PAID FAMILY CAREGIVING

STATE MEDICAID PATHWAYS FOR PAYMENT

Advocacy Action Guide for AAP Chapters

Overview

Children and youth with special health care needs (CYSHCN), including children with medical complexity (CMC), have high levels of health care utilization as well as unmet needs. Ongoing national shortages of home care services for such children, including private duty nursing, personal care, respite care, and therapists are drivers of such unmet needs. Without straightforward and consistent access to these essential services, CYSHCN are at increased risk for unnecessary hospitalization, institutionalization, and worsened health outcomes. Further, parents and caregivers often end up performing skilled tasks in the absence of home care services, which can increase stress, burnout, and financial hardship. One piece of the solution to the complex issue of home care workforce shortages and family burden is to enable parents and caregivers of CYSHCN to be paid for providing *personal care* and/or *home health* services. There are several potential pathways to paid family caregiving, involving a combination of assorted Medicaid *state plan authorities*, *waivers*, and changes to *state law and regulation*. This American Academy of Pediatrics (AAP) Advocacy Action Guide is intended as an introductory primer for AAP chapters on the need for and viability of these payment models, and considerations to address when advocating for coverage. Included in this resource are discussions of: *home health services vs personal care services; state plan benefits vs HCBS pathways; and state policy considerations*.

Background

Over the last few decades, care for CYSHCN has been shifting from institutions to the home or a community-based setting, thanks in large part to policy changes such as the Katie Beckett/Tax Equality and Fiscal Responsibility Act (TEFRA), the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act, Home and Community-Based Services (HCBS) waivers, Section 504 of the Rehabilitation Act, and caselaw such as Olmstead v L.C.[1] Today, approximately half of all CYSHCN receive care at home from a family member.[2] This proportion increases when children have more than one special health care need, including CMC.[3] While medical literature demonstrates this shift to home and community-based care improves health outcomes, there is a growing number of CYSHCN reporting unmet home care needs.[4]

The most prominent barrier to accessing quality home care services is a shortage of workforce, a hurdle that can be even higher when considering home care services that specialize in pediatrics. Home care workforce shortages are driven by difficult hiring practices, variable training requirements, and most significantly, inadequate payment.[5] Research demonstrates that a lack of access to home care services drives increased risk of prolonged hospitalization and increased costs.[6] When these gaps exist, families are increasingly called upon to deliver specialized care for their children at home and at considerable personal cost. These issues can lead to family members forgoing employment to care for their children, which in turn can drive financial instability, unsafe workloads, and family stress.[7]

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Family caregivers of CYSHCN in the United States provide about 1.5 billion hours of health care to approximately 5.6 million children annually.[8] The cost of these services, if provided by a home health agency, would total anywhere between $11.6 and $35.7 billion annually.[9] Further, while CMC make up just 0.4% of children in the US, the number of hours their families spend caring for them at home is exponentially more than even other CYSHCN.[10] Unsurprisingly, the issues of stress, burnout, and financial instability are more common for parents of CMC, even compared to parents of children with other chronic conditions.[11]

However, research shows that when states enable parents and caregivers of CYSHCN to be paid for the extraordinary care they provide to their children, there can be numerous potential benefits to the parents, child, and state, including:

- Parents being able to maintain their "emotional and moral commitment" to care for their child;
- Stable access to high quality care, which drives continuity of care;
- Increased options and flexibility for parents of CYSHCN;
- Betterment of the child's health and wellbeing;
- Enhanced family financial stability; and
- Acquisition and development of skills that are transferable, including to elder care, which can help parents find employment and boost the provider network when their children age out to adult care.[12]

During the COVID-19 pandemic, states had the option to adopt temporary policies to pay family caregivers for providing personal care services.[13] But with the expiration of these temporary flexibilities, states wishing to continue or expand paid family caregiving will need to make changes to their Medicaid programs, which can entail additional, and often confusing, legislative or regulatory action. Most states already enable paid family caregiving for seniors and adults with disabilities through an array of HCBS options, though to date only a small number of states have done so for children.[14] However, in recent years, a handful of states have crafted innovative policies enabling parents of CYSHCN to be paid family caregivers, *either by obtaining skilled licensure types and performing services through a home health agency*, or through *HCBS pathways enabling self-directed services, which doesn't require licensure*.

