



PRESS RELEASE
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NATIONAL AGING AND DISABILITY ORGANIZATIONS UNITED IN CALL FOR HEALTH CARE REFORM TO ADDRESS NEEDS FOR LONG TERM SERVICES AND SUPPORTS

Washington, DC (March 26, 2009) — In a historic step, national aging and disability organizations have come together to ensure that health care reform meets the needs of Americans for long-term services and supports. Yesterday, coinciding with a Senate Finance Healthcare Subcommittee hearing, nearly 100 national organizations sent a letter to President Obama and relevant Senate and House committee leadership working on health care reform that highlights the vital role and importance of long-term services and supports.

Long-term services and supports encompass a broad range of assistance with everyday activities, such as assistance and supervision with dressing, bathing, using the bathroom, preparing meals, taking medication, managing a home, and managing money. An estimated 10 million Americans currently have needs for long-term services. As the U.S. population ages and expands, the number of individuals needing long-term services is projected to increase to 26 million by 2050. However, the nation lacks a comprehensive, proactive national public-private system for delivering long-term services and supports.

Nearly half of all funding for long-term services is currently provided through Medicaid, which presents significant problems for beneficiaries. The Medicaid program requires individuals to become and remain poor to receive the services and support they need. In addition, there is an institutional bias in Medicaid where approximately two-thirds of all spending is directed towards nursing homes and other institutions instead of preferred community-based services. And lastly, there are hundreds of thousands of individuals with disabilities and families on waiting lists for services and supports.

Fortunately, there are viable policy options. Two significant pieces of legislation were reintroduced this week. On Tuesday, Senator Harkin (D-IA) and Representative Davis (D-IL) reintroduced the Community Choice Act which would provide individuals with disabilities and seniors with an equal choice of receiving home and community-based services in Medicaid. This legislation would help

correct the institutional bias by requiring a community-based personal attendant services and supports benefit within Medicaid. On Wednesday Senator Kennedy (D-MA) and Representative Pallone (D-NJ) reintroduced the Community Living Assistance Services and Supports (CLASS) Act. The CLASS Act would establish a new national insurance program financed by voluntary payroll deductions to provide benefits to adults who become severely functionally impaired. This new system will help to preserve the Medicaid program, which currently bears the brunt of covering long-term supports and services and will not be able to sustain an aging baby boom generation. It would promote independence and dignity across the lifespan by ensuring beneficiaries the right to control and choose what services they receive, how and where they are delivered and who provides them.

“While approximately 45 million Americans do not have medical insurance, over 200 million Americans lack any protection for the costs of long-term services and supports. Americans should no longer have to impoverish themselves to cover the costs of services they or their family members need in the event of disability or advancing age,” said Marty Ford, Chair of the Consortium for Citizens with Disabilities. The Community Choice Act and the CLASS Act will go a long way in meeting the current and future needs of Americans for long-term services and supports.

March 25, 2009

President Barack Obama
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Dear President Obama:

The undersigned 96 national organizations are writing to urge you to address issues concerning the financing and delivery of long-term services and supports in the health care reform proposals under development.

An estimated 10 million Americans currently need long-term services – personal care, assistive technology and other supportive services – and this number is projected to increase to 26 million by 2050. However, the nation lacks a coordinated, national public-private system for adequately and efficiently delivering high quality long-term services and supports. Nearly half of all funding for these services is now provided through Medicaid, which is a growing burden on states and requires individuals to become and remain poor to receive the help they need. There is also an institutional bias in Medicaid which directs approximately two-thirds of all spending to nursing homes and other institutions instead of preferred community-based services and supports.

An essential element of health care reform is ensuring that vulnerable populations have access to coverage that meets their care needs. For persons with disabilities and chronically ill older Americans – arguably the most vulnerable populations in the nation – long-term services and supports are their primary unmet care need, and are critical to promoting health and preventing illness. Real health care reform must not leave out the largest coverage gap in our current system. The unmet care needs of the most vulnerable and disadvantaged cannot be ignored. While approximately 45 million Americans do not have medical insurance, over 200 million adult Americans lack any insurance protection against the cost of long-term services and supports.

