



June 14, 2011

Dr. Donald Berwick
Administrator
Centers for Medicare and Medicaid Services
Department of Health and Human Services
Attention: CMS-2296-P
Mail Stop C4-26-05
7500 Security Boulevard
Baltimore, Maryland 21244-1850
Comments submitted electronically, <http://www.regulations.gov>

**Re: File Code CMS-22296-P
HCBS Waivers**

Dear Dr. Berwick:

The Assisted Living Consumer Alliance (ALCA) is a national collaboration of groups and individuals working together to promote consumer safety, choice, and rights in assisted living. We appreciate CMS's efforts to address the important issue of whether and when a communal residential setting (such as an assisted living facility) should be considered a home or community-based setting for the purposes of Medicaid HCBS reimbursement.

This letter addresses two aspects of the proposed regulations: HCBS Settings and Person-Centered Planning. Our comments track in many ways the comments submitted by the National Senior Citizens Law Center, which is one of ALCA's founding member organizations.

We have multiple suggestions for revising the proposed regulations, as these regulations deserve a careful balancing. Our many suggestions, however, should not obscure our principal message of support for CMS's development of these proposed regulations. For too long, HCBS money has been paid for assisted living services with little meaningful consideration of the content of those services. The increased use of HCBS funding is a positive step for the Medicaid program and for society generally, but it should be done with commensurate attention to how services are provided and in what settings.

1. HCBS Settings

We have discussed this issue with other members and with numerous other stakeholders. Our discussion of the issues is divided into separate sub-issues, as shown below.

Overall, we believe that the proposed regulation is on-target, and we appreciate CMS taking the initiative on this important issue. Current standards are insufficient to ensure the home-like character of HCBS settings, and some current HCBS settings are just as institutional as a nursing facility. The proposed regulation, when adopted, will be a strong step forward in ensuring that the home and community-based settings live up to their name.

Structure of Regulatory Requirements for HCBS Settings

As set forth by CMS, the proposed regulation lists in one sentence (subsection (b)(1)(iv)) the affirmative requirements regarding HCBS settings, and immediately thereafter lists (in subsection (b)(1)(iv)(A) and (B)) the negative requirements, i.e., those characteristics that will establish a setting as *not* being considered home or community based. We propose to alter this structure somewhat, by paring down dramatically the sentence listing affirmative requirements, and incorporating those affirmative requirements into a longer list of requirements in new subsections (b)(1)(v) and (vi). Some of these affirmative requirements are adapted from CMS's discussion of assisted living, as discussed in more detail immediately below.

Requirements for "Assisted Living"

The regulation as proposed by CMS does not address assisted living explicitly, although the discussion preceding the proposed regulation includes a substantial list of requirements for assisted living facilities. We recommend incorporating those requirements (with some revisions) into the regulations, as there seems to be no reason why these requirements in general should not apply to all HCBS beneficiaries. We propose applying most of the requirements to all HCBS settings, as set forth in our proposed subsection (b)(1)(v). We propose applying an additional requirement (pertaining to involuntary transfer and discharge) only to assisted living facilities, group homes, and comparable residential settings, as set forth in our proposed subsection (b)(1)(vi).

We propose that certain of these requirements not apply when the recipient has a significant cognitive impairment, or when the setting has a capacity of six or fewer persons. We have suggested these exceptions in our proposed regulatory language, and they are discussed in more detail below.

We note that references to "assisted living" add some uncertainty to a regulation, since states use differing terminology and "assisted living" does not have a universal definition. Also, a provider might attempt to avoid "assisted living" requirements simply by creating different legal entities for a housing provider and a service provider, even though in reality the housing and services are provided by the same entity. Our proposed regulatory language speaks

relatively broadly of “an assisted living facility, group home, or other residential setting that provides both housing and services”; if the term “assisted living” is ultimately used in the final regulation, CMS might want to develop a more precise definition.

Inpatient Institutions and Custodial Care (subsection (b)(1)(iv)(A))

CMS has proposed that HCBS funding be barred if the setting is in the same building as a “facility providing inpatient institutional treatment or custodial care.” We suggest that a barred facility be defined as a “hospital, intermediate care facility for individuals with mental retardation, institute for mental disease, or similar facility (but not including a nursing facility or any element of a continuing care retirement community) that provides inpatient institutional treatment or care.” Many older persons consider it beneficial to live in continuing care retirement communities and other settings that include a nursing facility, particularly when one spouse or partner needs nursing facility care and the other does not.

