

# Medicaid Enrollees Put at Risk When State Medicaid Programs Assume Support from Family Caregivers

*When Medicaid enrollees and their caregivers ask for at-home support, Medicaid programs often deny services by assuming that help is available from family and friends*

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This paper reports on the results of a review of state administrative decisions regarding Medicaid at-home assistance. Rachel Gershon co-authored this paper as a post-fellowship project with the support of Justice in Aging and the Borchard Foundation Center on Law and Aging. She began her legal career as a Borchard fellow at Justice in Aging. She is now a senior consultant at the [University of Massachusetts Medical School's Center for Health Law and Economics](#), specializing in Medicaid law and policy.

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## Introduction

Medicaid provides at-home assistance to enrollees based on an assessment of the enrollee's need. When assessing how much assistance a person needs, a state Medicaid program must consider the amount of available help from family and friends and adjust the amount of approved assistance accordingly. States are not allowed, however, to *compel* family and friends to provide an enrollee with at-home assistance. In other words, a Medicaid program cannot presume that voluntary assistance is available, or available at a specific level.

This report, the result of a review of over 100 administrative cases in several states, looks at how Medicaid programs assess the availability of voluntary assistance. State decision makers – both at the initial assessment and at the appeal level – often deny assistance based on unsupported assumptions about available assistance from family and friends.

When voluntary help is incorrectly assumed, the enrollee is left without needed assistance. In one example, a 53-year-old stroke survivor received at-home assistance both from his brother and from Medicaid. When the brother moved out of state, the enrollee asked for an increase in assistance from Medicaid, but his request was denied at both the assessment and appeal level. In the appeal decision, the state hearing officer found that an increase in assistance was not warranted because the enrollee's *medical* condition had not changed; the hearing officer did not explain who could provide voluntary support in the brother's place.<sup>1</sup>

In another example, a 92-year-old man lived with his granddaughter, who provided paid support. The state Medicaid agency then denied the man's request for additional support. On appeal, the additional hours were granted only because the hearing officer acknowledged that the granddaughter's work schedule did not allow for her to be available at the times support was needed.

When a Medicaid program denies necessary at-home assistance, it puts the person in a difficult situation — potentially facing a choice between staying at home in an unsafe situation, or moving into a nursing facility. This report outlines a state's responsibility to respect the voluntary nature of assistance, examines how some states approach the issue, and suggests public policy responses to ensure that states authorize adequate assistance.

## States must respect the voluntary nature of assistance from family and friends

State Medicaid programs provide health care to people with limited or no income. Medicaid is jointly funded and administered by the federal government and the states; states must follow federal law when administering the Medicaid program.

When faced with a chronic illness or disability, many people want to remain at home instead of moving into a nursing facility or other institution. In order to stay home, they often rely on help from family and friends, as well as paid assistance. Medicaid can offer coverage for at-home assistance, which includes help with moving, toileting, bathing, cleaning, shopping, and preparing meals, as well as other services and supplies. In the course of determining how many hours of assistance a person may receive, state Medicaid agencies consider how much help is available from family and friends. State Medicaid agencies must follow federal requirements when making these determinations.

Among persons with the same level of need, the more voluntary support that a person has available, the fewer hours of assistance that should be authorized. For example, if a Medicaid enrollee's son volunteers to help out with some care needs, the state will reduce the amount of authorized Medicaid at-home assistance accordingly. At the same time, federal law prohibits states from *compelling* individuals to provide unpaid care.<sup>2</sup> If the enrollee's son becomes unable to provide support, for example, a Medicaid program must adjust the amount of Medicaid assistance. A Medicaid program can neither force family and friends to provide assistance, nor can it reduce authorized at-home assistance based solely on a lack of voluntary assistance.<sup>3</sup>

An Ohio appeals court recently emphasized the requirement that assistance be voluntary. In the case, the Ohio Medicaid program reduced the amount of at-home assistance it would cover for a 44-year old woman with Down Syndrome, autism, intellectual disabilities, and cerebral palsy. The enrollee's brother provided around-the-clock support, with some of his hours paid by Medicaid. The Medicaid program then declared that the brother should be providing more of his support unpaid and reduced the number of approved hours of support for his sister. The Ohio appeals court disagreed, however, finding that “the compulsion of natural supports is antithetical to law.”<sup>4</sup>

