

May 18, 2009

The Honorable Henry A. Waxman
Chairman
Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

The Honorable Joe Barton
Ranking Member
Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Waxman and Ranking Member Barton:

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 Disability 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