



*Disability & Aging: Seeking Solutions to Improve Health, Productivity,
and Community Living*

A Mini-Conference of the 2005 White House Conference on Aging

July 21 & 22, 2005

Crystal City Marriott at Reagan National Airport
Arlington, Virginia

Final Report and Recommendations



Disability & Aging Mini-Conference

Executive Summary of Recommendations

Developed by the White House Conference on Aging Mini-Conference on Disability & Aging

1. Social Engagement and Productivity

Congress should enact legislation to provide incentives to create public and private partnerships to remove barriers so that employers can hire and retain older workers with and without disabilities. This will:

- Enable more older workers to gain entry and remain in the workplace
- Increase accommodations **of all kinds** as one ages in the workforce

2. Healthy Long-Term Living

Adopt and fully fund a system that will ensure that people aging *with* and aging *into* disabilities in mid- to later-life have access to competently trained health care providers and can choose from a full-range of timely and appropriate, culturally-sensitive, and consumer-directed home- and community-based health services and supports that meet individual needs.

3. Economic Security: Planning and Choice

For both persons who are aging *with* and *into* disability, expand options to participate in the economy and improve the overall standard of living of people aging with disabilities.

4. Assistive and Universally Designed Technologies and Environments

Bring the goal of an “accessible nation” within our reach by expanding the availability and utilization of assistive and universally designed technologies and environmental interventions.

5. Positive Messaging

Conduct a national positive messaging campaign to reduce the negative attitudes about disabilities and to build appreciation for individual choice and self-direction throughout the lifespan.



Background, Challenges, Recommendations, & Strategies Developed for Presentation to the WHCoA Policy Committee

Title of Event: *Disability & Aging: Seeking Solutions to Improve Health, Productivity, and Community Living* – A Mini-Conference of the 2005 White House Conference on Aging

Date of Event: July 21-22, 2005

Location of Event: Arlington, Virginia

Number of Persons Attending: 200

Sponsoring Organizations:

AARP

Aetna

America's Health Insurance Plans

American Association of People with Disabilities

MetLife Disability

National Council on Independent Living

Paralyzed Veterans of America

U.S. Department of Education, Office of Special Education and Rehabilitative Services

U.S. Department of Health and Human Services, Office on Disability

U.S. Department of Labor, Office of Disability Employment Policy

U.S. Department of Veterans Affairs

UnumProvident Corporation

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Background: While disability can arise at any age, the likelihood of acquiring a disability increases as a person ages. With America's baby-boom generation approaching retirement age, our nation must pay greater attention to the social, economic, physical, and mental well-being of middle-aged and older adults who are living with long-term disabilities, acquired at birth, in childhood or young-adulthood, as well as to those who are aging into disability for the first time in later life. Health care policies that emphasize institutional over community-based care are out of sync with the new demographic possibilities of "aging in place" and "living well with a disability," and have led to more than a million adults with unmet needs for assistance with basic daily activities such as bathing, eating, toileting, dressing, preparing meals, and getting around in the community. This institutional bias, combined with lack of access to affordable assistive technologies, also places adults aging *with* and aging *into* disability at increased risk of developing secondary health conditions, defined as preventable physical, mental, and social



disorders resulting directly or indirectly from an initial disabling condition, that diminished their quality of life and limit their opportunities to work and participate in community and family life.

Now is the time for America to take the steps necessary to fix the problems with our outdated systems of health care, income supports, and community programs by promoting greater coordination of services and emphasizing home- and community-based care over institutional care. Laws such as the 1990 Americans with Disabilities Act (ADA) have given us a new way to adjust our community infrastructures so that they are more welcoming of all people with disabilities across the age span. The President's 2001 New Freedom Initiative (NFI) also calls for actions to promote community living for persons of all ages with disabilities by increasing access to assistive and universally designed technologies and environmental accommodations, improving employment and educational opportunities, and expanding opportunities for full participation in community life. The nation should make our technologies more accessible and our communities more livable for residents with disabilities, and promote better integrated community-based health care systems that facilitate healthy, productive aging. In doing so, America can improve the lives of millions of older adults and persons with disabilities and benefit from their contributions to the workforce, their communities, and their families and friends for decades to come.