## Families contribute at-home assistance but need Medicaid's help

Family and friends provide the majority of at-home assistance in this country, valued upwards of \$470 billion per year.<sup>5</sup> Assistance has become more intense and complex over time. More than half of family caregivers report handling health-related tasks such as wound care, tube feedings, and injections.<sup>6</sup> Studies show that intense caregiving, while rewarding and important, can take a toll on a caregiver. Without adequate assistance from sources like Medicaid, family members can become exhausted, increasing the risk of nursing facility admission for their loved one.

When exhaustion threatens, Medicaid can step in for low-income individuals with at-home assistance. By filling in needed care where assistance is not otherwise available, Medicaid can ensure that seniors and people with disabilities get the assistance they need. Before the creation of Medicaid, Medicare, and Social Security, family caregivers also faced exhaustion. But in those days, when they could no longer care for family members at home, there were few many fewer options. Medicaid was created — and Medicaid at-home assistance bolstered over the years — with a growing focus on providing the right support at the right time.

Finding the right balance of family assistance and societal support is an important policy matter. Such decisions in the Medicaid context should be made consistently, fairly, and in accordance with federal requirements. Trying to enforce family responsibility by offering inadequate care is a recipe for neglect. On the other hand, following federal law and respecting the voluntary nature of assistance allows for older persons and their families to utilize Medicaid assistance when they need it.

## States often assume the availability of voluntary assistance

This report reviews several common scenarios in which states do not properly consider whether voluntary assistance is available.

There are some considerations to take into account when reading this report. First, the majority of cases are from Ohio. This is *not* an indication that Ohio makes unsupported determinations more than any other state. Rather, it is due to the excellent quality of Ohio's case database that makes these cases available for analysis. Second, in some of these cases, a person was ultimately successful in receiving authorization for hours once the person appealed. These cases are included because they still reflect unsupported decision-making made at the initial assessment level.

Finally, the availability of voluntary assistance is not always clear and state decision makers do not have much guidance regarding how to evaluate the availability of assistance. Many of the cases reviewed, then, reflect assumptions about the availability of support rather than carefully documented decisions. In any

individual case, it is hard to declare definitively that an *incorrect* decision was made; rather, it can only be said that an *unsupported* decision was made.

## States assume support is available without providing enough detail about that support

States sometimes assume that voluntary assistance is available, without providing any clarity about the assistance or how it might be accessed. In one example, a 63-year-old woman experiencing transient ischemic attacks (TIAs, sometimes called mini-strokes) and diabetes was assessed as needing 60 minutes of at-home assistance per day. On appeal, the state hearing officer denied her request for assistance, finding that she could receive help elsewhere. The hearing officer concluded that the “petitioner is not prohibited from applying for services through community organizations, churches, social services or adult protective services.” The state hearing officer did not offer the woman a more specific plan for obtaining help.<sup>7</sup>

Sometimes, a Medicaid agency describes or implies who should be providing voluntary assistance, but still does not offer enough detail about how much assistance it expects. In one case, a 46-year-old man with multiple health issues lived with his brother’s family. The state denied his application for assistance, asserting that family members were willing and able to provide needed assistance, but did not specify who would be providing that assistance. On appeal, the hearing officer rectified the situation, finding that the assessor had not provided enough evidence that family members were truly available. The hearing officer also found that the assessor did not specify how much support the family would be providing. The state was ordered to re-assess the person and reconsider the application.<sup>8</sup>

At a minimum, when a state bases a determination about at-home assistance on the assumption of available voluntary support, the written determination should be accompanied by an explanation of who is expected to provide the voluntary support, how much voluntary support is expected, and what type of support is expected. Without that information, a family may not be able to plan for the person’s care or effectively object to a state’s decision.