We suggest that the term “custodial care” be stricken, since “custodial care” might easily be interpreted to include the same level of care that is suitable for funding under an HCBS waiver. In relation to payment for nursing facility care under Medicare Part A, for example, the term “custodial care” often is used to describe the ADL assistance that does not qualify as the “skilled care” that is needed to justify Part A reimbursement.

We propose that the term “public institution” be revised to include the modifier “that provides inpatient institutional treatment or care.” Otherwise, there is a danger that “public institution” might be interpreted to include such “institutions” as schools, health clinics, or fire stations.

Housing Complexes Designed Around a Particular Diagnosis or Disability (subsection (b)(1)(iv)(A))

CMS has proposed that HCBS funding be barred if a recipient lives in “a housing complex designed expressly around an individual’s diagnosis or disability.” We suggest striking that language, primarily because we are familiar with desirable settings designed exclusively for recipients with Alzheimer’s disease or another dementia. In our experience, this focus on recipients with dementia is a positive attribute, and is perceived as such by recipients and their families. We believe that the other protections that we propose are sufficient to maintain an HCBS setting’s community-based character.

We are familiar with the arguments that a complex designed around a particular diagnosis is unduly segregational, but we think that concerns about segregation are often misplaced in reference to an older population. Older persons often choose to live with each other in intentional communities, and this cultural norm should be taken into account. If CMS feels that it is necessary to develop a regulatory restriction related to segregation by disability, we recommend that the restriction include exceptions based on age, Alzheimer’s disease and other dementias, and potentially other considerations. One important consideration would be how the regulation would treat HUD 811 projects, which provide supportive housing for persons with

disabilities. We strongly believe a HUD 811 project should be considered a setting in which a person can receive HCBS Medicaid coverage.

Secretary with Authority to Determine Settings with Institutional Qualities
(subsection (b)(1)(iv)(B))

CMS has proposed that HCBS funding be forbidden if a setting “[h]as qualities of an institutional setting, as determined by the Secretary.” We support this language as a useful protection for recipients, although we recognize that it may be less necessary if the final regulation includes the other, more specific requirements that we (and others) are proposing.

Leases

In a discussion preceding the proposed regulations, CMS has proposed that a lease be required as a condition for HCBS funding in an assisted living setting. We are not recommending such a requirement. The characteristics of a “lease” will vary from state to state, depending on state law and other factors, and some of those characteristics may be ill-suited for some HCBS settings. Also, in many states, a lease provides very minimal protections to tenants, and may allow eviction at a landlord’s discretion after a 30-day notice.

In lieu of a lease, we propose a written agreement as discussed below in reference to subsection (b)(1)(vi)(A), along with specific recipient protections that often would be associated with a lease. For example, for subsection (b)(1)(v)(E), we propose a requirement that “[t]he recipient’s living unit is a specific physical space that the recipient owns or rents,” to prevent recipients generally from being transferred within a building. Our proposed subsections (b)(1)(v)(H) and (I), and (b)(1)(vi)(B) similarly protect recipients from precipitous evictions and provide an administrative appeals process for challenging eviction from an assisted living facility.

In our proposed language, the term “living unit” refers to the house, apartment or other area specifically rented or owned by the recipient, including a bedroom, bathroom, kitchen, and/or kitchenette. A “living unit” does not include common space accessible to recipients generally. If necessary, the regulation could be revised to include a definition of this term.

Exceptions for Recipients with Dementia (subsections (b)(1)(v)(G), (K), & (L))

In general, hallmarks of a community-based setting include the ability to leave or to lock the living-unit door, and access to cooking facilities. We recognize, however, that these setting attributes can be a negative for a recipient with dementia, and so we propose that these requirements be subject to waiver by the person-centered plan of a recipient with dementia or a comparable cognitive limitation. We discuss this issue in more detail below.

Exceptions for Small Facilities (subsections (b)(1)(v)(J), (K), (L), (M))

In general, we require that living units include bathrooms, kitchenettes, and lockable doors. We propose that an exception be made, however, if a setting has a capacity of six or fewer persons (not including staff). We believe that a small-capacity facility is able to maintain a home-like character even with shared bathrooms and kitchens, and unlockable doors. Indeed, such small settings generally are located in houses in residential neighborhoods.

