



*Independence Through  
Enhancement of  
Medicare and Medicaid*  
COALITION

## **MEDIA KIT**

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## ITEM Coalition Fact Sheet

### **WHO –**

A consumer-led coalition comprised of national and state-based consumer and provider non-profit organizations interested in maintaining and improving access to and coverage of assistive devices, technologies and related services for Americans with Medicare, Medicaid or other health care coverage. The Coalition's steering committee is taking the lead in coordinating the initial efforts and includes representatives from American Foundation for the Blind, CCD's Health Task Force, Medicare Rights Center, Paralyzed Veterans of America, and the United Spinal Association.

### **WHAT –**

A sustained education and advocacy campaign in which the Coalition will seek to raise awareness of Americans' inadequate access to assistive devices, technologies and related services and build support for legislative and regulatory changes to address this problem through enhancing current coverage policies.

### **WHERE –**

The Coalition is based in Washington, D.C., but includes strong representation from organizations from around the country.

### **WHEN –**

The Coalition is an ongoing effort over at least the 109th Congress. The first meeting of the organizations interested in joining the Coalition took place on March 28, 2003, and the launch of the Coalition occurred on June 17, 2003.

### **WHY –**

People with disabilities and chronic health conditions throughout the life span have inadequate access under Medicare and Medicaid's (and other health care payers') current coverage policies to the assistive devices, technologies and related services which they require to be healthy, fully function and live as independently as possible. It is time to focus on achieving a comprehensive solution to this intractable problem.

## Principles of the ITEM Coalition

- Medicare, Medicaid, and other public programs and private plans must enhance their coverage policies to provide those assistive devices, technologies, and related services that Americans need to be healthy, functional, and independent.
- The ITEM Coalition will raise awareness and advocate solely for greater access to and coverage of assistive devices, technologies, and related services for people with disabilities and chronic conditions of all ages, including children and older Americans.
- Consumers will lead the Coalition and advocacy efforts will rely on the use of personal stories to highlight the importance of access to assistive devices, technologies, and related services in people's lives.
- The Coalition will promote a broad-based assistive device benefit that helps as many users of assistive devices, technologies, and related services as possible.
- Membership in the ITEM Coalition will be open to all consumer and non-profit provider organizations without any requirement to contribute financially.

## 2005 Policy Agenda

- Medicare's "in the home" restriction on mobility devices must be modified so that people with disabilities and chronic conditions can obtain the devices they need to participate in the workplace, school and community.
- Federal health programs and private payers must appropriately recognize improvements in function when determining whether assistive devices, technologies and related services are "medically necessary."  
*EXAMPLES:* hearing aids, powered mobility devices, CCTV, advanced prosthetic limbs, environmental control units
- Federal health programs and private payers must recognize prevention of primary and secondary injury when determining whether assistive devices, technologies and related services are "medically necessary."  
*EXAMPLES:* grab bars and other safety devices, powered and lightweight wheelchairs, voice-output blood glucose meters
- Increased federal funding must be committed to build the evidence base regarding the efficacy and cost-effectiveness of coverage of assistive devices, technologies and related services.

## Strategy

- Raise awareness among key hill and agency contacts in each major federal health program (Medicare, Medicaid, FEHBP, TRICARE and VA).
- Develop legislative and regulatory strategies to implement needed changes in each major federal program.
- Collect personal stories to document the need for improved access to assistive devices, technologies and related services.

