



## Paying Family Caregivers: State Options, Limitations, and Policy Considerations<sup>1</sup>

Elizabeth Edwards

Paying family caregivers for Medicaid home and community-based services (HCBS) has risen in popularity over the past several years due to provider shortages and increased use during the COVID-19 public health emergency (PHE).<sup>2</sup> Allowing paid family caregivers may optimize individual choice and ensure needs are met. While many individuals and families may want this option, not all states are as eager to authorize it. States policy concerns include family member caregiver burnout and regular reliance on family that typically serves as safety net providers, limiting the safety net. Limitations on paid family caregivers can also protect against compelling family members to provide both paid and unpaid supports.

Even where states are willing to allow paid family caregivers, Medicaid restrictions do not allow it for all programs and services. State licensure restrictions may also prevent paid family caregiving for certain services. However, the restrictions are limited and paid family caregiving is allowed at state option for most HCBS. There are also policy options that can help protect individual choice, support caregivers, and overall increase the pool of available supports.

### State Options for Permitting Paid Family Caregivers

State Medicaid programs have two primary avenues for covering family members as paid caregivers—state plan options and HCBS programs. Almost all states allow family to be paid caregivers in certain programs, mostly 1915(c) waivers, but very few pay a parent who is a guardian and even fewer pay parents of minor children.<sup>3</sup> During the PHE, many states allowed paid family caregivers for state plan personal care services under a Section 1135 waiver, but these waivers were specific to the PHE and ended with the end of the federal declaration of the PHE in May 2023.<sup>4</sup> States also used Appendix K amendments for 1915(c) waivers that temporarily allowed family caregivers for certain waiver services. For most states, those Appendix K amendments applied until Nov. 11, 2023 and continued if a state submitted an amendment to their waiver.<sup>5</sup> The difference between the Section 1135 and Appendix K flexibilities is that many states amended their 1915(c) waivers to keep Appendix K changes, but most Section 1135 changes could not be continued.

Despite the numerous mechanisms the Medicaid program has for allowing paid family caregivers, many states do not allow it or only allow it in certain programs. To be completely clear, paying family caregivers under any of the available authorities is an option for states that they may elect and not a requirement.

The key question for paying family caregivers is whether the service in question is provided as a state plan service or through another authority, such as a 1915(c) waiver, 1915(i), or 1915(k). If it is a state plan personal care service, family caregivers may not be paid to provide the service. If provided as a different type of service, such as home health, or through a 1915(c) or other HCBS authority, paying family caregivers is generally a state option with some limitations.

## **State Plan Options for Permitting Paid Family Caregivers**

### **Personal Care Services**

State plan personal care services have a statutory prohibition on payment of services by a family member.<sup>6</sup> The regulation further defines “member of an individual’s family” as a legally responsible relative.<sup>7</sup> The CMS State Medicaid Manual reinforces this definition and explains that there is a presumption that legally responsible relatives may not be paid for supports that they are ordinarily obligated to provide.<sup>8</sup>

Legally responsible relative is defined as spouses and parents of minor recipients, including stepparents who are legally responsible for minor children.<sup>9</sup> Legally responsible individual does not usually include the parent of an adult beneficiary, including a parent who may also be a legal guardian, or other types of relatives. However, state law may affect the definition of legally responsible relative, including through custody or guardianship arrangements.<sup>10</sup> Provider qualifications may further restrict whether a family member can provide the service if they are not licensed as required and by how the qualifications define family member.<sup>11</sup> For example, some state nurse practice requirements may allow unlicensed family members to perform tasks usually restricted to licensed nurses, but may define family different, may only allow the services if not paid services, or may have exceptions for self-direction.

The State Medicaid Manual has other provisions around non-legally responsible relatives and friends and providing state plan personal care services. According to the Manual, a person may have a relative or friend who is not legally responsible provide state plan personal care services if:

- the relative or friend meets the qualifications for providers of care,
- there are strict controls to assure that payment made to the relative or friend as providers only in return for specific services rendered, and
- the provision of care by the relative or friend is adequately justified, such as because there is a lack of other qualified providers in remote areas.<sup>12</sup>

As a practical matter, most of these provisions are met automatically under the provider qualification, payment, and provider choice processes within a Medicaid program. However, some Medicaid programs may have additional steps when a person chooses a family member other than the parent or spouse as their qualified provider of state plan personal care services. Typically, family members providing state plan personal care services are employed by a provider agency.

One important note is that if a state is providing personal care services to a child due to the obligations of Medicaid's Early and Periodic Screening, Diagnostic and Treatment (EPSDT) and cites the personal care statutory prohibition regarding family caregivers as a bar to payment, it is likely that the treatment can be provided under the home health service, which as discussed below, does not have the same restrictions.<sup>13</sup> For example, a child needs assistance with activities of daily living, and those needs can be met through either personal care or home health services. If limited provider availability means that in order to get the service or there are other medical necessity reasons a child needs a family caregiver, EPSDT-based arguments could be relevant to the care being provided as home health to avoid the personal care family caregiver restriction. Importantly, the arguments should be related to the child's medical needs, not family preferences.

