



March 9, 2017

Dear Senator Mitch McConnell;
Senator Chuck Schumer;
Senator Lamar Alexander;
Senator Patricia Murray;
Representative Paul Ryan;
Representative Nancy Pelosi;
Representative Greg Walden;
Representative Frank Pallone;
Representative Kevin Brady;
Representative Richard Neal;

As Congress moves to repeal the Affordable Care Act (ACA), there is a great deal of concern about the fate of several initiatives in the ACA that are completely unrelated to the primary provisions of the law. These initiatives are of critical importance to the Disability Community, and two of them underpin one of the most fundamental rights that Americans are guaranteed under the Declaration of Independence and Constitution: Liberty.

We are also concerned that efforts to give states flexibility and cap federal funding for Medicaid will further erode the ability of disabled and elderly individuals to live in the community because these services have historically been underfunded and states have typically limited access to them while funding institutional placements.

The undersigned organizations urge Congress to recognize these critically important policy issues as it moves forward this session with any legislation that reforms healthcare.

First, we appreciate statements supporting the preservation of protections for people with pre-existing conditions.

First, we appreciate statements supporting the preservation of protections for people with pre-existing conditions. We want to acknowledge the support from President-elect Trump and other conservatives for maintaining the protections for people with pre-existing conditions in healthcare. That said, we are deeply concerned by draft language which appears to allow consumers with pre-existing conditions to be penalized with raised premiums if their coverage has lapsed. Prior to the ACA's ban on insurance companies refusing coverage or charging more to cover people with pre-existing conditions, many disabled people could not afford coverage. Those who could were often refused coverage even when they could afford it. For many, being locked out of the insurance marketplace meant taking on burdensome debt and was often a path to financial ruin and forcing them onto public benefits. We are concerned that penalties for lapses in insurance will still result in this vicious cycle, and we urge you to remove these penalties from the bill.

It is also critical that you keep coverage meaningful. Rolling back the federal requirements for Essential Health Benefits (EHB), or even removing specific targeted EHBs, such as mental health services or rehabilitation, would be devastating to the disability community. Many people with disabilities require substantial services such as speech and language therapy, occupational therapy, physical therapy, mental health services, and other similar services over our lifetimes as a result of our disabilities. Thanks to the ACA, people with disabilities are finally able to get our money's worth from our health insurance; we know that if certain services are needed in order to increase or maintain function, we can access them. The loss of federal requirements for Essential Health Benefits would result in a world where people with disabilities would be required to either go without essential services we need in order to function, or else pay out of pocket on top of our existing – but much less functional – health insurance. We urge you to continue to require that health insurance plans meet minimum standards for coverage, including coverage for rehabilitative and mental health services.

Don't eliminate accessibility requirements for Diagnostic Medical Equipment.

Few people are aware that the ACA included provisions that authorize the U.S. Access Board to develop accessibility standards for medical diagnostic equipment. Inaccessibility of this equipment has deterred or prevented disabled individuals from getting appropriate diagnostic services which results in higher rates of secondary health issues – unrelated to an individual's primary disability. For example, studies have shown that women with chronic disabling conditions are less likely to receive breast cancer screenings. The inaccessibility of the diagnostic equipment – which contributes to this problem – was addressed in the ACA, but these accessibility requirements are at risk of being swept away in an across-the-board repeal of the ACA.

Don't Undercut the Constitutional Guarantee of Liberty.

The Constitution – in the Preamble – secures the blessings of liberty for Americans as a central principle of our government. The Constitution does not exclude disabled Americans who are equally entitled to freedom and liberty. Within the ACA, there are two program initiatives that advance the right of disabled Americans to live in freedom. Although they may not have been widely discussed by policy-makers, the importance of these programs cannot be overstated. The Money Follows the Person Program and the Community First Choice Option, together, help assure that the constitutionally-guaranteed right to liberty is afforded for millions of us in the Disability Community.