## Statistics on the Use of Assistive Devices, Technologies and Related Services

**Assistive devices, technologies, and related services are used by individuals with disabilities and chronic conditions of all ages to improve their health, independence and function:**

- Over fifteen million Americans with disabilities reported using assistive devices or technologies in recent surveys. (National Institute on Disability and Rehabilitation Research, 2001)
- Based on 1994-95 data, it has been estimated that 6.8 million Americans used some kind of assistive device for mobility, including approximately 1.7 million who used wheelchairs or scooters. (National Center for Health Statistics)
- In 1994, an estimated 4.6 million persons in the U.S. household population used assistive technology devices for orthopedic impairments (including missing limbs), 4.5 million for hearing impairments (not including impairments fully compensated by hearing aids), and 0.5 million for vision impairments. Use of any mobility device for all ages had the highest prevalence rate at 28.5 per 1,000 persons. (National Center for Health Statistics)
- The number of wheelchair users has grown to approximately 2.2 million. Another 6.4 million used some other ambulatory aid such as a cane, crutches or a walker. (United States Census Bureau, 2001)
- A third of persons 50 and over surveyed use some type of special equipment or assistive technology in their daily activities. (AARP, 2003) These devices and technologies include:
  - walker, cane or crutches (69%)
  - aids for bathing or using the toilet (51%)
  - wheelchair or scooter (47%)
  - other home modifications for movement (37%)
  - orthopedic equipment (37%)
  - other aids for daily activities (33%)
  - communications and reading equipment (14%)
  - oxygen or respirator (14%)
  - hearing aids (13%)
- Over 14 million Americans report living in homes and using cars or vans that have been modified to meet their needs. (National Institute on Disability and Rehabilitation Research, 2001)

### References:

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)

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

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.

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

## **Unmet Needs: Statistics on the Lack of Access to Assistive Devices, Technologies and Related Services**

**Millions of Americans do not have access to the assistive devices and technologies that they require to maximize their health and quality of life:**

- 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. (National Center for Health Statistics, 1992)
- Almost one-quarter of persons 50 and older with disabilities who do not use any special equipment said that equipment such as a hearing aid, wheelchair, cane, or walker would improve their lives. (AARP, 2003) These assistive devices and technologies included:
  - wheelchair or scooter (51%)
  - hearing aids (51%)
  - walker, cane, or crutches (38%)
  - aids for bathing or using the toilet (38%)
  - orthopedic equipment (34%)
  - other home modifications for movement (30%)
  - other aids for daily activities (24%)
  - communications and reading equipment (18%)
  - oxygen or respirator (12%)
- Between 1994 and 1997, 1.3 million Americans with disabilities working at the time reported needing one or more additional assistive devices. (National Institute on Disability and Rehabilitation Research, 2001)
- Less than 20% of the estimated 28 million Americans who could benefit from hearing devices currently have them. (*Hearing Review*, 2000)
- 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. (National Center for Health Statistics, 1992)
- Individuals with disabilities are only half as likely to have access to the internet as those without a disability: 21.6% compared to 42.1%. (National Telecommunication and Information Administration, 2000)
- More than one-third of homeowners would like to make home modifications that would prevent injuries and make their lives easier, such as installing grab bars in the bathroom, but have not done so, largely because of cost. (AARP, 2003)
  - 27% reported that they would like to add grab bars in the bathroom, 25% stated they would like to have an accessible shower with no shower lip, and 22% reported that they would like to add extra handrails in their halls and stairs.

### **References:**

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).

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).

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

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

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.

National Telecommunication and Information Administration, Falling Through the Net: Toward Digital Inclusion, 2000.

## Unmet Needs: American Stories

### Case Examples

**“Roger”** (not his real name), age 49 of New York City, has had cerebral palsy for most of his life, and also has a heart condition for which he had bypass surgery a year ago. He has been living independently since age 18 and is able to move around his apartment despite difficulty walking. In the past, Roger used a power operated vehicle (“POV”) to travel in his community, but now the POV is broken. Medicare will not provide coverage for a new POV because he does not need it to get around his home. As a result, he is completely homebound with the exception of taking meals with his mother, who has an apartment on the same floor.

Roger misses getting outside and being active with his synagogue and hobby of photography. Roger owned three POVs in the past that were covered through supplemental insurance, but the insurer no longer covers POVs. Today, he has Medicare and supplemental insurance through his mother’s retiree policy and lives on Social Security Disability Income (“SSDI”) benefits. Roger is deeply troubled by Medicare’s unwillingness to cover a POV which would help him get back to the community and lead a fuller life.

