

May 18, 2009

The undersigned organizations urge you to ensure that health care reform will eliminate the disability-based health disparities faced by the more than 54 million Americans with disabilities. Research shows that individuals with disabilities experience a lower rate of education, and employment, and a higher rate of poverty when compared to non-disabled persons. The Agency for Healthcare Research and Quality (AHRQ) reports that private health insurance is less available to people with disabilities. Two Surgeon Generals' reports have called attention to the need to address disability-based health disparities in access to clinical care, prevention and wellness, and public health services.

Individuals with disabilities are more likely to experience early death, chronic conditions, and preventable health conditions. Compared with the non-disabled population, individuals with disabilities experience higher incidence of obesity, osteoporosis, diabetes, high blood pressure, and oral disease. Research shows that individuals with disabilities experience greater unmet health needs than the non-disabled population and receive fewer routine and preventative services such as blood pressure checks, and cholesterol and cancer screenings.

Research shows that individuals with intellectual disabilities must contact 50 physicians before they can find one trained to treat them. The literature indicates that children with autism do not receive primary care consistent with the care provided in a medical home. With few exceptions, women who use wheelchairs lack physical access to mammograms. Communication barriers often prevent deaf and hard of hearing individuals from receiving mental and physical health services. Three out of five people with serious mental illness die from preventable, co-occurring chronic diseases, such as asthma, diabetes, cancer, heart disease and cardiopulmonary conditions. Inaccessible medical equipment and lack of trained physicians, dentists, and other health professionals prevent individuals with disabilities from receiving the basic care others take for granted, such as getting weighed, preventative dental care, pelvic exams, x-rays, physical examinations, colonoscopies, and vision screenings.

In spite of the startling evidence of health disparities among people with disabilities and the inherent costs to treat preventable conditions, current federal law does not consider individuals with disabilities a "medically underserved population," does not include disabilities under requirements for cultural competence and fails to recognize disability health disparities under any federal program that addresses other health disparities. Health reform must fix this injustice.

Healthcare reform must end these health disparities by ensuring:

- Access to affordable coverage for Americans with disabilities, including intellectual and developmental disabilities, without regard to pre-existing conditions, congenital impairments, or whether the intervention is habilitative or rehabilitative in nature;
- Access to quality care by health care providers trained to treat individuals with disabilities, including intellectual and other disabilities;
- Inclusion of individuals with disabilities in the definitions of “medically underserved populations” and “cultural competence;”
- A delivery system prepared to provide appropriate, accessible, and equivalent care for individuals with disabilities at all levels of service;
- Inclusion of individuals with disabilities in all data collection and reporting required for racial, ethnic, gender, or geographic health disparities, in a manner that can facilitate identification and reduction of disparities associated with physical, mental health, cognitive, sensory, intellectual, and/or developmental disabilities;
- Equal treatment of the population of individuals with disabilities in all policies, programs, and research designed to decrease health disparities.
- Inclusion of individuals with disabilities in prevention and wellness programs;
- A healthcare workforce trained to address the needs of individuals with disabilities, including physical, mental health, cognitive, sensory, intellectual, and/or developmental disabilities;
- Development of specific quality measures to improve primary and preventative care for individuals with disabilities;
- Development and strengthening of the “medical home” to meet the healthcare needs of individuals with disabilities;
- Health information technology systems that collect aggregate specific data about physical, mental health, cognitive, sensory, intellectual, and/or developmental disabilities while maintaining individual privacy; and
- Inclusion of “disabilities” and “sign language interpreters” in the Office of Minority Health’s National Standards on Culturally and Linguistically Appropriate Services (CLAS)

As the population ages, disabilities will affect even more Americans. This is the right time and healthcare reform is the right place to correct disability-based health disparities so that healthcare reform is for all Americans. Thank you.