AAP has created this Advocacy Action Guide to serve as an introductory primer for AAP chapters of the various pathways likely available in their states to unlock Medicaid payment for family caregiving of CYSHCN, including a discussion of the various policy considerations that should be taken into account when working with the state to advance these programs.

State Pathways for Medicaid Payment to Family Caregivers

Broadly speaking, models for paid family caregiving can be categorized one of two ways: *models that require licensure and home health agency employment,*[i] *and models that do not*. CMS refers to these two options as the "agency service delivery model" and the "self-directed service delivery model."[15] There are several potential Medicaid pathways available to states to unlock these models, which can involve combination of Medicaid state plan authorities, waivers, and changes to state law and regulation. Within Medicaid, pathways can include the state plan home health benefit, HCBS waivers and state plan amendments, and 1115 waivers, all of which interplay with Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit. In addition to identifying one or more Medicaid pathways, states will also likely need to analyze state law and regulations to either remove barriers or expressly authorize family caregivers to be paid. In particular, *home health services* are generally required to be provided by a home health agency and with the provider meeting some level of training, certification, or licensure, and are subject to rules about delegation, as determined by the state. Conversely, paid *personal care services* cannot normally be performed by a "legally responsible relative," unless through an HCBS pathway, which have their own policy and procedural safeguards states must meet.

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[i] *Note: There have been a small number of state models allow non-licensed individuals to provide services through a home health agency. Likewise, there have been a small number of states waivers allowing for self-direction of delegated skilled nursing tasks. However, these are largely exceptions to the rule.*

There are potential advantages and drawbacks to each pathway and service delivery model for the individual, the caregiver, and the state. As such, the model(s) and pathway(s) selected will likely be a state-by-state determination based on a number of policy considerations, which are discussed below.

1905(a)(7) Home Health Services

Home health, as defined in federal regulation, includes nursing and home health aide services through a home health agency, physical or occupational therapy, and the provision of medical supplies, all of which are 1905(a) services in and of themselves.[16] While these positions are able to perform skilled nursing tasks, they may also in the course of their duties provide services typically associated with personal care, as described below.[17] Home health is a mandatory state plan benefit when provided to an individual entitled to receive nursing facility services and for children is covered through EPSDT when medically necessary.[18] While there are no restrictions on a legally responsible relative's ability to be paid for providing home health services, these services generally have to be provided by a qualified provider through a home health agency, rather than be self-directed.[19] As such, states have enabled family caregivers to be paid for providing home health services if the family member (1) becomes employed by a home health agency, typically as some form of home health aide, and (2) meets state licensure and credentialing requirements – typically, LPN/RN, CNA, or newly-created parent caregiver licensure types (with a wide range of names, discussed below). Home health agencies need to meet federal Medicare standards, but states have flexibility to determine requirements for home health aides or these newly created licensure types, which can help lower barriers to entry for family caregivers.

1905(a)(24) Personal Care Services via HCBS

Personal care services include activities of daily living (ADLs), such as bathing and dressing, and instrumental activities of daily living (IADLs), such as cooking, cleaning, and shopping. Personal care is an optional state plan benefit; it nonetheless must be covered for children through EPSDT when determined to be medically necessary.[20] However, inconsistent application of EPSDT, compounded by provider shortages and the assumption parents are responsible for these tasks, can mean few eligible children actually receive this service. States set criteria for who can perform personal care services, including training requirements, supervision requirements, and whether personal care providers can operate independently or through an agency.[21] However, federal law prohibits "legally responsible relatives" from being paid for providing personal care services for minors under age 18, as the statue and regulations view these tasks as those a parent or guardian would otherwise be legally obligated to provide to a child.[22] Nevertheless, payment to a legally responsible relative for personal care services may be covered when included as part of a HCBS pathway, if the state demonstrates that performing these tasks for CYSHCN would be considered an "extraordinary" level of care.[23]

A Note on EPSDT

ESPDT is the Medicaid program's mandatory benefit for children, designed to ensure that any enrolled child can receive the care they need, when they need it, in the setting they need it. Through EPSDT, eligible children under 21 can receive any Section 1905 service necessary to "correct or ameliorate" a condition, regardless of whether the service is covered under the state plan. As home health is a mandatory benefit and personal care is an optional benefit under Section 1905, both are covered for children via EPSDT when determined to be medically necessary. Conversely, HCBS falls under Section 1915; as such, those services do not fall within EPSDT, but rather "wrap around" EPSDT to create a comprehensive benefit for children with disabilities. Therefore, while states may have CYSHCN enrolled in a HCBS program, this does not limit children's entitlement to receive services through EPSDT as well.

