



## Legislative & Advocacy Priorities

Spring 2012



## A Message from the Executive Director

Dear Advocates and Allies,

I am pleased to announce the release of the Spring edition of National Council on Independent Living's 2012 Policy Priorities. This publication will introduce you to a sample of the many legislative issues NCIL is currently pursuing in order to secure full inclusion and equality for people with disabilities in our great nation.

I would like to draw particular attention to issues surrounding Independent Living funding and the creation of an Independent Living Administration. Considering the substantial work left to be done in order to secure the civil and human rights of people with disabilities, NCIL is acutely aware that funding for Centers for Independent Living and Statewide Independent Living Councils is of the utmost importance to our Movement.

CILs and their statewide counterparts are the only organizations directly working to address the issues outlined in this publication. They use shoe-string budgets to successfully advocate for individuals with disabilities facing discrimination while fighting to win an even playing field and ensure the civil and human rights of all Americans.

It is crucial that we secure appropriate funding for the Independent Living Program while advancing its agenda of full participation, equality, and freedom of choice for all.

I am very proud of our community's hard work to bring these issues to Congress. Together we will see the passage of our legislative priorities, the restoration of our civil rights, and a world in which people with disabilities are truly valued equally and participate fully.

Sincerely,



Kelly Buckland  
Executive Director,  
National Council on Independent Living



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# Civil Rights and the *Americans with Disabilities Act*

## Standards for Accessible Design

The 2010 ADA Standards for Accessible Design are effective March 15, 2012 after years of waiting through the rulemaking process! NCIL has witnessed a stepped-up effort by the Department Of Justice to enforce the law in a way that sets an example with each settlement agreement they make public, and by their increased willingness to pursue not only injunctive relief, but meaningful penalties from those who, more than 20 years after the signing of our civil rights law, still discriminate against people with disabilities.

However, NCIL sees room for improvement in the rulemaking process, and would recommend Congress examine the regulatory process for updating the ADA Regulations and Standards for Accessible Design, so that revisions can be made in a more timely manner than in the past.



## Reauthorization of the *Violence Against Women's Act*

S. 1925

The NCIL Task Force on Violence Against People with Disabilities strongly supports the *Violence Against Women Reauthorization Act (VAWA)*, which was reintroduced as SB1925 on November 30th, 2011 by U.S. Senators Patrick Leahy (D-VT) and Mike Crapo (R-ID).

Since 1994, *VAWA* has helped to provide resources and support to victims of domestic violence and their children. *VAWA* provides funding for the National Domestic Violence Hotline, transitional housing, and legal assistance. It also gives grant money to help educate and better prepare law enforcement, advocates and shelters. It was reauthorized by Congress in 2000 and again in 2005, each time acquiring more funding and becoming more successful.

*The Violence Against Women Reauthorization Act* will provide a five year authorization for *VAWA* programs, and reduce authorized funding levels by more than \$144 million, or 19 percent, from the law's 2005 authorization. The Leahy-Crapo legislation also includes important minimum funding formulas that apply to all states for key grant programs in order to ensure that small, rural states have access to the victim services grants authorized under *VAWA*, including STOP grants, grants under the Sexual Assault Services Program, the Rural Program, Rape Prevention Education grants, and transitional housing grants. It is of the utmost importance that congressmen and senators know that NCIL cares about *VAWA* and supports its reauthorization and improvement.

## Judicial Nominations

NCIL supports the nomination and confirmation of federal judges with disabilities and those who respect the ADA and the civil rights of people with disabilities. NCIL urges the Senate to ask nominees tough questions on judicial philosophy on the civil rights of people with disabilities.



## Election Reform

The *Help America Vote Act (HAVA)* takes important steps to tear down barriers to voting by requiring polling places to meet the needs of all voters. The purchase and installation of newer, accessible voting machines will make it possible for a growing number of people with disabilities to exercise their right to vote and have their voices heard. It is important in this election year that we continue to move forward in election reform by removing barriers to voting and encouraging active participation in the political process. However, legislation requiring photo identification will only reduce voter turnout and present an additional barrier to voting. NCIL opposes photo identification requirements for voting.



We must engage in election reform to eliminate voter fraud and voter suppression where it threatens election security. At the same time, we must be vigilant in complying with the *Voting Rights Act*, the *Civil Rights Act*, and *HAVA* to ensure increased access to voting for all Americans. Measures requiring the use of photo identification to vote have not proven to be an effective tool to fight voter fraud. Indeed, such a requirement will even erect barriers to voting for particular segments of the nation's citizenship, including people with disabilities.

## ***SAMHSA Modernization Act***

*H.R. 5466*

The *SAMHSA Modernization Act* was introduced in the House during the 111th Congress to amend the *Public Health Service Act* to reauthorize the Substance Abuse and Mental Health Services Administration (SAMHSA). NCIL recommends including the following requirements in reauthorization:

- consumers should represent a majority on State Mental Health Planning and Advisory Councils, which are required to review and comment on State Community Mental Health Block Grant (MHBG) plans;
- consumer peer support organizations and / or consumer-run community mental health services should be provided by each state in their MHBG plan; and
- State Mental Health Planning and Advisory Councils should coordinate activities with Statewide Independent Living Councils (SILCs) under section 705 of the *Rehabilitation Act*.



## ***ADA Notification Act***

*Not Yet Introduced in the 112th Congress*

Yet to be introduced in the 112th Congress, some form of an *ADA Notification Act* may still be introduced, which draws less support each session. NCIL has vehemently opposed each introduction of this bill on the grounds that civil rights are intrinsic to all Americans; a violation of which cannot require 'notification' prior to occurrence. States should address problematic issues within state law; not create additional federal law that cannot be enforced.

# Independent Living and Reauthorization of the *Rehabilitation Act*

## **Senate Introduces Reauthorization of WIA that Includes an Independent Living Administration**

The National Council on Independent Living is very proud and excited to announce that a discussion draft has been created in the Senate HELP (Health, Education, Labor & Pensions) Committee that creates the establishment of a new Independent Living Administration (ILA) and strengthens America's Independent Living Program. A similar draft is being discussed in the House.

