

Public Policy Division
1212 New York Ave NW
Suite 800
Washington, DC 20005

202.393.7737 p
866.865.0270 f
www.alz.org



Chantal Virgile
Outreach Assistant
Federal Communications Commission
Consumer and Government Affairs Bureau
Consumer Affairs and Outreach Division
445 12th Street SW
Washington, DC 20554

January 22, 2016

Re: Telecommunications Needs of the Cognitive Disability Community

Dear Ms. Virgile,

The Alzheimer's Association appreciates the opportunity to comment on the telecommunications needs of persons with cognitive disabilities, including cognitive impairment. We commend the Federal Communications Commission's (FCC) interest in improving their access and experience.

The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. Today, there are more than 5 million Americans living with Alzheimer's disease. Alzheimer's is the sixth leading cause of death in the United States, and the only cause of death among the top 10 without a way to prevent, cure, or even slow its progression. Many symptoms of dementia, such as memory loss and confusion, make daily life challenging. This can include something as basic as making a telephone call. However, some technological advances can help many persons with dementia, particularly those in the early stages of the disease, maintain dignity and some degree of independence while staying socially connected. These advances can also help family and friends care for persons with dementia as well as receive much-needed support. Improved awareness of, access to, and education on how to use advances in telecommunications present tremendous opportunities for this population, so we encourage the FCC to consider the following comments.

Barriers and Challenges

As noted above, persons living with Alzheimer's disease or another form of dementia often encounter challenges with the most common aspects of everyday life, including using basic technology. For example, a hallmark of Alzheimer's disease is memory loss, which begins slowly, meaning that persons in the early stages of dementia may forget phone numbers. But as memory loss worsens, they may be unable to remember conversations or recognize voices. Similarly, dementia can cause affected persons to withdraw from their communities, leading to social isolation. Wandering is another common behavior, leaving individuals disoriented or possibly unable to recognize unsafe situations. Finally, cultural stigma and assumptions about aging--including the idea that older people or persons with cognitive impairments

are incapable of learning and using technology--continue to be major barriers to more vigorous research and development.¹

Access

Access to technology and ease of use of features or applications are two kinds of barriers. We encourage the FCC to continue its work to increase Americans' access to robust, affordable broadband and voice services. Expanding access to telecommunications products and services will help to provide additional valuable resources for persons with cognitive impairment.

Increased access alone, however, will not ensure adoption of technology unless it is easy to use and incorporates features designed for the daily challenges and needs of impaired persons. Persons living in the early stages of dementia use smartphones and other devices for voice, sound, or visual (e.g., text) prompts as medication reminders and to receive care remotely. They record notes and discussions, including those with their physicians, and call family and friends via visual (e.g., photos) or written cues, even when they can't remember names and numbers. They use them to stay safe with GPS tracking features and step-by-step mapping instructions to reduce the risk of becoming lost. In addition, easy, ready access to 911 can help in an emergency, as can a medical folder feature that allows emergency medical staff to access important contact information. As the FCC works to expand and enhance access to such practical uses, it should consider the following guidelines:

- Because cognitive impairment affects individuals in different ways, devices and features or applications should be easily modifiable to suit personal needs.
- Ample opportunities for training and reminders on how to use features should be built into devices. Many persons with the disease prefer to be confident in how to use their existing devices and features before considering new platforms.
- The operation of these features should be designed in a way not only to facilitate easy use, but to minimize frustration, another common experience of persons with dementia.

Informing the Community and Advocates

The FCC's approach to informing and educating persons with cognitive impairment and advocates should be individualized and high-touch. The Association, including its chapters across the country, would be pleased to work with the FCC to inform our constituents about assistive telecommunications. The FCC should also consider outreach to organizations and persons working with and caring for older adults, such as health care professionals, geriatric social workers, senior centers, and Area Agencies on Aging, among many others. The FCC should also explore opportunities for collaboration with other federal agencies that care for and support affected persons, like the Administration for Community Living and the Centers for Medicare & Medicaid Services.

Thank you for the opportunity to comment. The Alzheimer's Association would be pleased to serve as a resource to the FCC as it considers these important issues and how they relate to individuals living with

¹ Dishman E, Carrillo MC. Perspective on everyday technologies for Alzheimer's care: Research findings, directions, and challenges. *Alzheimer's & Dementia* 2007; 3:227-234.

Alzheimer's and related dementias. Please contact Laura Thornhill, Manager of Regulatory Affairs, at 202-638-7042 or lthornhill@alz.org if you have questions or if we can be of additional assistance.

Sincerely,

A handwritten signature in black ink, appearing to be 'RE', with a long horizontal stroke extending to the right.

Robert Egge
Executive Vice President, Government Affairs