniform Long-Term Care-100.2 intake assessment form](#).⁵⁶ Services that can be participant-directed are limited to "health maintenance activities" that includes skin care, nail care, mouth care, dressing, feeding, exercise, transferring, bowel care, bladder care, medical management, and respiratory care.⁵⁷ These activities are typically performed by professionals such as certified nursing assistants (CNAs), licensed practical nurses (LPNs), or registered nurses (RNs), but Colorado has waived this requirement for this program.⁵⁸ The waived requirement reduces qualification barriers for family caregivers, including legally responsible persons and legal guardians, who are eligible to be reimbursed for the services they provide. Colorado's waiver limits participants' employer authority by excluding the ability to directly hire staff. Instead, caregivers are registered as attendants through a local in-home support service agency that oversees hiring, onboarding, training, and service quality in partnership with the child and legal representative.⁵⁹ The child must also have an authorized representative to support management of the participant-directed services, and this representative cannot also be the paid caregiver.⁶⁰
- **Texas's** 1915(c) waiver for the Medically Dependent Children Program (MDCP) offers community-based services for medically fragile children and youth under age 21 who are financially eligible for Medicaid, meet the institutional level of care need as determined by the Texas Health and Human Services Commission and the state's Medicaid agency, and have an unmet need for one or more MDCP service.⁶¹ Medical necessity is determined by the [STAR Kids Screening and Assessment Instrument](#) completed by a

Medicaid managed care organization (MCO) or service coordinator.⁶² Through the MDCP, relatives and legal guardians can be reimbursed for providing flexible family support services and respite.⁶³ Family caregivers must be 18 or older, have a high school diploma or equivalent, complete cardiopulmonary resuscitation (CPR) and first aid certification, and pass criminal history checks.⁶⁴ Flexible family support services (FFS) may only be used when the child's primary caregiver and/or legally responsible person is working, attending job training, or attending school. FFS services promote an enrollee's participation in childcare, independent living, and post-secondary education and include personal care supports for daily living and instrumental activities of daily living, skilled care, and non-skilled care. Legally responsible individuals cannot be reimbursed for personal care or similar services. To match what the state would pay if the enrollee was in institutional care, all MDCP members must have a service plan within 50 percent of the cost the state would pay if the member was served in a nursing facility.⁶⁵ For MDCP members with needs that exceed the cost limit, the state maximizes the use of state plan services, examines third-party resources, considers transitioning to another waiver, or offers institutional services.⁶⁶

1915(i) Home and Community-based State Plan Option

The 1915(i) Home and Community-based state plan option allows participant direction as an option for HCBS.⁶⁷ It is similar to the 1915(c) waiver in terms of allowable services, the ability to target services to specific populations, and the required individualized assessment and plan of care. This state plan option differs in that it does not require an institutional level of care for participants to be eligible, and states cannot limit the number of participants or the geographic service area.⁶⁸ While several states allow respite services to be provided by relatives through this state plan option, few states allow family caregivers to be paid directly for services.⁶⁹

- **California's** 1915(i) state plan option is targeted to serve individuals with developmental disabilities. In addition to respite services, the state plan option allows participant-directed services that can be provided by family caregivers, including skilled nursing and non-medical transportation, and community-based training services.⁷⁰ Relatives and legal guardians may receive payment for all 1915(i) services as long as they meet the specified provider qualifications, but legally responsible relatives are ineligible.⁷¹ To be reimbursed for skilled nursing services, family members must be a registered nurse or licensed vocational nurse. Individuals providing respite services must be CPR- and first aid-trained. Family caregivers are overseen and paid by regional centers, monitored by the Department of Health Care Services (DHCS) and the Department of Developmental Services. Provider rates are determined by three methods:
 - Matching the rate regularly charged by a regional vendor;
 - Following the DHCS fee schedule whereby rates are established by the state Medicaid agency; or
 - By capping provider rates based on the regional center or statewide median rate.⁷²

1915(j) Self-Directed Personal Assistance Services State Plan Option

The 1915(j) Self-Directed Personal Assistance Services state plan option can be used to allow participant-directed personal care services through a state's existing 1915(c) waiver or through the optional state plan personal care services, which 34 states had implemented as of 2018.⁷³

Participants are only required to meet an institutional level of care need if the state plan option is applied to a 1915(c) waiver. The 1915(j) authority does not require statewide application and the state can limit the number of participants. States can only target a specific population if they are using this authority in conjunction with a 1915(c) waiver. States can opt to provide cash payments to participants to pay for their goods and services, and the 1915(j) waiver is the only authority that requires budget authority for participants.⁷⁴ In addition to offering financial management services, states must offer “support brokers and consultants” to help develop service plans and monitor a participant’s budget management, among other support functions.⁷⁵

