

Q & A Relatives as Paid Providers¹

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- Q: Our state allows some parents to be compensated for providing Medicaid services in certain programs, but will not pay parents to provide other services. Can the state restrict parents as paid providers in this way?
- A: Yes, states may choose when to permit relatives or legally responsible individuals to be paid for providing Medicaid services. There is some variation in the rules regarding different home and community based services (HCBS) and there are separate limitations for other Medicaid State plan services. For HCBS programs, the approved waiver or State plan document should describe the criteria for paying relatives as providers.

Background

State policies on the provision of HCBS services by relatives varies both across states and by program and population served.² Almost all states allow relatives to provide paid care in certain programs, but only 21 states pay a parent who is also a guardian and even fewer, six, pay parents of minor children.³ Although HCBS services often allow

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² Robert J. Necome, et al., *Allowing Spouses to Be Paid Personal Care Providers*, 52(4) THE GERONTOLOGIST 517-530, (2012), available at <http://www.medscape.com/viewarticle/767749>.

³ Robin E. Cooper, NASDDDS, *Paying Relatives Providing Supports: Practices, Issues, Lessons Learned* (Aug. 2010), <http://www.reinventingquality.org/docs/rcooper10.pdf> (citing survey conducted by NASDDDS as reported in Cooper, *Caring Families, Families Giving Care*:

relative providers, especially in self-directed options, State plan personal care services clearly prohibit payment for services by a family member, defined as a legally responsible person.⁴ State policies also differ on whether there are restrictions on the provider living with the individual being served, qualifications of the relative provider, application processes to serve as relative provider, etc.

State officials are sometimes reluctant to pay relatives as providers of care. They cite the existing responsibility for children and spouses, fear that substituting paid care for unpaid family care will increase costs, overreliance on a limited number of individuals as both paid supports and unpaid natural supports, burnout of caregivers, conflicts of interest, and isolation from the larger community if care is only provided by family members. But, studies have shown that those who receive paid supports from family members reported higher satisfaction with paid care and had either better or no worse outcomes on self-reported quality measures.⁵ Moreover, positive effects of respite may not occur if individuals or their family members do not trust others to provide quality care.⁶ Paid family caregivers have also been associated with neutral or positive outcomes, such as fewer hospital admissions and fewer institutional placements.⁷

Paying legally responsible relatives is explicitly an option, not a requirement, for states in most HCBS programs.⁸ The following is an overview of the federal program requirements. However, because state policy choices on this topic vary it is important to check the approved waiver and state plan documents for additional information about a state's policies regarding whether and when to allow paid family.

Using Medicaid to Pay Relatives Providing Supports to Family Members, NASDDDS (June 2010).

⁴ 42 U.S.C. § 1396d(a)(24)(B) (“not a member of the individual’s family”); 42 C.F.R. § 440.167 (personal care services are not provided by a member of the individual’s family and for purposes of this section, family member means a legally responsible relative). This prohibition is based on the presumption that legally responsible individuals may not be paid for supports that they are ordinarily obligated to provide. CMS, STATE MEDICAID MANUAL § 4442.3.B.1.

⁵ Newcome, *supra* note 2; A.E. Benjamin and Ruth E. Matthias, *Comparing Consumer- and Agency-Directed Models: California’s In-Home Supportive Services Program*, 24(3) GENERATIONS 85-87 (2000), available at http://laborcenter.berkeley.edu/homecare/pdf/benjamin_01.pdf.

⁶ Newcome, *supra* note 2.

⁷ *Id.*

⁸ CMS, APPLICATION FOR A § 1915(C) HOME AND COMMUNITY-BASED WAIVER: INSTRUCTIONS, TECHNICAL GUIDE AND REVIEW CRITERIA 1915(C) TECHNICAL GUIDE 119 (Jan. 2008), <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/Technical-Guidance.pdf> [hereinafter 1915(C) TECHNICAL GUIDE].

1915(c) Waivers⁹

In 1915(c) HCBS waivers, states have the option of allowing waiver services to be provided by individuals who are related to the participant, including legal guardians. The State must make a separate choice regarding whether it will allow the provision of State Plan personal care services (PCS) or similar services by a legally responsible relative.¹⁰ PCS or waiver services can only be provided by a qualified individual who is not a legally responsible relative, except in specific extraordinary circumstances.¹¹ For the purpose of waiver services, a legally responsible person is defined as “spouses or parent of minor children, when the services are those that these persons are already legally obligated to provide.”¹²

A person may have a relative or friend who is not legally responsible provide State Plan PCS 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.¹³

In limited circumstances, a legally responsible relative may provide “extraordinary services requiring specialized skills (e.g., skilled nursing, physical therapy) which such people are not already legally obligated to provide.”¹⁴ Extraordinary care means, “care 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.”¹⁵ If a state allows for the provision of paid services by a legally responsible relative, it must specify:

- the types of legally responsible individuals who may be paid and what services they may provide,

⁹ 1915(d) waivers, although rarely used, do not allow the participant’s spouse to provide services. 42 C.F.R. § 441.360(g).