The ILA would elevate the IL Program at the federal level, and would create an administration independent of and parallel to the Rehabilitation Services Administration (RSA) within the Department of Education.

The creation of this new administration marks a truly historic moment in the Independent Living Movement, and IL advocates across the country have much to celebrate.

The ILA is created through the reauthorization of the *Rehabilitation Act of 1973*, which is contained in the larger *Workforce Investment Act (WIA)*.

NCIL has been pushing for the reauthorization of *WIA* and the *Rehabilitation Act* for nearly a decade, and the introduction of a bill to reauthorize both pieces of legislation presents a unique opportunity to improve the IL Program and substantially increase consumer control at the federal level.

NCIL has been working closely with the Senate to create legislative language that will drastically overhaul America's IL Program and fix problems that have frustrated Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs) for years.



Although the majority of IL fixes and enhancements in this legislation cannot be listed in this document, here are some of the highlights:

- **Creation of an ILA:** a new organization within the Department of Education, completely separate and independent of RSA. The ILA Director will report directly to the Secretary of Education.
- **Carryover Authority:** CILs will now be allowed to carryover Part C funds not spent during the first year into a second year.
- **Addition of a 5th Core Service:** transitioning people with disabilities from nursing homes and other institutions to home and community-based residences.
- **Clarification of the Role of SILC:** Because of RSA's interpretations of the *Rehabilitation Act*, several clarifications regarding SILC activities are present in the bill, including the duties of providing advice and assistance to the Designated State Unit (DSU), facilitating the improvement and coordination of services, resource development activities, and carrying out systems advocacy functions.
- **Parts B and C:** Remain as separate funding streams as they have different uses.

- **Funding Formula Change:** Part C dollars should be allowed to be shared among all states and territories; states with the largest populations would receive more funding proportionally.
- **Accessibility at WIA One-Stop Centers:** one-stop centers will be required to be physically and programmatically accessible, regardless of disability.

After reading the draft legislative language reauthorizing *WIA* and the *Rehabilitation Act*, it is obvious that the Senate has listened to NCIL’s concerns and worked hard to create a piece of legislation that will empower and increase the independence of Americans with disabilities. It is also clear that we have the bipartisan support necessary to move this bill forward, but the fight to get the votes necessary in both chambers of Congress to pass this reauthorization into law has only just begun.

More than ever, IL advocates from across the country must now mobilize to push this historic legislation through Congress. Remember, this bill was created for us! We must immediately employ the full resources of the IL community to reach out to members of Congress and urge them to support the reauthorization of *WIA* and the *Rehabilitation Act*, specifically the inclusion of Title V language that creates an ILA and strengthens independent living.



Our unique opportunity to advance is now, and the time for action is today. Our first order of business is to get this through the Senate HELP Committee. If we are successful in our efforts, we will achieve one of the greatest advancements in the history of the Independent Living Movement.

*Remember.*

- The creation of the ILA does not require any new or additional funding.
- The creation of the ILA does not create unnecessary new bureaucracy. It simply streamlines the IL Program and enhances consumer control.

## The Independent Living Program

Centers for Independent Living are community-based, cross-disability, non-profit organizations that are designed and operated by people with disabilities. CILs are unique in that they operate according to a strict philosophy of consumer control, wherein people with all types of disabilities directly govern and staff the organization.

Centers for Independent Living Provide:

- Peer Support
- Information and Referral
- Individual and Systems Advocacy
- Independent Living Skills Training

America is home to:

- 403 Centers for Independent Living (CILs)
- 330 branch offices
- 56 Statewide Independent Living Councils (SILCs)

## Healthcare and Long-Term Services and Supports

NCIL has been very involved and supportive of the *Patient Protection and Affordable Care Act (PPACA)* since its inception, and we continue to advocate for an end to discrimination in the insurance market, the creation of affordable, comprehensive insurance options that meet the needs of people with disabilities, and finally addressing the long-term care crisis in our nation. NCIL strongly opposes any legislation that attempts to repeal, circumvent, or weaken the following provisions of the *PPACA*:

1. Community First Choice Option (CFCO)
2. Accessible Diagnostic equipment
3. Maintenance of Effort for State Medicaid Programs
4. Health Insurance Market Reforms:
  - a. Prohibition of pre-existing condition exclusions from coverage
  - b. Prohibition of discriminatory premium rates based on health status
  - c. Guaranteed issuance and renewability of coverage; all who apply must be accepted and maintained
  - d. Prohibition of discrimination in coverage: no eligibility requirements can be made by health insurers based on disability, health history or status, genetic information, or claims experience

## Ending Medicaid's Institutional Bias

NCIL strongly endorses legislation that requires states to provide alternatives to institutionalization for people with disabilities. Currently, every state is required by law to provide nursing facility placement, but community-based services remain optional, leaving them open to funding cuts year after year, despite Supreme Court decisions affirming that people with disabilities have the right to live in the most integrated setting. Consequently, millions of seniors and people with disabilities are forced into institutions to receive personal assistance services. We need legislation that requires states to offer community-based supports for Medicaid consumers who want to live in their homes and communities. It will provide a real alternative to institutional care that too many states lack.

## Reform Medicaid, Don't Gut It!

Medicaid is the public funding stream that provides health coverage for low-income children and adults, as well as long term services and supports for people with disabilities and low income seniors. Over 58 million Americans rely on Medicaid services, and millions more are connected to Medicaid in some way. Rather than cut Medicaid or pass legislation authorizing states to gut this critical safety net, Congress should implement real Medicaid reform by:

**Expanding the use of community-based services:** studies have demonstrated that by reducing the over-reliance on institutions and nursing facilities and shifting toward more cost-effective community-based services, states can contain Medicaid spending.

