



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

August 27, 2014

House of Representative/Senator
Washington, D.C.

Dear NAME OF MEMBER:

On behalf of the Consortium for Citizens with Disabilities (CCD) Technology and Telecommunications Task Force, **we are writing to request your support for Rep. Cathy McMorris Rodgers' Dear Colleague letter, "Ensure ALS Patients Retain Access to Critical Communication Tools; Join letter to CMS urging clarification of recent Speech Generating Device policies," addressed to the Centers for Medicare and Medicaid Services (CMS). The letter requests an explanation for recent policy changes that have significantly limited Medicare beneficiaries' access to speech generating devices (SGDs) and SGD accessories. By doing so, Congress will ensure that CMS remains accountable to the constituents it is mandated to serve.**

Speech-generating devices, also known as voice output communication aids, are electronic augmentative and alternative communication (AAC) systems used to supplement or replace speech or writing for individuals with severe speech impairments, enabling them to verbally communicate their needs. On April 1, 2014, CMS implemented a policy that soon will begin denying payment for SGDs and leave this patient group with no way to communicate. Despite CMS's decision to delayed implementation of the coverage determination from September 1, 2014, until December 1, the ultimate outcome remains the same: these essential devices and accessories will no longer be covered by Medicare.

These devices are necessary to the well-being of many Americans who require them to participate in society. Consider the recent story of a woman from Minnesota with multiple sclerosis (MS). She had weak voice and poor breath control, so she primarily communicated to family, friends, and medical team via e-mail using a standard mouse and on-screen keyboard. After losing the use of her hands, she could no longer use a standard mouse. For this patient the best option clearly would be an AAC device with access to a computer, e-mail, and phone. Unfortunately, CMS's new rules would make it difficult, if not impossible, for this woman to obtain a single device for speaking, writing, e-mail, and phone access.

There have been many meetings with CMS, in addition to hundreds of comments opposing the new regulations, yet CMS continues to make no changes to this imminent policy. Americans from all backgrounds—including people with MS, ALS and autism—will be affected by this change. This Dear Colleague letter ultimately serves your constituents by asking that CMS provide a rationale for its decision.

In order to sign on to this Dear Colleague letter, please contact Nick Magallanes at nick.magallanes@mail.house.gov or (202) 225-5107 in Congresswoman Cathy McMorris Rodgers' office to sign on to this bicameral letter. Please ensure that patients have access to these devices at a time when they need them the most.

The Consortium for Citizens with Disabilities is a coalition of more than 100 national disability organizations working together to advocate for national public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society. The Telecommunications and Technology Task Force focuses on ensuring national policy on matters of telecommunications and technology, including assistive technology, helps move society toward our ultimate goal of full inclusion of all people with a disability. **On behalf of people with disabilities that benefit from these SGDs, we ask that you please ensure they have access to these devices in order for them to continue to communicate and engage with the world around them.**

Thank you for considering to sign on to this Dear Colleague letter. If you have any questions, please feel free to contact one of the CCD Technology and Telecommunications Task Force Co-Chairs: Eric Buehlmann, eric.buehlmann@ndrn.org; Mark Richert, 4justice@concentric.net; Audrey Busch, audrey.busch@ataporg.org; Theresa Morgan, Theresa.Morgan@PPSV.com; or Michael Brogioli, mbroglioli@resna.org.

Sincerely,

Eric Buehlmann, National Disability Rights Network
Mark Richert, American Foundation for the Blind
Audrey Busch, Association for Assistive Technology Act Programs
Theresa Morgan, Perkins
Michael Brogioli, Rehabilitation Engineering and Assistive Technology Society of North America