Nevertheless, longstanding inconsistencies in state implementation of EPSDT have posed significant barriers to CYSHCN accessing the care they are entitled to. The policy pathways described within represent ways to work around barriers to family members providing these services – the need for home health services to be furnished by a qualified provider, and a prohibition on "legally responsible relative" providing paid personal care services.

For a robust discussion of EPSDT requirements, see the recent CMS guidance, SHO # 24-005.

HCBS

HCBS is a patchwork of Medicaid waivers and state options that enable eligible individuals to receive institutional facility levels of care in their home or homelike setting in their community, rather than an institution. These programs enable coverage for services that are otherwise not available through Medicaid because they do not fit in a category listed in 1905(a), or can extend 1905(a) services beyond their normal amount, duration or scope.[24] As such, through HCBS pathways, states can enable a legally responsible relative to be paid for providing personal care services, either through becoming a qualified provider employed by a home health agency – similar to home health care state plan services – or through an option known as *participant-directed* or *self-directed care*, where the Medicaid enrollee essentially sets their own provider qualifications and "hires" their own provider.

While HCBS pathways can enable payment for personal care, there are hurdles the state must clear to overcome the federal limitation on paying legally responsible relatives for providing personal care.[ii] The state must establish that the care being provided is "extraordinary care" and develop a criteria for determining as much.[25] The state must also establish other safeguards, including: demonstrating the delivery of personal care by a legally responsible relative is in the child's best interest and will not hinder their ability to engage in meaningful community activities; implementation of appropriate oversight mechanisms to ensure the individual receives the services being paid for; and procedures to ensure payments are made for services rendered.[26]

There are several varying HCBS waivers and state plan pathways states can leverage to enable payment for family caregivers. States will need to asses the costs and benefits of pursuing paid family caregiving models through a waiver or its state plan, or even through multiple pathways, as discussed below.

1915(c) Home and Community-Based Services waiver

- The most common HCBS pathway, 1915(c) waivers enable states to tailor a wide array of services to specific populations as an alternative to institutionalization.
- States can elect to allow enrollees to self-direct services and/or have legally responsible relatives be employed by a Medicaid-enrolled home healthcare agency.
- If personal care services are provided by a legally responsible relative, must establish "extraordinary care" and the safeguards as described above.
- Individuals provided services under 1915(c) *must require* an institutional level of care.

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

- Enables states to provide HCBS services akin to 1915(c) to individuals who require *less than* an institutional level of care.
- Commonly used to limit service to a carefully constructed population
- If personal care is provided by a legally responsible relative, must establish "extraordinary care" and other safeguards

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

- Enables participants to directly hire and self-direct personal care services and/or other 1915(c) HCBS services, including defining their own provider qualifications and managing their own personal care budget.
- States can elect to allow enrollees to hire a legally responsible relative, or other family member.

[ii] See Elizabeth Edwards' excellent National Health Law Program (NHeLP) resource, *Paid Family Caregivers: State Options, Limitations, and Policy Considerations*, for a more detailed discussion of the procedural and technical requirements of an HCBS waiver for paid family caregiving. https://healthlaw.org/wp-content/uploads/2023/12/Paid-Family-Caregivers-NHeLP-2023.pdf

1915(k) Community First Choice State Plan Option

- ACA-created option that enables higher FMAP percentage for community-based attendant services and supports.
- States can elect to allow enrollees to set their own provider qualifications and self-direct services and/or have legally responsible relatives employed by a Medicaid-enrolled home health agency.
- Can't have waiting lists.

