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Barbara Edwards
Director, Disabled and Elderly Health Programs Group
Centers for Medicare & Medicaid Services
7500 Security Boulevard, Mail Stop 1426
Baltimore, Maryland 21244

January 28, 2015

Dear Ms. Edwards:

On behalf of the Alzheimer's Association, I write concerning our ongoing conversation with CMS to ensure that home- and community-based services (HCBS) are accessible to all individuals who need it. We appreciate CMS's continuing efforts to ensure their safety, dignity, and autonomy.

In our August 2014 letter, we noted our support of the final rule and its many positive, person- and family-centered provisions, including the use of a person-centered service plan. We also expressed concern, however, about a letter to the California Department of Health Care Services that we interpreted to contradict the final rule. In that letter, CMS stated that adult residential facilities and group homes that employ secured perimeters or means of delayed egress could not serve individuals receiving HCBS. The Association noted that CMS, in the final rule, stated "restricting independence or access to resources is only appropriate...when considered carefully in the person-centered service plan." This guidance is at odds with the California letter.

We write now to request that CMS confirm that residential settings that employ secured perimeters or means of delayed egress are eligible for HCBS so long as a person's individualized need for security is documented as necessary for his safety in his person-centered service plan. In its recent "HCBS Final Regulations 42 CFR Part 441: Questions and Answers Regarding Home and Community-Based Settings," CMS addresses whether the "right to freedom from restraint prohibits locked doors or doors with alarms for individuals who are incapable of protecting themselves unsupervised in the community and/or who have documented histories of wandering." CMS states that "In a provider-owned or controlled residential setting, states must ensure that any necessary modification of the requirements specifying the rights of individuals receiving services is based on individually assessed need and justified and documented in the person-centered plan as described in § 42 CFR section 441.301(c)(4)(vi)(F)." The Alzheimer's Association supports this approach, which balances personal safety with access to the community and autonomy.

As we noted in our August letter, wandering is a prominent safety concern for many individuals with Alzheimer's disease or other dementias. While the Association fully supports a case-by-case approach in determining whether and how an individual's personal freedom should be restricted due to wandering concerns, it remains an unfortunate reality of the disease for affected individuals and their families.

The Alzheimer's Association remains ready and willing to work with CMS to ensure that individuals receiving HCBS are able to live according to their choices, goals, and needs. Please do not hesitate to contact Laura Thornhill, Manager of Regulatory Affairs, at 202/638-7042 or lthornhill@alz.org if we can be of assistance.

Sincerely,

A handwritten signature in black ink, appearing to read "R. Egge".

Robert Egge
Executive Vice President, Government Affairs