¹⁰ 42 U.S.C. 1396n(c); 42 C.F.R. § 441.310(a)(2)(ii); 1915(C) TECHNICAL GUIDE, *supra* note 8, at 116. In a waiver application, item C-2-e asks about general waiver services and C-2-d is a much narrower question regarding personal services.

¹¹ CMS, STATE MEDICAID MANUAL § 4442.3.B.1.

¹² CMS, STATE MEDICAID MANUAL §4442.3.B.1.

¹³ *Id.* at B.2.

¹⁴ *Id.*

¹⁵ 1915(C) TECHNICAL GUIDE, *supra* note 8, at 119

- the applicable state policies that describe the circumstances when payment is authorized, including how the state distinguishes extraordinary from ordinary care,¹⁶
- how the State ensures that the provision of services by the legally responsible individual is in the best interest of the participant, and
- the controls that are used to ensure that payments are made only for services rendered.¹⁷

When a state provides for payment to legally responsible individuals for extraordinary care, it must monitor the services. The State must also have safeguards, such as limiting the amount of paid services that a legally responsible individual may furnish so as to take into account the amount of care that they would ordinarily provide; implementing payment review procedures; and addressing other foreseeable risks from such provision of services and any effect payment to the legally responsible person may have on the participant's eligibility.¹⁸ The guidance regarding safeguards for relatives and/or legal guardians that are not legally responsible or are not providing personal care is slightly different, but not substantially so.¹⁹

It is in the state's discretion whether to allow the provision of services by family members and to specify the circumstances under which payment is permitted. These conditions are usually specified in the waiver document. They could include the lack of other providers available to serve the individual, that the specific needs of the individual can only be met by the legally responsible individual, etc. In addition to these conditions, the person must always meet the provider qualifications that apply to a service.²⁰

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.²¹ 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.

There must be additional policies and control 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:

¹⁶ *Id.*

¹⁷ *Id.* at 118.

¹⁸ *Id.* at 119.

¹⁹ *Id.* at 121-122.

²⁰ *Id.* at 118.

²¹ 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).

- who may be paid to provide State plan HCBS;
- the specific State plan HCBS that can be provided;
- 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 person care or similar services, the policies to determine and ensure that the services are extraordinary.²²

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.²³ States may choose to allow people enrolled in a PAS to hire legally liable relatives, which 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.²⁴ It is up to the States to determine what other relationships they include in their definition of legally responsible relatives.²⁵

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.²⁶ In a PAS program, the supports broker or consultant is supposed to provide sufficient assistance in dealing with service issues and CMS declined to require additional safeguards, relying on the financial management service entities to report irregularities and the oversight and monitoring activities of the State Medicaid agency.²⁷

²² This language is in the 1915(i) preprint under the Services section. See, e.g., Indiana’s 1915(i) for Behavioral and Primary Healthcare Coordination Services (SPA 13-013) (May 30, 2014) (state plan page 146), <http://www.medicaid.gov/State-resource-center/Medicaid-State-Plan-Amendments/Downloads/IN/IN-13-013.pdf>

²³ CMS, Self-Directed Personal Assistance Services 1915(j), <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/self-directed-personal-assistant-services-1915-j.html> [last visited Nov. 13, 2014].

²⁴ 42 U.S.C. 1396n(j)(B)(i); 42 C.F.R. § 441.450(c).

²⁵ 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).

²⁶ 42 C.F.R. § 441.480.

²⁷ Self-Directed Personal Assistance Services Program State Plan Option, 73 Fed. Reg. at 57869.

1915(k) Community First Choice Option

Community First Choice (CFC) options allow for paid relative caregivers, but if a person is acting as an individual's legal representative, that person may not also be a paid caregiver of an individual receiving services and supports.²⁸ 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.²⁹ If the person is in a self-directed program, the individual has the right to hire "family members, or any other individual[]...provided they meet the qualifications to provide the services and supports established by the individual, including additional training."³⁰

CMS interprets the statute to require states to allow individuals in self-directed models to hire family members qualified to provide any service on the person-centered plan, but recognized that States have the option of only offering the agency-provider model. While CMS expects that the agency-provider model should allow an individual to exercise maximum control over who provides services to them, CMS cannot mandate agencies to employ individuals' family members for the purpose of providing CFC services.³¹ However, it is strongly encouraged.³² However, a person cannot be a person's individual representative and their provider.³³

State Plan Personal Care Services

States call personal care services (PCS) a variety of names, including personal attendant services, personal assistance services, or attendant care services. State plan PCS can only be provided by a qualified individual "who is not a member of the individuals' family."³⁴ The regulation further defines a family member as "a legally responsible relative."³⁵ Generally, legally responsible relative refers to spouses of recipients and parents of minor recipients, including stepparents who are legally

²⁸ 42 C.F.R. § 441.505.

²⁹ *Id.*

³⁰ 42 C.F.R. § 42 C.F.R. § 441.565(c). 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).

³¹ Community First Choice Option, 77 Fed. Reg. 26828, 26879-80 (May 7, 2012) (to be codified at 42 C.F.R. pt.441).