In our proposed regulatory language, subsection (b)(1)(v)(M) exempts such small facilities from the requirements of subsections (b)(1)(v)(J), (K), and (L). We refer to "persons" rather than "recipients" because "recipient" refers only to persons reimbursed through Medicaid. For example, if a setting provides services to 5 recipients along with 10 additional persons, the setting should not be considered small for the purposes of this exception.

Access to Community (subsection (b)(1)(v)(A))

In the discussion preceding the proposed regulation, CMS twice refers to access to the community. The first reference is in subsection (b)(1)(iv); the second is in the discussion of assisted living. As we have explained above, we propose to import the assisted living issues into the regulation itself. Hence, we propose to address access in subsection (b)(1)(v)(A), and our proposed language draws from both CMS references to access to the community.

Choice (subsection (b)(1)(v)(B))

We support CMS's strong statement in favor of resident choice. Our proposed language is drawn from CMS's proposed subsection (b)(1)(iv) and—in the reference to "meal and sleep times"—from CMS's discussion preceding the proposed regulations.

Private Occupancy (subsection (b)(1)(v)(C))

In the assisted living discussion preceding the proposed regulation, CMS has proposed that a recipient have the right to decide whether to share a room and with whom. We support that requirement, but propose additionally that recipients not share bedrooms unless they are spouses or partners. Currently, in many facilities certified to accept Medicaid HCBS reimbursement, unrelated recipients share bedrooms because the state Medicaid program and its reimbursement rate offer no real alternative. The resident "chooses" to share but it is not really a choice, given the lack of alternatives. This type of shared occupancy is not faithful to the principles of HCBS and assisted living and, accordingly, we propose that only spouses and partners share a bedroom under HCBS reimbursement.

Visitors (subsection (b)(1)(v)(D))

Our language regarding the right to receive visitors is adapted from CMS's assisted living discussion preceding the proposed regulations. We propose slightly different language that specifies that a visitor may stay overnight. Persons living in an apartment or house can choose to have a visitor stay overnight; furthermore, this is a right that normally accompanies one's entry into adulthood. A recipient in an HCBS setting must have the same freedom.

Prohibiting Transfers Within a Setting (subsection (b)(1)(v)(E))

As we mention above in our discussion of leases, we propose that a recipient not be subject to transfers within a setting. This concept is taken from CMS's proposal, in the assisted living discussion preceding the proposed regulations, that "[l]eases may not reserve the right to assign apartments or change apartment assignments."

Furnishing Living Units (subsection (b)(1)(v)(F))

We propose that a recipient have the right to furnish and decorate the living unit. The setting would be unduly institutional if a recipient were prevented from doing so.

Leaving the Setting (subsection (b)(1)(v)(G))

This concept is drawn from CMS's assisted living discussion preceding the proposed regulations. CMS refers to recipients' ability to "leave the setting at times and for durations of their own choosing." We have modified this language by adding a waiver if (as discussed above) the recipient has dementia and, as a result of the dementia, the person-centered plan says that the recipient should not leave the setting without supervision.

Aging in Place (subsection (b)(1)(v)(H))

In the discussion preceding the proposed regulations, CMS has proposed that an assisted living setting be required to follow "aging in place" as a "common practice." We have retained this concept but have strengthened it by 1) applying it to all HCBS settings and not just to assisted living settings, and 2) setting a more rigorous standard. Regarding the standard to be used, it is not workable to have a requirement based on determining a "common practice." Such a requirement would provide recipients with little protection because the requirement could not be enforced meaningfully. Whenever a setting might force a recipient to leave because of the recipient's increased needs, the setting could claim nonetheless that aging in place was its "common" (but not universal) practice. Accordingly, we propose that a setting be required to accommodate a recipient's care needs unless relevant law (for example, a facility licensure rule) prohibits the setting from doing so, even after consideration of the reasonable accommodation provisions of the Americans with Disabilities Act (ADA). This requirement is consistent with the concept of aging in place and the ADA.