## Home Health

A state must cover home health services for an individual entitled to receive nursing facility services, and are otherwise an optional benefit for adults.<sup>14</sup> The home health benefit is pretty broad ranging, but may include home health aides, skilled nursing, medical supplies and equipment, and specialized therapies.

State plan home health services do not have the same statutory or regulatory prohibition on paying family caregivers as personal care services.<sup>15</sup> Family members, including legally responsible individuals, may be paid providers if they meet the qualifications and are employed by or under arrangement with a home health agency. Under home health regulations, providers of personal care aide services may be qualified by a demonstration of competency in the services they are required to provide.<sup>16</sup> Provider qualification standards and licensure standards in most states would prohibit unlicensed family caregivers from being paid to provide

certain services, such as nursing, but on occasion an unlicensed family member may be allowed to do so.<sup>17</sup>

## HCBS Program Options for Permitting Paid Family Caregivers

### 1915(c) Waivers

States most commonly allow paid family caregivers in 1915(c) waiver programs, but this is a choice by a state and may differ within a state by waiver program and by service within a waiver. For example, within a given state, a waiver targeted to people with physical disabilities may not allow paid family caregivers while the state's waiver for people with developmental disabilities does. For the purposes of a waiver, "legally responsible relative" has a definition very similar to that of state plan personal care services, "as defined in state law but typically the parent of a minor child or a spouse."<sup>18</sup>

Within a given 1915(c) waiver, a state must indicate separately whether it will allow paid family caregivers for personal care services within the waiver and other waiver services. In a waiver application, Appendix C-2-d is the narrow question regarding paid family caregivers for waiver personal care service, and Appendix C-2-e is the broader question for other waiver services.<sup>19</sup> This section will refer to different appendices of an approved waiver application, which should help locate where the information is in a waiver and advocates can also use the 1915(c) Technical Guide, which also explains policies by the waiver sections and appendices.<sup>20</sup>

#### 1. Waiver Personal Care or Related Services

For purposes of waiver services, personal care or similar services refers to assistance with activities of daily living (ADLs) or incidental activities of daily living (IADLs) furnished in the home or community and closely related services such as home health aide, homemaker, chore, and companion services.<sup>21</sup> The important question is not what the service is called, but what function the service is providing or the needs that are being met.

The next part of the analysis is whether the waiver service being provided is considered "extraordinary care." A state may choose to pay "legally responsible relatives" for waiver personal care or similar services through a 1915(c) waiver when such services are deemed "extraordinary care."<sup>22</sup> A state must describe in the waiver application how it will distinguish extraordinary from ordinary care.<sup>23</sup> CMS describes extraordinary care as:

[C]are exceeding the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age, and which are necessary to assure the health and welfare of the participant and avoid institutionalization.<sup>24</sup>

A paid family caregiver must meet all the requirements of a qualified provider for personal care or similar service under the waiver, as described in Appendix C-3 of the waiver application. A state must also conduct monitoring visits, including monitoring of required documentation and assurances that services are provided in accordance with person-centered plan. There must also be an executed provider agreement.<sup>25</sup>

At a minimum, a state must describe in Appendix C-2-d regarding paying family caregivers for personal care or related services:

- the types of legally responsible individuals who may be paid and what services they may provide;
- the applicable state policies that describe the circumstances when payment is authorized, including how the state distinguishes extraordinary from ordinary care;
- how the state ensures that the provision of services by the legally responsible individual is in the best interest of the participant;
- the controls that are used to ensure that payments are made only for services rendered; and
- limitations on the amount of personal care or similar services that may be provided.<sup>26</sup>

States may, but do not have to, include other limitations. These limitations include that paid family caregivers are only allowed when there is lack of available providers when the family members would otherwise be away from the home.<sup>27</sup> Other limitations in approved waivers include hours limits for paid family caregivers or an individual caregiver, limitations on the period over which family caregivers may be paid, proof of provider search, and processes to be approved as paid family caregivers.

CMS also recommends additional safeguards, such as:

- Protections around the best interests of the individual, such as limitations on self-referral when the family caregiver has decision-making authority.<sup>28</sup> Under the person-centered planning regulations, even when a person has a legal guardian the individual directs the process as much as possible and is supposed to reflect their wants and needs.<sup>29</sup> However, because the person-centered planning rules allow a person with legal decision-making authority to step into the shoes of the individual, a state may want to put additional protections in place for situations where the legal guardian is also exercising the choice to select themselves as a paid provider.<sup>30</sup>
- Limiting the family caregiver's hours, such as setting a 40 hours per week limit.<sup>31</sup> If a state opts for such a limitation, it should be identified in the waiver application either in Appendix C-2-d or in the service specification in Appendix C-3.<sup>32</sup> Some states have

policies that set hard limits on total paid hours provided by an individual family caregiver or group of family caregivers, but some of those states also have exceptions policies. Regardless, it may be a reasonable accommodation for a person to request an exception to such a policy, depending on the circumstances.

