

## Just Like Home:

### The Impact of the Federal HCBS Regulations on Older Adults, with State-Level Advocacy Recommendations

ISSUE BRIEF • JUNE 2015

Written By

**Eric Carlson**

Directing Attorney, Justice in Aging

**Fay Gordon**

Staff Attorney, Justice in Aging

**Hannah Weinberger-Divack**

Skadden Fellow, Justice in Aging

## Introduction and Recommendations

In regulations finalized in March 2014, the federal government for the first time established standards for when a setting can be considered “community-based” for purposes of Medicaid-funded home and community-based services (HCBS). The regulations address concerns that too many “community-based” settings have been overly institutional in their structures and procedures. For older adults, each state’s strategy for compliance with the new regulations has significant implications for the quality and character of adult day services, assisted living programs, and other Medicaid-funded HCBS.

Under the new regulations, each state must develop a transition plan to guide the state in coming into compliance. Additionally, the state, for each iteration of a transition plan, must solicit and consider public comment, as required by the federal Centers for Medicare and Medicaid Services (CMS). Thus far, all states’ initial transition plans have (among other

## Table of Contents

Introduction and Recommendations.....	1
Background on the Regulations.....	2
Analysis and Recommendations.....	2
Assessing Settings .....	2
Community Integration .....	4
Protections Against Eviction .....	6
Alzheimer’s and Dementia- Specific Issues .....	7
Application of Regulations.....	9
Conclusion.....	9

things) proposed further assessments of programs and settings, along with development of subsequent transition plans to incorporate assessment information.

A number of issues of particular concern to older adults have surfaced in states' initial transition plans. Based principally on the transition plans from Florida, New Jersey, South Dakota, Virginia, and Washington, this issue brief makes the following recommendations:

## RECOMMENDATIONS

### 1. ASSESSING SETTINGS

- a. States should solicit and consider input from program participants.
- b. States should conduct onsite assessment of settings.

### 2. COMMUNITY INTEGRATION

- a. States should require integration with the community, and not just with non-Medicaid-funded service recipients.
- b. In residential settings, states should apply the regulations' protections to all residents, regardless of a resident's source of payment.
- c. States should carefully consider whether an assisted living facility can be considered a community-based setting when the assisted living facility shares a building with a nursing facility.

### 3. PROTECTIONS AGAINST EVICTION

- a. States should ensure eviction protections for assisted living residents.

### 4. ALZHEIMER'S and DEMENTIA-SPECIFIC ISSUES

- a. States should carefully address the issue of "secure" units (where participants are restricted in their ability to leave the setting or unit).
- b. States should not disregard the privacy rights of persons with dementia.

### 5. APPLICATION OF REGULATIONS

- a. The federal government should require compliance with the federal regulations for all Medicaid-funded home and community-based services, regardless of the Medicaid funding mechanism involved.

A state's development of a transition plan will require years, not months — under the federal regulations, the absolute deadline for compliance is March 2019. Consumers and their advocates should be diligent in participating in the transition plan process, pointing out important issues, and advocating for policies that protect consumers' interests.

## BACKGROUND ON THE REGULATIONS

An introduction to the federal regulations is available in another Justice in Aging guide, *Just Like Home: An Advocate's Guide to Consumer Rights in Medicaid HCBS*.<sup>1</sup> Justice in Aging also published an advanced-level guide to the regulations, *Just Like Home: An Advocate's Guide for State Transitions Under the New Medicaid HCBS Rules*.<sup>2</sup> Information about the regulations also is available from CMS<sup>3</sup> and the HCBS Advocacy website.<sup>4</sup>

---

1 *Just Like Home: An Advocate's Guide to Consumer Rights in Medicaid HCBS*, JUSTICE IN AGING (2014), available at <http://justiceinaging.org/wp-content/uploads/2015/03/RE-Advocates-Guide-HCBS-Just-Like-Home-05-06-14-2.pdf>.

2 *Just Like Home: An Advocate's Guide for State Transitions Under the New Medicaid HCBS Rules*, JUSTICE IN AGING (2014), available at <http://justiceinaging.org/wp-content/uploads/2015/03/RE-Just-Like-Home-An-Advocates-Guide-for-State-Transitions-Under-the-New-Medicaid-HCBS-Rules.pdf>.