## States assume that roommates can provide assistance

State assessors and hearing officers sometimes assume that a roommate will provide care. In one case, a 54-year-old woman with multiple sclerosis lived with a roommate who did not provide assistance. The state reduced the woman’s personal care aide hours, noting that a roommate was present and implying that he would provide voluntary care. On appeal, the state hearing officer restored the woman’s hours.<sup>9</sup>

Of course, roommates *do* sometimes provide assistance, but providing care at one point in time should not obligate a roommate to provide care indefinitely. In one case, a state Medicaid agency denied a request for additional at-home assistance for a man with post-traumatic stress disorder, seizures, and bullet-wound injuries. The man’s roommate had moved in to provide support after the man was released from the hospital. While providing unpaid support was feasible in the short-term, the man’s roommate needed to earn an income. In order to make ends meet, the roommate needed to either be relieved of some of his care duties or get paid for his assistance. The state assessor, however, assumed that the man’s roommate would continue to provide all support unpaid, without establishing that as fact. On appeal, the state hearing officer properly recognized the voluntariness of the roommate’s assistance, finding that even though he was currently providing assistance without pay, he was under no obligation to continue to do so. The state

hearing officer approved the request for the roommate to be paid for caregiving.<sup>10</sup>

Unsupported assumptions about roommates can have negative policy consequences. Living with roommates is a key strategy for low-income people looking for housing. Imposing care requirements on roommates that go above and beyond typical expectations can make the search for affordable housing that much harder.

## States assume that parents and significant others can provide assistance

State assessors and hearing officers sometimes assume that parents will provide assistance. In one example, a 42-year-old woman with cerebral palsy and intellectual disabilities lived at home with her mother. The state reduced her personal care aide hours from 16 to 12 hours per day, incorrectly arguing that personal care should not be provided for the “convenience” of her mother. This determination was made in part on an Ohio regulation that disallows the state from making medical necessity decisions based on the convenience of a provider or other person.<sup>11</sup> Her mother already provided unpaid assistance at night, including toileting, bathing, and changing bedding when accidents occurred. On appeal, the state hearing officer reversed the prior decision and the woman regained her at-home assistance. Despite the fact that state regulations had a “convenience clause,” the state hearing officer noted that the state had reduced hours without significant evidence that care needs had decreased.<sup>12</sup> Also, it should be noted that any state law regarding caregiver “convenience” would be superseded by the federal regulation that prohibits a Medicaid program from compelling natural supports.

In another example, a 30-year-old man with quadriplegia lived with his parents and worked full-time as a teacher. His mother provided six to seven hours per day of unpaid support. She lost her paid job and was having a hard time finding another job that would fit around her schedule of unpaid support. She became a licensed caregiver and requested that she be paid for her care work. The state initially declined her request, and she lost on appeal. The state made the incorrect argument that she should provide unpaid care. When she appealed a second time, she was granted her requested hours.<sup>13</sup>

Sometimes, the assumption of available assistance is made about significant others. In one example, a 62-year-old man with lung and kidney cancer lived with his caregiver, who was paid for her work. The state determined that support was available to him, and as a result terminated all of his at-home assistance. On appeal, the hearing officer determined that his paid caregiver was his significant other, and made the unsupported conclusion that she should provide assistance without compensation.<sup>14</sup>

In another example, a 59-year-old man recovering from a hip fracture lived with his significant other. The state denied his application for additional at-home assistance, noting that his additional needs could be met with voluntary support. He argued that his significant other, at age 71, was unable to provide the support he needed. Her grandchildren helped out with laundry, shopping, and heavy chores, but more help was needed. On appeal, the hearing officer found that his needs could be met with voluntary support, despite his objections, and denied his request for additional assistance.<sup>15</sup>

Even just suspicion of a romantic relationship can lead to expectations about care obligations. In one example, a woman lived with her paid caregiver. She requested an increase in the amount of at-home assistance, but instead the state, assuming a romantic relationship between the woman and her caregiver, *decreased* the amount of authorized at-home assistance. The state assumed that her paid caregiver would provide some of the support on a voluntary basis.<sup>16</sup>

Unsupported assumptions about parents and significant others can have some negative policy consequences. They can dissuade a person's family and friends from offering support. For example, a mother of an adult son with disabilities may want to provide space in her home for him, but may worry that doing so will reduce the personal care hours authorized for him. Enrollees should feel free to live where they want, without fear that their services will be reduced if they live with loved ones.