- Using payment review procedures to take a closer look at whether the services by a paid family caregiver have been provided in accordance with the service plan and conditions a state has set. Advocates may want to take a close look at such procedures to ensure that they are effective and do not simply create greater barriers or higher scrutiny on family caregivers that may not be as well-positioned as other paid caregivers to meet paperwork or procedural requirements. For example, in some states that have paid family caregivers for services that must meet electronic visit verification (EVV) requirements, they carefully examined what EVV systems would work well for workers, including paid family caregivers.
- Other protections to address “foreseeable risks” of paying family caregivers.<sup>33</sup> Although CMS does not expand on these protections, protections could include increased respite hours, that a waiver includes caregiver support services and that paid family caregivers make use of such services, and increased case management to help with the development of non-family paid caregivers.

A state is also supposed to consider whether paying for family caregivers will affect the waiver participant’s Medicaid eligibility by affecting the household income.<sup>34</sup> For certain categories of Medicaid eligibility this impact may not be significant due to the income counting rules that disregard HCBS waiver payments.<sup>35</sup> However, it is not clear that these “difficulty of care payments” are always properly accounted for in an individual’s pay stubs and tax paperwork or in Medicaid eligibility decisions.<sup>36</sup> Some states treat a minor child as a household of one for eligibility purposes through one of the available eligibility avenues so paid family caregiver earnings will not affect the child’s eligibility. However, the family member’s eligibility may be affected, especially if the payments are not properly excluded as difficulty of care payments. For example, if a parent is Medicaid eligible under the parent-caretaker category, which typically has lower income limits than some other categories, and they begin providing paid HCBS, not counting the caregiving income may be critical to the parent maintaining Medicaid eligibility, especially in a non-expansion state.

## 2. Provision of Waivers Services Other than Personal Care Services by Family Caregivers

States may also choose to allow paid family caregivers for waiver services other than personal care and related services.<sup>37</sup> The description of what a state allows should be found in Appendix C-2-e. Like for personal care services, a family caregiver must meet the provider qualifications for the service as listed in Appendix C-3 of the waiver, services must be monitored as described in Appendix D-2, and there must be an executed provider agreement.

States may select to either not allow paid family caregivers for these services, allow them in specific circumstances, allow without special circumstances, or set a different policy.

If a state allows paid family caregivers “Only in Specific Circumstances,” those circumstances must be specified in the waiver, as follows:

- The types of relatives or legal guardians that may be paid providers, such as allowing only relatives who do not live in the household or only relatives, but not legal guardians. Some states only allow family caregivers to be paid for services that require specialized skills, such as physical therapy or skilled nursing.
- The types of waiver services that may be provided by family caregivers and the method for determining when any required special circumstances are met.
- Procedures for ensuring payment is only made for services rendered, and that services by paid family caregivers is in the best interest of the individual.<sup>38</sup>

If a state chooses that “Specific Circumstances Do Not Apply,” then this indicates family caregivers may be paid without limits, other than those that are already on a given service, such as the relative meeting provider qualifications and authorized hours. When a state chooses this option, it must indicate whether types of relatives or legal guardians are excluded, indicate for each service in Appendix C-3 which services allow “relative/legal guardian,” and specify procedures to ensure payment is only made for services rendered.

Notably, CMS guidance does not indicate that there should be an evaluation of the best interest of the beneficiary under this option, but best practice would be for a state to still do so.<sup>39</sup> In addition, person-centered planning rules regarding provider choice would still apply.<sup>40</sup> However, in a situation where a person has a legal guardian and that guardian is selecting themselves, state procedures against self-referral and to protect the best interest of the individual would be important. A state may also choose “Other Policy” and then is expected specify all of the information required for the other choices.<sup>41</sup>

Waivers that allow for self-direction, as would be described in Appendix E of a waiver, may opt for differences in the payment of family caregivers for those self-directing versus using agency directed care. This could include differences in not only who is allowed to be a paid family caregiver, but also the services they are allowed to provide and other limitations. For example, a state may decide that due to conflicts of interest a person using self-direction with a legal guardian will not be allowed to have their legal guardian as a paid family caregiver, *e.g.*, self-referral. This use of paid family caregivers should be described in Appendix C of the waiver application, but additional information may be found in Appendix E regarding self-direction.

Regardless of whether the state is opting to allow family caregivers to be paid providers for personal care or other services under a 1915(c) waiver, they should describe the limitations and safeguards in place as discussed in the payment for waiver personal care services section.