Compliance with Person-Centered Plan Not Condition of Continued Stay
(subsection (b)(1)(v)(I))

In the assisted living discussion preceding the proposed regulations, CMS states that compliance with a person-centered plan should not be a condition of a lease. We support this concept, although we have re-worded the concept as seen in our proposed subsection (b)(1)(v)(H). We do not refer to a lease; as discussed above, using the term "lease" adds uncertainty because laws governing leases will vary from state to state. Also, we have deleted the qualifier "in the event that the individual has shared his/her plan or the landlord is also the provider of services" because this qualifier is unnecessary.

Bathroom (subsection (b)(1)(v)(J))

This requirement is drawn from CMS's assisted living discussion, which calls for "individual living, sleeping, bathing and cooking areas." Our proposed language specifies a full bathroom and, as discussed above, provides an exception in subsection (b)(1)(v)(M) for settings with a capacity of six or fewer persons (not including staff).

In discussing these proposed regulations with various stakeholders, we are aware of proposals that standards for bathrooms and kitchens/kitchenettes be relaxed so that reasonable, easy access to a shared bathroom or kitchen/kitchenette would be deemed adequate. We understand the reasoning behind these arguments, but also believe that a "reasonable access" standard could easily be exploited in a way that would allow an overly-institutional setting to nonetheless be eligible for HCBS funding. If CMS is inclined to insert a "reasonable access" exception to the requirements of a private bathroom or kitchen/kitchenette, we recommend that CMS write the exception carefully so that the exception does not swallow the rule.

Kitchen or Kitchenette (subsection (b)(1)(v)(K))

This requirement also is drawn from CMS's assisted living discussion which, as discussed immediately above, calls for "individual living, sleeping, bathing and cooking areas." Our proposed language refers to a kitchen or kitchenette and, as discussed above, provides an exception in subsection (b)(1)(v)(M) for settings with a capacity of six or fewer persons (not including staff). Also as discussed above, we propose a waiver of this requirement if the recipient has dementia and, as a result of the dementia, the presence of the kitchen or kitchenette would present a danger to a recipient living in the unit, as determined by the person-centered plan.

Pursuant to our discussion above in relation to bathrooms, we urge CMS to tread carefully if the agency is inclined to consider any standard based on reasonable access to a shared kitchen.

Lockable Access and Egress (subsection (b)(1)(v)(L))

This requirement also is drawn from CMS's assisted living discussion, which proposes that recipients "have lockable access to and egress from their own apartments." Our proposed language, as discussed above, provides an exception in subsection (b)(1)(v)(N) for settings with a capacity of six or fewer persons (not including staff). Also as discussed above, we propose a waiver of this requirement if the recipient has dementia and, as a result of the dementia, the person-centered plan says that locks should not be used.

Written Agreements and Limitations on Involuntary Transfer or Discharge (subsection (b)(1)(vi))

As discussed above, CMS has proposed that leases be required in HCBS settings, but as an alternative we propose that regulations specify certain lease-like protections. One important protection limits the circumstances under which the recipient can be involuntarily transferred or discharged. We propose in this subsection that a recipient be allowed to stay in the setting unless the recipient's care needs cannot be met in the setting, the recipient's presence in the setting endangers the safety or health of others, the setting is ceasing to operate, or the recipient has failed to pay. These standards are limited to assisted living facilities, group homes, or other residential settings that provide both housing and services.

Standards are of limited use unless a recipient has a forum in which to assert those standards. Accordingly, we propose that a recipient have an appeal right through a State-developed administrative process.

These comprehensive provisions are vital to ensure that aging in place becomes a reality in HCBS settings. It is insufficient to only prohibit a setting from relying on certain justifications for involuntary transfer or discharge, because the setting probably can develop other justifications that will accomplish essentially the same thing from the setting's point of view. For that reason, we recommend that CMS specify the only legitimate justifications for involuntary transfer or discharge, and require that an administrative appeals process be available.

Proposed Regulatory Language on HCBS Settings: 42 C.F.R. § 441.301(b)(1)(iv)-(vi)

(iv) Only in home and community based settings that are home and community based, integrated in the community, provide meaningful access to the community and community activities, and choice about providers, individuals with whom to interact, and daily life activities. A setting is not integrated in the community if it is:

(A) Located in a building that houses is also a publicly or privately operated hospital, intermediate care facility for individuals with mental retardation, institute for mental disease, or similar facility (but not including a nursing facility or any element of a continuing care retirement community) that provides inpatient institutional treatment or custodial care; or in a building on the grounds of, or immediately adjacent to, a public institution that provides

inpatient institutional treatment or care; or a housing complex designed expressly around an individual's diagnosis or disability, as determined by the Secretary; or

(B) Has qualities of an institutional setting, as determined by the Secretary.