3 *Home & Community Based Services*, MEDICAID.GOV (2015), available at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html>.

4 *Information for advocates about the new home and community-based service rules*, HCBS ADVOCACY (2015), available at [www.hcbsadvocacy.org](http://www.hcbsadvocacy.org). This website is a collaborative project of the Association of University Centers on Disabilities, the National Association of Councils on Developmental Disabilities, and the National Disability Rights Network.

## ANALYSIS AND RECOMMENDATIONS

### ASSESSING SETTINGS

*States should solicit and consider input from program participants.*

Service providers and program participants each have valuable insight about HCBS programs and settings. That being said, participant input should be recognized as particularly important. The new regulations, after all, focus on establishing a homelike, non-institutional environment, and the best person to judge the environment is the participant. Service providers, furthermore, have an obvious bias — they need to be considered in-compliance in order to continue receiving Medicaid HCBS reimbursement, so have clear motivation in self-assessments to identify few or no deficiencies.

Many states' transition plans, however, indicate an overreliance on provider input, with a corresponding deficiency in collecting and considering input from participants. New Jersey, for example, sent a self-assessment to assisted living facilities and other residential settings, with responses due in April 2015.<sup>5</sup> The state, however, has not made a similar effort to obtain comparable direct input from participants, aside from participating in the National Core Indicators Project for settings licensed by the Division of Developmental Disabilities, and listing the state's intention to participate in the National Core Indicators – Aging and Disabilities Initiative.<sup>6</sup> The Core Indicators are useful performance measures, but they are not designed specifically for judging compliance with the federal HCBS regulations; in addition, data from the Core Indicators' first aging-focused

---

5 *NJ Statewide Transition Plan*, NJ DEPARTMENT OF HUMAN SERVICES, at 23 (Apr. 17, 2015), available at [http://www.nj.gov/humanservices/dmahs/info/hcbs\\_trans.html](http://www.nj.gov/humanservices/dmahs/info/hcbs_trans.html). (The assisted living facilities and other residential settings are identified as HCBS Settings Licensed under NJAC 8:36.) The Residential Provider Self-Assessment Survey is available at [www.state.nj.us/humanservices/dmahs/info/Residential\\_Provider\\_Self-Assessment\\_Survey.pdf](http://www.state.nj.us/humanservices/dmahs/info/Residential_Provider_Self-Assessment_Survey.pdf).

6 *NJ Statewide Transition Plan* at 30-31.

survey cycle will not be available until December 2015 at the earliest.<sup>7</sup> Based on public comments on the draft transition plan, New Jersey “included” participants in site visits (conducted in an unspecified percentage of facilities) and in remediation plans for non-complying settings, but such inclusion does not repair the imbalance between the survey of residential providers and the limited solicitation of input from participants.<sup>8</sup>

In Florida, the problem has been less an imbalance between provider input and participant input, and more of a failure to obtain input from any non-state source. The state’s transition plan, in discussing assessment of residential settings, reported only state-conducted assessments, with the note that state reviewers are “instructed to employ multiple assessment tactics when analyzing each standard including independent observation, record and file review, provider interviews, and resident/ recipient questions as appropriate.”<sup>9</sup>

Some other states have shown a greater willingness to solicit and consider participant input. In Washington, for instance, the state conducted resident interviews in all assisted living facilities that presumptively were not considered non-HCBS settings.<sup>10</sup> In

one assisted living facility, residents expressed concern about their inability to go into the community for activities, said they wished they could socialize more, and expressed concern about the lack of activities. As a result, the state determined that the setting was not in compliance with the HCBS regulations and required the facility to develop a plan to provide residents with meaningful community access.<sup>11</sup>

**Recommendation:** In assessing programs and settings, the state should develop and implement strategies to receive input from assisted living residents and other HCBS participants.