**“Mary”** (not her real name), a 64-year-old African American woman who resides in Washington, D.C., is eligible for Medicare because she has multiple sclerosis. Mary is not able to move the lower half of her body and has been unable to walk or stand since 1992. She lives independently by navigating through her home in a power operated vehicle (“POV”), and using a “trapeze” bar to get in and out of bed, a chair lift to reach drawers and shelves, and grab bars in the bathroom. Mary was diagnosed with multiple sclerosis in 1986, but continued working as a supervisor at the IRS until her medical condition prompted her to retire in 1988. She also has bowel and bladder problems.

Mary lives on a government pension of \$25,000 a year and has federal employee retiree benefits to supplement her Medicare coverage. She takes six medications for which she pays about \$1,200 each year in co-payments. Because of narrow Medicare coverage, Mary has exhausted much of her savings to modify her home so she can live and function independently. For example, in June 2002, she paid \$300 for full-length bed rails that her doctor prescribed because she was falling out of bed due to muscle spasms. Medicare denied coverage for the rails because regulations require that this equipment only be rented, even though no companies in Mary’s area rent bed rails. Mary has also paid thousands of dollars to have grab bars installed in her bathroom, to purchase “trapeze” bars, and to purchase a humidifier to address side-effects from

medications that prevent her from sleeping at night. The POV that Mary is using does not have the kind of seat that her rehabilitation specialist recommended, but Mary compromised because Medicare would not have covered the proper model. Consequently, she frequently has pressure ulcers and is pursuing a special seating system on her own.

### **Americans Speak Out**

**Anonymous Consumer:** “I have post polio syndrome. I use one of two ventilators 24 hours daily, seven days weekly: one is on my wheelchair and the other is by my bed. The ventilator by my bed I use when I sleep. I refer to this ventilator as my "primary" ventilator. The ventilator on my wheelchair provides me with independence: with it I can go to work, maneuver around my home, and go shopping at the mall. I refer to this ventilator as my "backup" ventilator because should my primary ventilator fail, I can use the ventilator on my wheelchair. Without it I'd be bed ridden.

“Now, all ventilators eventually fail, and mine are no exception. If my primary ventilator should fail, I must get to my backup ventilator within five minutes or else I'm dead. Similarly, should my backup ventilator fail, I must get to a ventilator within five minutes. I've used two ventilators for years.

“But then (In January of 1998,) Medicare began denying me coverage for my second, vital backup ventilator. I had my doctor write a letter of "medical necessity" to Medicare, but again I was denied coverage.

“Can you imagine the sleepless nights I spent worrying that my independence had ended? Can you imagine my worry that my life might end because Medicare wouldn't cover the cost of my ventilator? The culprit here, should either of these things happen, would be Medicare.

“Every month my ventilator supplier must appeal Medicare's denial of coverage. My life, therefore, is in limbo from one month to the next. In effect, since 1998, Medicare has terrorized me. Will the terror ever stop?”

**Anonymous Consumer:** “I have been using wheelchairs since 1944. My doctor submitted a request to Medicare 1 ½ years ago for a new chair and the request was denied. In addition, I was denied the repair of my old chair. As a result, I have been using an uncomfortable chair. How long must I suffer?”

**Anonymous Consumer:** “Toward the end of her life my mother received chemotherapy and Medicare refused to cover the cost. Even after I went to my congressman Medicare still refused her coverage. What could I do but pay for it myself? So I did pay for it myself, and as a result my finances were drained.

”It's too late, of course, for my mother, but what about for me? I am taking chemotherapy medication, one of the side effects of which is hearing loss. Now, Medicare refuses to cover the cost of hearing testing or for a hearing aid for me.”

**Anonymous Consumer:** “I use a machine to pump air into my lungs when I sleep. Without it, I would die. The machine has various pieces of equipment, including headgear. Medicare has repeatedly denied me coverage for new headgear. I was told it wasn't "medically necessary." My doctor then submitted a letter to Medicare documenting my need for the headgear, but again I was denied coverage. Without my air pump I die! I had to have my doctor submit numerous letters to Medicare before coverage for new headgear was approved. Is this health insurance?

