

Voluntary Means Voluntary: Coordinating Medicaid HCBS with Family Assistance

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Executive Summary

When an older adult can no longer live independently, and is eligible for Medicaid, he or she often qualifies for home and community-based services (HCBS) that enable the individual to stay at home, rather than move to a nursing facility or other health care institution. The same is true for persons with disabilities. HCBS are provided under a service plan; under federal Medicaid regulations effective since March 2014, those service plans cannot compel unpaid assistance by family members such as adult children.

As illustrated by Medicaid hearing decisions from Florida, however, state Medicaid programs (frequently through managed care organizations) often compel unpaid assistance from family members. The managed care organizations (MCOs) authorize service levels with the presumption that family members should be

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providing a certain level of personal care assistance. This leads to a lower level of Medicaid-funded service hours, which in turn requires family members to provide assistance to cover the service gap.

One problem in Florida is a “medical necessity” definition that denies Medicaid-funded services to the extent that those services are provided for caregiver convenience. This definition has been cited by MCOs and hearing officers to justify reduced levels of services, even when the caregiver’s “convenience” is his or her need to hold employment outside the home. Furthermore, twelve other states also have a similar “caregiver convenience” provision in the state’s Medicaid medical necessity definition.

In Florida and across the country, Medicaid beneficiaries and their advocates should address this problem. Florida advocates have made some progress in this area, and the state now agrees that service authorizations should respect a family caregiver’s outside employment. The Florida experience suggests the type of advocacy that could and should be pursued in Florida and other states. In individual service requests and appeals, beneficiaries and advocates should forcefully assert the voluntariness requirement of the federal service planning regulations. On a systemic level, advocates should argue for the removal or revision of “caregiver convenience” provisions, and advocate for service authorization procedures that explicitly incorporate the voluntariness requirement.

Report Analysis

Under Federal Regulations, Family Assistance Must Be Voluntary

When an older adult can no longer live independently, he or she frequently receives assistance from family members. In the most common situation, an adult child helps a parent. An adult son or daughter may assist the parent with activities of daily living such as dressing, bathing or eating. Often the adult child will provide food or transportation, or coordinate and administer medications. Annually in the United States, about 40 million family caregivers

provide an estimated 37 billion hours of care. This unpaid assistance is valued at \$470 billion.¹

Meanwhile, these family caregivers juggle other responsibilities and activities. In one example, discussed in more detail below, an 82 year-old woman in Florida needed significant help with all of her activities of daily living. She lived with her daughter, who for years had both assisted her mother and held down a more-than-full-time job. Finally, unable to keep up, the daughter on her mother’s behalf applied for Medicaid-funded at-home assistance. The Medicaid program granted the application but for an insufficient number of hours, claiming that any additional hours would only serve to enable the daughter to continue her job. According to the Medicaid program, accommodating the daughter’s need to hold outside employment was an invalid focus on the daughter’s “convenience.”

Similar issues arise across the country, raising the question of how family assistance should be coordinated with Medicaid-funded services. The relevant mechanism is the Medicaid service plan. Since March 2014, federal regulations have set standards for service planning in Medicaid home and community-based services (HCBS).² One regulation applies to services provided through HCBS waivers, and an almost identical regulation applies to services provided through the HCBS state-plan option.³ In other Medicaid HCBS funding mechanisms — most notably, Section 1115 demonstration waivers — CMS is likely to require similar standards, even in the absence of a regulation.

The service planning regulations govern the planning *process* as well as the *plan* resulting from that process. Both the process and the plan are described as “person-centered.”⁴ The consumer leads the planning process whenever possible, and is assisted by persons of his or her choice. The process must reflect relevant cultural considerations, and all information must be provided in an accessible manner for persons with disabilities and persons with limited English proficiency.⁵

The plan itself must address the consumer’s needs, strengths, preferences, and goals. He or she must

indicate agreement with the plan by signing it. The plan also must be signed by all persons and entities (through representatives) that are responsible for implementing the plan.⁶

As mentioned above, this issue brief focuses on how the Medicaid program treats services provided by family members. The service planning regulations address this issue in part by requiring the service plan to include all services and supports to be received by the consumer, whether those services and supports are paid or unpaid. The regulations specifically highlight the need to include natural supports, which are described as “unpaid supports that are provided *voluntarily* to the individual in lieu of” Medicaid HCBS.⁷