### *States should conduct onsite assessment of settings.*

An overreliance on provider surveys is particularly troubling in states that do not conduct onsite assessments. New Jersey, for example, will conduct site visits in only an unspecified percentage of the assisted living facilities.<sup>12</sup> By contrast, the state will conduct an onsite evaluation of every licensed residential setting in the Division of Developmental Disabilities (DDD) system.<sup>13</sup>

In Florida, the state “analyzed the past year’s data” to “assess” less than a third of the residential facilities (415 out of 1,763) before determining compliance. Based on this review, the state concluded that all residential facilities will be able to meet the requirements of the new federal regulations.<sup>14</sup>

---

7 NASUAD, National Core Indicators – Aging and Disabilities, NASUAD (2015), available at <http://www.nasuad.org/initiatives/national-core-indicators-aging-and-disabilities>.

8 See *NJ Statewide Transition Plan* at 31.

9 *Florida Statewide Transition Plan*, AGENCY FOR HEALTH CARE ADMINISTRATION, at 6 (March 17, 2015), available at [http://ahca.myflorida.com/medicaid/hcbs\\_waivers/docs/transition/Revised\\_Statewide\\_Transition\\_Plan\\_and\\_Summary\\_of\\_Public\\_Comments\\_to\\_CMS\\_3-17-15.pdf](http://ahca.myflorida.com/medicaid/hcbs_waivers/docs/transition/Revised_Statewide_Transition_Plan_and_Summary_of_Public_Comments_to_CMS_3-17-15.pdf).

10 *Washington State’s Statewide Transition Plan for New HCBS Rules*, Appendix B, DEPARTMENT OF SOCIAL AND HEALTH SERVICES (Mar. 11, 2015), available at <https://www.dshs.wa.gov/sites/default/files/ALISA/stakeholders/documents/HCBS/Washington%20State%20Transition%20Plan%20for%20New%20HCBS%20Rules.pdf>. Under the federal regulations, a presumption of being non-HCBS applies to residential settings that share a building with a nursing facility, share grounds with a “public institution” (such as a state hospital), or have “the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS.” 42 C.F.R. § 441.301(c)(5)(v).

---

11 *Washington State’s Statewide Transition Plan for New HCBS Rules Attachment: Details of Facility-Specific Reviews Submitted to CMS*, DEPARTMENT OF SOCIAL AND HEALTH SERVICES, at 30-31 (Mar. 11, 2015) (on file with authors).

12 See *NJ Statewide Transition Plan* at 10.

13 See *NJ Statewide Transition Plan* at 14.

14 *Florida’s Draft Waiver Specific Transition Plan*, HCBS ADVOCACY, at 3 (Feb. 3, 2015), available at [http://ahca.myflorida.com/medicaid/hcbs\\_waivers/docs/transition/DRAFT\\_LTC\\_Transition\\_Plan\\_1-30-2015.pdf](http://ahca.myflorida.com/medicaid/hcbs_waivers/docs/transition/DRAFT_LTC_Transition_Plan_1-30-2015.pdf).

**Recommendation:** Standards such as community integration and a non-institutional environment are not easily judged through a review of data, particularly given the limited data that generally are available at this point to state officials. Participants and their representatives have good reason to not be satisfied with paper determinations of “compliance,” and should advocate for on-site assessments and other procedures that are more likely to produce meaningful determinations of a setting’s current character.

## COMMUNITY INTEGRATION

*States should require integration with the community, and not just with non-Medicaid-funded service recipients.*

The federal regulations require that program participants have “full access ... to the greater community ... to the same degree of access as individuals not receiving Medicaid HCBS.”<sup>15</sup> In a similar provision of the regulations, an integration requirement is expressed as a presumption against compliance for any setting which tends to isolate “individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS.”<sup>16</sup> CMS repeatedly uses the same “broader community” formulation in its Guidance on Settings that Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community.<sup>17</sup>

By focusing in the regulations on the phrase “individuals not receiving Medicaid HCBS,” some states wrongly have found “integration” based on program participants’ contact with non-Medicaid-funded service recipients. The clear intent of the

regulations, however, is to establish integration with the *community*, not just with service recipients of various payment sources.