(v) To be considered home or community based, a setting must possess all of the following characteristics:

(A) A recipient has meaningful access to the greater community based on the recipient's needs and preferences.

(B) A recipient has a choice of providers, of individuals with whom to interact, and of daily life activities, including but not limited to meal and sleep times.

(C) A recipient shares a unit only at the recipient's choice. Unless residents sharing a unit are spouses or partners, each resident has an individual bedroom.

(D) A recipient has the right to accept visits (including overnight visits) at any time from a person or persons of the recipient's choosing.

(E) The recipient's living unit is a specific physical space that the recipient owns or rents, and thus the setting's owner or operator does not have the right to transfer the recipient from one unit to another.

(F) Recipients have the freedom to furnish and decorate their living units.

(G) Recipients may leave the setting at times and for durations of their own choosing, unless leaving unsupervised is rejected by the recipient's person-centered plan, based on the recipient's dementia or comparable cognitive limitation.

(H) The inability to meet a recipient's care needs in the setting is not grounds for involuntary transfer or discharge from the setting unless those care needs require services or a level of service that is not allowable in that setting under relevant state or federal law, including but not limited to consideration of the reasonable accommodation provisions of the Americans with Disabilities Act.

(I) A recipient's non-compliance with his or her person-centered plan is not grounds for involuntary transfer or discharge from the setting.

(J) Each living unit must include at least one full bathroom.

(K) Each living unit must include a kitchen or kitchenette, unless the presence of the kitchen or kitchenette would present a danger to a recipient living in the unit, as determined by the person-centered plan.

(L) Each living unit must offer lockable access and egress, unless the use of lockable doors is rejected by the person-centered plan of a recipient living in the unit, based on the recipient's dementia or comparable cognitive limitation.

(M) Subsections (J), (K) and (L) do not apply when a setting has a capacity of no more than six persons, not including staff members.

(vi) If a setting is an assisted living facility, group home, or other residential setting that provides both housing and services, the setting is considered home or community based only if:

(A) The recipient has a written agreement with the housing provider that is consistent with the requirements of this section, and does not waive any right of the recipient.

(B) Involuntary transfer or discharge from the setting is limited to situations in which the recipient's care needs cannot be met in the setting, the recipient's presence in the setting endangers the safety or health of others, the setting is ceasing to operate, or the recipient has failed, after reasonable and appropriate notice, to pay for (or to have paid under Medicaid or another payor) a stay in the setting. Interpretation of these standards shall incorporate the standards set forth in subsections (b)(1)(v)(H) and (I). A recipient shall have the right to appeal a transfer or discharge through a State-developed process meeting the standards of Subpart E of Part 431.

2. Person-Centered Planning

We support the regulatory proposal that the written plan of care for waiver participants be a person-centered plan developed through a person-centered process. These requirements would bring more dignity and independence to participants.

In order to achieve the goals of these proposed requirements, we offer the following recommendations. First, CMS should specify that waiver participants may challenge the denial of the service and/or provider of the participant's choice, or any failure of the service plan or the planning process to comply with the regulatory requirements. These appeal rights are consistent with the fair hearing rights already specified in the HCBS Waiver Application, Version 3.5, Appendix F-1, entitled "Participants Rights: Opportunity to Request a Fair Hearing."

Second, we recommend that CMS articulate more clearly the responsibilities of states to ensure a person-centered process that "reflects the cultural considerations" of beneficiaries. Without more than is currently proposed, the regulation may be too vague for meaningful enforcement.

Third, we recommend certain additions to the regulatory language to incorporate regulatory provisions recently proposed for the Community-First Choice Option (CFCO). To a great extent, the elements proposed in the HCBS waiver regulations for the person-centered planning process and the person-centered plan are the same as were proposed several months ago in CMS' proposed regulations for the CFCO. Several important provisions, however, have been

omitted from the HCBS waiver regulations. Specifically, the proposed CFCO regulation includes subparagraphs (c), (d), and (e), which mandate, among other things, that the person-centered planning process be timely, that a plan “ensure . . . the services and supports meet the individual’s needs,” and that a plan be signed and “agreed to by the individual.”