The Money Follows the Person (MFP) program was initiated under President George W. Bush's administration as part of his New Freedom Initiative to integrate people with disabilities into the community. Through advocacy by the Disability Community, this initiative was extended through the ACA, and it has helped states ensure that countless disabled and older Americans are able to get out of institutions and nursing facilities. MFP has been adopted by at least 44 states, and has helped contain unnecessary and costly Medicaid for unwanted institutionalization. In so doing, MFP has allowed states to serve more people at the same or lower funding levels. Because of political gridlock, this program is sunseting. The 115th Congress can take immediate action to support the liberty of disabled Americans by implementing proposals from the National Council on Independent Living and ADAPT to extend this program.

The Community First Choice Option (CFCO) resulted from decades of advocacy by the Disability Community to ensure that disabled Americans are able to remain in their own homes rather than be forced into unwanted institutionalization and denied their basic liberty. A number of states, including Texas, have selected CFCO. CFCO creates a powerful incentive for these states to provide services and supports in the community, and advocates across the country are working with their states to select

CFCO. Disabled people have fought long and hard for the opportunity to live in the community in a manner that virtually every other American takes for granted. In fact, CFCO was not included in the original legislation creating the ACA and was only added because of the work of disability advocates. We urge you to preserve CFCO as it has become one of the most effective tools for making community living a reality for all people with disabilities.

Don't devastate Medicaid healthcare and community-based services needed by disabled Americans.

Most disabled Americans rely on Medicaid for their healthcare and disabled Americans who require Long Term Services and Supports (LTSS) depend on the Medicaid program in their state to ensure that they can live in the community. We are gravely concerned that efforts to provide states with greater flexibility while capping federal funding will result in reductions in vital healthcare and home and community-based services. The Disability Community has identified ways to reform Medicaid which can contain costs without gutting the program. We urge you to work with us to identify and implement real reform rather than balance budgets on the backs of disabled Americans.

The Disability Community includes people of all political persuasions. These issues matter to us because they support our freedom, allow us to be contributing members of society, spend time with our families, and live our lives! These programs secure the Constitutional right to Liberty for People with Disabilities, and we urge you to preserve and advance these important programs as you make enact legislation to reform the healthcare.

Sincerely,
The National Disability Leadership Alliance

NDLA Steering Committee Organizations

ADAPT
American Association of People with Disabilities (AAPD)
Association of Programs for Rural Independent Living (APRIL)
Autistic Self Advocacy Network
Little People of America (LPA)
National Association of the Deaf
National Coalition for Mental Health Recovery
National Council on Independent Living (NCIL)
Not Dead Yet
United Spinal Association
National Organization of Nurses with Disabilities (NOND)

National Organizations

ADA Legacy Project - National
Autism Women's Network - National
Disability Power & Pride - National
Disability Rights Center - National
Parent to Parent USA - National
Disability Rights Center - National
Disability Rights Education & Defense Fund (DREDF) - National
Disability Rights, Education, Activism, and Mentoring (DREAM) - National
FilmDis - National
Healthcare Rights Coalition - National

Independent Movement Paratransit Riders for Unity, Vehicles, Equality (IMPRUVE) - National
Manyata Ministries - National
National LGBTQ Task Force Action Fund - National
NMD United - National
Partnership for Inclusive Disaster Strategies (PiDS) - National
Starkloff Disability Institute - National
The ADA Legacy Project (TALP) - National
World Institute on Disability - National

State and Local Organizations

Ability360 CIL - Arizona
DIRECT Center for Independence - Arizona
Arkansas ADAPT - Arkansas
Arkansas Support Network - Arkansas
Disability Resource & Advocacy Center - Arkansas
Spa Area Independent Living Services (SAILS) - Arkansas
California Foundation for Independent Living Centers - California
California IHSS Consumer Alliance - California
Community Resources for Independent Living - California
Dayle McIntosh Center - California
Independent Living Resource Center San Francisco - California
Northern California ADAPT - California
Placer Independent Resource Services - California
Senior and Disability Action - California
Service Center for Independent Life - California
Silicon Valley Independent Living Center - California
Atlantis ADAPT - Colorado
Atlantis Community Inc. - Colorado
Chanda Plan Foundation - Colorado
Colorado Cross-Disability Coalition - Colorado
Cripple Concepts - Colorado
Front Range Home Care Services - Colorado
The Association for Successful Parenting - Colorado
The Independence Center - Colorado
Connecticut Legal Rights Project - Connecticut
Connecticut State Independent Living Council -
ADAPT Delaware - Delaware
DC Metro ADAPT - District of Columbia
Center for Independent Living of South Florida (CILSF) - Florida
Disability Resourc Center, Inc. - Florida
Florida Alliance for Assistive Services and Technology (FAAST) - Florida
Access to a Better Tomorrow, Inc. - Georgia
Decatur ADAPT - Georgia
disABILITY LINK - Georgia
Georgia ADAPT - Georgia
Disability Action Center NW - Idaho
ID Federation of Families for Children's Mental Health - Idaho
Idaho State Independent Living Council - Idaho