For example, New Jersey initially demonstrated an off-target focus on payment source. The New Jersey draft transition plan, in concluding that its assisted living facilities were sufficiently integrated, relied heavily on a finding that “MLTSS members who are in an AL facility are part of the broader community of individuals who are living there.”<sup>18</sup> The state’s provider self-assessment form was based on similar reasoning; one self-assessment question asked whether “the facility/setting prevent[s] the isolation of MLTSS beneficiaries *from private pay individuals* living at the facility/setting.”<sup>19</sup> In a similar vein, a question in the “Integration with the Community Section” asked whether MLTSS beneficiaries are “able to participate in the facility’s/setting’s unscheduled and scheduled community activities in the same manner *as other people who are living there.*”<sup>20</sup> In the same section, another question asked whether MLTSS beneficiaries “live/receive services in the same areas *as the other residents who are living there.*”<sup>21</sup>

Fortunately, the transition plan submitted by New Jersey (as opposed to the *draft* transition plan) did not include any explicit statements treating the “broader community” as being limited to persons receiving services in the setting. Also, in reference to day programs, the submitted transition plan requires program participants to “spend *the majority of their time* engaging in integrated activities with the broader

15 42 C.F.R. § 441.301(c)(4)(i).

16 42 C.F.R. § 441.301(c)(5)(v).

17 *Guidance on Settings that Have the Effect of Isolating Individuals Receiving HCBS from the Broader Community*, MEDICAID.GOV (Mar. 2014), available at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Settings-that-isolate.pdf>.

18 *NJ Draft Statewide Transition Plan*, NJ DEPARTMENT OF HUMAN SERVICES, at 15 (March 17, 2015), available at <http://www.nj.gov/humanservices/dmahs/info/Statewide-Transition-Plan-DRAFT.pdf>.

19 *Residential Provider Self-Assessment Survey of the Home and Community-Based Services Final Regulation’s Setting Requirements*, NJ DEPARTMENT OF HUMAN SERVICES, Question B1, Section B: Physical Location (2015) (emphasis added), available at <http://www.state.nj.us/humanservices/dmahs/info/Residential-Provider-Self-Assessment-Survey.pdf>.

20 *Id.*, Question C1, Section C: Integration with the Community (emphasis added).

21 *Id.*, Question C5, Section C: Integration with the Community (emphasis added).

community of non-HCBS recipients *inside and/or outside of the day facility.*<sup>22</sup>

None of this discussion should be taken as condoning discrimination or segregation based on payment source: Medicaid beneficiaries should be wholly integrated with service recipients with different payment sources. Integration regardless of payment source, however, is not equivalent to integration with the broader community.

**Recommendation:** It is not enough for MLTSS beneficiaries to commingle with service recipients with other payment sources. When considering integration, states should take a step back and carefully determine whether particular assisted living facilities (or other settings) are adequately integrated with the broader community outside of the setting.

*In residential settings, states should apply the regulations' protections to all residents, regardless of a resident's source of payment.*

Settings should offer a community-based environment for all participants, regardless of his or her source of payment. Assume a contrary procedure — that the regulations were deemed inapplicable to participants without Medicaid funding, and that those participants were (for example) segregated from the broader community, denied food between meals, and subject to eviction by the setting's unilateral, unappealable decision. Such practices would create an institutional environment that should disqualify any setting from being considered community-based, even if Medicaid-funded participants were to receive better treatment.

**Recommendation:** Participants and their advocates should be vigilant in advocating for consistent application of the standards. Discrimination based on payment source conflicts with the letter and spirit of the federal regulations.

22 *NJ Statewide Transition Plan*, NJ DEPARTMENT OF HUMAN SERVICES, at 3 (Apr. 17, 2015), available at [http://www.nj.gov/humanservices/dmahs/info/hcbs\\_trans.html](http://www.nj.gov/humanservices/dmahs/info/hcbs_trans.html).

