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5 September, 2014

The Honorable Dr. Sylvia M. Burwell  
Secretary of Health and Human Services  
200 Independence Ave SW  
Washington, DC 20201

RE: Changes to CMS Coverage for Augmentative and Alternative Communication Devices Severely Limit the Utility of these Crucial Devices

Dear Madam Secretary:

We are speech-language pathologists and members of the American Speech Language and Hearing Association (ASHA) working at **ICAN™ Talk Clinic** of the AAC Institute. Our primary mission, as a non-profit clinical organization, is to provide evidence-based augmentative and alternative communication (AAC) services to individuals with severe and multiple disabilities who cannot talk. We design our treatment approaches to result in the most effective communication possible – the ultimate goal of AAC. We believe that the strongest and most compelling evidence that exists related to the effectiveness of AAC treatment is in the provision and integration of a high performance AAC system (CMS term is Speech Generating Device, or “SGD”) during intervention. AAC treatment using an SGD under the supervision of a qualified speech language pathologist meets medical necessity standards, results in improved functional communication, maximizes an individual’s potential, and improves quality of life.

Only a small percentage of United States citizens and Medicare beneficiaries may ever require an SGD. Yet the limitations placed on a patient and his family to maintain or return communication function or competence either due to a congenital, degenerative or acquired disability has been essentially lost in the changes to CMS coverage for SGDs. We refer particularly to the Capped Rental policy and/or CMS Coverage Reminder limiting functionality of SGDs to speech output only.

In your role as the Secretary of Health and Human Services, you are aware of the details and processes that have been set in place that make these imposed policies the first harmful and regressive landmarks in the history of AAC rehabilitation and assistive technology services.

Among the patients we serve are individuals with Huntington’s disease. We have had success using SGDs with these adults to achieve various patient-oriented communication outcomes along with maintaining orientation, communication and interaction with their medical staff, loved ones and daily environments as long as possible. However, the family of our most recent 55-year old patient with Huntington’s disease was told by her primary physician that he would not write the letter of medical necessity for the recommended SGD after a comprehensive AAC evaluation, trial, and monitoring of her performance to document need, BECAUSE he felt her condition probably would deteriorate within a year and require hospice care where, as you know, an SGD would be removed. In the meantime, she was left

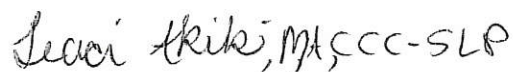
without her only effective and efficient means of communication. Despite her relatively preserved cognition and memory, she was enrolled in hospice without the hope of being able to communicate at end of life. Essentially, the CMS policy negatively impacted our patient's quality of life. Instead of promoting social closeness and meaningfulness through the use of the SGD, we observed her alone, pushed up against the wall of the nursing home unable to communicate with her family members or turn on her music using SGD features.

For our most severely disabled cases, access to their SGD's functions like the internet (email, social networking, study, entertainment, etc.) and other peripheral devices is often the only means they have to interact, work, contribute to and exercise a degree of independence and control of the world around them.

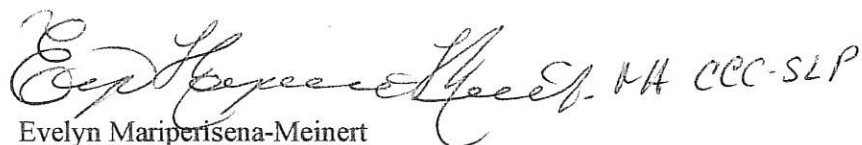
We at ICAN™ Talk Clinic ask that you review the Capped Rental policy and Coverage Reminder and (1) abandon the capped rental policy for direct purchase of an SGD that cannot be removed upon entering hospice; (2) clarify the Coverage Reminder to allow SGDs that are Class II Medical Devices or otherwise are ordered by a physician's prescription to have multiple functions (and not be limited to speech generation only); and (3) develop new guidelines that focus on the needs of your beneficiaries and do not inhibit advances in technology.

We are proud of the clinical work we provide and even more proud of our clients and families who must struggle with the barriers and burden imposed by these policies. We invite you to visit our clinic's website at [www.icantalkclinic.com](http://www.icantalkclinic.com) to learn about the quality AAC services that make a real difference in the lives of Medicare beneficiaries who need SGDs and their families.

Respectfully submitted,



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