



## Legislative & Advocacy Priorities

Summer 2012



## A Message from the Executive Director

Dear Advocates and Allies,

I am pleased to announce the release of the Summer 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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# Independent Living and Reauthorization of the *Rehabilitation Act*

NCIL is very proud and excited to announce that Democrats in the House have introduced *H.R. 4227, the Workforce Investment Act of 2012* with language proposed by NCIL on the historic establishment of an Independent Living Administration (ILA).

A discussion draft has been created in the Senate HELP (Health, Education, Labor & Pensions) Committee that establishes an Independent Living Administration and strengthens America's Independent Living Program. This means that there is now a bill in both the House and Senate containing language creating the new national IL Administration at no additional cost.

Unfortunately, House Republicans have also created their own bill to reauthorize *WIA* and the *Rehabilitation Act: the Workforce Investment Improvement Act of 2012 (H.R. 4297)*. NCIL opposes *H.R. 4297* because it does not include language creating an IL Administration.

The ILA would elevate the IL Program at the federal level and 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.

NCIL has been pushing for the reauthorization of *WIA* and the *Rehabilitation Act* for over 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 House and 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.

Two bills to reauthorize *WIA* have been introduced in the House and one in the Senate.

NCIL supports:

- *H.R. 4227*
- *Draft Senate HELP Committee Legislation*

NCIL opposes:

- *H.R. 4297*

- **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 legislators have 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 IV language that creates an ILA and strengthens independent living.

Our unique opportunity to advance is now, and the time for action is today. The first order of business is to contact members of the House Education & the Workforce Committee and the Senate HELP Committee expressing our strong support for passage of the reauthorization of *WIA* and the *Rehabilitation Act*. 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:

- |   |  |
|---|--|
| <ul style="list-style-type: none"> <li>• Peer Support</li> <li>• Information and Referral</li> <li>• Individual and Systems Advocacy</li> <li>• Independent Living Skills Training</li> </ul> | <p>America is home to:</p> <ul style="list-style-type: none"> <li>• 403 Centers for Independent Living (CILs)</li> <li>• 330 branch offices</li> <li>• 56 Statewide Independent Living Councils (SILCs)</li> </ul> |
|---|--|

## 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 a 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), which is part of the *PPACA*, or some variation of CLASS, the Medicaid program will continue to bear 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 round two in 2013 to 100 of the largest metropolitan statistical areas (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 a lack of access to vendors of critically needed supplies, 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.

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.

# 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 aging of the population.

## Appropriations

NCIL opposes the House Budget Resolution, which may result in 22% cuts to HUD programs. [HUD Secretary Donovan has estimated it would result in loss of housing for over 1 million households.](#) NCIL supports HUD's efforts to transform its programs and create sustainable neighborhoods with input from NCIL and other organizations and is opposed to cuts in programs such as:

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

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

*H.R. 5781*

*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. NCIL has opposed *AHSSIA* in the past, but it currently is being revised. There are not enough details yet, but it is very possible that the changes will improve *AHSSIA*. Previously, the Center for Budget and Policy Priorities' analysis of *AHSSIA* indicated 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. HUD has never fully evaluated the current Moving to Work programs. NCIL's opposes expansion until a thorough evaluation has taken place.

## ***Veterans, Women, Families with Children and Persons with Disabilities Housing Fairness Act***

*H.R. 284*

NCIL opposes housing discrimination, particularly as it pertains to individuals with disabilities. According to the National Fair Housing Alliance, 44% of all housing discrimination complaints are connected to disability concerns in 2011. This legislation would provide more support to address the housing discrimination through increased funding and stronger reporting requirements for HUD.

## Civil Rights and the *Americans with Disabilities Act*

Several bills pending in the House and Senate would, if passed, prevent the Department of Justice from enforcing regulations to increase access for people with disabilities to swimming pools, lakes, recreation centers, and resorts:

*H.R. 4200*

Sponsor: Dave Schweikert (R-AZ)

*H.R. 4256*

Sponsor: Mick Mulvaney (R-SC)

*S. 2186 and S.2191*

Sponsor: Jim DeMint (R-SC)

The bills are part of a targeted process to undermine the strong federal enforcement role urgently needed under the *ADA* and would set a dangerous precedent that could deny people with disabilities the chance to participate in a broad range of activities extending far beyond swimming pools. Access to recreational activities is a critical part of participating fully in the community. The bills would affect both Title II (concerning state and local governments) and Title III (concerning privately operated places of public accommodation) of the *ADA*.