### 1915(i) State Plan Option

A state may choose to allow relatives, legally responsible individuals, and legal guardians to provide 1915(i) services. The standards or protections used are very similar to those for 1915(c) waivers.<sup>42</sup> A state must provide assurances that it has policies regarding the payment to qualified persons furnishing state plan HCBS who are relatives of the individual.<sup>43</sup>

There must be additional policies and controls if the state makes payment to qualified legally responsible individuals or legal guardians who provide state plan HCBS. These policies are substantially similar to 1915(c) in that the state must specify:

- who may be paid to provide 1915(i) services and for which services;
- how the state ensures that the provision of services by such persons is in the best interest of the individual;
- the state's strategies for ongoing monitoring of services provided by such persons;
- the controls to ensure that payments are made only for services rendered; and
- if legally responsible individuals may provide personal care or similar services, the policies to determine and ensure that the services are extraordinary.<sup>44</sup>

### 1915(k) Community First Choice Option

Community First Choice (CFC) options allow for paid family caregivers. However, if a person is acting as an individual's legal representative, that person may not also be a paid caregiver of an individual receiving CFC services and supports.<sup>45</sup> Under the agency provider model, an individual should have control over who provides services to them, but CMS strongly encourages, not mandates, that agencies employ an individual's family members.<sup>46</sup> Under a self-directed 1915(k) program, a person can hire family members as long as they meet the qualifications.<sup>47</sup> However, states do not have to allow self-direction in a 1915(k).

### 1915(j) Self-Directed Personal Assistant Services

In self-directed personal assistance services (PAS), participants set their own provider qualifications, train their PAS providers, and determine how much they pay for a service, support, or item.<sup>48</sup> States may choose to allow people enrolled in a PAS to hire legally liable relatives and determine what other relationships the state includes.<sup>49</sup> If a person is acting as a participant's representative to direct the provision of self-directed PAS, that person may not act

as a provider of self-directed PAS to the participant.<sup>50</sup> Section 1915(j) PAS is not common in states.

## Policy Considerations

Paying family caregivers should be an option, but it is important that family is not compelled into providing supports, paid or unpaid.<sup>51</sup> State policies should be crafted such that they protect individual choice and autonomy of the person receiving services. Paying family caregivers should be a choice among an array of available qualified providers, through agency or self-directed care. Policy advocacy regarding paying family caregivers should consider:

- **Conflict of Interest Provisions.** Conflict of interest provisions include whether a legal guardian of an adult can both self-direct care and hire themselves; also known as self-referral.<sup>52</sup> Although there are good policy reasons, including around abuse/neglect and community integration, to have this restriction, there are also other ways to achieve the policy concerns. Overly restrictive policies may mean that individuals with limited family members involved in their lives may lose out on the benefits of self-direction, including to hire other caregivers of their choice, if their legal guardian cannot also be a paid provider. For example, adults with divorced parents or single parents who are their legal guardian may have their choices limited compared to those with more family members. Options to allay the policy concerns include, more frequent in-person case management visits or other monitoring; requiring additional community integration activities that involve other service providers or provide interaction external to the household; training on conflicts for individual care givers; and providing, or potentially requiring, more respite hours than normally authorized. They could also use an ombudsman or other individual in the person-centered planning process to support the individual in the process to help address the conflict.
- **Limits on Hours.** One of the most commonly cited policy concerns for paying family caregivers is caregiver burnout. States often cite this concern when putting in place restrictions on hours. While caregiver burnout is very real concern, the issue is not really addressed if what happens in reality is that the care is simply improperly compelled as natural supports.<sup>53</sup> Some states that use caps do not have hard limits, but require exemptions for more than the set number of hours. Some states also have time limits on the exemptions, limits which sometimes may be overcome. For example, NC's waiver for individuals with intellectual and developmental disabilities sets a recommendation at 40 hours per week for any one relative, with up to 56 hours approved in exceptional circumstances and has an approval process.<sup>54</sup>

Caregiver burnout concerns may also be able to be addressed through additional respite hours; caregiver supports services; more community integration services that involve the individual in community activities, employment, etc.; and specific supports to help identify, develop, and train non-relative provider options to meet the individual's needs and preferences. The state may also choose to require an emergency plan if there is concern that there is over reliance on a small group of family caregivers and any illness or absence by the caregiver would create safety or institutionalization risks for the individual.

States may also be using limits on hours to avoid overtime issues. Overtime may impact a person's budget and how many of hours of services a budget will cover. Overtime can also be complex for states to deal with operationally. The rules on when a home care worker must be paid overtime are complicated and depend on the employer, employment status of the worker, tasks performed, and whether the worker lives in the same home as the individual.<sup>55</sup> Within a given waiver, there may be a mix of self-direction and agency-based care; people living with their caregivers and not; and a range of service types. This means that within a given waiver, there are a variety of overtime and overtime exempt scenarios. To complicate labor questions even more, some states have service definitions that would pay family caregivers a daily rate. While this type of rate structure can help avoid complications of overtime and some of the documentation burdens, it still must meet labor rules regarding minimum wage.<sup>56</sup> There are also certain circumstances in which an individual may be allowed to count the cost of housing and food provided to a worker's minimum wage payment. Because of the complexity of the rules, states may look to 40 hour per week maximums to limit administrative burden. Regardless of the reason for a policy limiting hours, states may have exceptions policies, or grant exceptions to such maximums as reasonable accommodations when necessary.