Nearly all states have active HCBS waivers, if not multiple. Research by KFF indicated that in FY2020 there were 267 HCBS waivers in place across 47 states + DC, with a large majority (255) of these waivers being 1915(c) waivers.[27] In 2022, KFF identified eighteen (18) 1915(c) waivers focusing exclusively on children who are medically fragile or technology dependent (other states may address children with medical fragility through other non-exclusive programs).[28] As of 2022, 32 states had HCBS waivers allowing legally responsible relatives to be paid for certain services; however, only 11 states had used a 1915(c) waiver to enable a legally responsible relative to be paid for personal care services (though this number is likely larger now).[29] Similarly, a 2023 survey of states by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) found that nearly all states allow payment for HCBS services delivered by a *non*-legally responsible relative, but only 12 at the time allowed payment to legally responsible relatives for personal care services, though most focus on parents of adults with disabilities who have guardianship.[30]

While the above HCBS pathways give states significant flexibility to craft programs that encompass payment for caregivers, there can also be limitations. Most notably, most HCBS options do not have a prohibition on enrollment caps or waitlists. As of 2020, the average wait time for HCBS waiver services for medically fragile or technology dependent children was 23 months (no data exists for children in waivers co-mingled with other populations).[31] That said, HCBS may be the most-favorable pathway for the state because the flexibility inherent in the program allows states to control costs by limiting the scope of services, number of recipients, and geographic area.

1115 Waiver

Section 1115 waivers are the most flexible waiver option for states to innovate. This option, which is not specific to HCBS services, gives states broad authority to test out new models of services and payments that advance the goals of the Medicaid program (within the constraints of budget neutrality). While HCBS services are usually delivered through a HCBS waiver, there are a handful of states (AZ, DE, HI, NJ, NY, RI, VT, WA) that deliver HCBS services through 1115 waivers, though not specifically for purposes of paid family caregiving.[32, 33] This is usually done to streamline eligibility processes and provide faster access to services.

Policy Considerations

As indicated above, identification of a viable pathway for paid family caregiving for CYSHCN will be a state-by-state determination based on a number of factors, including the needs of the state's CYSCHN Medicaid population, fiscal and administrative costs to the state, the state's current utilization of HCBS pathways, and barriers located in state law and regulation. When assessing these pathways there are several policy considerations advocates and the state should take into account. Likewise, program evaluations such as those mentioned in the section below indicate a number of benefits that states can work to enhance, and some perceived drawbacks states can work to reduce.

Employment through agency or direct payment – When crafting a paid family caregiving policy, the state will need to weigh whether it will allow the Medicaid enrollee to self-direct their own care and hire a family member or guardian to provide personal care services, or whether family caregivers will need to be employed by a home health agency. As previously stated, home health services must be performed by a qualified provider through a home health agency. The provider types that typically perform home health aide services and their associated licensure, training, and certification requirements are prescribed by state law and nursing regulations, which may need to be amended to include parent caregivers. Self-direction options may reduce costs to the

state, but can also be associated with increased administrative burden, including state oversight of the paid care giver and quality assurance processes.[34] Conversely, employment through a home health agency can enable the caregiver to be paid for providing low acuity tasks, which in turn can free up RNs to focus on higher acuity tasks and can boost the home health care workforce in the longer term, but may be associated with higher fiscal costs to the state.

Delegation – States may have nursing statutes or regulations that either enable or restrict delegation of skilled nursing tasks from a RN to a nursing assistant/aide. Assistants/aides are typically only permitted to provide low acuity tasks. While families of CMC may be highly familiar with complex care such as tracheostomy care and feeding tubes, in order to be paid for providing these home health services, it may be necessary to ensure delegation of these tasks is allowable under state law.

Nomenclature – State laws/regulations often have differing professional titles for the role that would be carried out by a family member providing paid home health services. Depending on the title, there could be associated certification and training requirements. For example, the term "Home Health Aide" is used in FL, IN, PN, and NJ, while the term "Complex Care Assistant" is used in MA and MT. Other states expressly indicate certification in the use of the titles "Certified Home Health Aide" (CA), "Certified Nursing Assistant" (CO), and "Certified Health Aide" (TX). Meanwhile, others expressly indicate licensure through the state nursing board, such as "Licensed Health Aide" (AZ) and "Licensed Nurse Aide" (NH). States will need to examine their own laws and regulations to determine which title will best fit within existing schemes.