The high-priority recommendations contained in this report are forward-looking, reasonably ambitious, actionable, and represent the consensus of participants across five broad themes:

- Social Engagement and Productivity
- Healthy Long-Term Living
- Economic Security, Planning, and Choice
- Technology, Universal Design, and Environments
- Positive Messaging

Social Engagement and Productivity

While the risk of disability increases with age, disability and aging are not synonymous. Further, disability is not an illness. What connects aging and disability is common interest in productivity, self-determination, and social engagement and the strong desire to avoid dependence, economic insecurity, and diminished opportunities for work and self-expression. Contrary to frequently held negative stereotypes, both productivity and social engagement are real possibilities for individuals who are:

- **Aging with disability** — Individuals who have been born with or acquired a physical, sensory, cognitive, or behavioral disability and now are entering their 50s and 60s **and** experience changes in work capacity and community participation.



- **Aging into disability** — Individuals who have been relatively free of injury, illness, or impairment but who, as they enter into their 50s, 60s, or 70s experience chronic disease and disabilities that affect work capacity and participation in community and family life.

Challenges:

The challenges to productive aging and continued social engagement are embedded in: (1) the lack of public and private collaboration providing incentives for individuals to continue working with an impairment; (2) the lack of incentives for employers to maintain a flexible and adaptable workplace; and (3) the need to strengthen incentives for U.S. health care providers to offer health care services, including prevention, screening, diagnosis and treatment, that are both accessible and affordable, and focused on preventing the onset and mitigating the impact of chronic disease and disability on work capacity and mobility.

Recommendation:

Congress should enact legislation to provide incentives to create public and private partnerships to remove barriers so that employers can hire and retain older workers with and without disabilities. This will:

- Enable more older workers to gain entry and remain in the workplace
- Increase accommodations of all kinds as one ages in the workforce

Strategies:

1. Enact legislation to provide incentives and remove barriers for employers in hiring and retaining older workers with and without disabilities.
2. Establish a coherent research agenda to address the full range of critical work disability issues related to aging, including improved measurement, identification of risk factors, evaluation of public and private sector initiatives, and testing of innovative strategies to increase the hiring and retention of older workers, with or without disabilities.
3. Promote funding to support increased worksite accommodations as one ages in the workforce.
4. Promote funding for affordable and accessible mass transit and ensure that new housing and communities include plans for connection to mass transit.



Healthy Long-Term Living

Everyone of any age in the United States is at risk of disability. The chance of acquiring a disability is predicted by a broad array of factors including age, health history, socioeconomic status, and education. This risk increases with age: Every person age 65 and over is likely to have at least one disability. The critical issue is not the presence of a disability, but the extent to which an individual's health and wellness are affected by that disability, directly or indirectly. The relationship between health and wellness and all other aspects of life for persons aging *with* and aging *into* disability necessitates:

- Increased attention to the availability of integrated health services and providers respectful and knowledgeable of individual needs and capacities, and
- Health promotion and wellness services accessible to persons with all types of disabilities.

Challenges:

The American health care system is not sufficiently prepared to meet the community-based health care needs of the expanding population who are aging *with* or aging *into* disability. The lack of a seamless system of health care services and appropriately trained health care providers (including geriatricians, geropharmacists, and rehabilitation specialists), who understand the special health care needs of middle-aged and older adults with disabilities, all too often results in serious medical conditions and premature deaths due to incorrect diagnoses, inappropriate drug therapy, and inadequate management of secondary conditions resulting from a disability that could have been prevented. By providing early prevention and wellness services along with a seamless system of health services that ensures access to needed health care, the special needs of older adults with disabilities can be addressed effectively. Consistent with the goals of the 2005 "Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities," if we "pay now" rather than "pay more later," the result can be a more effective, efficient system of health care that helps individuals with disabilities reside in the community, prevents clinically unnecessary hospitalizations and nursing home placements, and eliminates excessive health care costs.

Recommendation:

Adopt and fully fund a system that will ensure that people aging *with* and aging *into* disabilities in mid- to later-life have access to competently trained health care providers and can choose from a full-range of timely and appropriate, culturally-sensitive, and consumer-directed home- and community-based health services and supports that meet individual needs.