- **Financial Impact.** States often bring up the financial impact of paying family caregivers. However, such statements should be investigated. If family members are paying for services already authorized, this simply replaces non-family providers with family providers. If a state's budget is based on historic utilization data based on times when the individual was not able to find providers to fill approved hours, that is creating a misleading fiscal impact. If the job market changed and there were far more direct support staff available to fill the hours, that would have the same impact.
- **Individual Choice.** There are many reasons behind the push for paying family caregivers, including provider shortages, the need for stable caregiving, health and safety, and lack of caregivers to meet the specific needs of individuals. With all of the pressing reasons, the choice of the individual must remain the primary focus. The services in question are for the individuals and to support them in the community. Policy

considerations should reflect individual choice and concepts such as dignity of risk (the right to take reasonable risks even if there are negative consequences), supported decision-making, etc.

- **Equity Concerns.** States should evaluate whether their policies around family caregivers are equitable for all waiver participants. They should examine their policies to ensure that they do not adversely impact services authorized, budgets, or choice for any subset of the waiver participants. States should make sure that all individuals who may pay family caregivers understand that they have this option through the person-centered planning process. Advocates often report that they more commonly see requests for assistance regarding paid family caregiver policies from higher income families. States should examine whether there is any disparate impact on who is selecting paid family caregiving and if there are any planning practices or policies limiting access. For example, provider qualification policies may also have a disparate impact on families of color. For example, many states have provider qualifications that would not allow providers with any type of criminal record to provide paid care, regardless of the age or type of record. Racist police practices and the criminalization of Black and brown communities combined with strict provider qualifications may limit choice for Black and brown waiver participants. States should examine the equity impacts of their outreach and education, budget allocation, person-centered planning, and provider policies impacting availability and use of paid family caregivers.
- **State Licensure Limitations.** As discussed earlier, what a family caregiver may be allowed to do versus be paid to do may vary widely by state under state licensing board requirements. This is particularly true of tasks such as skilled nursing tasks. However, some states' licensure requirements have exceptions for family caregivers, self-direction, or allow nurse delegation which allows a non-licensed nurse to perform certain nursing tasks based on a showing of competency and/or under the direction of a nurse. States may need to carefully define paid family caregiving services such that they fall within current exceptions to licensure limitations. States and advocates may need to work with licensure boards to change requirements to allow for paid family caregiving for the relevant services.

Policies around paying family caregivers can be complicated due to the mix of policy concerns. While paying family caregivers is an important piece of states ensuring access to services, they must continue to focus on developing sufficient providers to ensure there is true choice of provider. A person should only be choosing a family caregiver because that is truly their first choice, not because that is their only reliable and qualified choice. As advocates work on paying family caregiver issues, they should also be pushing states on other steps they are taking to expand provider options.

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**ENDNOTES**

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<sup>2</sup> NASDDDS, *Caring Families: Paying Family Caregivers Topic Brief* (July 2023), [https://www.nasdds.org/wp-content/uploads/2023/07/Caring-Families\\_final-0713.2023tss.pdf](https://www.nasdds.org/wp-content/uploads/2023/07/Caring-Families_final-0713.2023tss.pdf). NASDDDS surveyed its members in Spring 2023 to better understand which states elected to pay family caregivers during the PHE and which expected to continue the practice post-PHE. Only about half of the states responded to the survey. Among respondees, there was quite wide variation in allowing paid family caregivers, especially around legally responsible relatives, and what services could use paid family caregivers. The survey results showed that of the states that added flexibilities for paid family caregivers during the PHE, 77% intended to continue those flexibilities, with 25% already adding the flexibility to their waivers at the time of the survey. Nearly all of the responding states (90 percent) indicated they allow payment to non-legally responsible relatives, and half pay for legally responsible relatives.

<sup>3</sup> Almost two-thirds of states allow legally responsible relatives to be paid providers, but only 11 do so for state plan personal care services. This survey did not count the states that indicated they had elected to be pay family caregivers during the PHE. Molly O'Malley Watts et al., Kaiser Family Found., *State Policy Choices About Medicaid Home and Community-Based Services Amid the Pandemic* (Mar. 4, 2022), <https://www.kff.org/report-section/state-policy-choices-about-medicaid-home-and-community-based-services-amid-the-pandemic-appendix/#table7>. Comparatively, in 2018, five states allowed legally responsible relatives to provide state plan personal care services, 30 states allowed certain legally responsible relatives to be paid providers for certain waivers and services within those waivers. MaryBeth Musumeci et al., Kaiser Family Found., *Key State Policy Choices About Medicaid Home and Community-Based Services* (Feb. 2020), <https://files.kff.org/attachment/Issue-Brief-Key-State-Policy-Choices-About-Medicaid-Home-and-Community-Based-Services>; Alice Burns et al., Kaiser Family Found., *Ending the Public Health Emergency for Medicaid Home- and Community-Based Services* (Apr. 19, 2023) (39 states allowed paid family caregivers under a PHE authority).