*States should carefully consider whether an assisted living facility can be considered a community-based setting when the assisted living facility shares a building with a nursing facility.*

Any setting that is located in the same building as an institution is presumed not to meet the requirements of the HCBS regulations, unless the state can provide “strong evidence to the contrary,”<sup>23</sup> and the federal government, through “heightened scrutiny,” concludes that the setting has the qualities of home and community-based settings.<sup>24</sup> Under these standards, South Dakota’s draft statewide transition plan is problematic because it is too quick to classify settings inside nursing facility buildings as home and community-based. Noting that rural areas often have limited options, the transition plan states:

In some areas of South Dakota, the population simply cannot support separate Assisted Living and long term care facilities. Instead, a wing or percentage of the beds in the long term care facility are designated as assisted living beds. Situations where individual rooms or suites within the long term care facility have been designated as assisted living have historically been in response to a need in the community.<sup>25</sup>

The state identifies its position as being based on a limited-scope initial analysis, and plans to seek additional feedback from community members, service providers, and assisted living residents. The state already notes, however, that it “anticipates the additional analysis will support our preliminary findings and demonstrate the HCBS nature of these settings.”<sup>26</sup>

23 79 Fed. Reg. 2948, 2969 (January 16, 2014).

24 42 C.F.R. § 441.301(c)(5)(v).

25 *South Dakota Home and Community Based Services Statewide Transition Plan*, SOUTH DAKOTA DEP’T OF SOCIAL SERVICES, DIVISION OF MEDICAL SERVICES, at 22 (2015), available at <https://dhs.sd.gov/dd/documents/SDH-CBSStatewideTransitionPlan.pdf>.

26 *Id.*

A conclusion that a setting is community-based, however, should not be based principally on findings that the setting has been in operation for a many years, or that currently few options exist. A better plan of action is to follow the federal regulations and CMS guidance more scrupulously, and investigate whether each assisted living setting is adequately integrated with the community. When South Dakota seeks its additional feedback, it should emphasize how the operations of current settings might be improved. South Dakota's rural nature should be a factor, but not a determinative factor.

**Recommendation:** The “heightened scrutiny” requirement should be taken seriously. When a setting is located within the same building as a nursing facility or other institution, but the state contends that the setting should be eligible for HCBS funding, the state should provide specific evidence as to how the setting meets each requirement of the regulations. The explanation must comprehensively address how the setting overcomes the institutional influence that is likely to occur when a purported HCBS setting is located inside a nursing facility or other institution.

## PROTECTIONS AGAINST EVICTION

### *States should ensure eviction protections for assisted living residents.*

The HCBS regulations require that an individual receiving HCBS services in a provider-owned or controlled residential setting must have protections from eviction at least comparable to consumer protections under state landlord-tenant law. Some states, however, have seemed inclined to not put enough thought and detail into this requirement.

For years, Florida advocates have raised concerns about the lack of eviction protections for residents of assisted living facilities (and other community residential facilities). Nonetheless, Florida's submitted transition plan fails to address this issue in a systematic way. The state's review tool, an attachment to the transition plan, lists “probing questions” that include questions as to whether the individual has a lease or residency agree-

ment, and whether the lease or agreement “include[s] protections to address eviction processes and appeals comparable to Florida's landlord-tenant law.”<sup>27</sup> This type of question fails to recognize the complications in establishing, in assisted living settings, eviction protections that are comparable to those in landlord settings. The state should recognize the importance of issue, and develop its own recommendations or protocols for settings to adopt or modify.

New Jersey's draft transition plan was similarly problematic, although the subsequent draft (the version submitted to CMS) is much improved. For assisted living residences, assisted living programs, and comprehensive personal care homes, the state initially reviewed existing state regulatory requirements and concluded that the settings were generally compliant with the HCBS regulations, but did not discuss eviction protections.<sup>28</sup> By contrast, the state's draft transition plan recognized the need to add eviction protections for residents of licensed group homes, supervised apartment programs, community care residences, supportive living programs, and other licensed residential programs serving HCBS beneficiaries with Intellectual and developmental disabilities.<sup>29</sup>

At this point in New Jersey's transition process, the public comment requirements paid dividends. In the transition plan submitted to CMS, the state recognized that commenters had noted the failure to ensure assist living eviction protections. In response, the submitted transition plan “was revised to state that whatever steps are necessary will be taken to ensure that an agreement between a facility and each resident is in place and that the document provides protections that address eviction processes and appeals comparable to those provided

<sup>27</sup> *Florida Statewide Transition Plan*, AGENCY FOR HEALTH CARE ADMINISTRATION, Attachment III, at 25 (March 17, 2015), available at [http://ahca.myflorida.com/medicaid/hcbs\\_waivers/docs/transition/Revised\\_Statewide\\_Transition\\_Plan\\_and\\_Summary\\_of\\_Public\\_Comments\\_to\\_CMS\\_3-17-15.pdf](http://ahca.myflorida.com/medicaid/hcbs_waivers/docs/transition/Revised_Statewide_Transition_Plan_and_Summary_of_Public_Comments_to_CMS_3-17-15.pdf).