The *ADA* has required access into the water for state and local government swimming facilities since its passage nearly 22 years ago, so hotel and other pool owners were not taken by surprise by new regulations that were slated to go into effect in March, 2012. The *ADA's* accessibility requirements for barrier removal in existing facilities are very reasonable and require only what can be done without much difficulty or expense. Tax incentives, which have always been available and under- utilized by businesses, negate the financial hardship argument put forth by the hospitality industry. IRS Tax code 44 and 190 provide generous credits and deductions that let the hotel owner recoup the money spent.

## ***The Violence Against Women Reauthorization Act***

*S. 1925*

NCIL strongly supports the *Violence Against Women Act* and adamantly endorses its reauthorization in the House as it was passed by the Senate. *The Violence Against Women Reauthorization Act* provides a five year authorization for *VAWA* programs, and also includes important all-state minimum funding formulas for key grant programs, to ensure that small, rural states have access to the victim services grants authorized under *VAWA*. Over the past 17 years, *VAWA* has created highly successful programs and laws that have changed the landscape for victims of domestic violence, dating violence, sexual assault, and stalking. *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. Since *VAWA* was passed in 1994, reporting of domestic violence has increased as much as 51% and the number of individuals killed by an intimate partner has decreased by 34% for women and 57% for men. *VAWA* saved \$12.6 billion in its first six years alone.

## **Voting Rights**

NCIL opposes photo identification requirements for voting. The *Help America Vote Act (HAVA)* takes important steps to tear down barriers to voting by requiring polling places to be accessible. It is important that we continue to move forward in election reform by removing barriers to voting and encouraging active participation in the political process. Measures requiring the use of photo identification to vote have not proven to be an effective tool to fight voter fraud and legislation requiring photo identification to vote will only reduce voter turnout by erecting yet another barrier.

Many states are moving to vote-by-mail systems. Oregon and Washington no longer have polling places, and half of California votes are cast by mail. A mail-in ballot does not comply with *HAVA's*

accessibility mandate. Therefore, NCIL supports technology and systems that allow citizens with disabilities to cast accessible, secret, and independent ballots by mail.

### ***SAMHSA Modernization Act***

A companion has not yet been introduced in the Senate, but *H.R. 5466* was introduced in the last Congress to amend the *Public Health Service Act* to reauthorize the Substance Abuse and Mental Health Services Administration. NCIL recommends including the following in reauthorization:

- require a majority of consumers on state mental health planning and advisory councils (which are required to review and comment on state community mental health block grant – MHBG – plans);
- require that each state provide for consumer peer support organizations and / or consumer-run community mental health services in its MHBG plan; and
- require that state mental health planning and advisory councils coordinate activities with Statewide Independent Living Councils under section 705 of the Rehabilitation Act.

NCIL supports the legislation that protects consumers from abuse or civil rights violations, including:

- *H.R. 3126 and S. 1667, the Stop Child Abuse in Residential Programs for Teens Act of 2011*, establishes standards to prevent child abuse and neglect in private and public residential programs that serve children with emotional, behavioral, mental health or addiction challenges.
- *H.R. 3027, the Ending Corporal Punishment in Schools Act of 2011*, prohibits the Secretary of Education from providing funding to any educational agency or institution that allows school personnel to inflict corporal punishment upon a student to punish or modify behavior.
- *H.R. 1381 and S. 2020, the Keeping All Students Safe in School Act*, would protect students from the harmful practices of restraint and seclusion by prohibiting use unless the student poses an immediate danger of physical injury and less restrictive interventions would be ineffective.
- *H.R. 3165, the Positive Behavior for Safe and Effective Schools Act*, amends the *Elementary and Secondary Education Act of 1965 (ESEA)* to encourage the use of school-wide positive behavior support to improve school climate and foster students' academic and social success.
- *S. 541, the Achievement through Prevention Act*, amends the *ESEA* to increase implementation of school-wide positive behavioral interventions and supports, as well as early intervention services.

### ***ADA Notification Act***

After being introduced in the House in 2011 as *H.R. 881*, some new form of an *ADA Notification Act* bill may be introduced, which historically draws less support each session, but has seen a recent renewal of interest generated by many of the same groups who want to undermine the authority of the Department of Justice to enforce our civil rights laws. 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.

# Employment and Economic Equity



## Social Security

Social Security must start supporting paid work and stop being the barrier to it. Social Security has started work on a White House-approved Social Security Work Incentives Simplification Pilot (WISP). WISP promises to offer Social Security disability beneficiaries a much easier set of work rules. The proposed new rules would not end benefits or health coverage eligibility because of job earnings. WISP must also allow Social Security to provide 21st century wage reporting rules in the Title II (SSDI and CDB), the Title XVI (SSI) and the Title XIX (Medicaid) programs, in partnership with the Centers for Medicare and Medicaid Services (CMS). NCIL requests that Social Security work incentive reform include concrete steps to stop chronic overpayments to Social Security disability beneficiaries, especially to beneficiaries when they return to work or start work for the first time.