**Demedicalizing services:** by reducing the reliance on costly medical personnel to provide assistance by allowing attendants to perform these tasks, states could use the same amount of Medicaid funding to support more seniors and people with disabilities living in their own homes.

**Expanding consumer directed service options:** by empowering people to manage their own services and reducing the need for administrative overhead, states can also reduce Medicaid expenditures.

**Reorganizing Medicaid services to eliminate wasteful bureaucracy:** the current system wastefully organizes services based on diagnosis and age even though people may have the same functional needs. By organizing services based on functional needs states can eliminate redundant and needlessly expensive bureaucracies and reduce Medicaid expenditures.

## **Long-Term Care Insurance**

NCIL strongly supports a voluntary long-term care insurance program for working adults with disabilities. Such program would take the pressure off Medicaid, so that Medicaid can better serve the needs of people with disabilities and low income communities. Without a program like CLASS (Community Living Assistance Services and Support) or some variation of CLASS (which is part of the PPACA), the Medicaid program will continue to take on the load of long term service needs for many Americans, who will be forced into a lifetime of poverty to qualify for this assistance. NCIL will continue to support a voluntary, federally administered, consumer-financed insurance plan like the CLASS program and has urged that Members of Congress reform, rather than repeal, the program. Those who choose to participate in a plan would be able to get needed assistance in a place they call home. NCIL is concerned that repealing the CLASS program would result in Congress ignoring the crisis in long term services and supports. For this reason NCIL opposes *H.R. 1173, the Fiscal Responsibility and Retirement Security Act*.

## ***The Fairness in Medicare Bidding Act, Legislation to End Competitive Bidding***

*H.R. 1041*

The Centers for Medicare and Medicaid Services (CMS) created the competitive bidding program for purchasing Durable Medical Equipment, Prosthetics, Orthotics, and Supplies (DMEPOS). The program establishes rates for certain categories of equipment. It was intended to cut costs and reduce billing discrepancies. It has instead resulted in people not being able to find local providers, and delays in deliveries that have lengthened hospital stays and driven up costs. In 2008 the program was delayed, but again resumed stage one in 2011, and is in place in:

- Miami – Fort Lauderdale – Pompano Beach (FL)
- Orlando (FL)
- Cleveland – Elyria – Mentor (OH)
- Cincinnati – Middletown (OH, KY, IN)
- Charlotte – Gastonia – Concord (NC, SC)
- Dallas – Fort Worth – Arlington (TX)
- Kansas City (MO and KS)
- Pittsburgh (PA)
- Riverside – San Bernardino – Ontario (CA)

With the introduction to *H.R. 1041* and pressure from advocates, Congress delayed round two implementation until summer of 2013, which NCIL welcomed! Because of this competitive bidding, vendors have been eliminated from doing DMEPOS business with CMS. Currently, individuals living in the affected areas have been limited to choosing from only one or two vendors.

As this expands, in 2013 to 100 in the largest metropolitan statistical areas in round two, and requires the use of competitively bid prices in all areas by 2016, we're going to see more and more people with disabilities affected by this, especially in the rural areas of our nation. For this reason, NCIL supports *H.R. 1041*.

# Healthcare and Long-Term Services and Supports

## Reauthorization of the *Traumatic Brain Injury (TBI) Act*

*Yet To Be Introduced in the 112th Congress*

NCIL supports introduction and passage of a strong reauthorization of the *TBI Act*, which is set to expire in 2012. This is the only federal legislation that specifically assists states and other entities to develop and expand service delivery systems and provide needed advocacy to meet the needs and protect the rights of individuals who have sustained a TBI and their families. TBI is a leading cause of death and disability among young Americans and continues to be one of the signature injuries of the wars in Iraq and Afghanistan. From the battlefield to the football field, American adults, youth, and children sustain TBIs at an alarming rate. Federal assistance through *TBI Act* programs continues to address the needs of this growing population. The Centers for Disease Control (CDC) estimates that at least 3.17 million children and adults live with a permanent disability as a result of a TBI. The *TBI Act* offers balanced and coordinated public policy in brain injury prevention, education, and research, and provides advocacy and community-based services for individuals living with TBIs and their families. Specifically, the *TBI Act*:

- Authorizes CDC to identify strategies to prevent TBI and implement public education programs to increase awareness and understanding of TBI;
- Authorizes the Health Resources and Services Administration (HRSA) to make grants to states to coordinate, expand, and enhance service delivery systems;
- Directs the National Institutes of Health (NIH) to conduct basic and applied research related to TBI; and
- Authorizes HRSA to make grants for the Protection and Advocacy for Traumatic Brain Injury (PATBI) program, which provides critical advocacy services to ensure that people with TBIs live full and independent lives free from abuse, neglect, and financial exploitation.

Reauthorization of the *TBI Act* is critical for individuals and families impacted by a TBI. Individuals who have sustained a TBI often need a complex array of services, including medical and social services and employment assistance, and the *TBI Act* provides programs that allow citizens to work and live in their homes and communities. The law also authorizes programs that increase public awareness for citizens and the medical community alike, so that the prevalence of TBI is reduced and the best treatment options are available across the nation.

## Prohibiting Discrimination Based on Disability in Healthcare

Comprehensive implementation and enforcement of nondiscrimination laws, regulations, and principles will help reduce healthcare disparities based on disability and reduce the impact of societal prejudice and negative stereotypes on access to quality healthcare.

In addition, the reauthorization of the *Traumatic Brain Injury (TBI) Act* and its funding for protection and advocacy services for people with TBI can help prevent various forms of discrimination against people with traumatic brain injury, including healthcare discrimination. Following a traumatic brain injury, individuals are frequently comatose or non-responsive for a significant period of time. While neurological data indicates that a one year waiting period is sufficient to enable a relatively reliable prediction that the individual will not become responsive, some healthcare providers are not observing a one year waiting period but are rushing to judgment. Healthcare providers that rush to

judgment express the opinion that the individual will never awaken and / or that the individual will be “severely disabled”, and either persuade family members to withhold food and fluids or other life support from the individual or unilaterally withhold healthcare under futile care policies. Protection and advocacy services can help prevent this lethal form of disability discrimination.