<sup>28</sup> *NJ Draft Statewide Transition Plan*, NJ DEPARTMENT OF HUMAN SERVICES, at 15 (March 17, 2015), available at [http://www.nj.gov/humanservices/dmahs/info/Statewide\\_Transition\\_Plan\\_DRAFT.pdf](http://www.nj.gov/humanservices/dmahs/info/Statewide_Transition_Plan_DRAFT.pdf).

<sup>29</sup> *Id.* at 17, 20-23.

under New Jersey's landlord-tenant law."<sup>30</sup>

**Recommendation:** All transition plans should include detailed strategies for implementing the lease and eviction protections for HCBS enrollees in all residential settings. States should develop standardized templates and revise state licensing requirements as necessary.

## ALZHEIMER'S AND DEMENTIA-SPECIFIC ISSUES

*States should carefully address the issue of "secure" units (where participants are restricted in their ability to leave the setting or unit).*

To this point, CMS has not issued clear guidance on whether or how secured units for people with dementia comply with the settings regulations. The issue for the time being is being left to the states and stakeholders, with some indication that CMS will be willing under some circumstances to authorize HCBS funding for people in secured settings. On one hand, such settings may limit access to the broader community to such an extent that they cannot be considered compliant with the federal regulations. On the other hand, secured units are arguably necessary to meet the needs of some people with dementia.

States should engage consumers and providers in a thoughtful dialogue to determine how to comply with the federal regulations in relation to secure units for people with dementia. The balancing of individual autonomy with the complex challenges of dementia warrants thorough debate from the state, consumers, and providers. Given that CMS appears inclined to allow secure units in HCBS settings, the responsibility is on the state to devise an approach that protects individual rights while offering security for those persons who may need secure perimeters and locked doors.

30 *NJ Statewide Transition Plan*, NJ DEPARTMENT OF HUMAN SERVICES, at 31-32 (Apr. 17, 2015), available at [http://www.nj.gov/humanservices/dmahs/info/hcbs\\_trans.html](http://www.nj.gov/humanservices/dmahs/info/hcbs_trans.html).

Some states' transition plans show insufficient effort to balance the various considerations. Virginia's draft transition plan, in reference to the state's Alzheimer's Assisted Living Waiver, contains sweeping conclusions regarding locked settings. The transition plan states broadly that "[i]ndividuals require safety mechanisms regardless of the setting they are in to prevent wandering (therefore use of secured units or buildings is necessary)."<sup>31</sup> This generalization is much too expansive, particularly in the context of regulations to integrate people with disabilities with the broader community. Alzheimer's disease is progressive and, contrary to the above-quoted statement, not all individuals with an Alzheimer's diagnosis require secured units or buildings.

Similarly, in New Jersey, the submitted transition plan does not respond adequately to the observation (in the draft transition plan) that nearly 80% of New Jersey's licensed assisted living facilities have specialized units for persons with Alzheimer's disease or dementia.<sup>32</sup> The submitted plan suggests that the locked settings would be justified on a resident-by-resident basis, based on the resident's assessment and service plan:

The DHS expects that any locked units would be based on a client's individually assessed need, justified and documented in the PCP. It is important to note that these special units for MLTSS members are a critical component in an HCBS setting when controlled entry and exit are necessary for safety.<sup>33</sup>

The state's expectation, however, fails to recognize

31 *Commonwealth of Virginia Transition Plan for Compliance with the Home and Community Based Services (HCBS) Final Regulation's Setting Requirements*, DEPARTMENT OF MEDICAL ASSISTANCE SERVICES, Appendix C, at 19 (2015), available at [http://www.dmas.virginia.gov/Content\\_archs/ltc/Virginia%20Statewide%20Transition%20Plan.pdf](http://www.dmas.virginia.gov/Content_archs/ltc/Virginia%20Statewide%20Transition%20Plan.pdf).