CMS further illuminates the issue in its discussion accompanying the release of the service planning regulations. In response to 2008 draft regulations for the HCBS state-plan option, one commenter had noted that the discussion accompanying the draft regulations — but not the regulations themselves — had required voluntariness, with the discussion stating that a plan of care “should neither duplicate, nor compel, natural supports.”⁸ The commenter recommended that the voluntariness requirement be incorporated into the state-plan option regulations themselves, and CMS indeed followed that recommendation.⁹

CMS similarly emphasized the importance of voluntariness in its discussion of the service planning requirements for HCBS waivers. CMS noted that commenters had urged a requirement that natural supports be voluntary, and CMS concurred with an unambiguous statement: “The planning process must not compel unpaid services.”¹⁰

As a practical matter, the federal regulation is most frequently relevant in the common situation where a Medicaid consumer receives assistance from an adult son or daughter. It should be noted that Medicaid’s voluntariness requirement does not lessen any state-law legal obligation that a parent has to care for a Medicaid-eligible minor child, or that one spouse may have to care for the other.

Family Members Have Been Compelled to Provide Assistance

Service Hours Denied for Daughter’s “Choice” to Go to Job

In practice, Medicaid programs often compel natural supports. They do so by assuming that the family member will be providing unpaid assistance, and then by taking that unpaid assistance into account in refusing or reducing Medicaid-funded personal care services. One revealing example comes from Florida.

Attorneys from Florida Legal Services represented Olga B., an 82 year-old woman who was terminally ill from late-stage Alzheimer’s disease. She lived with her daughter, Karen B.¹¹ Olga was extremely limited physically, and could not turn over in bed or change position in a chair. As a result, she needed help in order to eat, dress, bathe, or perform any other activity of daily living. She was incapable of responding to an emergency, and required constant attention and supervision.¹²

Karen cared for her mother without assistance for six years, while simultaneously working a 60 hours-per-week job (including transportation to and from work). Ultimately, Karen was no longer physically or financially able to both hold down her job and care for her mother, so Karen filed a Medicaid application on her mother’s behalf for in-home health care services. The application was approved, with the services to be provided through a managed care program contracted with the Florida Medicaid program.¹³

Olga and Karen requested 76 hours weekly of in-home services, with another 92 hours to be provided by Karen. Although the Medicaid managed care organization (MCO) agreed that Olga needed around-the-clock attention to protect her health and safety, it authorized only 58 hours of assistance, contending that Olga’s request for additional hours was “simply to facilitate the caretaker’s work schedule.”¹⁴ Following Olga’s appeal, the MCO’s questions in a fair hearing highlighted their theory that any deficit in services was due to Karen’s

“choice” to work, rather than the amount of services authorized by the MCO. At the hearing, the MCO asked Karen:

[Is it] safe to say that [Olga’s choice to receive seven days worth of Medicaid services over five days is] to enable you to be able to go to work on the schedule in the job that you have chosen and on that work schedule that your employers are enabling you to work on, to be able to do that?¹⁵

Similarly, the MCO asked a question that essentially blamed Karen and her job for any inadequacy in the MCO’s authorization of services:

[I]f you were not working the number of hours you are working, ... would you still have the same problem [with insufficient service hours from the MCO]?¹⁶

The hearing officer ruled against Olga, noting that Olga was requesting additional companion care so that her daughter Karen could have some relief on the weekends. The hearing officer found that this request did not establish medical necessity, and could “be considered a convenience to the caregiver.”¹⁷

In response to this ruling, Olga’s attorneys filed a further appeal with the Florida District Court of Appeal. The claim ultimately was settled by the parties on confidential terms.