Additional forms of healthcare discrimination based on disability should be addressed through a combination of protection and advocacy enforcement efforts, regulatory development focused on preventing disability based discrimination, and policy work guided by the principle “nothing about us without us.” Among the most urgent areas of concern are:

- discrimination in organ transplants and related services;
  - transplant organs are often denied based solely on disability, as we saw recently in Philadelphia
- discrimination in organ procurement practices;
  - proposed protocols allow organ procurement to be discussed prior to the decision to withdraw life-sustaining treatment from some persons with disabilities
- discriminatory "futile care" policies allowing healthcare providers to use quality of life judgments to overrule the decision to receive life-sustaining treatment made by individual, surrogate, or advance directive;
- discriminatory relaxing of constitutional and statutory constraints on the power of guardians to withhold or withdraw life-sustaining treatment from people with disabilities; and
- discriminatory rush to judgment and denial of life sustaining treatment of newly injured persons based on hasty and unsupportable diagnosis of "persistent vegetative state" (PVS) earlier than 90 days for an anoxic brain injury, or one year for a traumatic brain injury, and before careful testing consistent with guidance from research studies on misdiagnosis of PVS.



## Assisted Suicide

Finally, NCIL has long opposed the legalization of assisted suicide. Equal rights include equal suicide prevention. In the two states that have legalized assisted suicide by ballot referendum, Oregon and Washington, data indicates that people request assisted suicide for reasons directly related to disability-based oppression, such as feelings of loss of autonomy and dignity, and feelings of being a burden on others.

These factors are the direct result of both negative stereotypes and public policies that deny people the consumer-controlled long-term services and supports that they need to feel respected and valued throughout life to a natural death. Assisted suicide laws set up a double standard whereby most suicidal people get suicide prevention while certain others get suicide assistance. For those who are old, ill, or “disabled enough”, society will not only agree that suicide is appropriate but will provide the lethal means to complete the act. This form of discrimination violates the *ADA* and must be opposed.

## **Employment and Economic Equity**

The Social Security Administration (SSA) has begun work on the Social Security Work Incentives Simplification Pilot (WISP) to provide beneficiaries a simpler set of work rules that no longer terminate benefits based on earnings. NCIL states that the WISP project is not enough to change current law and SSA programs to today's mindset that Americans with disabilities belong in the workplace with good jobs and benefits.

NCIL strongly recommends that any SSA work incentives improvements include internal Social Security reform to stop chronic overpayments to Social Security disability beneficiaries, especially to beneficiaries who return to work or start work for the first time.

Social Security must take steps now to change wage reporting rules in the Title II (SSDI), Title XVI (SSI) and Title XIX (Medicaid) programs in a proactive partnership with the Centers for Medicare and Medicaid Services.

NCIL requests the Social Security Office of Operations, in partnership with the Social Security Office of Employment Support Programs, to establish basic, thorough, and public guidelines that prescribe a business model partnership between local Social Security Field Offices, Social Security Work Incentives Planning and Assistance (WIPA) grantees, and anyone who processes Social Security Title II, Title XVI and Title XIX work incentive rules by January 2013.

## **Employment Support Insurance: Frame the Two-Plan Vision**

Since Senator Harkin's Disability Community Employment Retreat in 2010, the World Institute on Disability-NCIL-Mathematica Policy Research Employment Summit in 2011, and the creation of WID's new Center on Economic Growth, major economic empowerment proposals have come to light and been discussed. It is time to frame the vision and transform current employment and benefit proposals into legislative action.

NCIL continues to support creation of an Employment Support Insurance (ESI) program that would provide health coverage through new models of Medicare, benefits planning services, and referrals to employment support services.

Employment Support Insurance is the missing policy link between breaks in employment, worker's compensation and today's Social Security disability programs. ESI would be similar to the social insurance model that SSDI uses now, with Federal Insurance Contributions Act (FICA) payroll deductions to fund some of its services. ESI would provide needed supports that are now missing between jobs, or when seeking employment and receiving SSI or SSDI.

The current SSDI program – or one like it - would maintain its earnings replacement components under an improved Earnings Replacement Insurance (ERI) program. Medicare coverage would be available right away in a new ERI program. The ESI program would provide income support, health coverage, benefits planning, and referral services to people transitioning off the ERI program when returning to work.

A well thought out two-plan model protects the life-saving aspects of current disability insurance systems while addressing their oppressive nature and inefficiencies. A two-plan model, with one program supporting work success and the second program accessed because of the documented high costs of managing a long-term disability could, together, replace current SSA disability programs and do no harm in the process. It is time for us to frame the vision and help Congress implement it.

NCIL seeks Congressional action this year on three legislative initiatives:

## **Social Security Work Incentive Amendments of 2012**

*Not Yet Introduced in the 112th Congress*

It is uncontested that SSA disability program work rules remain complex and impossible to navigate without expert help and current information. SSA projects to simplify their disability program work rules remain in the pilot stage. Findings from SSA-funded research estimate that each current WIPA benefits counselor has an estimated caseload of 5,000 beneficiaries who are taking concrete steps to seek work, an impossible caseload by anyone's standard.

NCIL urges Congress to immediately introduce, improve, and pass Social Security's January 2012 legislative draft sent to Congress, cited as the "Social Security Work Incentive Amendments of 2012." Flat funded since 2000, the SSA Work Incentives, Planning and Assistance Program remains underfunded based on recent findings regarding the numbers of SSA disability beneficiaries who are making attempts to work or working today (Livermore 2009). Based on many public discussions and forums with SSA senior officials, the new bill should increase funding for employment and benefits counseling and require widespread use of online tools that save time and staff costs, and can reach wider numbers of beneficiaries planning to work.