32 *NJ Draft Statewide Transition Plan*, NJ DEPARTMENT OF HUMAN SERVICES, at 15 (March 17, 2015), available at [http://www.nj.gov/humanservices/dmahs/info/StatewideTransitionPlan\\_DRAFT.pdf](http://www.nj.gov/humanservices/dmahs/info/StatewideTransitionPlan_DRAFT.pdf).

33 *NJ Statewide Transition Plan*, NJ DEPARTMENT OF HUMAN SERVICES, at 36 (Apr. 17, 2015), available at [http://www.nj.gov/humanservices/dmahs/info/hcbs\\_trans.html](http://www.nj.gov/humanservices/dmahs/info/hcbs_trans.html).

that, under the federal regulations, modification through a service plan only applies to certain requirements specific to provider-controlled settings, and does not apply to the overarching requirement that a setting support access to the “greater community.”<sup>34</sup> Also, New Jersey’s residential provider self-assessment survey seems to assume, wrongly, that integration is unimportant for persons with dementia, excluding persons with Alzheimer’s Disease/dementia from consideration in the questions examining the possible isolation of HCBS beneficiaries.<sup>35</sup>

**Recommendation:** After a thorough stakeholder process, states should carefully examine the concept of and procedures related to secured settings.<sup>36</sup>

### *States should not disregard the privacy rights of persons with dementia.*

People with Alzheimer’s disease have a right to privacy to the same extent as other persons. Under the federal regulations, an “individual’s rights of privacy, dignity and respect, and freedom from coercion and restraint” are not one of the requirements that can be modified through the person-centered planning process.<sup>37</sup>

In Virginia, however, however, the draft transition

<sup>34</sup> 42 C.F.R. § 441.301(c)(4)(i), (vi)(F).

<sup>35</sup> *Residential Provider Self-Assessment Survey of the Home and Community-Based Services Final Regulation’s Setting Requirements*, NJ DEPARTMENT OF HUMAN SERVICES, Question B1, Section B: Physical Location, and Question E7, Section E: Choice and Independence (2015), available at [http://www.state.nj.us/humanservices/dmahs/info/Residential\\_Provider\\_Self-Assessment\\_Survey.pdf](http://www.state.nj.us/humanservices/dmahs/info/Residential_Provider_Self-Assessment_Survey.pdf).

<sup>36</sup> See, e.g., Letter from Eric Carlson, Directing Attorney, Justice in Aging, to Teri Morgan, Va. Department of Medical Assistance Services (Mar. 9, 2015) (comments on VA transition plan), available at <https://hcbadvocacy.files.wordpress.com/2014/04/justice-in-aging-comments-va-transition-plan.pdf>.

<sup>37</sup> 42 CFR § 441.301(c)(4)(iii), (vi)(F).

plan explicitly disregarded privacy rights for participants in the state’s Alzheimer’s Assisted Living Waiver. The draft transition plan stated: “[r]esidents like being congregated with other people and the need for increased privacy has historically not been a concern.”<sup>38</sup> To the state’s credit, the final transition plan demonstrated an improved awareness of the issue, clarifying that the quoted language from the draft plan was taken from provider self-assessments and was not the state’s position. The state acknowledged that “additional training and education in person centered planning and practices are needed.”<sup>39</sup>

**Recommendation:** The value of privacy should be recognized for all residents, including those with dementia. Residents with dementia may in fact experience particular benefit from privacy and calm environments.

## APPLICATION OF REGULATIONS

*The federal government should require compliance with the federal regulations for all Medicaid-funded home and community-based services, regardless of the Medicaid funding mechanism involved.*

New Jersey’s transition plan states that the HCBS regulations do not apply to adult medical day care

<sup>38</sup> *Draft Commonwealth of Virginia Statewide Transition Plan for Compliance with the Home and Community Based Services (HCBS) Final Regulation’s Setting Requirements*, DEPARTMENT OF MEDICAL ASSISTANCE SERVICES, Appendix C, at 19 (2015), available at [http://www.dmas.virginia.gov/Content\\_atchs/ltc/Virginia%20Statewide%20Transition%20Plan.pdf](http://www.dmas.virginia.gov/Content_atchs/ltc/Virginia%20Statewide%20Transition%20Plan.pdf).