Medical Necessity Definition Has Been Exploited to Compel Family Assistance

Because Olga’s situation raised issues relevant to many other Florida Medicaid beneficiaries, her attorneys on her behalf filed a petition for rulemaking with the Florida Agency for Health Care Administration (AHCA), asking that AHCA promulgate regulations to address two deficiencies in current Florida law. The first deficiency is a failure to specify that adult companion care includes necessary supervision; because of this deficiency, Medicaid MCOs limit companion care to the time necessary to complete specific tasks, without regard to the supervision required by many persons with dementia. The second deficiency is a failure to accommodate a family caregiver’s outside work schedule when determining the amount of Medicaid assistance to be authorized.¹⁸

This issue brief focuses on issues related to the second deficiency, and how those issues are present in state Medicaid programs across the country. In Florida, the problem is rooted in the state’s definition of “medical necessity” in authorizing Medicaid coverage — specifically, how the state excludes services from coverage if they are “primarily intended for the convenience of ... the recipient’s caretaker.”¹⁹ The rulemaking petition requests that AHCA establish that services are not provided for a caregiver’s “convenience” when those services are needed to allow the caregiver to hold employment outside the home, and to travel to and from that employment.²⁰

The petition cites four reasons justifying the requested regulation. Three of these reasons are based solely on Florida law and are not discussed here.²¹ The fourth reason rests on the federal regulatory requirement that a Medicaid service plan not compel services and supports from a consumer’s family.²² As discussed earlier, federal regulations require that “natural supports” be voluntary. Florida regulations are deficient because, by not requiring that Medicaid MCOs accommodate family caregivers’ out-of-home work schedules, the Florida regulations allow MCOs to authorize services in a way that effectively compels natural supports from the family caregiver.²³

Administrative Hearing Decisions Illustrate Compelled Family Assistance

Other Florida hearing decisions illustrate similar situations in which Medicaid services have been denied on the assumption that certain necessary services should be provided by family members.²⁴ These denials effectively force family members to stay home and provide care, by calculating Medicaid service levels with the presumption of natural supports being provided at a certain level. Notably, none of these hearing decisions even mention the federal regulation requiring that natural supports be voluntary.

Personal Care Hours Reduced Despite Caregiver Burnout

One decision involved Agnes,* a 77 year-old woman who was legally blind, and who had

Alzheimer's disease, chronic obstructive pulmonary disease, and diabetes. Agnes used a wheelchair, had a hospital bed, and required the use of a Hoyer lift for transfers to and from bed. According to her physician, she was "mentally incapacitated due to Dementia and it is medically necessary for her to have a [certified nurse assistant] in the home and would need 24 hour care."²⁵ Agnes had been married for 52 years. Her husband had Parkinson's disease, chronic obstructive pulmonary disease, and diabetes. He suffered two strokes eight months prior to the administrative hearing.²⁶

The dispute involved the request by the husband (on Agnes' behalf) for continued personal care assistance from 9 a.m. to 5 p.m. each day, for a total of 63 hours weekly.²⁷ In response, the Medicaid MCO approved 46 hours of personal care weekly, plus five hours of companion care, for a total of 51 hours weekly. The hearing officer sided with the MCO, finding that the couple had not proven that 51 hours would be insufficient. The hearing officer noted that the husband "is able to assist in providing care," and that respite care, rather than personal care, was "the appropriate service to address caregiver burnout."²⁸ Respite care, however, was not at issue in the hearing.

[Personal Care Hours Denied Despite Husband's Need to Seek Outside Employment](#)

Barbara, a 58 year-old woman, lived with her husband and 17 year-old son. Barbara had a brain tumor in the 1980s; in 2010, while home alone, she suffered a severe head injury with a subdural hematoma. As a result of these incidents, Barbara required assistance with all activities of daily living. She could follow only the simplest of commands and experienced memory lapses, such as forgetting her husband's and son's names. She required scheduled toileting to avoid accidents, and needed assistance in order to walk.²⁹

Barbara's husband was unemployed and seeking work; as a result, he was not home during weekdays. On his wife's behalf, he requested 30 hours per week of personal care assistance, and 15 hours of companion care, for a total of 45 hours weekly. The Medicaid MCO, however, authorized only 23 hours

of personal care and 10 hours of companion care, for a total of 33 hours weekly.³⁰

The hearing officer ruled in favor of the MCO, finding that the 33 hours from the MCO "along with support from petitioner's community and family will meet her needs."³¹ The hearing officer explained that "any additional hours beyond the thirty-three hours per week would be for the convenience of petitioner's caregiver."³²

[Home-Delivered Meals Denied, Forcing Father to Buy and Prepare Food for Adult Daughter](#)

Carol, an adult woman with cerebral palsy, lived in the family home with her father. Due to her mental and physical condition, Carol could not purchase or prepare food, and she was fed through a PEG tube at night. Through Medicaid, Carol received 16 hours of attendant care weekly, along with two hours of homemaker services.³³