## **ABLE Act**

*H.R. 3423*

NCIL recommends the Congress improve, amend, and pass *H.R. 3423*, which creates a new subsection (f) within Section 529 of the Internal Revenue Code. Well known and uncontested research shows that living with a long term disability comes with higher out of pocket costs (Fremstad, 2009). The bill will encourage individuals and families to save private funds in an ABLE Account to support individuals with disabilities to maintain our health, employment, independent living, and self-sufficiency.

## **SSI Savers Act of 2011**

*H.R. 2103*

NCIL recommends the Congress improve, amend, and pass the *SSI Savers Act*, which would enable and encourage recipients of the Supplemental Security Income (SSI) program to work, save and build wealth, to increase asset limits from \$2,000 (single) and \$3,000 (married) to \$5,000 and \$7,500 respectively, and to exclude retirement accounts, education savings, and individual development accounts from counting against current SSI asset limit rules.

NCIL recommends adding the following policy to either the *ABLE Act* or the *SSI Savers Act* through the amendment process:

With respect to the *Social Security Act* Title XVI (SSI) program and all Title XIX Medicaid services and waivers, any royalty which is earned in connection with any publication of an individual's work shall be treated as earned income irrespective of the extent to which a pattern of publication of such individual's work has been established; and any portion of any grant, scholarship, or fellowship which is allowed to be used by the recipient for the costs incurred to access personal assistance services (PAS) shall be excluded from all income rules in the referenced programs and federal waivers.

## Education

All students with disabilities have the right to an equal education. Furthermore, students with disabilities must be assured a high quality education that provides the opportunity to acquire the same knowledge and skills as their peers through participation in the general curriculum and access to teachers qualified to teach students with diverse learning needs.

Implementation and enforcement of the *Individuals with Disabilities Education Act (IDEA)* and the *Elementary and Secondary Education Act (ESEA)* must be improved.

Reauthorization of *ESEA* provides Congress with the opportunity to reaffirm and strengthen provisions that will ensure that all students receive a quality education. Specific items that need strengthening include:

- empowerment of students with disabilities with information about education rights, services, and expectations;
- integration of academic instruction, school activities, and planning to promote successful transition from school to adult life;
- accountability standards focused on improving the graduation rate of students with disabilities;
- integration of *IDEA*, *ESEA* and Section 504 of the *Rehabilitation Act* requirements;
- development of standards to ensure all students have full, meaningful access to quality instruction in the regular curriculum;
- assessment programs aligned with the curriculum and used as a means to make schools accountable to students and their families; and
- requirements for disaggregation of assessment data and use of the data to improve educational opportunities.



### ***Keeping All Students Safe in School Act***

*H.R. 1381 and S. 2020*

Restraining and secluding students must be ended. The Government Accountability Office (GAO) reported widespread misuse of restraint and seclusion.

This necessary legislation was introduced to make it clear to schools that continued use of these dangerous, harmful and unnecessary practices end.

The bill will impose a floor of protections against the use of restraints and seclusion for students.



## Veterans' Issues

NCIL supports efforts to provide all Veterans and their families with services and benefits in the most effective and efficient manner possible in recognition of their service and sacrifice. Specifically, NCIL supports:

- Reform by the VA and Congress for the Veterans Benefits Administration (VBA) claims process to ensure consistency, true reforms with timely processing, and adjudication of claims.
- A focus by the Department of Defense (DoD), VA, and Congress to provide proper supports for veterans who have PTSD, Traumatic Brain Injury, and Mental Health issues as a result of service.
- Transition from military to civilian life involves the veteran's ability to work competitively. Congress must provide funding for education, employment, and training programs to meet increasing needs.
- Congress must ensure that the Veterans Health Administration (VHA) receives appropriate and sufficient funding for veterans' healthcare while sustaining quality and satisfaction. This would include continued expansion of community-based living options such as Veterans Directed Home and Community Based Services, Medical Foster Homes, and the *Family Caregivers Act*.
- Our President and Congress should continue to address the issue of current homeless Veterans and support efforts to prevent homelessness. Such efforts already include supporting housing resources through VA and HUD.



NCIL recommends that consideration be given to including USDA Rural Development / Rural Housing as a partner, since they already provide housing services across the country and could include targeted education and outreach to Veterans and active duty populations on housing issues especially in non-urban parts of the country.

- Congress must ensure that existing benefits received by veterans and their families are not reduced. In addition, there should be no reduction in future benefits for veterans and their families.

Since September 2001 there have been benefits created specifically for post-9/11 military members and deservedly so. It is time to examine the availability of those benefits for veterans who served pre-9/11.

- There are factors affecting the daily living of families and veterans that require the services they need to be available in the communities where they live.



There needs to be continued effort by Congress, DoD, and the VA to engage and collaborate with community-based organizations like Centers for Independent Living, which stand ready to continue serving veterans and their families.

# Protecting and Expanding Our Housing Opportunities

NCIL supports initiatives to increase accessible, affordable, healthy / non-toxic, decent, safe, and integrated housing. NCIL is a cross-disability organization and applies the term accessible broadly, emphasizing physical accessibility, accommodations for persons with sensory (visual or hearing), emotional, developmental and intellectual disabilities, and persons with chemical and electrical sensitivities. The need for housing that accommodates a wide-range of disabilities is increasing due to community living options replacing costly and unjust institutionalization, many veterans returning with disabilities, the high rate of homelessness among people with disabilities, and the aging of the general population.

## Appropriations

As of publication of this document, the appropriations discussion in Congress has become very contentious. NCIL believes that programs serving communities have been enormously beneficial to people with disabilities, and is opposed to cuts in programs such as:

- Community Development Block Grants (CDBG) and HOME Investment Partnership Program
- Project-based Housing (Both HUD and USDA Rural Housing)
- Public Housing
- Housing and programs for people who are homeless
- Housing Choice Vouchers (including those for persons with disabilities)

In addition, NCIL supports the efforts of the Department of Housing and Urban Development to transform its programs and create sustainable neighborhoods with input from NCIL and other organizations.