<sup>39</sup> *Commonwealth of Virginia Statewide Transition Plan for Compliance with the Home and Community Based Services (HCBS) Final Regulation’s Setting Requirements*, DEPARTMENT OF MEDICAL ASSISTANCE SERVICES, Appendix H, at 84 (Mar. 17, 2015), available at [http://www.dmas.virginia.gov/Content\\_atchs/ltc/Virginia%20Statewide%20Transition%20Plan%20CMS%203%2017%202015.pdf](http://www.dmas.virginia.gov/Content_atchs/ltc/Virginia%20Statewide%20Transition%20Plan%20CMS%203%2017%202015.pdf).

services because they are state plan services.<sup>40</sup> However, this is at odds with the policy of the HCBS regulations to ensure that Medicaid-funded HCBS settings are truly home and community based. For example, CMS is requiring California to modify its adult day health care program (called Community-Based Adult Services, or CBAS) to come into compliance with the HCBS regulations, even though the CBAS program is funded under a Medicaid demonstration waiver rather than through a program established through Sections 1915(c), 1915(i), or 1915(k) of the Social Security Act (which are the programs explicitly covered by the HCBS regulations).<sup>41</sup> Also, CMS currently is proposing that Medicaid managed care plans be held to the HCBS regulations for all services that could have been authorized under the programs explicitly covered by the HCBS regulations, even if those services actually were authorized under different statutory authority (such as the state-plan statutory authority at issue in New Jersey).<sup>42</sup>

**Recommendation:** States should transition all of their HCBS programs into compliance with the HCBS regulations. A beneficiary's protection should not vary depending on the Medicaid funding mechanism that happens to apply. Specifically, seniors and people with disabilities should not be denied the protections of the HCBS regulations simply because a setting is a state-plan service, as opposed to a waiver service.

---

40 *NJ Statewide Transition Plan*, NJ DEPARTMENT OF HUMAN SERVICES, at 8 (Apr. 17, 2015), available at [http://www.nj.gov/humanservices/dmahs/info/hcbs\\_trans.html](http://www.nj.gov/humanservices/dmahs/info/hcbs_trans.html). The term "state plan services" relates to how services are included in a state's overall package of Medicaid services. "State plan services" are authorized through a state's Medicaid state plan, rather than through a Medicaid waiver application.

41 *Draft CBAS Transition Plan and Public Comment Process*, Cal. Dep't of Aging, available at [https://www.aging.ca.gov/ProgramsProviders/ADHC-CBAS/HCB\\_Settings\\_Stakeholder\\_Process/Transition\\_Plan/Default.aspx](https://www.aging.ca.gov/ProgramsProviders/ADHC-CBAS/HCB_Settings_Stakeholder_Process/Transition_Plan/Default.aspx); see 42 C.F.R. §§ 441.301 (Section 1915(c)), 441.530 (Section 1915(k)), 441.710 (Section 1915(i)).

42 80 Fed. Reg. 31098, 31114 (June 1, 2015) (proposed 42 C.F.R. § 438.3(o)).

## CONCLUSION

True compliance with the HCBS regulations requires a full commitment from the state, providers, and consumers. The HCBS regulations offer residential and non-residential providers the opportunity to provide care and services to persons in the most integrated setting of their choosing. As states work toward complying with the regulations, and transition plans evolve with greater detail, both advocates and policymakers should pay close attention to the special issues impacting older adults.

*Justice in Aging thanks the Atlantic Philanthropies for support of both this issue brief, and the underlying advocacy and education that has informed the issue brief.*

### WASHINGTON

1444 Eye Street, NW, Suite 1100  
Washington, DC 20005  
202-289-6976

### LOS ANGELES

3660 Wilshire Boulevard, Suite 718  
Los Angeles, CA 90010  
213-639-0930

### OAKLAND

1330 Broadway, Suite 525  
Oakland, CA 94612  
510-663-1055