Carol's MCO terminated its delivery of meals to Carol's home, arguing that the father had enough support to purchase and prepare food himself. Also, according to the MCO, the request for home-delivered meals was motivated by finances rather than by care needs — Carol's financial assistance was insufficient to cover all of her food costs, and the father had "previously expressed financial concerns over having to purchase food for the petitioner."³⁴

The hearing officer upheld the termination, finding that the father was "able to purchase and prepare food for the petitioner." Accordingly, the meals were "being primarily requested for the convenience of the caregiver."³⁵

[Personal Care Hours Denied, Forcing 78 Year-Old Mother/Caregiver to Provide Additional Assistance](#)

David, a 60 year-old man, was diagnosed with multiple sclerosis in 1991. He became quadriplegic and required complete assistance with all activities of daily living. He used a bladder catheter and wore diapers. He transferred from his bed to a motorized wheelchair with the use of a Hoyer lift, and required assistance to operate the chair.³⁶

David lived alone, although his 78 year-old mother

lived in a separate but adjacent residence. She had breathing problems and required oxygen on a regular basis.³⁷

Given David's significant needs, he had been authorized for around-the-clock Medicaid personal care services (including homemaker services and companion care). He also was authorized for seven hours weekly of skilled nursing services, in order to provide catheter care and set up medications.³⁸

Based on a computerized recommendation, David's managed care organization reduced his personal care authorization from 168 hours weekly (around-the-clock coverage) to 51 hours. An appeal was filed on David's behalf, arguing that he could not request help in case of an emergency, and had a history of going into a coma-like state when suffering urinary tract infections. The appeal request cited evidence that David had fared poorly in a nursing facility, and had improved significantly after being supported with adequate services at home.

In justifying the reduction, the MCO claimed that weekly service hours exceeding 51 hours were for the convenience of the mother. The hearing officer, however, rejected this claim, finding that the evidence did not support the requested reduction. The hearing officer noted that the MCO was requesting roughly a 70% decrease in personal care hours ($117 \div 168 = 69.6\%$), and cited David's care needs and the mother's own health limitations.

Florida Medicaid Program Is Addressing Caregiver Availability and Service Authorization

Both on an individual and systemic level, Florida Legal Services' advocacy for Olga B. has begun to bear fruit. As mentioned above, Olga's appeal of the service authorization was settled on confidential — but presumably favorable — terms. Also, the Florida Agency for Health Care Administrative penalized Olga's MCO for how it had limited the services authorized for her. The amount of the penalty was relatively small — \$2,500 — but the language in the penalty letter is encouraging as to AHCA's position on these issues:

On September 8, 2014, [the MCO] denied services for [Olga]. During a fair hearing held on March 20, 2015, [the MCO] stated they partially denied the adult companion care services due to the request primarily being intended for the convenience of the caregiver. [The MCO] incorrectly interpreted the Agency's definition of medical necessity, since the use of this condition was based on the caregiver's work schedule. The Agency does not consider an enrollee's caregiver not being available due to their work schedule as a reason to apply this condition to the denial, reduction, termination or suspension of services.³⁹

Consistent with the penalty imposition, AHCA also initiated rulemaking in response to Olga's petition.⁴⁰ Based on preliminary text, the proposed regulation will establish a Florida Medicaid Long-Term Care Program Coverage Policy, to be incorporated by reference into state Medicaid regulations.⁴¹ The text of the Coverage Policy is not available at this point — it is expected, at a minimum, the policy will establish that natural supports are not to be presumed when provision of such supports would conflict with the family caregiver's outside employment.

In Many States, Medical Necessity Definitions Exclude Services Provided for Caregiver "Convenience"

As discussed above, the Florida Medicaid medical necessity definition excludes coverage for services "primarily intended for the convenience of ... the recipient's caretaker."⁴² Several other states employ similar Medicaid rules. Colorado requires that services be "[n]ot primarily for ... the convenience of the client, caretaker, or provider."⁴³ Ohio likewise requires that services be "[n]ot provided primarily for ... the convenience of the provider or anyone else other than the recipient."⁴⁴ Similar rules are followed by at least ten other states: Iowa,⁴⁵ Kentucky,⁴⁶ Maryland,⁴⁷ Mississippi,⁴⁸ Nebraska,⁴⁹ New Hampshire,⁵⁰ New Mexico,⁵¹ North Dakota,⁵² Tennessee,⁵³ and Wisconsin.⁵⁴

Because of these state laws, Medicaid programs in these states are particularly likely to violate the federal regulation requiring that natural supports not be compelled. At a minimum, these states should promulgate rules establishing that a caregiver’s “convenience” does not include time necessary for the caregiver to hold outside employment, or to travel to and from such employment — this is the request made in the Florida rulemaking petition.