## ***Inclusive Home Design Act***

*Not Yet Introduced in the 112th Congress*

The *Inclusive Home Design Act* requires that newly constructed, federally assisted single family houses and town houses include at least one level that complies with accessibility features for persons with mobility disabilities including: an accessible entrance, accessible interior doors, accessible environmental controls, an accessible habitable space, and an accessible bathroom. These features will make housing available to persons with mobility disabilities, prevent unnecessary expenses for renovations, and will allow seniors to age in place, negating the need for costly institutionalization.

## ***Preserving Homes and Communities Act of 2011***

*H.R. 1477 and S. 489*

This bill would provide some additional protections to homeowners facing foreclosure by requiring the lender to make their best effort to assist the homeowner with loan modifications and alternative options to foreclosure. It would also prohibit the lender from proceeding with the foreclosure as the borrower tries to modify the mortgage. It would also establish mediation programs through HUD grants for those facing foreclosures. It would fund the National Housing Trust Fund with \$1 billion using the sale of assets (stocks) acquired by the Treasury Department through the Troubled Asset Relief Program.

## **National Housing Trust Fund**

The National Housing Trust Fund (NHTF) was created in 2008 with funding intended to originate from Fannie Mae and Freddie Mac. After the real estate market crash, the futures of both agencies are

uncertain. Full funding of the NHTF has been a NCIL legislative priority since its inception. The NHTF will create and preserve housing for the lowest income Americans, which disproportionately includes households with a member who has a disability. There is currently a proposal to fund the NHTF in the *Preserving Homes and Communities Act*. Unfortunately, there are also attempts to abolish the NHTF. NCIL opposes any attempts to abolish the Trust Fund.

## ***Section 8 Voucher Reform Act and Affordable Housing and Self-Sufficiency Improvement Act***

*H.R. 1209; Not yet introduced in the 112th Congress*

NCIL understands the need to simplify the Section 8 program in a manner that is cost-effective for the federal government and does not result in increased rental payments for a majority of tenants. The *Section 8 Voucher Reform Act (SEVRA)* and the *Affordable Housing and Self-Sufficiency Improvement Act of 2011 (AHSSIA, formerly the proposed Section 8 Savings Act)* are intended to simplify the rules concerning the Section 8 Housing Choice Voucher program. While NCIL supports many of the reforms, we are very concerned that some changes would have a negative impact on people with disabilities, such as higher minimum rents.

There are several work disincentives in the *SEVRA* bill, including replacing the Earned Income Disregard for people returning to work after receiving benefits for at least 12 months. In addition, the reductions in the income adjustments for unreimbursed medical expenses have the potential to make subsidized rent unaffordable for many seniors and persons with disabilities.

NCIL believes that while *SEVRA* was well-intentioned and had the potential to achieve many of its stated goals, the people who can least afford it would be impacted negatively. Our initial analysis shows that some people with disabilities receiving housing assistance will see their portion of the rent increase. The Center for Budget and Policy Priorities' analysis of *AHSSIA* indicates that people with higher medical expenses, such as people with disabilities and older adults, would also still face rent increases under *AHSSIA*. Both *SEVRA* and *AHSSIA* also include the Moving to Work expansion, discussed in the next section. As long as both bills include changes harmful to people with disabilities and the Moving to Work expansion, NCIL will oppose these bills.

## **Moving to Work**

Moving to Work (MTW) is an unproven pilot program involving a small number (35) of Public Housing Authorities that allows PHAs to waive many federal regulations covering the use of funding for housing programs. NCIL is concerned that those changes can negatively impact households with a member with a disability. There has been no thorough study of the impact of Moving to Work on its tenants, and in fact, there are indications that Moving to Work PHAs are less effective in the use of federal funding.

*SEVRA* proposes a MTW-style expansion called "Housing Innovations Program" that would double the number of eligible agencies. *AHSSIA* would allow an unlimited number of agencies to participate in the Moving to Work program. Moving to Work also has been proposed as a stand-alone bill by Representative Gary Miller which, according to the Center on Budget and Policy Priorities (CBPP), would change it into a block grant program. CBPP notes that historically, block grant programs have not fared well in budget appropriations and a MTW expansion would very likely result in smaller housing appropriations and harsh cuts by the PHAs. HUD has never fully evaluated the current Moving to Work programs. NCIL's opposes expansion until a thorough evaluation has taken place.

## Transportation: The Lynchpin to Independence

In today's society, economic competitiveness and success in the 21st century is dependent upon revolutionary ideas and solutions providing Americans, including individuals with disabilities, with accessible transportation options which connect our cities, regions, and rural areas. The goal of NCIL's transportation committee is to promote the inclusion of individuals with disabilities into society by designing accessible transportation systems and encouraging pedestrian safety.

NCIL would like all new and innovative public and private transportation systems that transfer passengers including individuals with disabilities from one point to another to be accessible for all passengers. Also, pedestrian safety and the rights-of-way must be designed to maximize accessibility to all community-based services, programs, activities, and employment opportunities that are available to the general public.

There are three areas of concentration that will maximize community integration, involvement, and participation of individuals with disabilities in the following ways:

- Rural transportation services, including transportation services between one municipality and another: NCIL strongly supports increased availability and greater access to affordable and accessible rural transportation as well as a coordinated plan to ensure such transportation services among and between all; cities, urban, and rural areas. To maximize the availability of rural accessible transportation services, this rule of accessibility must also apply to small airplanes.
- Livable communities: Safe and accessible rights-of-ways including Complete Streets Legislation, which are all essential elements of community life.
- Private Transportation Services: Legislation is needed to increase the number and availability of accessible vehicles within the private transportation industry i.e. taxis, limousines, shuttle service, car rentals, buses, trains etc.

Without reforming the current outdated transportation infrastructure, increased investment in transportation alone will not solve the problems that plague Americans, especially individuals with disabilities on a daily basis who are ready for a new direction and demand transportation options that are affordable and accessible.