<sup>4</sup> Ctrs. for Medicare & Medicaid Servs., All-State Medicaid and CHIP Call 5 (June 6, 2023), <https://www.medicaid.gov/sites/default/files/2023-06/covid19allstatecall06062023.pdf> (including the agenda item of Paid Family Caregivers for Personal Care Services – Options Beyond the COVID-19 Public Health Emergency). Federal agencies have also identified

strategies to support family caregivers, including identifying federal actions like prioritizing providing technical assistance to states to encourage making changes to 1915(c) waivers and other authorities to pay family caregivers. *See, e.g.*, Admin. Community Living, 2022 National Strategy to Support Family Caregivers: Federal Actions (Sept. 21, 2022), <https://acl.gov/CaregiverStrategy>.

<sup>5</sup> Ctrs. for Medicare & Medicaid Servs., Dear State Medicaid Director (Aug. 2, 2023) (SMD # 23-004), <https://www.medicaid.gov/sites/default/files/2023-08/smd23004.pdf> (extending 1915(c) Home and Community-Based Services Waiver Appendix K expiration dates).

<sup>6</sup> 42 U.S.C. § 1396d(a)(24)(B). State plan personal care services go by a number of different names in states, including personal attendant services, personal assistance services, or attendant care services.

<sup>7</sup> 42 C.F.R. § 440.167.

<sup>8</sup> CMS, STATE MEDICAID MANUAL § 4442.3.B.1.

<sup>9</sup> Coverage of Personal Care Services, 62 Fed. Reg. 47896, 47899 (Sept. 11, 1997) (to be codified at 42 C.F.R. pt. 440); STATE MEDICAID MANUAL, 4480.D. This definition is identical to that for HCBS waiver services. If stepparents are not legally responsible for the recipient in some states, they could be providers under this definition, but states can further restrict which family members can qualify as providers by extending the definition to apply to individuals other than those legally responsible for the recipient.

<sup>10</sup> CMS, STATE MEDICAID MANUAL § 4480.D.

<sup>11</sup> Coverage of Personal Care Services, 62 Fed. Reg. at 47899.

<sup>12</sup> *Id.* at B.2.

<sup>13</sup> States must cover medically necessary health care, diagnostics services, treatment and other measures to correct or ameliorate the conditions of covered individuals under 21 if those services are described in § 1396d(a), regardless if the state includes those services in its Medicaid program, with only limited exceptions. 42 U.S.C. § 1396a(a)(10)(A); 1396a(a)(43); 1396d(a)(4)(B), 1396d(r). *See generally* Jane Perkins & Amanda Avery, Nat'l Health L. Program, *Q&A: Medicaid EPSDT Litigation* (Mar. 7, 2022).

<sup>14</sup> 42 U.S.C. § 1396d(a)(7). Home health has mandatory and optional components. Medical supplies, equipment, and appliances are part of the mandatory home health benefit. 42 C.F.R. § 440.70. Equipment and appliances are covered under home health if they meet certain criteria. *Id.* § 4407.70(b)(3)(ii). For a further discussion of home health, *see* Jane Perkins, Nat'l Health L. Program, Q&A: The Medicaid Home Health Service Final Rule (Feb. 26, 2016) (discussing home health generally and the impact of 2016 rule changes); Jane Perkins, Nat'l Health L. Program, Q&A: State Medicaid Policy Regarding Policy Regarding Exclusive Coverage Lists (Aug. 30, 2019) (discussing home health benefit in the context of durable medical equipment and supplies).

<sup>15</sup> 42 U.S.C. § 1396d(a)(7).

<sup>16</sup> 42 C.F.R. § 484.80(i). There are significant regulatory differences in home health aide services versus personal care services. *Compare* 42 C.F.R. § 440.70(b)(2); 484.80 (describing home health aides and qualifications) *with* 42 C.F.R. § 440.167(a)(2) (regarding personal care).

<sup>17</sup> *See, e.g.*, Hawai'i QUEST Integration 140-41 (Oct. 14, 2020),

<https://www.medicaid.gov/sites/default/files/2020-10/hi-quest-expanded-ca.pdf>

(allowing self-direction of nursing tasks delegated to non-nurse staff); Texas Healthcare Transformation and Quality Improvement Program (June 26, 2023), <https://www.medicaid.gov/sites/default/files/2023-06/tx-healthcare-transformation-appvl-06262023.pdf> allowing nurse-delegated tasks under personal assistance services and allowing relative or legal guardian, other than a spouse to be a paid provider if they meet the qualifications); *see also* Indiana Aged & Disabled Waiver, IN.0210.R07.00 (July 1, 2023) (participant directed home care services allow nurse delegation, but not relative provided care). Whether nurse level services or other “skilled” services can be delegated often depend on state licensure requirements, some of which allow those without licenses to provide care but may not allow payment for the services, and may also have variations based on definition of relatives and whether the individual is self-directing services. *See also, e.g.*, Team Select Home Care, States Offering the FCNA Program, <https://tshc.com/states-where-the-program-is-available/> (tracking states that have allowed families members to be paid providers of certain services through that particular model).