Another essential element of health care reform is ensuring real health security. Individuals and families should not go bankrupt paying for needed care. Health care reform must focus on areas in which Americans are now forced to pay the highest, catastrophic out-of-pocket costs. Under our current long-term services and supports system, families must impoverish themselves by spending down their life savings before receiving the care they need under Medicaid. To a family struggling to make ends meet, there is no difference between spending \$20,000 on hospital care and spending \$20,000 on home care or nursing home care. It is still \$20,000 they do not have. Individuals and families should not be forced to impoverish themselves to cover the costs of services they or their family members need in the event of disability or advancing age. Every family faces these potential costs, and we need to reform the system to support families and keep those in need at home and in their communities.

A third essential element of health care reform is strengthening and sustaining the Medicaid safety net for Americans with limited means. Medicaid is the primary payer for long-term services and supports but states are having an increasingly difficult time affording it. Almost 10% of state budgets are now spent on Medicaid long-term services and supports. Since the fastest growing segment of our population is people over age 85 – those at highest risk of needing care – state budget challenges will grow much worse without necessary reforms. National financing reform of long-term services and supports can achieve significant Medicaid savings. Unless health care reform improves access to cost effective home and community-based services for all those in need, there is a great risk that spending on long-term services and supports will squeeze out other state spending priorities, such as education and health coverage for children. We also urge that Medicaid be improved to ensure that people always have the option to choose home and community-based services.

Health care reform should also improve economic growth and productivity. Improving access to home and community services will enable many persons with disabilities to continue working. Such reforms will also support family caregivers, thereby reducing absenteeism and improving business productivity.

There is broad consensus among advocates representing older Americans and persons with disabilities about how to reform our long-term services and supports financing system. It can be accomplished in a financially sound way for families and taxpayers, with significant Medicaid savings. Such a consensus proposal can and should be crafted to complement and provide additional support for the entire health care reform package.

We must recognize that although states, communities, families, and individuals have important roles to play, financing for long-term services and supports is a national problem that requires a national solution. We must create a public program that allows all people, including individuals with disabilities and those near retirement, the opportunity to contribute to and prepare for the costs of long-term services and supports. The program should provide a strong foundation of protection while providing opportunities for personal planning that include a role for private sector options. It should provide for broad pooling of risk and appropriate low-income subsidies to make premiums affordable enough so that all people, regardless of income and health status, can participate. The program should not force people to impoverish themselves to qualify. It should provide actuarially sound funding, such as through voluntary premiums that build reserves over time sufficient to pay for future needs in a way that is affordable to individuals and to society as a whole. The program should also support family caregivers, ensure adequate wages and benefits to improve recruitment and retention of needed direct care workers, and assure beneficiaries access to information about providers and the quality of their services. Finally, it should promote independence and dignity across the broad continuum of services and supports by ensuring beneficiaries the right to control and choose what services they receive, how and where they are delivered and who provides them.

We urge you to support legislation that is consistent with these principles and include it in the health care reform package.

Americans favor including long-term services and supports in health care reform. According to a survey of 800 likely voters by the Mellman Group and Public Opinion Strategies in August 2008, 78% stated that long-term care should be included in the health care reform proposals being debated (87% of Democrats). According to a survey of 1,000 voters by the Glover Park Group in September 2007, 94% stated that reforming the long-term care system is important (99% of Democrats), including three quarters (74%) who feel it is very important.

Thank you for your leadership on health care reform and for your consideration of these issues. We welcome the opportunity to meet with you and your staff to discuss them further. We look forward to working with you to craft a comprehensive, bipartisan proposal that addresses the care needs of vulnerable populations, ensures health security, strengthens the health care safety net, and improves economic growth and productivity.