## Employment Support Insurance: Frame and Implement the Two-Plan Vision

NCIL has the vision and the plan to transform current health and benefit programs to equitably serve those who work as well as those who are not working. NCIL supports creation of a new Employment Support Insurance (ESI) program that would provide health coverage through new models of Medicare, Medicaid, employment and benefits counseling services, with referrals to needed employment support services. Employment Support Insurance is the missing national policy between breaks in employment, worker's compensation and today's Social Security disability programs. ESI would be like the SSDI social insurance model, with *Federal Insurance Contributions Act (FICA)* payroll deductions funding its services. ESI would provide the needed supports that are now missing between jobs, or when seeking employment and receiving SSI or SSDI.

The current SSDI program would maintain earnings replacement benefits 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 work and benefits insurance model protects the life-saving aspects of disability insurance systems while addressing their oppressive nature and their gross inefficiencies. A two-plan model, one program supporting work success, and a second program, available because of the documented high costs of managing a long-term disability, could replace the Social Security disability programs we have now, and do no harm in the process. It is time we define this vision and help Congress to implement it.

## President Obama: Reverse Social Security Decisions that will hurt jobless Americans with Disabilities

On March 9, 2012, Commissioner of Social Security Michael Astrue made a precipitous decision to shut down two key employment support information and counseling services for Social Security disability beneficiaries who work or plan to work. Social Security's Work Incentives, Planning and Assistance (WIPA) counseling program will shut down by June 30 and the Agency's Protection and Advocacy for Beneficiaries of Social Security (PABSS) will shut down by September 30, 2012. Abandoning these programs is a strategic blunder and will cause pain. The Commissioner's decisions threaten Social Security's Congressional mandates prescribed in the 1999 *Ticket to Work and Work Incentives Improvement Act*. NCIL urges the White House to request that Commissioner Astrue act on procedures within his existing budget and reverse his decision. WIPA counseling and information services can and should play a counseling role into 2014, so that SSA disability beneficiaries transitioning to work understand and make informed decisions as the *Affordable Care Act* coverage changes go into effect.

NCIL seeks Congressional action this year on three legislative initiatives:

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

Not Yet Introduced in the 112th Congress

On January 5, 2012, Commissioner Astrue sent to the Congress White House-approved draft legislative text that has not been introduced to reauthorize the WIPA and PABSS counseling programs. An introduction of an employment supports and counseling bill with appropriate committee hearings should have happened by now. It is uncontested among experts that Social Security 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 recent 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 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 that large numbers of SSA disability beneficiaries are making attempts to work or working today (Livermore 2009). 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 that can reach much wider numbers of beneficiaries planning to work.

### ***ABLE Act***

*H.R. 3423 and S. 1872*

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 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.



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### ***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.

## 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 their access to all community based services, programs, activities employment opportunities etc. 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 and fairies.
- **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 cruise ships, airplanes 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 and private 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 and limousines.

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

*H.R. 1780 and S. 1056*

*The safe and 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***

*H.R. 3200 and S. 1992*

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***

*H.R. 7*

*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 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 for several years.

# Convention on the Rights of Persons with Disabilities

On July 30, 2009, following the 19th anniversary of the Americans with Disabilities Act, the United States signed the Convention on the Rights of Persons with Disabilities (CRPD). The CRPD is an international treaty that describes the obligations of ratifying countries to promote, protect and ensure the rights of persons with disabilities including the right to live independently, the right to work and employment, and the right to an accessible environment.

## Status of the CRPD in the United States

The Convention embodies the traditional American ideals that form the basis of the ADA: empowering persons with disabilities to be independent, to claim personal responsibility for their own lives, and to be able to make their own choices. Ratification of the CRPD would be reaffirmation of these values and provide new opportunities to advance these values worldwide. Following the signing of the treaty, the Obama Administration prepared a CRPD treaty package for the U.S. Senate. In May 2012, the Obama Administration transmitted this treaty package to the Senate for their advice and consent for ratification. Senate rules provide that the Senate Foreign Relations Committee will be the first step in this next phase.

## American Disability Community's Role in Ratifying the CRPD

The U.S. disability community engagement in the ratification process is especially critical now that the Senate has received the Administration's treaty 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 ensure widespread Senate support to ratify this landmark treaty.

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

USICD offers a speakers bureau that connects CRPD presenters to diverse audiences. Anyone who is interested in a presentation on the treaty or would like to be involved in the grassroots effort to advocate for ratification is encouraged to contact USICD's Disability Rights Program Manager, Esme Grant, at [egrant@usidc.org](mailto:egrant@usidc.org), or visit [www.usidc.org](http://www.usidc.org).