## States assume without support that paid caregivers will provide voluntary support

State assessors and hearing officers sometimes assume that paid caregivers will also provide voluntary assistance. In the example described in the introduction, a 92-year-old man had his request for additional support denied because the state assumed that his granddaughter would provide support beyond what she was being paid to provide. The state only provided additional support for him because the granddaughter's work schedule precluded her from providing more support. Her preferences were not the deciding factor.<sup>17</sup>

Such unsupported assumptions can have some negative policy consequences. Given the at-home assistance provider shortage nationwide, family members often take on paid caregiving roles when other paid caregivers cannot be found. Requiring those caregivers to provide unpaid hours effectively drives down their already low caregiving wages, and has the potential to exacerbate the provider shortage.

## States assume that inappropriate persons will provide voluntary support

At times, a state assumes voluntary support from someone inappropriate for that role. In one case, a 51-year-old woman with Cerebral Palsy lived with her adult son. Her son was emotionally and verbally abusive to her. The state denied her request for additional care hours because it assumed her son was available to provide voluntary care, despite the fact that her son's abuse had been documented by the state in her care plan. The woman appealed, but the state hearing officer upheld the denial. She appealed again, and was granted additional care hours.<sup>18</sup>

Just as inappropriate caregivers should not be paid for providing care, they also should not be relied upon for voluntary assistance. By assuming that voluntary care will be provided by an abusive person, the state can put a person at risk for abuse.

## Recommendations

Expenditures for at-home assistance are rising across the nation, putting pressure on state Medicaid agencies. At the same time, family members sometimes are being expected to take care of each other even when such assistance is not feasible. State decisions about the availability of supports are made in this context, often with the decision maker's assumptions about family duties and abilities grafted onto what should be a somewhat straightforward question of availability. States should be asking if family and friends are able, appropriate, and willing, instead of asserting that it is "only natural to assume" some level of care from family and others close to the enrollee.

» **During the assessment and appeal processes, enrollees and their representatives should be explicit about the amount of care available**

Enrollees and their representatives should be clear about the amount, kind, and duration of support available from family and friends. They should be specific about barriers to increasing available support, including the would-be caregiver's work, work search, school, and family obligations. If the enrollee lives with others, enrollees and their representatives should make clear that caregiving work goes above and beyond their usual household tasks.

» **States and advocates should educate decision makers, beneficiaries, and family members about the voluntariness rules**

The voluntariness standard should be communicated clearly to assessors and state hearing officers. Such instructions could be put in assessment forms, assessor manuals, and websites. Western New York's Law Center's website describing personal care attendants states, for example, "Informal care must be voluntary... Family cannot be assumed to be available, and should be specific as to whether and when they can assist – which days, at what times, etc."<sup>19</sup>

Instructions can be made available to assessors at the point of assessment. For example, an assessment form used in the field could include a statement in the caregiver section that explains how assistance must be voluntary.

» **States should ensure decisions are sufficiently detailed**

Care determinations should be sufficiently detailed so that enrollees understand what voluntary care is expected. Such detail should include:

- How much assistance is needed;
- Who is expected to provide assistance;
- What care they are expected to provide;
- Why the state thinks that the caregiver is able, appropriate, and willing; and
- How the assessor came to these conclusions.

In describing the level of detail required to demonstrate the level of needed assistance, one Ohio hearing officer stated, "The Agency did not provide any documentation or evidence regarding the time required to perform each task for the Appellant, or how the twenty-three hours of weekly services, as provided by the Appellant's brother, were being calculated."<sup>20</sup> This illustrates the level of detail required to adequately explain a Medicaid program's decision regarding at-home care.

» **States should approach medical necessity with voluntariness in mind**

States can deny coverage of a service on the basis that it is not "medically necessary." Different states have different definitions of medical necessity for Medicaid services. As discussed above, some states define medically necessary services to exclude services provided for the convenience of a provider or caregiver.<sup>21</sup> Such state laws have been interpreted to deny services that would enable a family member to hold a job or conduct other activities.<sup>22</sup> In the case of unpaid assistance, a caregiver's convenience in fact *should* be taken

into consideration, because the assistance must be voluntary and the caregiver can decide how and when to provide assistance. If a state has a convenience provision in its law, the state should (at a minimum) provide guidance around how that clause does not apply to voluntary caregivers.

