



Congress of the United States
House of Representatives
Washington, DC 20515

November 4, 2014

Marilyn Tavenner
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
200 Independence Ave., S.W.
Washington, D.C. 20201

Dear Administrator Tavenner,

I write today about pending and current regulatory actions taken by the Centers for Medicare & Medicaid Services that are negatively affecting access to speech generating devices (SGD) for individuals who have serious communication limits and difficulties due to a disabling medical condition like amyotrophic lateral sclerosis (ALS).

Southwestern Pennsylvania is a leader in developing technologies to help the severely disabled communicate with loved ones and healthcare providers, maintain some forms of independence, and improve their quality of life. Semantic Compaction Systems, based in my district, is the holder of dozens of U.S. and foreign patents on language implementation services, which are used in many SGD models on the market today. I have met with both Semantic employees and dedicated advocates for those who have ALS and depend on SGDs. I have also been privileged to meet those who use SGDs regularly in their everyday lives.

These individuals have told me about three troubling policy decisions made by CMS that severely impact their ability to obtain and use SGDs when they are most needed. First, CMS Durable Medical Equipment Administrative Contractors have recently begun denying requests for eye-tracking technology attachments to SGDs — even after a physician has determined it is the only way a patient can functionally use his or her device. Second, in April 2014, CMS initiated a “capped rental” policy that is forcing patients to give up their personalized SGDs when entering a nursing facility or hospice care. Finally, beginning on December 1st CMS intends to reinterpret its policy determination to deny coverage for any SGD that can be “unlocked” at the patient’s personal expense for non-medical environmental controls, such as locking doors and text messaging.

In September, I joined 200 House Republican and Democratic colleagues in urging you to provide a more detailed explanation for these changes. To date, this issue has not been resolved. To gain a better understanding about the rationale for these regulatory actions, I ask that you provide information on the following questions within fifteen (15) business days:

1. The Secretary has the authority under the Social Security Act Sec. 1834(a)(19) to allow patients to upgrade their device at their own cost. Why has CMS failed to create a process for patients to expand SGD functionality to best accommodate a user’s needs?

2. Why has CMS determined that an SGD, which is customized and fitted for each patient's needs, does not fall under the Section 1834(a)(4) provision allowing for the purchase of devices that are "uniquely constructed or substantially modified to meet the specified needs of an individual patient?" Please explain why a capped rental policy was put in place for SGDs.
3. Does CMS plan to enforce its policy that inpatient, nursing, or hospice facilities must provide a specialized and customized SGD and proper training to each patient upon admission?
4. How much does Medicare expect to save by restricting SGD upgrades and expansions that are paid for by the patient out of his or her own pocket?
5. Please explain why SGD eye-tracking technology would be deemed "not medically necessary" even after a paralyzed patient's physician has provided the required documentation demonstrating that it is the only appropriate option for said patient.
6. Has CMS found any cases of fraud in which a patient did not truly need eye-tracking technology? If so, please provide supporting documentation.
7. How does CMS plan to address the backlog of eye-tracking technology appeals claims that span the course of two years or more?

I trust you share my view that these patients, who are most in need of intensive habilitative services, must have speech generating devices so they can communicate with their loved ones and caregivers. To take away this tool at a moment when these individuals are already suffering would be cruel and uncompassionate. I stand ready to work with you to ensure CMS policies continue to allow these individuals to live life to the fullest extent possible. Again, thank you for your attention to this matter. I await your timely reply and stand ready to answer any questions you may have.

Sincerely,


Tim Murphy
Member of Congress

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