³² *Id.*

³³ For an example of a state policy on how to address this conflict, see Oregon, <http://www.dhs.state.or.us/policy/spd/transmit/ar/2013/ar13085.pdf>. Oregon transitioned its 1915(c) waiver into a 1915(k) state plan option and had to adjust the policies because of the 1915(k) rules.

³⁴ 42 U.S.C. § 1396d(a)(24); 42 C.F.R. § 440.167(a)(2).

³⁵ 42 C.F.R. § 440.167(b).

responsible for minor children.³⁶ 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, the definition of legally responsible relative will vary, depending on the responsibilities imposed under State law or under custody or guardianship arrangements.³⁷ States can also further restrict which family members can qualify as providers through the way they define “family members” for purposes of PCS.³⁸ Therefore, the family members who may be allowed to be a qualified provider for state plan PCS may be different based on the state and the individual’s own situation.

Case Law

Limited case law exists on the question of relative providers. In *Calenzo v. Shah*, a participant in one of the State’s self-directed waiver options contested the denial of his stepfather providing paid support services.³⁹ In *Calenzo* the state regulation did not allow payment for personal care services by a spouse, parent, son, son-in-law, daughter, or daughter-in-law and the Department had refused to allow the adult individual’s step-father to be a paid provider, saying that step-parents were supposed to be included in the term “parent”. The Department argued that such a reading would be consistent with the federal regulations and statute. The court found that the lack of ambiguity in the language of the state regulations and the detailed list of relationships, including the failure to include stepparents, did not give fair notice and the denial lacked a rational basis, thus the denial should be overturned. The court said that if the state regulations were inconsistent with federal, then the solution was to amend the regulation, not read into the regulation a term that is clearly not there.⁴⁰

In *Peers v. Harvey*⁴¹, Mr. Peers’ sister was providing State plan personal care services to her adult brother. When their mother had to go to the hospital and could not provide the care she was providing to Mr. Peers, the sister asked for additional hours to cover the additional services. During this request, the Department realized that the sister was being paid to provide care, in violation of their state statute and the federal regulations at the time. Mr. Peers’ filed suit to continue to allow his sister to provide services, saying

³⁶ 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 provide PCS 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.

³⁷ CMS, STATE MEDICAID MANUAL §4480.D.

³⁸ Coverage of Personal Care Services, 62 Fed. Reg. at 47899.

³⁹ 112 A.D.3d 709, 976 N.Y.S.2d 555 (App. Div. 2013).

⁴⁰ *Id.*

⁴¹ No. A-97-592, 1998 WL 800963 (Neb. Ct. App.).

that he may suffer harm if she does not provide services and that they may not be able to find a provider at the wages offered. They argued estoppel and laches and that the state should have to request a waiver. The court found none of these arguments persuasive.⁴²

Conclusion

The shortage of qualified providers in most states means that it is often difficult for all individuals to find the necessary providers. Many individuals rely on paid family members for the reliable, effective provision of supports. These difficulties may increase with the wage and hour rules on overtime requirements for home care workers that will soon go into effect.⁴³ Although the difficulty in finding providers may increase reliance on paid family support, there should be a sufficient network of non-family providers for the services. In addition, states cannot supplant needed paid services with natural, unpaid support unless those supports are provided voluntarily in lieu of an attendant.⁴⁴ Although states can set up policies for when a family member may provide services, any changes to provider policies should always consider the effect on access to providers. State policies regarding family providers are evolving and it is important to maintain focus on what the individual needs, maintaining sufficient providers to meet those needs reliably and how best to support a person's community living.

⁴² *Id.*

⁴³ U.S. Dep't of Labor, Fact Sheet #79F: Paid Family or Household Members in Certain Medicaid-Funded and Certain Other Publicly Funded Programs Offering Home Care Services under the Fair Labor Standards Act (FLSA) (June 2014), <http://www.dol.gov/whd/regs/compliance/whdfs79f.htm>. The rule goes into effect January 1, 2015, but the Department has announced a time-limited non-enforcement policy for six months and a subsequent six months during which the Department will exercise prosecutorial discretion, taking into consideration good faith efforts at compliance. U.S. Dep't of Labor, <http://social.dol.gov/blog/an-announcement-concerning-the-home-care-final-rule/>.

⁴⁴ See, e.g., 42 C.F.R. § 441.540; see also *Jensen v. Missouri Dep't of Health & Senior Servs.*, 186 S.W.3d 857 (Mo. Ct. App. 2006) (holding state requirements regarding unmet need and undue hardship conflict with federal law because they consider family resources of adult recipients). In *Jensen*, the court determined that the State's waiver requirement regarding unmet need and undue hardship conflicted with federal law to the extent that they considered family resources of the adult recipient. Ms. Jensen had been receiving aide hours provided by her mother seven days a week. These hours were cut to five days a week on the basis that she had not document that it would not be an "undue hardship" for her parents to meet her needs on the additional two days. The assessment of Ms. Jensen indicated an unmet need for seven days per week, but because the evaluator determined that the family would meet her needs if a paid assistant were not available, the Department only authorized five days of paid assistance. *Id.*