Strategies:

1. Support public and private funding for timely and coordinated health screenings, evaluations, and services to prevent decline, improve function, and eliminate or reduce the risks of secondary conditions associated with specific disabilities and chronic conditions.



2. Mandate and support interdisciplinary research across relevant Federal agencies on the health effects of aging with disability (whether physical, cognitive, sensory, behavioral, or in combination) and the role of environmental and lifestyle factors in promoting healthy long-term living.
3. Support the inclusion of disability-specific and gerontology-oriented educational curricula in formal training programs for medical students, physicians, and other providers of health care services and supports, and adapt this information for use in the training of informal care providers.

Economic Security: Planning and Choice

In the context of a rapidly maturing society faced with an economy that is evolving from an agricultural/manufacturing base to a 21st century global knowledge service-based economy, we want to preserve the economic security of all American across the lifespan. As such, we want to encourage lifelong development of transferable skills and incentives that will enable all Americans to participate in the economy according to the extent of their abilities and choices with appropriate supports and accommodations.

Challenges:

Adults living with disabilities very often face economic insecurity due to limitations on employment options; difficulty or impossibility of saving and investing; limitations of public programs; and added expenses that can accompany disability. Adults aging into disability can see their economic security disrupted by departure from the workforce earlier than planned; by diminished ability to save for retirement; and by additional expenses of a disabling illness or injury. Current practices in the private sector and programs in the public sector do not sufficiently support employment for those living with or aging into disability. Nor do private and public practices and programs adequately guarantee economic security to those living with disability or facing the onset of disability.

Recommendation:

For both persons who are aging *with* and *into* disability, expand options to participate in the economy and improve the overall standard of living of people aging with disabilities.

Strategies:

1. Preserve the overall solvency of the Social Security Trust Fund and enhance the income protection provided through the Social Security retirement, disability, and survivor programs.



2. Reform existing public and private income supports and public and private long-term service and support programs to:
 - a) Incorporate incentives and remove disincentives to:
 - Save;
 - Earn;
 - Learn;
 - Plan;
 - Participate in community life; and
 - b) Improve the standard of living of people with disabilities across the lifespan.
 3. Support public and private programs, such as tax credits for lifelong learning and educational programs that encourage American citizens and employers to plan ahead and take steps to preserve lifelong economic security— including steps to safeguard against the financial risk of disability.
 4. Integrate into public and private disability programs an early intervention orientation that will support people who choose to remain in the workforce as they age and as they experience impairments associated with aging.
 5. Establish a payroll deduction throughout the person’s work life that will enable the individual to access and finance long-term care services when needed.
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Assistive and Universally Designed Technologies and Environments

At some point during a lifetime, most people will need assistive or universally designed technologies and environmental accommodations to support health, productivity and community living. This is particularly true for the large number of Americans who are aging *with* and aging *into* disability in mid- to later life. To meet this need, we envision a nation in which all technology, products, services, systems and physical environments are accessible to, usable by, and actually used by the approximately 50 million adults living with disabilities. Creating an accessible nation is central to fulfilling the promise of the President’s New Freedom Initiative. Creating an accessible nation also will provide significant, measurable economic benefits to businesses and the American public through access to larger markets, to more diverse talent, and to the productive potential of all in our society.



Challenges:

Despite recent progress, the vision of an accessible nation has yet to be realized. Significant barriers remain that prevent assistive technologies (AT) and universally designed (UD) technologies and environments from being developed, deployed, and used by people with disabilities across the lifespan and by their families, caregivers, employers, and communities, including:

- Insufficient coordination of and investment in research and development;
- Inadequate education and training of researchers, engineers, and other professionals;
- Lack of support for prototype development, poor market data on needs for AT and UD, costs and questions of reimbursement which hinder commercialization;
- Legislative barriers and lack of coordination among public and private programs; and
- Lack of awareness among consumers, providers, policymakers and businesses regarding the availability and benefits of AT and UD.

Recommendation:

Bring the goal of an “accessible nation” within our reach by expanding the availability and utilization of assistive and universally designed technologies and environmental interventions.