Living Independence Network Corporation (LINC) - Idaho
United Vision for Idaho - Idaho
Access Living - Illinois
Advocates for Access - Illinois
AIM Center for Independent Living - Illinois
Black Network In Children's Emotional Health (BNICEH) - Illinois
Catholic Office of the Deaf, Archdiocese of Chicago - Illinois
Chicago ADAPT - Illinois
Health & Disability Advocates - Illinois
Illinois Parents of Adults with Developmental Disabilities Unite (IPADD) - Illinois
IMPACT CIL - Illinois
Living Independently Now Center, Inc. (LINC) - Illinois
PACE, Inc. Center for Independent Living - Illinois
Springfield Center for Independent Living - Illinois
Supporting Illinois Brothers and Sisters (S.I.B.S.) - Illinois
Will-Grundy Center for Independent Living - Illinois
Indiana ADAPT - Indiana
Kansas ADAPT - Kansas
National Action Network (NAN) - Kansas Chapter - Kansas
South Eastern Kansas ADAPT - Kansas
Southeast Kansas Independent Living - Kansas
Three Rivers Inc. - Kansas
Topeka Independent Living Resource Center - Kansas
New Horizons Independent Living Center - Louisiana
Maryland ADAPT - Maryland
Maryland United for Peace and Justice - Maryland
The IMAGE Center of Maryland - Maryland
Boston Center for Independent Living - Massachusetts
Braintree Special Education Parent Advisory Council - Massachusetts
Disability Policy Consortium - Massachusetts
Independence Associates, Inc - Massachusetts
Independent Living Center of the North Shore and Cape Ann - Massachusetts
MassADAPT - Massachusetts
Michigan ADAPT - Michigan
Minnesota Association of Center's for Independent Living - Minnesota
Northern Minnesota ADAPT - Minnesota
Options IRCIL - Minnesota
Twin Cities Metro ADAPT - Minnesota
Rural Advocates for Independent Living - Missouri
Saint Louis ADAPT - Missouri
ADAPT Montana - Montana
Living Independently for Today and Tomorrow (LIFTT) - Montana
Not Dead Yet Montana - Montana
Summit Independent Living - Montana
Granite State Independent Living (GSIL) - New Hampshire
Alliance Center for Independence - New Jersey
DIAL - Center for Independent Living - New Jersey
A Better Way of Living - New Mexico

Access to Independence of Cortland County, Inc. - New York
Action Toward Independence - New York
AIM Independent Living Center - New York
All About You Home Care (AAY) - New York
ARISE - New York
Bronx Independent Living Services - New York
Brooklyn Center for Independence of the Disabled - New York
Center for Disability Rights (CDR) - New York
Center for Independence of the Disabled, New York - New York
Church Women United in New York State - New York
Citizens United to Remove Barriers (C.U.R.B.) - New York
Consumer Directed Personal Assistance Association of New York State - New York
Directions in Independent Living - New York
Disabled In Action of Metropolitan New York - New York
Disability Awareness: An Empowering Ministry - New York
Finger Lakes Independence Center - New York
Harlem Independent Living Center - New York
Independent Living, Inc. - New York
Independent Living Center of Hudson Valley - New York
Independent Living of Niagara County - New York
Independent Living of the Genesee Region - New York
Long Island ADAPT - New York
Long Island Center for Independent Living, Inc. (LICIL) - New York
Massena Independent Living Center, Inc. - New York
Metro New York Health Care for All - New York
New York Association on Independent Living - New York
New York Statewide Independent Living Council - New York
Northern Regional Center for Independent Living - New York
NYC ADAPT - New York
Regional Center for Independent Living - New York
Resource Center for Independent Living - New York
Resource Center for Accessible Living, Inc. - New York
Rochester Spinal Association - New York
Southern Adirondack Independent Living (SAIL) - New York
Southern Tier ADAPT - New York
Southern Tier Independence Center - New York
Southwestern Independent Living Center, Inc. - New York
Staten Island Center for Independent Living - New York
Suffolk Independent Living Organization (SILO) - New York
Westchester Disabled On the Move Inc - New York
Westchester Independent Living Center - New York
Western New York Independent Living - New York
Disability Partners CIL - North Carolina
The Adaptables, Inc - North Carolina
Advocates for Ohioans with Disabilities - Ohio
Center for Independent Living Options - Ohio
The Access Center for Independent Living - Ohio
Progressive Independence CIL - Oklahoma