We recommend that most of the substance of these subparagraphs be incorporated into the HCBS waiver regulation. There does not appear to be a reason why the standards would be different, and CMS does not advance any such reasons in the preamble. We have not, however, included the element in the proposed CFCO regulation that establishes the minimum conflict of interest standards because (as we explained in our comments to the proposed CFCO regulation) we believe that service plan development should include family members and service providers. Additionally, we add a requirement that service plans be reviewed at least once every 12 months.

Fourth, we recommend a revision in subsection (b)(1)(i)(A)(3) to ensure that scheduling takes into account the availability and preferences of persons whom the participant has chosen for the planning process.

Fifth and finally, we recommend that subsection (b)(1)(i)(B)(4) include a requirement that the person-centered plan include the times when services and supports will be provided.

Proposed Regulatory Language on Person-Centered Planning: 42 C.F.R. § 441.301(b)(1)(i)

*(b) * * **

*(1) * * **

(i) Under a written services and support plan (also called plan of care) that is based on a person-centered approach and is subject to approval by the Medicaid agency.

(A) Person-Centered Planning Process. In addition to being led by the individual receiving services, the person-centered planning process:

(1) Includes people chosen by the individual.

(2) Provides necessary support to ensure that the individual has a meaningful role in directing the process.

(3) Occurs at times and locations of convenience to the individual and to the people chosen by the individual under subsection (1).

(4) Reflects cultural considerations of the individual.

(5) Includes strategies for solving conflict or disagreement within the process, including any conflict of interest concerns.

(6) Offers choices to the individual regarding the services and supports they he or she receives and from whom.

(7) Includes a method for the individual to request updates to the plan as needed.

(B) *The Person-Centered Plan.* The person-centered plan must reflect the services that are important for the individual to meet individual services and support needs as assessed through a person-centered functional assessment as well as what is important to the person with regard to preferences for the delivery of such supports. Commensurate with the level of need of the individual, the plan must:

(1) Reflect the individual's strengths and preferences.

(2) Reflect clinical and support needs as identified through a person-centered functional assessment.

(3) Include individually identified goals, which may include, as desired by the individual, items related to relationships, community living, community participation, employment, income and savings, health care and wellness, education, and others.

(4) Reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, and the times when those services and supports will be provided.

(5) Reflect risk factors and measures in place to minimize them, including back-up strategies when needed.

(6) Be signed by all individuals and providers responsible for its implementation.

(7) Be understandable to the individual receiving services and the individuals important in supporting him or her.

(8) Include a timeline for review, which must provide for review within at least 12 months.

(9) Identify the individual and/or entity responsible for monitoring the plan.

(10) Be distributed to everyone involved (including the participant) in the plan.

(11) Be directly integrated into self-direction where individual budgets are used.

(12) Prevent the provision of unnecessary or inappropriate care.

(C) Requirements of the plan. All of the State's applicable policies and procedures associated with the person-centered service plan development must be carried out and must include, but are not limited to, the following policies and procedures:

(1) Ensure the responsibilities for assessment of need and service plan development are identified.

(2) Ensure the planning process is timely.

(3) Ensure the individual's needs are assessed and the services and supports meet the individual's needs.

(D) Finalizing the person-centered service plan. The service plan must be finalized and agreed to in writing by the individual or, as appropriate, the individual's representative and a copy of the plan must be provided to the individual.

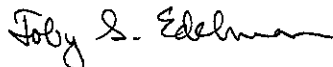
(E) Reviewing the person-centered service plan. The service plan must be reviewed, and revised upon reassessment of need, at least every 12 months, when the individual's circumstances or needs change significantly, and at the request of the individual or the individual's representative, as applicable.

(F) A waiver participant has a right to a Fair Hearing in accordance with 42 C.F.R. Part 431, Subpart E, if the participant is denied the service and/or provider of the participant's choice, or if, despite a request from the participant or the participant's representative, the person-centered plan or the person-centered planning process do not comply with the requirements of this paragraph.

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We thank CMS again for its initiative in proposing these regulations to improve the quality and availability of Medicaid home and community-based services.

Sincerely,



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