“My question is, why? Why is it so difficult for me to get to the coverage I so desperately need?”

**L.H.:** “I have a student who is currently wearing two hearing aids loaned to him by our school system. His mother works two jobs and cannot afford to buy him his own hearing aids. He has been in my special education class, for students with mental retardation and multiple disabilities for 2 1/2 years. This is his first set of hearing aids. It is my opinion that if he had had hearing aids all along he would not be in such a restrictive environment, but the lack of hearing aids had a large effect on his language development and learning to read. I am fearful of what his future will be like when he leaves the school system in a few years and does not have access to the loaner hearing aids. His skills have already been compromised and without hearing aids in the future his options will be minimal.”

## ITEM Coalition Members

### Steering Committee Members

American Foundation for the Blind (AFB)	Paralyzed Veterans of America (PVA)
United Spinal Association	National Multiple Sclerosis Society

### General Members

Adapted Physical Activity Council (APAC)	American Network of Community Options And Resources (ANCOR)
Advanced Medical Technology Association	American Occupational Therapy Association (AOTA)
Advancing Independence: Modernizing Medicare & Medicaid (AIMMM)	American Physical Therapy Association (APTA)
Alexander Graham Bell Association for the Deaf and Hard of Hearing	American Speech-Language-Hearing Association (ASHA)
Alpha One	American Therapeutic Recreation Association (ATRA)
American Academy of Audiology	Amputee Coalition of America
American Academy of Neurology (AAN)	Assistive Technology Industry Association
American Academy of Physical Medicine and Rehabilitation	Association for Education and Rehabilitation of the Blind and Visually Impaired (AER)
American Association for Homecare	Association for Persons in Supported Employment (APSE)
American Association of People with Disabilities (AAPD)	Association of Tech Act Projects (ATAP)
American Association on Health and Disability (AAHD)	Association of University Centers on Disabilities (AUCD)
American Congress of Community Supports and Employment Services (ACCSES)	Blinded Veterans Association
American Congress of Rehabilitation Medicine	Brain Injury Association of America (BIA)
American Medical Rehabilitation Providers Association (AMRPA)	Center for Disability Issues and Health Professionals
American Music Therapy Association	

Center for Independent Living Inc., Berkley, California	National Association of Rehabilitation Research and Training Centers (NARRTC)
Center for Medicare Advocacy, Inc	National Campaign for Hearing Health
Christopher Reeve Paralysis Foundation	National Coalition for Disability Rights
Consortium of Developmental Disabilities Councils (CDDC)	National Council on Independent Living (NCIL)
Council of Citizens with Low Vision International	National Family Caregivers Association
Council of State Administrators of Vocational Rehabilitation (CSAVR)	National Organization on Disability (NOD)
Disability Service Providers of America (DSPA)	National Rehabilitation Hospital—Center for Health and Disability Research
Easter Seals	National Respite Coalition (NRC)
Epilepsy Foundation (EF)	National Spinal Cord Injury Association
Families USA	National Stroke Association
Goodwill Industries International, Inc. (GII)	National Vision Rehabilitation Association
Helen Keller National Center (HKNC)	National Multiple Sclerosis Society
Inclusion Research Institute (IRI)	NISH
Long Island Center for Independent Living, Inc.	Research Institute for Independent Living (RIIL)
The Miami Project to Cure Paralysis	Rehabilitation Engineering and Assistive Technology Society of N. America (RESNA)
National Association for Home Care and Hospice	Self Help for Hard of Hearing People
National Association for the Advancement of Orthotics and Prosthetics	Service Employees International Union (SEIU)
National Association of Councils on Developmental Disabilities (NACDD)	Spina Bifida Association of America (SBAA)
National Association of Protection and Advocacy Systems (NAPAS)	The Arc of the United States
	Topeka Independent Living Resource Center
	United Cerebral Palsy Associations (UCPA)

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