<sup>18</sup> Ctrs. for Medicare & Medicaid Servs., Application for a § 1915(c) Home and Community-Based Waiver: Instructions, Technical Guide and Review Criteria 119-123 (Jan. 2019), [https://wms-mmdl.cms.gov/WMS/help/35/Instructions\\_TechnicalGuide\\_V3.6.pdf](https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf) [hereinafter 1915(c) Technical Guide] The Technical Guide discusses the prohibition of paying legally responsible individuals for state personal care services and cites to the regulatory prohibition at 42 C.F.R. § 440.167 and Section 4442.3.B.1 of the State Medicaid Manual. *Id.* Note, CMS proposed changes to the 1915(c) Application and Technical Guide in September 2023 that take away the requirement that the family caregiver be in the best interest of the individual and add a requirement to protect against self-referral when the parent/legal guardian has decision-making authority over the selection of providers. CMS, Agency Information Collection Activities CMS-R-21 and CMS-8003, 88 Fed. Reg. 62377 (Sept. 11, 2023), <https://www.govinfo.gov/content/pkg/FR-2023-09-11/pdf/2023-19500.pdf>; to access the proposed changes, see CMS, CMS-8003, <https://www.cms.gov/regulations-and-guidance/legislation/paperworkreductionactof1995/pra-listing-items/cms-8003>.

<sup>19</sup> *Id.*

<sup>20</sup> For approved 1915(c) waiver applications, see Medicaid.gov, State Waivers List, <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>; *see also* 1915(c) Technical Guide, *supra* note 18.

<sup>21</sup> *Id.*

<sup>22</sup> 1915(c) Technical Guide, *supra* note 18, at 120.

<sup>23</sup> *See, e.g.*, NASDDDS, *Caring Families*, *supra* note 2, at 7 (providing extraordinary care definition examples from six states).

<sup>24</sup> 1915(c) Technical Guide, *supra* note 18, at 120.

<sup>25</sup> *Id.*

<sup>26</sup> *Id.* at 121.

<sup>27</sup> *Id.*

<sup>28</sup> *Id.*

<sup>29</sup> 42 C.F.R. § 441.301(c)(1)

<sup>30</sup> *See* note 18 regarding proposed changes to 1915(c) guidelines that would include protections against self-referral for parents/legal guardians.

<sup>31</sup> 1915(c) Technical Guide, *supra* note 188, at 120-21.

<sup>32</sup> The 1915(c) Technical Guide says this limitation is supposed to be reflected in the service specifications in Appendix C-3, but the limitation often is listed in the section on family caregivers instead at Appendix C-2-d or C-2-e. *Id.*

<sup>33</sup> *Id.*

<sup>34</sup> *Id.*

<sup>35</sup> Wayne Turner, Nat'l Health L. Program, Fact Sheet: IRS Updated Guidance on HCBS Difficulty of Care Payments (Apr. 9, 2015), <https://healthlaw.org/resource/fact-sheet-irs-updated-guidance-on-hcbs-difficulty-of-care-payments/>; *see also* IRS, Internal Revenue Bulletin: 2014-4, Notice 2014-7 Foster Care Payments, Medicaid waivers (Jan. 21, 2014), [https://www.irs.gov/irb/2014-04\\_IRB#NOT-2014-7](https://www.irs.gov/irb/2014-04_IRB#NOT-2014-7); IRS, Q&A: Certain Medicaid Waiver Payments May Be Excludable From Income, <https://www.irs.gov/individuals/certain-medicaid-waiver-payments-may-be-excludable-from-income>.

<sup>36</sup> *See* IRS Q&A, *supra* note 35. Under the IRS guidance, it seems like the responsibility lies on employers to account for income differently for those who qualify for difficulty of care payments. As a practical matter it is not clear that this happens consistently. States should also be making efforts to determine whether an individual is impacted by the IRS rule for Medicaid eligibility purposes.

<sup>37</sup> 1915(c) Technical Guide, *supra* note 18, at 121-24.

<sup>38</sup> *Id.* at 122. A state must also indicate in Appendix C-3 for each service whether services may be provided by "relative/legal guardian." *Id.* at 123.

<sup>39</sup> Although it is not in the text of this section, the CMS Review Criteria in the 1915(c) Technical Guide for this Appendix as a whole still includes the best interest language. *Id.* at 124.

<sup>40</sup> 42 C.F.R. § 441.301(c)(2); *see also* 1915(c) Technical Guide, Appendix D: Person-Centered Planning and Service Delivery, *supra* note 1818, 190-201 (Appendix E of a waiver will also likely include information on the safeguards regarding paying family caregivers, even though most of these limitations and safeguards should be included in Appendix C).

<sup>41</sup> 1915(c) Technical Guide, *supra* note 18, at 124.

<sup>42</sup> The services allowed in a 1915(i) references those in 1915(c). 42 U.S.C. 1396n(i)(1). CMS seems to apply the 1915(c) standards about family providers to 1915(i).

