

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

Consortium for Citizens with Disabilities

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 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