- **Florida’s** 1915(j) state plan amendment creates the option for self-direction of state plan personal care services for children enrolled in their 1915(c) Developmental Disabilities Individual Budgeting (iBudget) Waiver and through their State Plan personal care services.⁷⁶ The state’s 1915(j) amendment allows individuals, including children under 21 years of age, who are enrolled in the iBudget waiver to enroll in the state’s Consumer Directed Care Plus (CDC+) program to access participant-directed services.⁷⁷ Florida opted to allow legally liable relatives to serve as paid caregivers of eligible enrollees including CYSHCN through this benefit. To reduce program integrity risks, all participants are able to assign an unpaid representative to manage the services and budget. Florida also provides training to all Medicaid participants regarding program integrity risks and the role of support coordinators. Waiver support coordinators review and approve the service plan budgets and assess the enrollee’s or their representative’s management capacity.⁷⁸
- **California’s** In-Home Support Services (IHSS) allows for participant direction of personal assistance services for CYSHCN through three Medicaid authorities, one of which is the 1915(j) state plan amendment.⁷⁹ This authorizes California’s IHSS Plus Option (IPO), which serves children who do not meet the nursing facility level of care need but would like a legally liable relative to provide services.⁸⁰ The state collaborates with county health departments to administer IHSS, including conducting assessments to determine a child’s eligibility and the number of hours allotted for IHSS. Through these assessments, county social workers also determine whether other eligibility requirements are met including legally liable relatives’ inability to gain or sustain full-time employment due to the child’s needs. The assessor must also determine that, without the legally liable relative’s care, the child would face “inappropriate placement or inadequate care” due to a lack of appropriate providers or other legally liable adults who could provide services.⁸¹ Counties also serve quality assurance and oversight functions, including conducting desk reviews to assess the accuracy of financial reports, home visits, and verification of services.⁸²

1915(k) Community First Choice State Plan Option

The 1915(k) Community First Choice state plan option requires that states’ delivery models offer at least some consumer control over service delivery. One delivery model that states may choose is the self-directed model with a service budget (budget authority).⁸³ Participants must meet the institutional level-of-care requirement to be eligible for services through this state plan option. This authority requires that states provide coverage of:

- ADLs, IADLs, and health-related tasks;

- Support for the individual to acquire skills necessary for ADLs and IADLs;
- Systems to ensure continuity of services; and
- Voluntary training for the participant for selecting, managing, and dismissing staff.

States may also choose to cover fiscal management services, costs of transitioning from an institution to the community, and “expenditures relating to an identified need that increases his/her independence of substitutes for human assistance.”⁸⁴ This state plan specifically excludes legal representatives from also being the paid caregiver.⁸⁵

States determine their own method for allocating individual service budgets and are allowed to provide direct cash payments to participants. This option does not allow states to limit the number of participants. As an incentive, services under this option are provided a six-percentage point federal medical assistance increase.⁸⁶

- **Connecticut’s** 1915(k) state plan aligns with the self-directed model and allows family caregivers of CYSHCN to provide attendant care to support ADLs and IADLs unless they are also the child’s legal representative or legal guardian.⁸⁷ The state allocates individual service budgets by categorizing participants into one of eight groups based on the needs assessment results. Children or their legal representatives set all hiring qualifications for their attendants, except that the provider of services to support the acquisition of skills for health-related tasks must be a registered nurse, occupational therapist, physical therapist, or speech therapist.⁸⁸ As an optional support, the state’s Department of Public Health provides medical task training for family caregivers to support the provision of more advanced services.⁸⁹
- **California’s** IHSS also offers a participant-directed program option through a 1915(k) waiver. Children enrolled in the 1915(k) program can receive services from relatives, including those who are legally liable. However, unlike the IHSS IPO program option through the 1915(j) state plan amendment, they must meet a nursing facility level of care need, in compliance with federal regulations.⁹⁰ Through all IHSS program options, children are eligible for up to 283 hours per month of services that are organized into service categories. If services are provided by a legally liable relative, the child is eligible for services within five categories: services related to domestic services, personal care services, accompaniment to medical appointments, protective supervision, and paramedical services.⁹¹ If services are provided by a family caregiver who is not a legally liable relative, the child is eligible for three additional service categories: heavy cleaning, yard hazard abatement, and teaching and demonstration. Another IHSS service category, domestic services, is only available to adults.⁹²