» **States should consider adding written documentation to ensure that voluntariness rules are understood**

At least two states have devised processes to improve clarity around the voluntary nature of unpaid assistance in specific circumstances. In some parts of the California Medicaid program, unpaid providers sign a statement acknowledging that they are choosing to provide care without compensation.<sup>23</sup> Also, longstanding New York State guidance regarding 24-hour personal care services outlines a voluntary written statement that family and friends can draft describing the care they plan to provide (with language that makes clear that the person can change the plan at any time).<sup>24</sup> This written statement allows enrollees to develop a plan for staying in the community when the costs associated with their care would otherwise lead to institutional placement. These types of statements and acknowledgments may add clarity to the question of how much voluntary care can be expected. It is important that such statements be used to inform enrollees' family and friends, and not be used to require family and friends to provide assistance that under federal law must be voluntary.

» **The federal government should require state documentation of compliance with voluntariness requirements**

When a state requests state plan amendments and waivers from the Centers for Medicare and Medicaid Services (CMS), the state must attest that it will follow federal law, and at times must detail how it plans to follow federal law. CMS should require states to attest to or explain how they will comply with voluntariness standards when states file state plan amendments or waiver applications that include at-home assistance.

## Conclusion

Families rely on Medicaid to provide at-home assistance so that loved ones can remain at home even as their care needs increase. As part of the assessment process for care, states are making unsupported assumptions about the amount of assistance already available. As a result, enrollees are at risk for receiving an inadequate amount of at-home assistance.

To prevent enrollees from losing services because of family members' outside obligations, states must respect the voluntary nature of assistance. States can address this challenge by educating decision-makers, ensuring that decisions are sufficiently detailed, and providing guidance around convenience clauses.

Families approach Medicaid for assistance after a long journey of decisions about what is and is not possible. Medicaid functions to allow individuals to live in the community, avoiding nursing facility admissions, institutional care, and caregiver burnout. Unsupported assumptions about the availability of assistance can have negative effects on family relations, quality of care, and quality of life. Federal law requires that states respect the voluntary nature of family caregiving. State Medicaid programs must ensure that their assessment process lives up to the federal requirements.