Training, credentialing, fees – For states that require caregivers to go through training and hold a certificate or license, states should subsidize the cost of training to minimize barriers to entry and financial burden to family members participating in the program. If it is required that the caregiver be employed by a home healthcare agency, the state should work with the agencies operating in their jurisdiction to cover the cost of training for the parent caregivers they will be employing. For example, in Colorado, participants take a 4-week course through the hiring home healthcare agency, which is designed specifically for parents to become certified nursing assistants, including scheduling around family-friendly hours, with only fees to the parent for testing and licensure.[35] It may also be possible for states to exempt family caregivers from licensure requirements under a showing of competency or supervision by a registered nurse.[36] If such exemptions already exist in state law/regulations, policymakers should carefully weave a new paid family caregiving program into those definitions/exemptions.

Optional vs mandatory participation – When working with the state to craft paid family caregiver policies, advocates should ensure that the state makes explicit that participation in paid family caregiving by eligible individuals is entirely optional and not a mandate. For many families of CYSHCN, it is appropriate and desirable for family members to serve as paid family caregivers. However, not all families of CYSHCN prefer that caregiving arrangement, and policies allowing paid family caregiving should not supplant coverage of the same services through other means, as available. Just as receipt of private duty nursing should not be conditioned on family availability, parents of eligible CYSHCN similarly should not be compelled to go through the steps to become a paid family caregiver.[37]

Who can provide – State policymakers should be deliberate when defining which persons are eligible to be a paid family caregiver. As mentioned above, federal Medicaid law restricts "legally responsible relatives" from being paid for providing personal care services through the personal care state plan benefit, but no such prohibition exists for the home health state plan benefit. States may have a variety of terms already codified that could have legal implications vis-à-vis this federal restriction, including "legally responsible person," "legally liable relative," "legal guardian," "relative," and "legal representative."[38]

Number of hours – States may set limits on the number of hours in a week that a legally responsible relative can be paid for providing home care services, whether it be personal care or home health. Per NASDDDS, many states that allow for payment of a legally responsible relative limit the hours to 40 per week.[39] Others, such as North Carolina, use 40 hours as the base, but may

allow up to 56 hours/week if there are extenuating circumstances.[40] Other states, such as Colorado, do not cap the number of hours that a parent can serve as a paid caregiver.[41]

Preventing burnout – Related to limits on hours, it is essential that when states craft these policies they consider options for respite care. A large percentage of parents of CMC want to care for their children at home, but the experience can be both exhausting and isolating.[42] Building care for the caregiver into the program can help protect against caregiver burnout, which in turn helps preserve quality of care and longevity of employment in the home health care workforce. Potential options for preventing caregiver burnout include prescribed respite hours, community-integration programs, support services, and ensuring that paid family caregiving services are appropriately supplemented with options delivered by non-relatives.[43]

Appropriate payment and eligibility considerations – One of the most frequently cited contributors to the home health care workforce shortage is the lack of adequate payment. Rates for personal care and home health services can vary widely by state, provider type, and service. Some states pay for home health services by visit, while others have an hourly rate. The average rate for a home health aide is around $36/hr, but can range from $15/hr to $60/hr.[44] Likewise, the average hourly rate for a provider of personal care services is about $22/hr, but can range from as low as $9/hr to $86/hr.[45] States should take care to craft their paid family caregiving program so as to support family stability and workforce development, but should also ensure that additional income from paid family caregiving does not impact the child's eligibility.[46] Likewise, states should take care to monitor the pass-through wages from agencies to families. To note, chapters should also monitor implementation of the HCBS provisions of CMS's recently released Access Rule, which could ultimately have the effect of increasing Medicaid payment for these services (See, AAP's Advocacy Action Guide on Access Rule and Managed Care Rule for a more robust discussion of these provisions).