NCIL believes that Congress must move toward a 21st century system that focuses on accountability and results while creating jobs, providing access to opportunity for all Americans, including individuals with disabilities, reducing carbon emissions and our dependence on foreign oil, and improving America's economic competitiveness.

Transportation is one of the most significant barriers facing people with disabilities and often affects the opportunity to live independently. When America honors the equal access intent of the *Americans with Disabilities Act* by ensuring accessible and affordable public transportation, people with disabilities will have the same travel options available to everyone else, allowing them to attend school, maintain employment, travel within the communities of their choice, and fully participate in the American Dream.

NCIL supports a federal standard requiring all taxi fleets in America to be wheelchair accessible and



universally designed as soon as feasibly possible and encourages the Access Board to develop and adopt a minimum standard of universal design for all taxicabs.

### ***Safe and Complete Streets Act***

*H.R. 1780 and S. 1056*

The *Complete Streets Act* requires all federally-funded transportation projects to use the “complete streets principles,” which provide safety and convenience standards. By establishing compliance standards, all users, including people with disabilities, will have better access to transportation and increased independence.

### ***Allowing Local Control of Federal Transit Funds Act***

*Not Yet Introduced in the 112th Congress*

Local transit systems need and require flexibility with federal funds through an incentive program where state and local governments will be able to use a percentage of their funds for operations. NCIL supports this legislative idea because it will reduce fare increases and cuts to vital Public transportation services, which are widely used by people with disabilities.

### ***Safe, Accountable, Flexible, Efficient Transportation Equity Act***

*Not Yet Introduced in the 112th Congress*

The *Safe, Accountable, Flexible, Efficient Transportation Equity Act (SAFETEA)* authorizes funds for highways, highway safety and transit programs, and paratransit, including fixed route and demand-responsive services. Reauthorization of this legislation is critical to providing equal access to public transportation in accordance with the *Americans with Disabilities Act*.

### **Non-Discrimination on the Basis of Disability in Air Travel**

NCIL is pleased to see that the *Air Carrier Access Act* might cover kiosks owned by airports in addition to those owned by carriers under new proposed rules by the Department of Transportation. However, this proposal should include an explanation that public airports otherwise covered by the *ADA* or the *Rehabilitation Act* are still accountable under those laws, which may be enforced by private parties.

NCIL supports many of the DOT’s substantive accessibility proposals for both websites and kiosks. We agree that the Website Content Accessibility Guidelines (WCAG) 2.0, Level AA, are the appropriate technical standards for websites. However, we strongly believe that it should be paired with a performance standard to maximize accessibility and usability. Technical standards alone will not ensure usability. NCIL recommends adding a performance standard that will guarantee that individuals with disabilities have the same access and website experience as users without disabilities and substantially similar ease of use.

Mandates for accessibility of websites and kiosks are long overdue; DOT must not make the same mistake by neglecting to address mobile apps until several years from now.



# Convention on the Rights of Persons with Disabilities (CRPD)

The Convention on the Rights of Persons with Disabilities (CRPD) is a treaty, adopted by the international community in 2006, confirming the human rights of people with disabilities.

The treaty does not create new or different rights for people with disabilities, but rather addresses existing human rights in the context of disability. The treaty's standards exceed those currently found in many countries and have advanced disability accessibility and inclusion around the world.

The treaty addresses equality, non-discrimination, and the right of access for people with disabilities in such areas as education, healthcare, and community life. In the same way that groundbreaking U.S. laws such as the *Americans with Disabilities Act* and the *Individuals with Disabilities Education Act* have achieved major societal changes domestically, the CRPD is changing the world for people with disabilities.

## Ratification of the CRPD in the U.S.

President Obama ordered the United States to become a signatory to the treaty on the 19th Anniversary of the ADA in 2009. The Obama Administration has now been reviewing the treaty text in preparation of sending it to the U.S. Senate for its advice and consent for U.S. ratification. Ratification would make the U.S. a full party to the agreement and legally bound to uphold its obligations.



Following its inter-agency review, the Administration submits to the Senate what is known as a "transmission package." This document will provide senators with an analysis of how U.S. law and policy currently comply with the treaty, and identify any areas where the U.S. may need to file a "reservation, understanding or declaration" regarding its obligations.

Soon, the Administration's review will conclude and treaty advocates expect to see the transmission package submitted to the Senate Foreign Relations Committee to begin the Senate process.

NCIL and a number of CILs are members of the U.S. International Council on Disabilities (USICD), a membership organization that is leading the education and advocacy campaign for U.S. ratification of the CRPD. NCIL supports United States ratification of the CRPD, and is working with USICD to raise awareness and understanding of this treaty.

The engagement of the U.S. disability community in the ratification process will become especially critical once the Senate has received the Administration's transmission package. In the U.S., ratification of a treaty requires a 2/3 super-majority vote of Senate (or 67 votes). Grassroots support will be vital in order to achieve the votes required to ratify this landmark treaty.

USICD's Education and Advocacy Initiative offers a speakers bureau connecting CRPD presenters to diverse audiences about the treaty via teleconference, webinars, or in person. Those interested in a presentation on the treaty are encouraged to contact USICD at [info@usidc.org](mailto:info@usidc.org). More information on the treaty is also available at [www.usidc.org](http://www.usidc.org).



## Available and Accessible Technology

NCIL strongly advocates for access to mainstream and assistive technologies (AT) that enable and enhance independence for people with disabilities through supporting the principles of Universal Design, inclusion, consumer control, and peer support as they apply to the use, development, and delivery of mainstream and assistive technologies.

People with disabilities are best served by available and affordable “hands-on” exposure to technology. NCIL encourages the use of Universal Design to make technology inclusive and accessible to people with disabilities and supports legislation and efforts that develop and enforce access standards in existing and emerging technologies.