Section 1115 Research and Demonstration Waivers

The Section 1115 Research and Demonstration waiver is the most flexible authority that states can utilize to provide funding for family caregivers through Medicaid. In comparison to the HCBS waivers and state plan options, there are few requirements that states must meet in their design of their Section 1115 waiver. States have discretion to select the waiver services that Medicaid can reimburse, including those provided by family caregivers, the eligibility categories, and whether to target specific groups or limit the number of people served by the authority. This authority is also the most flexible for family caregivers, as it is the only path that does not require

an agreement between service providers and the state Medicaid agency, and it is the only authority that can be used to offer prospective payments to family caregivers.⁹³

Several states use Section 1115 waivers to provide financial support for family caregivers. Tennessee’s Medicaid agency tailored its Section 1115 waiver to include policies specific to family caregivers of CYSHCN. Through Tennessee’s Supportive Home Care (SHC) benefit, family caregivers can be reimbursed for services as long as they do not live in the child’s home.⁹⁴ In lieu of receiving SHC, the waiver program offers family caregivers who live with the child and provide needed daily assistance a stipend of up to \$500 per month.⁹⁵

Home Health State Plan Benefit

States’ Medicaid State Plan Home Health benefit can be used to fund skilled nursing, home health aide, and other therapeutic services that may be provided by family caregivers of CYSHCN. States are required to include at least some home health services in their Medicaid state plans, and federal law does not restrict family members from reimbursement for these services. However, these services require the provider to meet certain professional qualifications and, often, to be employed by a home health agency, both of which may pose barriers for family caregivers. Additionally, very few states allow home health state plan benefits to be participant-directed, and therefore children or their legal representatives may not have the employer authority to hire their family caregiver to provide services.¹⁰⁰ Instead, states can modify provider qualifications to reduce education and training barriers for appropriate services, and develop policies that are designed to support family caregivers in gaining the necessary credentials to provide reimbursable services for CYSHCN in their families.

Medicaid Reimbursement to Family Caregivers in Response to COVID-19

States have pursued several different waiver authorities to increase support for family caregivers of CYSHCN during the COVID-19 pandemic. These include the 1135 emergency waiver, 1115 waivers, and 1915(c) Appendix K waivers. Each of these authorities temporarily add flexibilities to state Medicaid programs. These flexibilities aim to increase the home health service provider workforce to support the shift toward HCBS while reducing the number of people in long-term and intermediate care facilities. Policies that support the reimbursement of family caregivers can be particularly useful to alleviate gaps in care, as consumers have become more likely to decline agency-provided home health services during the pandemic.⁹⁶ Hawaii has implemented a Section 1115 waiver that allows family caregivers to be reimbursed for services they provide. Hawaii’s waiver specifies that this includes live-in caregivers and legally responsible individuals “when in certain circumstances the access to agency providers is limited.”⁹⁷ Georgia and Maryland have approved 1135 waivers to “permit payment for state plan personal care services rendered by family caregivers or legally responsible relatives.”⁹⁸ Arizona’s 1115 Appendix K waiver allows parents of eligible children to be reimbursed for providing personal care services.⁹⁹

- **Colorado’s** Home Health Program provides services to eligible CYSHCN, including skilled nursing, certified nurse aide (CNA) services, physical therapy, occupational therapy, and speech/language pathology services.¹⁰¹ Family caregivers can be reimbursed for services they provide through this benefit, but they must be a registered nurse, licensed practical nurse, or CNA. In

collaboration with the state Medicaid agency, Colorado's Title V CYSHCN program has issued guidance for caregivers regarding how to become a CNA to provide services for a child in their family.¹⁰² Colorado has also developed the [Pediatric Home Assessment Tool \(PAT\)](#) to help identify a child's level of need and the number of skilled care service hours that the child is eligible for through the home health services benefit. The PAT was developed based on stakeholder feedback that assessment criteria needed to be tailored to the pediatric population.¹⁰³

- **Arizona** and **Missouri** have taken steps toward a similar approach. Both states have passed legislation that requires the development of programs to facilitate family caregivers' ability to provide home health services as licensed nursing assistants to CYSHCN.¹⁰⁴

Key Considerations for Reimbursing Family Caregivers of CYSHCN

There are several key considerations for states working to design, implement, or modify policies that reimburse family caregivers of CYSHCN. While some considerations may apply to policies that reimburse family caregivers across the lifespan (adults and children), others apply to policies that reimburse families of children.