## CRPD Timeline

- 2001: Mexico proposes the idea of a comprehensive international treaty
- 2002-2004: National delegations draft the CRPD with active participation of the disability community
- 2006: The UN General Assembly adopts the CRPD
- 2007: Over 80 countries become signatories during the opening ceremony
- 2008: The CRPD enters into force as an international treaty after receiving its 20th ratification
- 2009: The United States signs the CRPD, joining 141 other signing nations in demonstrating support for the rights of persons with disabilities
- 2009-Present: With over 110 ratifications around the world, USICD continues to provide education about the CRPD and advocate for U.S. engagement through its own ratification

## Available and Accessible Technology

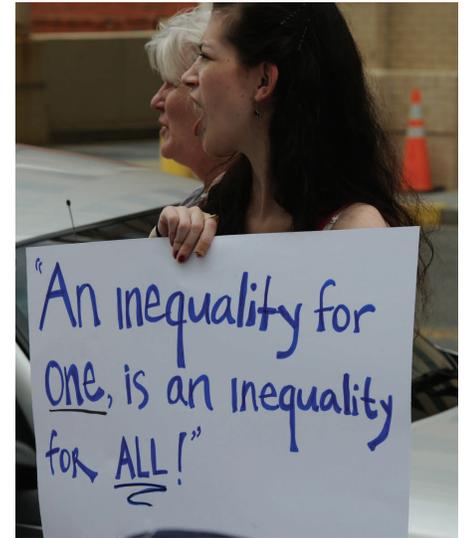
NCIL strongly advocates for access to mainstream and assistive technologies (AT) that enable and enhance independence for people with disabilities through supporting the principles of Universal Design, inclusion, consumer control, and peer support as they apply to the use, development, and delivery of 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 program or have a limited program. By supporting the Alternative Financing Programs and increasing its funding, Congress can help people with disabilities purchase the technology they need.

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 was asked by Congress to convene stakeholder input sessions around reauthorization of the *Assistive Technology Act*. NCIL held stakeholder meetings in DC and will continue to work towards improving the act based on consumer input.

## More Information

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



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## Legislation NCIL Supports:

- *ABLE Act*..... H.R. 3423 and S. 1872
- *Achievement through Prevention Act*..... S. 541
- *Allowing Local Control of Federal Transit Funds Act*..... H.R. 3200 and S. 1992
- *Assistive Technology Act*..... Not Yet Introduced
- *Community Choice Act*..... Not Yet Introduced
- *Safe and Complete Streets Act*..... H.R. 1780 and S. 1056
- *Ending Corporal Punishment in Schools Act*..... H.R. 3027
- *Fairness in Medicare Bidding Act*..... H.R. 1041
- *Inclusive Home Design Act*..... H.R. 5781
- *Keeping All Students Safe in School Act*..... H.R. 1381 and S. 2020
- *Positive Behavior for Safe and Effective Schools Act*..... H.R. 3165
- *Preserving Homes and Communities Act*..... H.R. 1477 and S. 489
- *SAMHSA Modernization Act*..... H.R. 5466
- *Social Security Work Incentive Amendments*..... Not Yet Introduced
- *SSI Savers Act*..... H.R. 2103
- *Stop Child Abuse in Residential Programs for Teens Act*..... H.R. 3126 and S. 1667
- *Veterans, Women, Families with Children and Persons with Disabilities Housing Fairness Act*..... H.R. 284
- *Workforce Investment Act of 2012*..... H.R. 4227
- *Workforce Investment Act Draft Senate HELP Committee Legislation*..... Bill Number Not Yet Assigned

### Reauthorization of:

- *Safe, Accountable, Flexible, Efficient Transportation Equity Act*..... H.R. 7
- *Traumatic Brain Injury (TBI) Act*..... Not Yet Introduced
- *Violence Against Women Act*..... S. 1925

### Ratification of:

- *Convention on the Rights of Persons with Disabilities*

## Legislation NCIL Opposes:

- *Affordable Housing and Self-Sufficiency Improvement Act*..... Not yet introduced
- *Attempts to Undermine the Americans with Disabilities Act*..... H.R. 4200; H.R. 4256; S. 2186; and S.2191
- *ADA Notification Act*..... Not yet introduced
- *Fiscal Responsibility and Retirement Security Act*..... H.R. 1173
- *Section 8 Voucher Reform Act*..... H.R. 1209
- *Workforce Investment Improvement Act of 2012*..... H.R. 4297

### Any legislation that:

- Attempts to abolish the National Housing Trust Fund
- Caps spending globally, including the CAP Act
- 
- Block Grants Medicaid
- Legalizes assisted suicide
- Requires photo identification to vote

# 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.





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