

Comments of the ITEM Coalition
White House Conference on Aging Listening Session
September 10, 2004
Presented by Peter W. Thomas

These comments are being submitted on behalf of the ITEM Coalition, which is an acronym for Independence Through Enhancement of Medicare and Medicaid. The ITEM Coalition was formed in 2003, and its over 70 member organizations include a diverse set of disability organizations, aging organizations, other consumer groups, labor organizations, voluntary health associations and non-profit provider associations.

The ITEM Coalition's purpose is to raise awareness and build support for policies that will improve access to assistive devices, technologies and related services for people of all ages with disabilities and chronic conditions. From coverage for hearing aids to augmentative communication devices (AACs) to advanced artificial limbs to screen readers for people with vision impairments, the Coalition's mission is a broad one with implications for virtually every person with a disability who relies on assistive devices to be healthy, functional and independent.

During the last decade, the issues and concerns of the disability and aging communities have become very much intertwined. While the ITEM Coalition addresses assistive devices, technologies, and related services in this statement as they relate to the aging community, we hope that the White House Conference will focus on general issues of mutual interest to both the aging and disability communities.

Assistive Devices, Technologies and Related Services

The ITEM Coalition uses the term "assistive devices, technologies and related services" because it encompasses an expansive range of items and related services that assist people with disabilities and chronic conditions of all ages in virtually all aspects of their lives. These devices range from low technology mobility aids such as canes and handheld magnifiers to high technology speech synthesizers and other augmentative

communication devices. Assistive technology can be medical in nature, e.g., a prosthetic limb, or completely non-medical but important to full function of the individual, e.g., a modified work station or an accessible van.

Additionally, assistive devices and services can play a critical role in preventing injuries in persons with disabilities and chronic conditions, thereby helping to maintain good health. For instance, a modest investment in safety devices such as grab bars for the shower and bathtub can prevent costly hospitalization and rehabilitation due to slips and falls.

According to the National Institute on Disability and Rehabilitation Research (NIDRR), in 2001 over 15 million Americans with disabilities reported using assistive devices or technologies.¹ AARP conducted a survey in 2003 in which they found that a third of persons 50 and over use some type of special equipment or assistive technology in their daily activities.² Based on 1994-95 data, it is estimated that 6.8 million Americans use some kind of assistive device for mobility, including approximately 1.7 million who use wheelchairs or scooters.³ The number of wheelchair users today has grown to approximately 2.1 million.⁴ Millions of Americans report living in homes and using cars or vans that have been modified to meet their special needs.⁵

Access

While the demand for assistive technology is significant, the greatest barrier to access is affordability and coverage. More than 2.5 million Americans report they need assistive technology that they do not have, with about 70% citing cost as the primary reason.⁶ Almost one-quarter of persons 50 and older with disabilities, who do not use any special

¹ Carlson, D., Ehrlich, N., Berland, B.J., and Bailey, N., Assistive Technology Survey Results: Continued Benefits and Needs Reported by Americans with Disabilities, National Institute on Disability and Rehabilitation Research, 2001.

² AARP, Beyond 50.03: A Report to the Nation on Independent Living and Disability, 2003 (using data collected as part of AARP/Harris Interactive Survey of Persons Age 50+ with disabilities, 2002).

³ National Health Interview Survey on Disability, Phase I file, National Center for Health Statistics, 1994-1995.

⁴ United States Census Bureau, Americans with Disabilities: Household Economic Studies, 2001 (using 1997 data).

⁵ Carlson, D., et. al., supra note 1.

⁶ National Health Interview Survey on Disability, Data File Documentation, National Center for Health Statistics, 1992.

equipment stated that equipment such as a hearing aid, wheelchair, cane or walker would improve their lives.² Less than 20% of the estimated 28 million Americans who could benefit from hearing devices currently have them.⁷ In fact, 50% of assistive technology users and 75% of those with home modifications paid for this assistive technology themselves or with the help of family members, with no help from third party payers.⁸

The barriers to access to assistive devices, technologies and related services have been documented to result in physical consequences, such as a general deterioration in health and a risk of secondary injuries, as well as strained relationships with family, friends, and colleagues, financial strain, decreased independence, and limitations in social participation.⁹

Next Frontier: As our population continues to age, improvements in coverage of assistive devices, technologies and related services become more and more imperative. Currently there are 76 million people over the age of 50 and by 2020 there will be 116 million people, or 36% of the population, over 50 years of age.¹⁰ Additionally, it is estimated that 33% of people 50 and over use some type of special equipment or assistive technology.¹¹ Given that such an enormous number of lives could be significantly improved and prolonged by enhancing access to wheelchairs, hearing aids, reading devices and other assistive technologies, the achievement of comprehensive coverage for these devices is essential.

In December 2003, the Medicare Modernization Act (MMA) was enacted, creating a much needed prescription drug benefit for Medicare beneficiaries. This expansion of Medicare benefits highlights the necessary goal of continually updating and modernizing health care programs as the demographics and needs of beneficiaries change. As the Centers for Medicare and Medicaid Services (CMS) implements the Medicare

⁷ Kochkin, S. and Rogin, C., Quantifying the Obvious: The Impact of Hearing Instruments on Quality of Life, *The Hearing Review* 7(1): 6-35 (2000).