- **Implement multiple Medicaid authorities that allow for reimbursement of family caregivers for CYSHCN.** Medicaid authorities that allow for reimbursement of family caregivers vary in several of their requirements. Some authorities require participants to meet an institutional level-of-care need while others allow states to establish a lower requirement level. Additional differences across authorities include whether they allow states to set service limits, define a target population, and provide participants with budget authority. Additionally, Medicaid waivers are temporary and require renewed applications, while state plan options continue until revoked. States can select the Medicaid authorities that best fit their state, and can also leverage multiple Medicaid authorities to develop a comprehensive set of options that allow CYSHCN with varying needs and conditions to receive services from their paid family caregivers (see the chart, Medicaid Authorities that Fund Family Caregiver Services, for a summary of the differences across these authorities.) For example, California has implemented 1915(i), 1915(j), and 1915(k) authorities. Family caregivers of children who do not meet an institutional level-of-care need are eligible for 1915(i) and 1915(j). If these children would like a legally liable relative to provide services, they are only eligible for 1915(j).
- **Institute oversight and training mechanisms to support the integrity of programs.** The primary challenge that states face in offering participant-directed services is program integrity. Because the employer authority shifts from the state Medicaid agency to the Medicaid enrollee, children or their legal representatives become the manager of the Medicaid-funded services. These non-traditional employers may require stronger oversight and monitoring mechanisms as well as additional administrative training and support, which may create additional costs for states. States can implement comprehensive quality assurance processes and use quality and monitoring reports to inform and enhance training. Financial management services that states must offer through these authorities, as well as consultants through the 1915(j) state plan option, can provide important support for participants. States can also work with MCOs, provider agencies, and local government agencies to implement quality assurance processes. For

example, Florida assigns waiver support coordinators and allows enrollees to select an unpaid representative, and Colorado registers caregivers through local IHSS agencies to support oversight functions and improve program integrity.

- **Clearly define who is eligible for reimbursement as a child’s family caregiver.** All participant-directed Medicaid authorities provide states with the option to *allow* legally responsible or liable persons, legal guardians, and/or all relatives to be paid as the child’s provider. However, many states have chosen to prohibit these groups from reimbursement, and some states have gone even further by developing specific requirements, including that family members who live in the child’s household or who serve as the child’s legal representative cannot also be the paid caregiver. These limitations often prohibit a child’s primary caregiver from reimbursement, and though it is not always the case, these caregivers are likely providers of certain services for the child. Requiring those who are not family members to provide services may be more expensive for the state if an agency provider must be hired instead of using an independent family caregiver. This may also cause disruptions in a child’s care, especially given the challenges of identifying a home health provider due to workforce shortages. State Medicaid authorities that allow flexible eligibility for family caregivers, along with detailed service and assessment regulations, can support an individualized approach that meets the range of situations and needs facing CYSHCN and their families. As many states have expanded their definition of eligible family caregivers during the pandemic, they may want to consider extending these temporary flexibilities to improve quality of care while addressing workforce shortages and budget limits beyond the pandemic.
- **Tailor family caregiver services available for reimbursement to the needs and conditions of CYSHCN.** Because it is generally expected that children’s primary caregivers or legally responsible relatives would assist their children with at least some tasks that qualify as ADLs or IADLs, understanding and defining the scope of services that family caregivers will be reimbursed for is particularly important for states to consider. Through the appropriate Medicaid authorities, states can identify which services can be participant-directed. States can specify which services are available to children, and further, which services are eligible for reimbursement if the provider is a family caregiver. Developing a more targeted approach to service eligibility allows states to reimburse family caregivers for services provided to CYSHCN while avoiding payment for services deemed inapplicable.
- **Adopt assessments that account for the varying needs of CYSHCN.** State Medicaid agencies vary in how they assess a child’s eligibility and level of need for participant-directed services. The assessment can identify the specific services that children are eligible to self-direct and the number of hours that are allocated for each task. States can also use the assessment to determine whether a family caregiver is eligible to be the paid provider, which may impact the number of hours and types of services that can be allocated for the child, depending on how a state has defined service eligibility for family caregivers. While states have noted the benefit of leveraging a universal assessment across home- and community-based service programs, children may benefit from an assessment that is tailored to identify their age-specific needs.¹⁰⁵ Additionally, assessments that incorporate caregivers’ perspectives may result in more appropriate service allocations.¹⁰⁶

