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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  
inflicts unreasonable pain and suffering on our most vulnerable citizens and their families

Dear Madam Secretary:

Mary's daughter thought she was doing what was best by having her mother sign the hospice papers for enrollment. After all, this decision was efficient and would be behind Mary and the family before hospice care was really needed. One burdensome and painful item off the end-of-life check list. However, that decision triggered a series of events that shut down Mary's Speech Generating Device (SGD) funding request. Trying to help, a local ALS Association worker came to the home, packed up Mary's loaner SGD from my clinic that had been customized for her, and left an unfamiliar, unmatched SGD from their loaner pool. In the time between talking with Mary, her daughters and hospice to see about removing her from hospice until she had her personal SGD, Mary was in tears because she now had no SGD for communication. The best solution was achieved for Mary! She was taken out of hospice, her recommended SGD was purchased and Mary benefitted from her SGD during the time she needed hospice. With today's CMS Capped Rental policy, Mary's end-of-life would have been traumatically different. With today's Coverage Reminder, Mary's use of the various communication features on her SGD would not be available, e.g. internet access, email, word processing, phoning and environmental control.

Why is CMS, PDAC and those appointed to protect our health care, placing the burden of reducing durable medical equipment (DME) costs on those who need SGDs? Individuals with severe and complex disabilities who need augmentative and alternative communication (AAC) are among the most vulnerable and neediest beneficiaries of CMS and our society. Yet they are often the most courageous and inspiring individuals that require CMS and society's benevolence. As an associate professor in the Department of Communication Disorders at the University of Pittsburgh teaching AAC assistive technology, and the co-founder of the AAC Institute, a non-profit organization dedicated to the most effective communication for people who need AAC interventions and an SGD (CMS term), I am troubled by policies being enacted by CMS that represent the first substantial setback to AAC technology, services, supports and enhancement to quality of life in the history of AAC rehabilitation.

Why is CMS, PDAC and those appointed to protect our health care, looking at an SGD as a simple piece of technology for providing the most minimal communication that is interchangeable with any other SGD? Although CMS approves SGDs based on proof of medical necessity and functional communication goals, achieving "functional communication" is surrounded and layered by complex issues associated with language abilities, metalinguistic skills, cognition, executive functioning, motor and sensory skills – the brain. Additional considerations involved in the evaluation and recommendation of an SGD include the person's environment, personality and emotional factors, family dynamics, to name a few. Primary, of

course, in the SGD selection process is **language**. How language is represented and generated to result in the most effective communication performance and patient-valued outcomes using an SGD is paramount. The Capped Rental and Coverage Reminder policies ignore the complex variables associated with how language and cognition interplay along with other human factors for Medicare beneficiaries to engage in interactive, interpersonal communication. The communication that makes and keeps us human! Communication that includes both spoken and written forms! SGDs behave very differently in this regard and the classification and coding system used to identify SGDs has failed to recognize this critical distinction for long-term effective SGD use.

Keith was a CEO of a private company and was near the end of his journey with ALS. I was accompanied by the CEO of the AAC company that manufactured Keith's SGD to my last visit to Keith at his home. Keith's SGD was hooked up to the internet so he could continue to mentor those now running his company. He emailed regularly. I sat next to Keith wiping his chin while I observed two CEOs interacting about their businesses for over an hour. No long pauses existed during Keith's turns and all his contributions to the conversation were spontaneous and novel. I couldn't interrupt, because I was overwhelmed by the accomplishment of technology and the partnership Keith had established with his SGD. I received a call 3 days later that Keith had died. At his funeral, his wife shared that the night before his death they had reminisced about their courtship. She said that she didn't even notice he wasn't using his 'real' voice. Keith's last words were spoken with his SGD and immediately after hearing his sentence they called for an ambulance; 30 minutes later Keith was gone.

My goal is that everyone with ALS or who is locked-in from another condition would have access to an SGD and clinical services and supports that result in the highest quality communication performance at end-of-life. The Capped Rental and Coverage Reminder policies will prevent this from happening. Again, the burden has been placed on the most vulnerable to assume that the SGD and clinical services they are receiving will result in evidence-based interventions. My clients' performances are monitored routinely using the data logging or language activity monitor (LAM) feature built-in to several SGDs. Their LAM data can be transmitted to the clinic via the internet so this does not require a clinic visit. Key measures are used so intervention regarding adjustments to the features of the SGD can be made so the client maintains functionally and performance over time. Peripherals can be added in a timely manner to avoid disuse or abandonment. The Coverage Reminder policy eliminates my ability to deliver the speech language services I know result in the best quality of life outcomes.

I believe that CMS, HHS and Congress are not aware of the complex issues and specialized skills associated with delivering AAC rehabilitation services, the nature of conducting a truly comprehensive AAC evaluation that results in the recommendation of an SGD, and the expertise needed to implement treatment and measure treatment effectiveness for individuals who need an SGD. If they did, then the Capped Rental and Coverage Reminder policies would not have been instituted. Instead, you would have had hearings to discuss an overhaul of the policies, codes and billing practices for SGDs. SGDs would not be considered DME, but **complex rehabilitation technology** requiring a speech language pathologist specializing in AAC diagnostic and clinical practice. You would have looked into under-trained or untrained individuals submitting SGD funding requests. You would openly admonished practitioners who have the AAC sales representative complete the SGD evaluation and request. You would have questioned why communication performance is not routinely gathered to compare SGDs or monitor usage. You would have looked into the limitations of access, approval and qualified clinical services that has been created by in-network and out-of-network policies. Perhaps one of the most restrictive practices to individuals who need AAC is getting approval for the services so they achieve the results they deserve!

John remains without AAC intervention despite his increasing loss of communication due to a degenerative neurological disorder waiting almost a year for approval to receive a

comprehensive AAC evaluation. The referral from a medical speech language pathologist and his physician to an out-of-network clinic was based on the fact that this clinic was the only group of speech language pathologists in the region who focused on AAC and could deliver services in the home and via telepractice. However, services were denied even after a peer-to-peer call. Currently, John is unable to receive the services he needs and may never have the SGD that would allow him to have a similar hopeful journey as Keith. John is likely to become a statistic that shows poor AAC outcomes. Not because of John's disability, medical condition, family support or lack of skilled practitioners, but solely due to his large insurance/hospital system denying a reasonable referral request to available, qualified services. John waits. John's health care system has failed his family and him.

I am hopeful that as the Secretary of Health and Human Services you will investigate these policies and practices that result in unreasonable pain and suffering on Medicare beneficiaries who need SGDs and their families before such policies become reality for individuals across the lifespan. I invite you visit the ICAN™ Talk Clinic website at [www.icantalkclinic.com](http://www.icantalkclinic.com) and learn more about the advocacy of the AAC Institute at [www.aac institute.org](http://www.aac institute.org). Join our "Ask me why I'm not talking" campaign and sign the petition at <http://chn.ge/1pfl67f>. Finally, I invite you to attend our October 25, 2014 Workshop on *Eye Gaze and Brain Computer Interface AAC: Evaluating your options*. Our special keynote luncheon speaker will be updating the audience and attendees on the government's response to the AAC community's advocacy against the policies discussed in this letter.

Please contact me if you would like any additional information on this topic or copies of the references included below. The clients, families and staff at the AAC Institute and ICAN™ Talk Clinic greatly appreciate your thoughtful attention.

Respectfully submitted,



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## References

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