ACCSES (formerly the American Congress of Community Supports and Employment Services)

ADAPT

Alliance for Retired Americans

Alzheimer's Association

Alzheimer's Foundation of America

American Association on Health and Disability

American Association on Intellectual and Developmental Disabilities

American Association of Homes and Services for the Aging

American Association of People with Disabilities

American Congress of Rehabilitation Medicine

American Group Psychotherapy Association

American Medical Rehabilitation Providers Association
American Network of Community Options and Resources
American Occupational Therapy Association
American Society of Consultant Pharmacists
American Therapeutic Recreation Association
Anxiety Disorders Association of America
Assisted Living Federation of America
Association of Academic Physiatrists
Association of BellTel Retirees
Association of Programs for Rural Independent Living
Association of Jewish Aging Services
Association of University Centers on Disabilities
Association for Ambulatory Behavioral Healthcare
Autistic Self Advocacy Network
Autism Society of America
Bazelon Center for Mental Health Law
Brain Injury Association of America
B'nai B'rith International
Catholic Health Association of the United States
Center for Self-Determination
Center for Medicare Advocacy
Clinical Social Work Association
Easter Seals
Epilepsy Foundation
Evangelical Lutheran Good Samaritan Society
Gray Panthers
Higher Education Consortium for Special Education
Lutheran Services in America
Medicare Rights Center
Mental Health America
National Academy of Elder Law Attorneys
National Adult Day Services Association
National Asian Pacific Council on Aging
National Association of Area Agencies on Aging
National Association of Professional Geriatric Care Managers
National Association of Social Workers
National Association of the Deaf
National Alliance for Caregiving
National Alliance on Mental Illness
National Association for the Advancement of Orthotics and Prosthetics
National Association of Councils on Developmental Disabilities
National Association of Nutrition and Aging Services Programs
National Association of State Head Injury Administrators
National Baptist Convention USA, Inc. Housing Board
National Coalition of Mental Health Consumer/Survivor Organizations
National Committee to Preserve Social Security and Medicare
National Council for Community Behavioral Healthcare
National Council on Aging
National Council on Independent Living
National Council of Jewish Women
National Disability Institute

National Disability Rights Network
National Down Syndrome Congress
National Down Syndrome Society
National Family Caregivers Association
National Health Council
National Indian Council on Aging
National Center for Learning Disabilities
National Low Income Housing Coalition
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Rehabilitation Association
National Respite Coalition
National Senior Citizens Law Center
National Senior Corps Association
NISH
NCCNHR, the National Consumer Voice for Quality Long-Term Care
OWL - The Voice of Midlife and Older Women
Paralyzed Veterans of America
Research Institute for Independent Living
Self Advocates Becoming Empowered
Service Employees International Union (SEIU)
Sibling Leadership Network
Special Olympics
Substance Abuse Resources and Disability Issues
TASH
Teacher Education Division of the Council for Exceptional Children
The Arc of the United States
United Cerebral Palsy
United Church of Christ, Justice and Witness Ministries
United Jewish Communities
United Spinal Association
US Psychiatric Rehabilitation Association
Volunteers of America
Wider Opportunities for Women

Cc: Edward Kennedy, Chair, Senate Health, Education, Labor, and Pension Committee
Michael Enzi, Ranking Member, Senate Health, Education, Labor, and Pension Committee

Max Baucus, Chair, Senate Finance Committee
Charles Grassley, Ranking Member, Senate Finance Committee

Henry Waxman, Chair, House Energy and Commerce Committee
Joe Barton, Ranking Member, House Energy and Commerce Committee

Charles Rangel, Chair, House Ways and Means Committee
Dave Camp, Ranking Member, House Ways and Means Committee

George Miller, Chair, House Education and Labor Committee
Howard McKeon, Ranking Member, House Education and Labor Committee