Strategies:

1. Establish a national accessibility and visitability tax credit for Americans to adapt their home environments to promote independent living and aging in place.
2. Direct increased Federal research and development investments toward accessible, assistive, and universally designed technologies and environmental interventions that will support independence, productivity, and community living for people aging with disabilities and older adults.
3. Expand market-driven, Federal procurement strategies beyond Electronic and Information Technology (e.g., Section 508 of the Rehabilitation Act) to promote increased availability and utilization of accessible, universally designed technologies that are effective in reducing other barriers to full participation in work and community life.
4. Amend the Older Americans Act to mandate the development and delivery of trans-generational accessible, assistive, and universally designed technologies and environmental interventions that support healthy and productive living in a safe and least restrictive environment.
5. Support the establishment of a national “consumer report” of users’ experiences with accessible products.

Positive Messaging

Despite the aging of society and the changing reality of disability, America's view of people who are aging and those who have disabilities is still based, to a large degree, on negative representations. These representations are reinforced throughout all media types and outlets and through the use of language that supports perceptions of peculiarity, incompetence, frailty, and helplessness, and affects every aspect of public, private, and community life. A coordinated, broad-spectrum effort to improve Americans' perceptions of disability and aging is needed to reduce negative attitudes toward disability and aging.

Challenges:

The primary challenge of a positive messaging campaign on disability and aging is the need for it to reach every aspect of American society with cost-effective, focused messages targeted to various constituencies. The Federal government is situated to facilitate this task successfully in partnership with states, localities, and the private sector. A successful positive messaging campaign can create opportunities to develop communities in which everyone can live, work, and participate fully, consistent with individual choice and direction, free of labeling, stigma, or discrimination.

Recommendation:

Conduct a national positive messaging campaign to reduce the negative attitudes about disabilities and build to appreciation for individual choice and self-direction throughout the lifespan.

Strategies:

1. Develop comprehensive, cost-effective, and cross-government plans for targeting key audiences with messages that promote full participation of aging Americans including those with disabilities.
2. Assess how government programs use partnerships, grants, procurements, and other mechanisms in reinforcing consistent messages.
3. Institute a commission to examine relevant programs and recommend ways that they could improve access to information and decision-making support to strengthen the ability of disabled and older Americans to self-direct services and supports.



Appendix: Disability Statistics Fact Sheet

**Prepared for 2005 White House Conference on Aging
Mini Conference on Disability –
*Disability & Aging: Seeking Solutions to Improve Health, Productivity and Community Living***

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(References provided below)

Prevalence of Disability

The Census Bureau defines a person with a disability as someone who has difficulty in performing functional tasks or daily living activities or meets other criteria, such as a learning or developmental disability. People are considered to have a severe disability if they are completely unable to perform one or more of these tasks or activities, need personal assistance or have one of the severe conditions described in the report. The following statistics are from the panel of the Survey of Income and Program Participation (SIPP) that started in 1996 and are intended by the Census Bureau to broadly represent persons who fit the definition of the Americans with Disabilities Act. 1

- According to the US Census Bureau's 1997 Survey of Income and Program Participation (SIPP), which provides the latest data available using a broad measure of disability, there were 52.6 million persons with a disability living in the community (ages 5 and older). Additionally, about 2 million people live in nursing homes and other long-term care facilities. Thus, bringing the total prevalence to the oft-cited 54 million Americans with disabilities.
- In 1997, nearly 1 in 5 Americans said they had some level of disability, while 1 in 8 -- 33 million -- reported they had a severe disability, according to the U.S. Census Bureau.
- The likelihood of having a disability increased with age.
 - o For those 45 to 54 years old, 22.6 percent had some form of disability, 13.9 percent had a severe disability, and 3.6 percent needed personal assistance.
 - o For those 65 to 69 years old, the comparable estimates were 44.9 percent, 30.7 percent, and 8.1 percent.
 - o For the oldest age group, 80 years old and over, the estimates were 73.6 percent, 57.6 percent, and 34.9 percent.



