

# Consortium for Citizens with Disabilities

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February 26, 1999

Ms. Nancy-Ann Min DeParle, Administrator  
Health Care Financing Administration  
U.S. Department of Health & Human Services  
Suite 314G, Hubert H. Humphrey Building  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

Dear Administrator DeParle:

Members of the Consortium for Citizens with Disabilities (CCD) Health Task Force and other national disability and chronic illness organizations write to bring to your attention a matter of great importance to persons with disabilities: Medicare's policy regarding coverage for alternative and augmentative communication (AAC) devices.

Augmentative communication devices are functional substitutes for the brain's speech center, the nerve pathways to the speech organs, and/or to the speech organs themselves, for beneficiaries who have speech-language impairments so severe that they are unable to communicate with others in any functional way. These impairments are caused by Cerebral Palsy, amyotrophic lateral sclerosis (ALS or Lou Gehrig's disease), and a few other conditions, but in total, their incidence is very low. People who use AAC devices include Bob Williams, a senior DHHS administrator, who has Cerebral Palsy, and Stephen Hawking, the physicist, who has ALS.

Medicare refuses to cover and provide AAC devices for these beneficiaries based on a policy statement, dating back to the mid-1980's, that classifies AAC devices as durable medical equipment (DME), and then states that they are to be denied because they are "convenience items." Medicare Carriers Manual, Section 60-9.

This policy statement is inconsistent with Medicare policy: Medicare covers speech-language pathology services, so "speech" cannot be a convenience; and it covers speech-related devices, such as the artificial larynx, Medicare Carriers Manual, Section 65-5, also demonstrating that speech-related devices cannot be a convenience. It also is inconsistent with the general classification of AAC devices as medical devices by the FDA: the FDA classifies AAC devices as physical medicine prosthetic devices, not durable medical equipment. 21 C.F.R. Section 590.3710. And it is inconsistent with the coverage decisions of every other major health benefits program in the nation: Medicaid programs; CHAMPUS, the VA, and hundreds of commercial insurers and benefits plans all cover and provide AAC devices.

In addition, HCFA lacks any justification for this policy. Most recently, HCFA was asked in mid-1998 to provide its files related to this guidance; it responded by stating it had lost them. July 8, 1998 letter to Elizabeth Carder, from Phillip Brown, C8FOIA9341D.

Moreover, a simple example demonstrates this policy is not even grounded in common sense. A Medicare beneficiary who develops throat cancer will, upon the onset of symptoms, be able to receive Medicare funded speech-language pathology services to improve the beneficiary's speech. If the cancer progresses and the beneficiary's larynx is removed, Medicare covers an artificial larynx to enable the beneficiary to speak despite the laryngectomy. If the cancer still progresses, and a glossectomy is required, the artificial larynx will no longer be of use, and an AAC device will be required. But at this point Medicare says the ability to produce speech is a convenience. There is no possible rational justification for enabling speech for a Medicare beneficiary when speech is only mildly affected, or when the larynx is removed, but claiming that enabling speech by the same beneficiary is a convenience when the tongue is removed.

We believe, and we hope you agree, that a review of the AAC device policy is necessary. Government policy that deters Medicare beneficiaries from filing funding requests, and that directs the denial of all requests that are filed, must have a basis consistent with contemporary medical literature, knowledge, policy and practice, as well as common sense. The Medicare policy exclusion for AAC devices, by contrast, has none of these characteristics.

We ask that you order a review of this policy immediately, and that it include input from AAC intervention professionals. The following national disability organizations look forward to your response to this communication through Bob Griss, Co-chair of CCD's Health Task Force and Director of the Center on Disability and Health in Washington, D.C. Thank you.

Sincerely,

American Foundation for the Blind  
American-Speech-Language-Hearing Association  
American Therapeutic Recreation Association  
Brain Injury Association  
Center on Disability and Health  
Easter Seals  
Hear Our Voices  
International Society for Augmentative and Alternative Communication  
National Association for the Advancement of Orthotics and Prosthetics  
National Association of Developmental Disabilities Councils  
National Association of People with AIDS  
National Association of Protection and Advocacy Systems  
National Council for Community Behavioral Healthcare  
National Organization on Disability  
Paralyzed Veterans of America  
Rehabilitation Engineering and Assistive Technology Society of North America  
The Arc of the U.S.  
United Cerebral Palsy Associations  
U.S. Society for Augmentative and Alternative Communication

cc: Donna Shalala, Secretary of Health & Human Services [same address]  
Harriett Rabb, Esq., General Counsel, Dept. of Health & Human Services [same address]  
Marcy Wilder, Esq., Deputy General Counsel, Dept. of Health & Human Services [same address]  
Chris Jennings, White House Health Policy Advisor, The White House, 1600 Pennsylvania Avenue, N.W., Washington, D.C. 20500  
Jonathan Young, White House Office of Public Liaison, The White House, 1600 Pennsylvania Avenue, N.W., Washington, D.C. 20500  
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