Implementation through multiple pathways – Given the differences between HCBS pathways, or even within the same pathway, with respect to eligibility requirements, the ability to target specific populations, set different service limits, or enable participant self-direction, states may want to consider implementing paid family caregiving across multiple authorities. Likewise, in practice, there can be significant overlap between personal care tasks and home health tasks, with home health tasks often encompassing personal care tasks. Leveraging multiple state plan and waiver authorities can help enable "a comprehensive set of options that allow CYSHCN with varying needs and conditions to receive services from paid family caregivers."[47]

Conclusion

Creating paid family caregiving programs for CYSHCN can be complicated given the various state plan and waiver pathways, state law and regulation barriers, and various policy considerations. However, as can be seen above, there is a great need to create better support for the family members who are already doing this work at great personal cost, and there are likely available pathways in each state for enabling some form of payment for either personal care or home health services. Enabling paid family caregiving is but one piece of the puzzle for ensuring adequate access to care and strong provider networks, but for those caregivers who desire to provide the services for their child, states should aid them in that choice. Furthermore, while paid family caregiving is one piece of the solution to improve the home care workforce shortage and ensure CYSHCN and CMC continue to receive supports in the community, states must also work to address the overarching barriers of difficult hiring practices, variable training requirements, and inadequate payment. AAP stands ready to assist chapters wishing to explore these policies in their home states. Contact AAP State Advocacy at stgov@aap.org for consultation and technical assistance.

Addendum: Examples of Recently Passed State Legislation[*+]

*This following list does not purport to be exhaustive of the number of active paid family caregiving programs or those in development, but rather is illustrative of the type of legislation that has recently advanced in state legislatures. It likewise does not include programs established exclusively through a waiver or state plan amendment. A recent presentation by the Lucile Packard Foundation, in collaboration with Team Select (a home health agency), indicated that **as of March 2023 programs were operating in CA (limited), AZ (full), CO (full), IN (limited), PA (limited), MA (partial), and New Hampshire (full)**. (see, Paid Family Caregiving for Children with Medical Complexity and Disabilities - Lucile Packard Foundation for Children's Health (lpfch.org))

+At the time of publication, there is active legislation pending in Illinois, Oklahoma, and Rhode Island. Likewise, in recent years legislation has been introduced, but not advanced, in New Mexico, Washington, Texas and Connecticut.

State	Year Passed	Bill Number(s)	Title Used	Summary
Arizona	2021	HB 2521	License Health Aide	• Creates position of "licensed health aide" – parent or guardian of a member of the Arizona long term care system currently receiving service. Licensed only to provide services to that eligible member. Same scope of practice as a "licensed nursing assistant," but may also provide medication administration, tracheostomy care, enteral care and therapy, and other tasks approved by the Board of Nursing. Services must be ordered by physician. • Add's licensed health aide services to definition of HCBS • Licensed Health Aide must submit application to Board of Nursing, including: proof the licensed health aide is a parent/guardian/family member of an individual <21 years of age eligible to receive continuous skilled nursing or skilled nursing respite care services; completion of basic curriculum and certificate from a training program prescribed the Board that must include medication administration, tracheostomy care, enteral care and therapy, and any other tasks required by the Board; completion of competency exam approved by Board. • License fee: $50 • Director shall request CMS approval no later than 60 days after promulgation of rules to implement;
Montana	2023	HB 449	Pediatric Complex Care Assistant	• Creates position of "Pediatric complex care assistant" • Must complete a training curriculum to be created by the Department and pass a hands-on examination. Training must include medication administration, airway clearance therapies, tracheostomy care, enteral care and therapy for persons <21. • Can only provide care to person < 21 for whom the assistant is a parent, guardian, other family member, or kinship care or foster care provider. • Services must be ordered by physician and consistent with plan of care • Duties limited to: Duties considered by the department equivalent to those of a certified nursing assistant; medication administration; tracheostomy care and enteral care and therapy; airway clearance therapies; other services as allowed by the department by rule • Department shall adopt rules to implement
Florida	2023	SB 452	Home Health Aide for Medically Fragile Children	• Creates the Home Health Aide for Medically Fragile Children Program (HHAMFC), allowing a family caregiver to be paid by Medicaid, through employment with a home health agency, for care provided to a relative < 21 with an underlying physical, mental, or cognitive impairment, eligible to receive skilled care or respite care services through Medicaid