- **Align policies that allow for reimbursement of family caregivers of CYSHCN with training and support.** Family caregivers face various technical, physical, and emotional challenges in providing medical assistance to CYSHCN, particularly those who are dependent on technology.¹⁰⁷ States can couple their policies that allow reimbursement of family caregivers with training and respite services that can help alleviate these challenges. Because family members are not federally prohibited from providing home health services, some states have implemented policies that publicize and facilitate opportunities for family caregivers to gain the credentials needed to provide these more advanced services to CYSHCN. Additionally, medical professionals can be trained to improve the level of information and support they provide to family caregivers. One example of this is the Caregiver, Advise, Record, Enable (CARE) Act, which has been implemented in the majority of states and requires hospitals to provide additional information and improve coordination with family caregivers about their caretaking responsibilities.¹⁰⁸ While some states' laws only apply to caregivers of adults, some now include the pediatric population.¹⁰⁹ Many states also offer respite services for family caregivers through their HCBS waivers and state plan options.
- **Collaborate with agencies that serve CYSHCN to strengthen policies that support their family caregivers.** State Medicaid agencies can form partnerships to strengthen their policies for reimbursing family caregivers of CYSHCN. States can partner with local county governments, private agencies, and MCOs to support administration, implementation, and oversight of policies that reimburse family caregivers. These partners are often responsible for conducting medical needs assessments, providing billing support, and monitoring services and budgets. To streamline payment processes, some states contract with financial intermediaries that pay family caregivers for services and then bill the state Medicaid agency for reimbursement. Collaborations with state Title V CYSHCN programs have also been leveraged to support training and administration of policies that reimburse family caregivers.

Conclusion

Family caregivers have been increasingly recognized as critical sources of unpaid care for CYSHCN. Reliance on these services without adequate support has contributed to the greater financial hardship that families of CYSHCN often experience. States have implemented Medicaid authorities that allow for participant direction, which in some cases allows for family caregivers to be reimbursed for these services. States have also developed policies that support family caregivers in providing home health services. While many of these policies have been limited in scope, particularly for children, states have added new flexibilities in response to COVID-19. As states face home health service workforce shortages and rising costs of care, states need to balance spending priorities with the need for state budget cuts. Policies that allow for reimbursement of family caregivers may be used to alleviate these challenges during and beyond the COVID-19 pandemic, while providing an essential support for families. The national strategy now under development through the RAISE Act may build upon these policies and identify additional approaches for states to implement comprehensive support systems for family caregivers of CYSHCN.

*Identified as Hispanic in the survey.

Chart: Medicaid Authorities that Fund Family Caregiver Services for Children and Youth with Special Health Care Needs (CYSHCN)

Medicaid authority	Reimbursable services by family caregivers of CYSHCN (at state's discretion)	Institutional level-of-care eligibility requirement	Budget authority	Target group identified by state (age, diagnosis, eligibility group, etc.)	Service limits allowed (geographic and number of participants)	Family caregiver groups that can be eligible service providers*
1915(c) Home and community-based waiver	Case management, homemaker, home health aide, personal care, habilitation, respite, and other	Yes	Allowed	Yes	Yes	Legally responsible individuals,** relatives, legal guardians
1915(i) State Plan Home and Community-based Services	Case management, homemaker, home health aide, personal care, habilitation, respite, and other	No (set by the state, below institutional level of care)	Allowed	Yes	No	Legally responsible persons,** relatives, legal guardians
1915(j) Self-Directed Personal Assistance Services State Plan Option	Personal care services, other services if used with 1915(c), other services to increase independence at the state's discretion	Yes, if 1915(c) No, if State Plan Personal Care Services	Required	Yes, if used with 1915(c)	Yes, if used with 1915(c)	Legally liable relatives
1915(k) Community First Choice Option	ADLs, IADLs, health-related tasks, support for the individual to accomplish ADLs and IADLs, mechanisms for continuity of services, voluntary training. Can also cover fiscal management, transition costs, and other expenditures at the state's discretion.	Yes	Allowed	No	No	None (state may choose to include/exclude groups)
1115 Research and Demonstration Waiver	State's discretion	No (state's discretion)	Allowed	Yes	No	None (state may choose to include/exclude groups)
Home health services/Early, Periodic Screening, Diagnosis, and Treatment (EPSDT) state plan benefit	Nursing services; medical supplies and equipment; home aide services, physical therapy, occupational therapy, speech pathology and audiology services provided by a home health agency	No (for EPSDT, must be a medically necessary service)	Not allowed	Not allowed	Not allowed	None (state may choose to include/exclude groups)

*While there are specific options available under some Medicaid authorities, states can choose to develop their own definition of who is eligible to provide services as a family caregiver.

**If a state chooses to reimburse legally responsible individuals for personal care or similar services through 1915(c) or 1915(i), a state must identify its criteria for meeting the "extraordinary care" requirements and its assessment methods, and how it will establish that the care provided by a legally responsible person is in the child's best interest, among other requirements.

Source: Adapted from the Centers for Medicare & Medicaid Services, Authority Comparison Chart, HCBS Technical Assistance Website, <http://www.hcbs-ta.org/authority-comparison-chart>

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