Focusing solely on employment, however, does not fully honor the requirement that natural supports be voluntary. Under true voluntariness, the caregiver is not required to prove to a Medicaid program that he or she has justifiable scheduling conflicts that preclude certain hours of caregiving. If voluntary truly means voluntary, the caregiver must have the right to decide when he or she wishes to provide unpaid caregiving services.

Recommendation: Advocacy Needed to Ensure Medicaid Programs Honor Voluntariness Requirement

To this point, evidence suggests that the voluntariness requirement has had limited impact in most states. In many Medicaid programs, service planning has not changed in any appreciable way since the service planning regulations became effective in March of 2014. If anything, an increased reliance on computerized service authorization algorithms may be exacerbating the problem. Furthermore, as discussed above, Medicaid service authorizations often justify decreased hours of Medicaid personal care with the presumption that family members are obligated to provide certain levels of personal care.

If these trends dominate, the voluntariness requirement will have little impact. Service plans may recite that a family member’s assistance is voluntary, but that recitation often will be contradicted by the realities of service authorizations. No family assistance can be truly voluntary if it is needed to compensate for reduction or termination of a Medicaid-funded service.

The work of Florida advocates suggests a path forward. In service requests and appeals, Medicaid beneficiaries and their advocates should forcefully assert the voluntariness requirement. As shown by the administrative hearings discussed above, Medicaid programs, MCOs, and (sometimes) hearing officers may be inclined to allocate personal care services to a beneficiary’s family members. To counteract this tendency, beneficiaries and their advocates must insist that natural supports be factored into service authorization decisions only to the extent that those supports are provided voluntarily.

Systemic advocacy also is required. Caregiver “convenience” provisions in medical necessity definitions should be deleted. A state might argue alternatively for the term “convenience” to be retained but tightly defined, but this argument should be rejected to the extent possible. The term “convenience” is inherently broad; in any case, true voluntariness allows a caregiver to make decisions based on convenience.

Comparable systemic advocacy also is required in those states without an explicit “convenience” provision, as those states’ Medicaid programs and MCOs are also likely to base service authorizations on presumptions that a family member should provide certain services. Definitions and service authorization procedures should clearly establish that a family’s personal care services are only to be taken into account if the family member is legally obligated to provide those services, or the family member has volunteered. Also, to honor the concept of voluntariness, a volunteering family member must have the ability to change his or her mind, if for whatever reason the family member no longer wishes to perform the services in question.

Endnotes

*Agnes, Barbara, Carol and David are pseudonyms.