				• Reimbursement rate: $25/hr, up to 8 hours/day • Directs the Department to file any state plan amendments or waivers necessary to implement • Authorizes HHAMFC to perform tasks delegated by a registered nurse, such as medication administration, tasks associated with activities of daily living, maintaining mobility, nutrition and hydration, and safety and cleanliness. • Requires services provided by HHAMFC to result in a reduction in the number of private duty nursing service hours provided to an eligible recipient. • Prohibits services provided by a HHAMFC from duplicating private duty nursing services provided to an eligible recipient • Requires AHCA, in consultation with the Board of Nursing, to approve a training program • Establishes civil liability protection for a home health agency • Requires AHCA to conduct annual assessment of program and report the findings to Governor and Legislature
New Jersey	2023	S 1307	Homemaker -home health aide	• Directs the State Medicaid agency to establish a program in which family members of Medicaid enrollees can seek certification through the Board of Nursing to become a "homemaker-home health aide" and provide certified nursing assistant services through a home health agency. • Enrollee must be <21 and entitled to receive private duty nursing services through Medicaid • Requires family member to complete any training and certification required by state or federal law and requires the employing home health agency to cover all costs of training and certification • Tasks delegated to homemaker-home health aides shall be consistent with those consistent to ones allowed by the Board of Nursing to be delegated to certified nursing assistants • Reimbursement rate: no less than $30/hr • Provides Department and Board of Nursing with rulemaking authority • Requires Department to issue report to the governor and legislature 3 years after implementation on the viability of the program
Maine	2023	HP 163	Home health aide	• Directs Maine Dept of HHS to file a state plan amendment by 7/1/24 enabling qualifying parents of children and youth with in-home personal care needs eligible for MaineCare program to be reimbursed for providing home health aide services under the Medicaid home health benefit • Department to promulgate rules to establish and implement the program

Additional Recommended Resources

- National Health Law Program – Paid Family Caregivers: State Options, Limitation, and Policy Considerations (2023)
- National Association of State Directors of Developmental Disability Services – Caring Families: Paying Family Caregivers Topic Brief (2023)
- Lucile Packard Foundation – Medicaid Paid Family Caregiving for Children (2023)
- National Academy for State Health Policy – State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs Through Medicaid (2021)

Endnotes

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[21] CMS, Preventing Medicaid Improper Payment for Personal Care Services.

[22] *"[P]ersonal care services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility for the [individuals with intellectual disabilities], or institution for mental disease that are (A) authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State) otherwise authorized for the individual in accordance with a service plan approved by the State, (B) provided by an individual who is qualified to provide such service and* ***who is not a member of the individual's family****, and (C) furnished in a home or other location."* Social Security Act § 1905(a)(24)

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[28] States with 1915(c) waivers for medically fragile or technology dependent children: AK, CA, CO, CT, FL, IL, KS, MD, MN, NM, NY, NC, ND, OK, OR, SC, TX, UT. O'Malley Watts, Musumeci, Ahmula, M, *State Policy Choices*.

[29] Per KFF, as of 2022 there were 32 states that allowed legally responsible relatives to be paid providers for HCBS waiver services: AL, AK, AR, CO, DE, FL, HI, ID, IL, IN, KS, KY, ME, MD, MN, MO, MT, NH, NM, NC, ND, OH, OK, PA, SD, TN, UT, VT, VA, WV, WI, and WY. However, there were only 11 states that allowed legally responsible relatives to be paid providers for personal care state plan services: AK, AR, CA, ID, IN, IA, MN, MT, NJ, OR, and VT. O'Malley Watts, Musumeci, Ahmula, M, *State Policy Choices*.

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[31] O'Malley Watts, Musumeci, Ahmula, M, *State Policy Choices*.

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[34] Randi, Girmash, Honsberger, *State Approaches to Reimbursing Family Caregivers*.

[35] Carter, Blakely, Zuk, Brittan, Foster, Employing Family Caregivers.

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[40] Edwards, *Paid Family Caregivers*.

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[43] Edwards, *Paid Family Caregivers*.

[44] O'Malley Watts, Musumeci, Ahmula, M, *State Policy Choices*.

[45] Ibid.

[46] Edwards, *Paid Family Caregivers*.

[47] Randi, Girmash, Honsberger, *State Approaches to Reimbursing Family Caregivers*.