### **National**

ACCES

Alexander Graham Bell Association for the Deaf and Hard of Hearing

American Academy of Developmental Medicine and Dentistry

American Association for Physical Activity and Recreation

American Association of People with Disabilities

American Association on Health and Disabilities

American Association on Intellectual and Developmental Disabilities

American Foundation for the Blind

American Music Therapy Association

American Network of Community options and Resources  
American Occupational Therapy Association  
American Physical Therapy Association  
American Public Health Association Disability Section  
Amputee Coalition of America  
Association of University Centers on Disabilities  
Autism Society of America  
Autistic Self Advocacy Network  
Bazelon Center for Mental Health Law  
Blaze Sports America  
Brain Injury Association of America  
Burton Blatt Institute  
Center for Disability Issues and the Health Professions at Western University of Health Sciences  
Center for Self-Determination  
CHADD (Children with Adults with Attention-Deficit/Hyperactivity Disorder)  
Coalition on Human Needs  
Dan Marino Foundation  
Disabled Action Committee  
Disability Rights Education & Defense Fund  
Easter Seals  
Elizabeth M. Boggs Center on Developmental Disabilities  
Epilepsy Foundation  
Feminist Majority  
Feminist Response in Disability Activism (FRIDA)  
Global Disabilities Solution Group  
Hearing Loss Association of America  
Higher Education Consortium for Special Education  
Little People of America  
Lutheran Services in America  
Mental Health America  
Mill Neck Family of Organizations  
National Alliance on Mental Illness  
National Association of Councils on Developmental Disability  
National Association of County Behavioral Health and Developmental Disability Directors  
National Association of State Directors of Developmental Disabilities Services  
National Association of Social Workers  
National Association of State Directors of Special Education  
National Association of the Deaf  
National Center for Environmental Health Strategies, Inc.  
National Centers on Independent Living  
National Coalition of Mental Health Consumer /Survivor Organizations  
National Council on Independent Living  
National Disabilities Rights Network  
National Down Syndrome Congress  
National Down Syndrome Society  
NHeLP – National Health Law Program  
National Youth Leadership Network  
New Focus Partnerships

Self Advocates Becoming Empowered (SABE)  
 Sibling Leadership Network  
 Special Olympics, Inc.  
 TASH  
 The Arc of the United States  
 The National Rehabilitation Association  
 The National Women's Law Center  
 Trust for America's Health  
 The University of Massachusetts Medical School Eunice Kennedy Shriver Center  
 United Cerebral Palsy  
 United Jewish Communities  
 United Spinal Association  
 Ventilator Support Network  
 Women's Sports Foundation  
 World Institute on Disability

### **State**

ADAPT Montana  
 Arkansas Independent Living Council  
 Autism Society of Michigan  
 Family Voices of New Jersey  
 Granite State Independent Living Center New Hampshire  
 Illinois Lend, Institute on Disability and Human Development, University of Illinois-Chicago  
 Education Law Center – Newark, NJ  
 Illinois LEND and Illinois UCEDD – University of Illinois at Chicago  
 Institute of Social Medicine and Community Health  
 Iowa Prevention of Disabilities Policy Council  
 Kansas University Center on Developmental Disabilities  
 New York Association on Independent Living  
 North Central Independent Living Services, Inc. (Black Eagle, Montana)  
 NorthEast Independent Living Services – Missouri  
 Northern West Virginia Center for Independent Living  
 Omaha Down Syndrome Parents Network  
 Pennsylvania Council on Independent Living  
 Parent to Parent of New York State  
 S.M.I.L.E. on Down Syndrome  
 Statewide Parent Advocacy Network of New Jersey  
 The Texas State Independent Living council

### **Local**

Abilities in Motion – Reading, PA  
 Achievements, Inc. – Libby, Montana  
 Action Toward Independence - Middletown, NY  
 Arlington Special Education Parent Advisory Council – Arlington, MA  
 Boston Center for Independent Living, Inc.  
 Bronx Independent Living Services  
 Center for Independence, Pueblo, Colorado  
 Center for Independence of the Disabled, NYC

CIL Opportunities (York, Adams and Franklin County, PA)  
City of Helena ADA Compliance Committee (Montana)  
Differently Abled Associates, Inc. – Reading, Pennsylvania  
Disability Empowerment Center, Lancaster, Pennsylvania  
disability Resource Center, North Charleston, South Carolina  
Down Syndrome Foundation of Orange County (California)  
Eastern Oregon Center for Independent Living  
Enid Twisters, Enid, Oklahoma  
Genesee Region Independent Living Center, Inc., Batavia, NY  
Harlem Independent Living Center, New York City  
Houston Center for Independent Living  
Illinois/Iowa Center for Independent Living, Rock Island, Illinois  
Independent Living Center of the Hudson Valley, Inc.  
Independent Living Center, Southern Tier Region of New York State  
Madison Area Down Syndrome Society, Madison, Wisconsin  
North County Center for Independence, Plattsburgh, New York  
Northern Regional Center for Independent Living, Inc. – Watertown, New York  
Placer Independent Resource Services, Inc., Auburn, CA  
Resource Center for Accessible Living, Inc.  
Services for Independent Living, Columbia, Missouri  
Southeast Alaska Independent Living  
Southern Adirondack Independent Living Center, Queensbury, New York  
Southern Tier Independence Center, Binghamton, New York  
The Westchester Institute on Human Development, Valhalla, New York