- 1 Susan C. Reinhard et al., AARP Public Policy Institute, *Valuing the Invaluable: 2015 Update*, at 1 (July 2015).
- 2 79 Fed. Reg. 2,948 (2014) (regulations effective March 17, 2014).
- 3 *See* 42 C.F.R. §§ 441.301(c)(1)-(3) (HCBS waiver), 441.725(a)-(c) (HCBS state-plan option). The HCBS waiver often is called a Section 1915(c) waiver, since it is authorized by Section 1915(c) of the Social Security Act, which is codified at 42 U.S.C. § 1396n(c). The HCBS state-plan option often is called a Section 1915(i) program; it is authorized by Section 1915(i) of the Social Security Act, which is codified at 42 U.S.C. § 1396n(i).
- 4 42 C.F.R. §§ 441.301(c)(1)-(2), 441.725(a)-(b).
- 5 42 C.F.R. §§ 441.301(c)(1), 441.725(a).
- 6 42 C.F.R. §§ 441.301(c)(2), 441.725(b).
- 7 42 C.F.R. §§ 441.301(c)(2)(v), 441.725(b)(5) (emphasis added).
- 8 73 Fed. Reg. 18,676, 18,681 (2008) (discussion accompanying 2008 draft regulations); 79 Fed. Reg. at 2,990- 2,991 (discussion of comment, accompanying release of final regulations).
- 9 79 Fed. Reg. at 2,990- 2,991.
- 10 79 Fed. Reg. at 3,008.
- 11 This issue brief refers to the mother and daughter by their first names, rather than their last name, to protect their confidentiality and to allow the reader more easily to distinguish between mother and daughter.
- 12 *Petition to Initiate Rulemaking by Olga B.*, at 2 (Oct. 20, 2015) (petition on file with Justice in Aging).
- 13 *Petition to Initiate Rulemaking*, at 3.
- 14 *Petition to Initiate Rulemaking*, at 3.
- 15 *Petition to Initiate Rulemaking*, at 18.
- 16 *Petition to Initiate Rulemaking*, at 18.
- 17 Florida Dep't of Children and Families, Office of Appeal Hearings, Appeal No. 14F-08642, at 9 (May 14, 2015).
- 18 *Petition to Initiate Rulemaking*, at 1-2.
- 19 Fla. Admin. Code r. 59G-1.010(166)(a)(5).
- 20 *Petition to Initiate Rulemaking*, at 1.
- 21 *Petition to Initiate Rulemaking*, at 25-28.
- 22 42 C.F.R. § 441.301(c)(2)(v).
- 23 *Petition to Initiate Rulemaking*, at 26-27.
- 24 The cited hearing decisions were obtained by Florida Legal Services through a public records request for hearing decisions relating to long-term services and supports provided by Medicaid MCOs.
- 25 Fla. DCF, Office of Appeal Hearings, Appeal No. 14F-07273, at 3 (Dec. 5, 2014).
- 26 Appeal No. 14F-07273, at 10.
- 27 Personal care assistance includes personal care services and homemaker services.
- 28 Appeal No. 14F-07273, at 18.
- 29 Fla. DCF, Office of Appeal Hearings, Appeal No. 14F-05477, at 3 (Sept. 10, 2014).
- 30 Appeal No. 14F-05477, at 5-6.
- 31 Appeal No. 14F-05477, at 7.
- 32 Appeal No. 14F-05477, at 12.
- 33 Fla. DCF, Office of Appeal Hearings, Appeal No. 14F-10574, at 2-4 (July 2, 2015).
- 34 Appeal No. 14F-10574, at 3, 5.
- 35 Appeal No. 14F-10574, at 8.
- 36 Fla. DCF, Office of Appeal Hearings, Appeal No. 14F-10190, at 3-4 (March 13, 2015).
- 37 Appeal No. 14F-10190, at 3.
- 38 Appeal No. 14F-10190, at 3, 5.
- 39 Letter from David Rogers, Assistant Deputy Secretary of Medicaid Operations, AHCA, to Lori Halpern, United Healthcare of Florida (Nov. 4, 2015) (letter on file with Justice in Aging).
- 40 *Order re: Petition to Initiate Rulemaking by Olga B.*, Case No. 15-07 OM (Nov. 19, 2015) (order on file with Justice in Aging).
- 41 Fla. Admin. Reg., vol. 41, No. 226, at 5,677 (Nov. 20, 2015); Fla. Admin. Reg., vol. 42, No. 42, at 879 (March 2, 2016).
- 42 *See* Fla. Admin. Code r. 59G-1.010(166)(a)(5).
- 43 10 Colo. Code Regs. 2505-10, § 8.076.1(8)(iii).
- 44 Ohio Admin. Code § 5160-1-01(C)(6).
- 45 Iowa Admin. Code r. 441-79.9(2)(c).
- 46 907 Ky. Admin. Regs. 3:130(2)(1)(b)(3).
- 47 Md. Regs. Code 10.09.36.01(B)(10)(d).
- 48 Miss. Code R. 23-000-200, 5.1(B)(4).
- 49 Neb. Admin. Code tit. 417, § 1-002.02A(5).
- 50 N.H. Code Admin. R. He-W 530.01(e)(2).
- 51 N.M. Admin. Code § 8.302.1.7(A)(4).
- 52 N.D. Admin. Code § 75-02-02-03.2(8).
- 53 Tenn. Comp. R. & Regs. 1200-13—16-.05(2).
- 54 Wis. Admin. Code DHS § 101.03(96m)(b)(7).