## Endnotes

- 1 Ohio Dep't of Job and Fam. Servs., Bureau of State Hearings, Case #5090090936; Appeal #1857686 (Dec. 20, 2012).
- 2 Federal law requires states to consider natural supports, and states that natural supports are voluntary. 42 C.F.R. §§ 441.301 (c)(2)(v), 441.725(b)(5) (Regulations for 1915(c) HCBS waiver services and 1915(i) HCBS state plan option, respectively) (plans of care are required to reflect natural supports, which are provided voluntarily); 42 C.F.R. § 441.540(b)(5) (regulations for 1915(k) Community First Choice Option services) (“Natural supports cannot supplant needed paid services unless the natural supports are unpaid supports that are provided voluntarily to the individual...”); HHS, Home and Community-Based State Plan Services, 73 Fed. Reg. 18,676, 18,681 (April 4, 2008) (Preamble to proposed 1915(i) HCBS state plan option regulations) (“...we conclude that the statute requires that the plan of care should neither duplicate, nor compel, natural supports...”); HHS, 77 Fed. Reg. 26,828, 26,857 (May 7, 2012) (preamble to 1915(k) final rule) (“We expect that the identification of these natural, unpaid supports be taken into consideration with the purpose of understanding the level of support an individual has, and should not be used to reduce the level of services provided to an individual unless these unpaid supports are provided voluntarily to the individual.”)
- 3 Some family members are considered “legally responsible relatives” – relatives who are inherently responsible for meeting personal care needs. CMS considers spouses and parents of minor children to be such legally responsible relatives. A Medicaid program, when administering the state plan personal care program, cannot pay a legally responsible relative for at-home assistance. *See* 42 U.S.C. § 1396d(a)(24) (state plan personal care program). This does not mean that a legally responsible relative ever is expected to provide unlimited unpaid care. When care goes “above and beyond,” unpaid care should not be expected (either in the case of state plan personal care or other personal care services). *See, e.g.,* *Samantha A. v. Dep't of Social and Health Services*, 171 Wash.2d 623 (Wash. 2011) (finding, in the case of state plan personal care services and HCBS waiver services, that federal law requires an individualized determination of a child's care needs; a child's care needs can be greater than their developmental needs).
- 4 *Mocznianski v. Ohio Dep't of Job and Fam. Servs.*, 195 Ohio App.3d 422 (Oh. Ct. App. 2011). The plaintiff was receiving services through a 1915(c) Individual Options HCBS waiver.
- 5 Susan C. Reinhard, Lynn Friss Feinberg, Rita Choula, and Ari Houser. *Valuing the Invaluable: 2015 Update* (July 2015).
- 6 Lynn Feinberg, Susan C. Reinhard, Ari Houser, and Rita Choula, AARP. *Valuing the Invaluable: 2011 Update*.
- 7 N.J. Office of Admin. Law, OAL Docket #HMA05788-15, Agency Case #719284075 (August 14, 2015).
- 8 Ohio Dep't of Job and Fam. Servs., Bureau of State Hearings, Appeal #3101305 (June 23, 2016).
- 9 Ohio Dep't of Job and Fam. Servs., Bureau of State Hearings, Appeal #3052455 (January 25, 2016).
- 10 Ohio Dep't of Job and Fam. Servs., Bureau of State Hearings, Appeal #3071800 (February 19, 2016).
- 11 Oh. Admin. Code 5160-1-01.
- 12 Ohio Dep't of Job and Fam. Servs., Bureau of State Hearings, Appeal #3057396 (January 20, 2016).
- 13 Ohio Dep't of Job and Fam. Servs., Bureau of State Hearings, Administrative Appeal Section, Docket #AA-14779, Appeal #2023708, AG #5069476959 (August 19, 2014) (Reversing Ohio Dep't of Job and Fam. Servs., Case #5069476959, Appeal #2023708 (July 17, 2014)).
- 14 Wis. Div. of Hearings and Appeals, Decision #FCP 159165 (September 22, 2014).
- 15 Ohio Dep't of Job and Fam. Servs., Bureau of State Hearings, Appeal #3136298 (November 14, 2016).

- 16 Wis. Div. of Hearings and Appeals, Decision #CWA 162930 (March 10, 2015).
- 17 Ohio Dep't of Job and Fam. Servs., Bureau of State Hearings, Case #5012731260, Appeal #1885685 (May 24, 2013).
- 18 Ohio Dep't of Job and Fam. Servs., Bureau of State Hearings, Administrative Appeal Section, Docket #AA-15588, Appeal #2042627, AG #5028204203 (December 15, 2014).
- 19 New York Health Access, Medicaid Personal Care or Home Attendant Services <http://www.wnyc.com/health/entry/7/>.
- 20 Ohio Dep't of Job and Fam. Servs., Bureau of State Hearings, Appeal #3101392 (June 23, 2016); see also Wis. Div. of Hearings and Appeals, Decision #166861 (September 11, 2015) (“In this case, petitioner makes [a claim that more time is needed], but the agency’s assertion fails. The agency relies on its own task allocation list which was not fully explained at hearing. It remains unclear how the agency arrived at the minutes it typically allows for each task.”)
- 21 See, e.g., Oh. Admin. Code 5160-1-01, Wis. Admin. Code DHS §101.03(96m)(b)(7), and Wis. Admin. Code DHS §101.03(96m)(b)(7).
- 22 Ohio Dep't of Job and Fam. Servs., Bureau of State Hearings, Appeal #3057396 (January 20, 2016); WI DHA 2015 164314 MPA.
- 23 California Social Services Standards Manual at 30-757.176, <http://www.cdss.ca.gov/ord/entres/getinfo/pdf/ssman2.pdf>.
- 24 New York State Local Commissioner Memorandum, Transmittal Number 95 LCM-76 (July 18, 1995), <http://ocfs.ny.gov/main/policies/external/1995/LCMs/95-LCM-076%20Continuous%20Care%20Case%20Review;%20Personal%20Care%20Services%20Program,%20Burland%20TRO;%20and%20Statements%20of%20Understanding.pdf>.