<sup>43</sup> Ctrs. for Medicare & Medicaid Servs., 1915(i) State Plan HCBS Pre-Print 11, [https://www.medicaid.gov/sites/default/files/2019-12/1915i-application\\_0.pdf](https://www.medicaid.gov/sites/default/files/2019-12/1915i-application_0.pdf).

<sup>44</sup> *Id.*

<sup>45</sup> 42 C.F.R. § 441.505. For purposes of the CFC option, a legal representative may be a parent, family member, guardian, advocate, or other person authorized by the individual to serve as a representative in connection with the provision of CFC services and supports. *Id.*

<sup>46</sup> Community First Choice Option, 77 Fed. Reg. 26828, 26879-80 (May 7, 2012) (to be codified at 42 C.F.R. pt. 441).

<sup>47</sup> 42 C.F.R. § 441.565(c). Under self-direction with a service budget, "an individual has the option to permit family members, or any other individuals, to provide Community First Choice services and supports identified in the person-centered plan, provided they meet the qualifications to provide the services and supports established by the individual." *Id.* This follows the intent of the statute that the supports in a CFC program be "provided by an

individual who is qualified to provide such services, including family members (as defined by the Secretary)." 42 U.S.C. 1396n(k)(1)(A)(iv)(III). *See generally* Ctrs. for Medicare & Medicaid Servs., Community First Choice State Plan Option Technical Guide 16 (2019), [https://www.medicaid.gov/sites/default/files/2019-12/cfc-technical-guide\\_0.pdf](https://www.medicaid.gov/sites/default/files/2019-12/cfc-technical-guide_0.pdf).

<sup>48</sup> CMS, Self-Directed Personal Assistance Services 1915(j), <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/self-directed-personal-assistant-services-1915-j/index.html> (last visited Oct. 15, 2023).

<sup>49</sup> 42 U.S.C. 1396n(j)(B)(i); 42 C.F.R. § 441.450(c). For 1915(j), legally liable relatives are defined as "persons who have a duty under the provisions of State law to care for another person" and may include that parent (biological or adoptive) of a minor child, or the guardian of the minor child who must provide care to the child, legally-assigned caretaker relatives, and a spouse." *See also* Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling), 73 Fed. Reg. 57854, 57859 (Oct. 3, 2008) (to be codified at 42 C.F.R. pt. 441).

<sup>50</sup> 42 C.F.R. § 441.480. In a PAS program, the financial management service entities are expected to report irregularities in how services are performed. Self-Directed Personal Assistance Services Program State Plan Option, 73 Fed. Reg. at 57869.

<sup>51</sup> 42 C.F.R. §§ 441.301(c)(2)(v); 441.725(b)(5) (not allowing compelled natural supports in most HCBS programs, including 1915(c) waivers); *see also* HCBS Final Rules, 79 Fed. Reg. 2948, 3008 (Jan. 16, 2014), <https://www.govinfo.gov/content/pkg/FR-2014-01-16/pdf/2014-00487.pdf>; *Waskul v. Washtenaw Cnty. Cmty. Mental Health*, 979 F.3d 426, 451-52 (6th Cir. 2020) (discussing the prohibition on compelling natural supports); *Mocznianski v. Ohio Dept. of Job & Family Servs.*, 2011-Ohio-4685, 195 Ohio App. 3d 422, 430-33 (natural supports cannot be compelled or have the number assigned without reason).

<sup>52</sup> *See* note 18 *supra* discussing proposed changes to the 1915(c) application and technical guidance about parent/legal guardian self-referral protections.

<sup>53</sup> 42 C.F.R. §§ 441.301(c)(2)(v); 441.725(b)(5) (not allowing compelled natural supports in most HCBS programs, including 1915(c) waivers).

<sup>54</sup> *See* NC Medicaid North Carolina Innovations, Medicaid and Health Choice Clinical Coverage Policy No. 8-P, att. G, 129 (Mar. 15, 2019), <https://files.nc.gov/ncdma/documents/files/8-P.pdf>; *see also, e.g.*, Alliance Health Plan, NC Innovations Individual and Family Guide 52-55, <https://www.alliancehealthplan.org/document-library/59271/> (describing the policy and the managed care plan's suggested additional questions to consider, including the offer of a neutral advocate, to ensure the individual's needs are being met). In NC, the decision to deny a family caregiver may be grieved, but arguably there are situations in which a person should be able to file an appeal depending on the impact on their services.

<sup>55</sup> *See, e.g.*, U.S. Dep't of Labor, *Paying Minimum Wage and Overtime to Home Care Workers: A Guide for Consumers and their Families to the Fair Labor Standards Act* (Mar. 2016), [https://www.dol.gov/sites/dolgov/files/WHD/legacy/files/Homecare\\_Guide.pdf](https://www.dol.gov/sites/dolgov/files/WHD/legacy/files/Homecare_Guide.pdf).

<sup>56</sup> *Id.* at 31.