ADAPT of Erie PA - Pennsylvania
Center for Independent Living - Pennsylvania
Center for Independent Living of Central PA - Pennsylvania
Disabled in Action - Pennsylvania
Independence Edge Studio - Pennsylvania
Liberty Resources, Inc - Pennsylvania
Pennsylvania Statewide Independent Living Council (PA SILC) - Pennsylvania
Philly ADAPT - Pennsylvania
Pittsburgh Center for Autistic Advocacy - Pennsylvania
Southwestern PA ADAPT - Pennsylvania
Tri-County Patriots for Independent Living (TRIPIL) - Pennsylvania
MOVIMIENTO PARA EL ALCANCE DE VIDA INDEPENDIENTE (MAVI) - Puerto Rico
Homeless Organizing for Power and Equality's Women's Caucus - Tennessee
Memphis ADAPT - Tennessee
Memphis Center for Independent Living - Tennessee
ADAPT of Texas - Texas
Brazoria County Center for Independent Living - Texas
Coalition for Barrier Free Living/Houston Center for Independent Living - Texas
Coastal Bend Center for Independent Living - Texas
Conroe Houston ADAPT - Texas
Disability Connections CIL - Texas
East Texas Center for Independent Living - Texas
El Paso Desert ADAPT - Texas
Personal Attendant Coalition of Texas - Texas
REACH Resource Centers on Independent Living - Texas
RISE CIL - Texas
Valley Association for Independent Living, Inc (VAIL) - Texas
Disabled Rights Action Committee - Utah
Utah ADAPT - Utah
Champlain Valley Down Syndrome Group - Vermont
Disability Rights Vermont - Vermont
Disabled Access & Advocacy of the Rutland Area - Vermont
Green Mountain ADAPT - Vermont
Vermont Center for Independent Living - Vermont
Vermont Coalition for Disability Rights - Vermont
Vermont Workers' Center - Vermont
Blue Ridge Independent Living Center - Virginia
Lynchburg Area Center for Independent Living (LACIL) - Virginia
Our Invisible Disability - Virginia
Resources for Independent Living, Inc. - Virginia
Center for Independence - Washington
Northern West Virginia Center for Independent Living - West Virginia
Access to Independence, Inc. - Wisconsin
Center for Independent Living for Western Wisconsin (CILWW) - Wisconsin
Central Wisconsin ADAPT - Wisconsin
Independence First - Wisconsin
Independent Living Council of Wisconsin - Wisconsin
Midstate Independent Living Consultants - Wisconsin

New Horizons Unlimited, Inc. - Wisconsin
North Country Independent Living of Wisconsin - Wisconsin
Options for Independent Living - Wisconsin
Southeast Wisconsin (SEWI) ADAPT - Wisconsin
Wisconsin Coalition of Independent Living Centers - Wisconsin
Wyoming Services for Independent Living - Wyoming

The National Disability Leadership Alliance (NDLA) is a national cross-disability coalition, led by disability groups run by persons with disabilities, with support from allies to build a strong and unified cross-disability movement so that we, as individuals with disabilities, have the power to shape national policies, politics, media, and culture. NDLA is led by 15 national organizations run by people with disabilities with identifiable grassroots constituencies around the country.