⁸ National Health Interview Survey on Disability, Data File Documentation, National Center for Health Statistics, 1992 (using survey data collected in 1990).

⁹ Neri, M.T., and Kroll, T., Understanding the Consequences of Access Barriers to Health Care: Experiences of Adults with Disabilities, *Disability and Rehabilitation* 25(2): 85-96 (2003).

¹⁰ Security Industries Association. http://www.sia.com/springboard/html/whos_there.html (2004).

¹¹ AARP, supra note 2.

prescription drug benefit, it must also look ahead to the next frontier: the improvement of assistive technology coverage. Just as the prescription drug benefit will likely bring, increased coverage of assistive devices, technologies, and related services will help ensure the safety and independence of the “baby boomers” as they enter the Medicare program. Therefore, the ITEM Coalition recommends that the White House Conference on Aging devote significant attention to this issue. Our hope is that the aging community will join together with the disability community to press Congress and CMS to work to improve and expand Medicare coverage of assistive technology, as Medicare often provides a model from which other public and private health programs take their cues.

Marketing the Appropriate Products: We know that assistive devices, technologies, and related services can improve the health, safety, and independence of the aging population. Unfortunately, the benefits are often not realized because the appropriate products may not be the products marketed to aging consumers. This rings especially true when it comes to seniors with disabilities. There are thousands of innovative and high-technology devices developed every year. However, it is often the simplest, low-technology devices that prove most valuable to the aging population. Deployment of consumer products with complex menus, remotes, and touch screens remain a major problem for older people who lack motor skills. Basic market research is needed to assess the level of acceptance and rejection of various assistive technologies within the aging population in order to promote maximal use of these devices.

Training: Research and coverage policies should also ensure that new and innovative assistive technologies are adopted and actually *used* by individuals who need them. Many ITEM Coalition member organizations state that in their experience such training is often overlooked, and thus, a high percentage of assistive devices are rejected by potential consumers. For seniors who may have compromised vision, hearing or touch, it is of particular importance to provide hands-on training and information with regard to assistive technology.

Conclusion

The ITEM Coalition thanks the White House Conference on Aging Policy Committee for this opportunity to speak and submit comments. As the government continues to develop new policies that reflect a changing aging community, we have no doubt the assistive technology will prove to play an essential role in the goal of health and independence for which this community strives. The ITEM Coalition recommends that the policies and initiatives put in place in the coming years with regard to assistive technology should reflect the need for improved and expanded coverage, especially in the Medicare system. Additionally, the Coalition hopes that government agencies and private companies will not only focus on the development of assistive technology but also placing the appropriate technology, combined with necessary training, into the hands of the aging consumer.

The ITEM Coalition looks forward to White House Conference on Aging in October 2005 and hopes to continue to be a part of the planning process. If you have any questions or comments please contact the ITEM Coalition at (202) 349-4260.

ITEM Coalition Members

Adapted Physical Activity Council
Advancing Independence
Advanced Medical Technology Association
Alexander Graham Bell Association for the Deaf and Hard of Hearing
Alpha One
American Academy of Audiology
American Academy of Neurology
American Academy of Physical Medicine and Rehabilitation
American Association for Homecare
American Association of People with Disabilities
American Association on Health and Disability
American Congress of Community Support and Employment Services
American Congress of Rehabilitation Medicine
American Foundation for the Blind
American Medical Rehabilitation Providers Association
American Music Therapy Association
American Network of Community Options And Resources
American Occupational Therapy Association
American Physical Therapy Association
American Speech-Language-Hearing Association
American Therapeutic Recreation Association
Amputee Coalition of America
Assistive Technology Industry Association
Association for Education and Rehabilitation of the Blind and Visually Impaired

Association for Persons in Supported Employment
Association of Tech Act Projects
Association of University Centers on Disabilities
Blinded Veterans Association
Brain Injury Association of America
Center for Disability Issues and Health Professionals
Center for Independent Living Inc.,
Berkeley, California
Center for Medicare Advocacy, Inc.
Christopher Reeve Paralysis Foundation
Consortium of Developmental Disabilities Councils
Council of Citizens with Low Vision International
Council of State Administrators of Vocational Rehabilitation
Disability Service Providers of America
Easter Seals
Epilepsy Foundation
Families USA
Goodwill Industries International, Inc.
Helen Keller National Center
Inclusion Research Institute
Long Island Center for Independent Living
Medicare Rights Center
The Miami Project to Cure Paralysis
National Association for Home Care and Hospice
National Association for the Advancement of Orthotics and Prosthetics
National Association of Councils on Developmental Disabilities
National Association of Protection and Advocacy Systems
National Association of Rehabilitation Research and Training Centers
National Campaign for Hearing Health
National Coalition for Disability Rights
National Council on Independent Living
National Family Caregivers Association
National Multiple Sclerosis Society
National Organization on Disability
National Rehabilitation Hospital – Center for Health and Disability Research
National Respite Coalition
National Spinal Cord Injury Association
National Stroke Association
National Vision Rehabilitation Cooperative
NISH
Paralyzed Veterans of America
Research Institute for Independent Living
Rehabilitation Engineering and Assistive Technology Society of North America
Self Help for Hard of Hearing People
Service Employees International Union
Spina Bifida Association of America
The Arc of the United States
Topeka Independent Living Resource Center
United Cerebral Palsy Associations
United Spinal Association