- Other highlights:
 - The poverty rate among the population 25-to-64 years old with no disability was 8 percent, compared with 10 percent for people with a nonsevere disability and 28 percent for people with a severe disability.
 - In 1997, 9.7 million people age 16 to 64 had a disability that prevented them from working and another 7.2 million were limited as to the kind or amount of work they could do.

Number of Americans Aging *with* Long-Term Disabilities

- For the first time in history, many individuals with significant disabilities, like their non-disabled counterparts before them, are surviving long enough to experience the rewards and challenges of "aging." 2, 3
- However, determining the size of this emerging segment of the disabled population has been difficult due to lack of appropriate survey questions that ask about age of onset and duration of primary disability. 4
- The only analyses available to date are from the 1990 U.S. Census and suggest that there may be as many as 25,000,000 Americans who are aging with various types of early-onset and long-term disabilities. 5

Prevalence of Secondary Conditions among People with Disabilities

- People living with long-term with disabilities are at increased risk for “secondary conditions,” defined as preventable physical, mental, and social disorders resulting directly or indirectly from an initial disabling condition.⁶ The Centers for Disease Control and Prevention in their Healthy People 2010 Report targeted prevention of secondary conditions as a major component of health promotion for people with disabilities. 6
- In a recent article Kinne, Patrick and Lochner report on the first effort to collect (self-report) population data on population prevalence and impact of 16 common secondary conditions.⁸ Prior to this article, what has been known about the prevalence of secondary conditions stems primarily from clinical studies of patients and convenience samples. 7
- According to data from 2075 respondents to the disability supplement of the 2001 Washington State Risk Factor Surveillance Survey, 87 percent of respondents with disabilities reported at least one secondary condition compared to only 49 percent of respondents without disabilities. People with disabilities also reported more conditions than did those without limitations, with an average of 4.02 vs. 1.28 conditions per respondent ($p < .0001$). 8



- For the 8 most prevalent conditions (pain, weight problems, fatigue, difficulty getting into the community, falls and injuries, sleep problems, muscle spasms, bowel and bladder problems) having a disability was the strongest predictor of the presence of the condition compared to age, gender, education, income and health status. Age and health status contributed more to having anxiety, depression, social isolation, and asthma than did disability, but disability remained a significant factor. 8

Needs and Costs of Personal Assistance and Community-Based Services

The following statistics were compiled by the NIDRR-funded Rehabilitation Research and Training Center on Personal Assistance Services (RRTC on PAS) at the University of California, San Francisco based on tabulations of public use data from the Census Bureau's American Community Survey (ACS) for 2003, which contains information on over 1 million residents of randomly selected U.S. households

http://www.pascenter.org/state_based_stats/state_statistics_2003.php?state=us).

- Over 13 million adults (6.2 million aged 65 and older) living in the home and community receive an average of 31 hours of week of personal assistance services with activities of daily living. 9
- Only 16 percent of total care is paid care. The economic value of informal personal care is estimated to be over \$200 billion per year (for all adults). 9
- About 1 million adults have unmet needs for help with two or more activities of daily living for about 17 hours per week. Those individuals with unmet needs for help are significantly more like to have adverse consequences including discomfort, weight loss, dehydration, falls, burns, and dissatisfaction with help received. 10
- The US spent an estimated \$151 billion on long term care in 2003. Of this total, 73 percent was spent on institutional care. 11
- Medicaid is the major payer of long term care in the US, paying for 40 of total long term care expenditures. 12
- In 2004, Medicaid spent \$89 billion on long-term care and of this, 64 percent is spent on institutional services and 36 percent on home and community based services. Of the total Medicaid spending, 32 percent was for long term care in 2004. 12
- Medicaid home and community based waivers, personal care, and home health care are the major sources for providing personal care to the aged and disabled. These programs provided care to over 2 million participants and spent over \$25 billion in expenditures in 2002. There is waiver interstate variation in the amount and types of services provided. The total number of people on waiting lists of HCBS is 206,427 in 2004. The aged and disabled represent 53% of those on waiting lists. 13
- Using the latest expenditures data, it would cost an estimated \$4 billion in new funds to provide Medicaid community based attendant services and support (MiCASSA) to individuals with unmet need in the US. 14



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