### ***Assistive Technology Act***

*Not Yet Introduced in the 112th Congress*

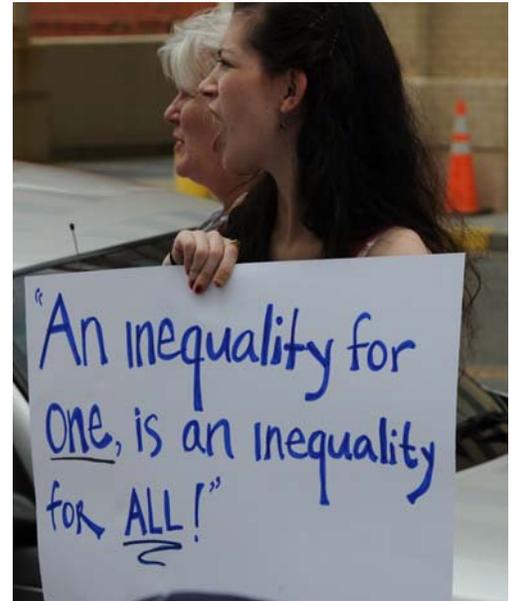
NCIL supports funding of the *Assistive Technology Act* by Congress because it assists consumers in learning about, experimenting with, and acquiring assistive technology in pursuit of their independence.

Eight years after the 2004 amendments, many of the state AT Programs, not including the territories, have yet to receive the \$410,000 minimum grant award authorized in the *Assistive Technology Act*.

Many states have no alternative finance programs or limited programs. By supporting the *Assistive Technology Act* and increasing its funding, Congress can help people with disabilities.

NCIL was encouraged by Congress’s support of the *Assistive Technology Act* by infusing an additional two million dollars into the act to support Alternative Finance Programs and strengthening consumer control measures for new entities competing for those funds.

NCIL is charged by Congress to convene stakeholder input sessions around reauthorization of the *Assistive Technology Act*.



## More Information

For more information about the issues in this document, please contact the NCIL Policy Team.



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# About the National Council on Independent Living

The National Council on Independent Living is the longest-running national cross-disability, grassroots organization run by and for people with disabilities.

## Mission

As a membership organization, NCIL advances Independent Living and the rights of people with disabilities through consumer-driven advocacy.

## Vision

The National Council on Independent Living envisions a world in which people with disabilities are valued equally and participate fully.

## History

Founded in 1982, the National Council on Independent Living is one of America's leading and the oldest cross-disability, national grassroots organization run by and for people with disabilities.

We represent Centers for Independent Living (CILs,) Statewide Independent Living Councils (SILCs,) and other disability rights organizations serving hundreds of thousands people with disabilities in every state and territory of the country.

An outcome of the national Disability Rights and Independent Living Movements, NCIL was founded to embody the values of disability culture and Independent Living philosophy, which creates a new social paradigm and emphasizes that people with disabilities are the best experts on their own needs, that they have crucial and valuable perspective to contribute to society, and are deserving of equal opportunity to decide how to live, work, and take part in their communities.

Since its inception, NCIL has carried out its mission by assisting member CILs and SILCs in building their capacity to promote social change, eliminate disability-based discrimination, and create opportunities for people with disabilities to participate in the legislative process to affect change.

NCIL promotes a national advocacy agenda set by its membership and provides input and testimony on national disability policy.

NCIL works with people with disabilities and other important community organizations concerned with the civil and human rights of the disability community to advocate for crucial legislation that gives legal standing to the rights of people with disabilities and expands the possibility for full integration and equal opportunity.



**Legislation NCIL Supports:**

<i>Not Yet Introduced</i>	<i>Community Choice Act</i>
<i>H.R. 5466</i>	<i>SAMHSA Modernization Act</i>
<i>H.R. 1041</i>	<i>The Fairness in Medicare Bidding Act, Legislation to End Competitive Bidding</i>
<i>Not Yet Introduced</i>	<i>Social Security Work Incentive Amendments of 2012</i>
<i>H.R. 3423</i>	<i>ABLE Act</i>
<i>H.R. 2103</i>	<i>SSI Savers Act of 2011</i>
<i>H.R. 1381 and S. 2020</i>	<i>Keeping All Students Safe in School Act</i>
<i>Not Yet Introduced</i>	<i>Inclusive Home Design Act</i>
<i>H.R. 1477 and S. 489</i>	<i>Preserving Homes and Communities Act of 2011</i>
<i>H.R. 1780 and S. 1056</i>	<i>Safe and Complete Streets Act</i>
<i>Not Yet Introduced</i>	<i>Allowing Local Control of Federal Transit Funds Act</i>
<i>Not Yet Introduced</i>	<i>Safe, Accountable, Flexible, Efficient Transportation Equity Act</i>
<i>Not Yet Introduced</i>	<i>Assistive Technology Act</i>
<i>Not Yet Introduced</i>	<i>Ratification of the Convention on the Rights of Persons with Disabilities</i>
Reauthorization of:	
<i>Not Yet Introduced</i>	 <i>Rehabilitation Act, with increased funding for Independent Living</i> <i>Violence Against Women’s Act</i> <i>Traumatic Brain Injury (TBI) Act</i>
<i>S. 1925</i>	
<i>Not Yet Introduced</i>	

**Legislation NCIL Opposes:**

<i>H.R. 1209</i>	<i>Section 8 Voucher Reform Act</i>
<i>Not Yet Introduced</i>	<i>Affordable Housing and Self-Sufficiency Improvement Act</i>
<i>H.R. 1173</i>	<i>Fiscal Responsibility and Retirement Security Act</i>
<i>Not Yet Introduced</i>	<i>ADA Notification Act</i>
<i>H.R. 2</i>	<i>Repealing the Job-Killing Health Care Law Act and related measures</i>
<i>S. 868</i>	<i>State Flexibility Act</i>
<i>H.R. 1173</i>	<i>Fiscal Responsibility and Retirement Security Act</i>
	Any legislation that:
	<ul style="list-style-type: none"> <li>• Caps spending globally, including the <i>CAP Act</i></li> <li>• Block Grants Medicaid</li> <li>• Requires photo identification to vote</li> <li>• Legalizes assisted suicide</li> </ul>



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