



Legislative & Advocacy Priorities



Spring 2013

A Message from the Executive Director

Dear Advocates and Allies,

I am pleased to announce the release of the Spring edition of the National Council on Independent Living's 2013 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 continuing to work closely with the House and Senate to reauthorize the *Workforce Investment Act (WIA)* and the *Rehabilitation Act* contained within it. NCIL is proud of the significant progress on reauthorization made last year in the 112th Congress. For the first time, there was legislation in both the House and Senate with language that would create a new Independent Living Administration (ILA).

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.

The bipartisan discussion draft created by the Senate HELP (Health, Education, Labor & Pensions) Committee, and the *Workforce Investment Act of 2013 (H.R. 798)*, which was introduced by House Democrats, both establish an ILA and strengthen America's Independent Living Program. These bills would reduce the bureaucracy that Centers for Independent Living operate within at no additional cost to taxpayers.

The ILA will 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.

The ILA 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 solutions and enhancements that affect Independent Living contained 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 the SILC:** Because of RSA's interpretations of the Rehabilitation Act, several clarifications regarding SILC activities are present in the bill, including the duties of 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.

After reading *H.R. 798* and the legislative language drafted by the Senate HELP Committee 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, we must now mobilize to get this legislation reintroduced and pushed through Congress. Remember, this bill was originally created for us! Our unique opportunity to advance is now, and the time for action is today. If we are successful in our efforts, we will achieve one of the greatest advancements in the history of the Independent Living Movement.

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*, specifically the inclusion of Title IV language that creates an ILA and strengthens Independent Living.

Remember:

- The creation of the Independent Living Administration does not require any new or additional funding.
- The creation of the ILA does not create unnecessary new bureaucracy. It will streamline the Independent Living Program and enhance 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

Key Legislators to Contact in the 113th Congress:

- Senator Tom Harkin (D-IA)
- Senator Lamar Alexander (R-TN)
- Representative John Kline (R-MN)
- Representative George Miller (D-CA)

America is home to:

- 427 Centers for Independent Living (CILs)
- 271 branch offices
- 56 Statewide Independent Living Councils (SILCs)

Healthcare and Long-Term Services and Supports

Ending Medicaid's Institutional Bias

NCIL's advocacy was instrumental in getting the Community First Choice Option included in the *Patient Protection and Affordable Care Act*. So far, eight states have announced that they are selecting the Community First Choice Option, which should give seniors and people with disabilities in those states a *real choice* in where they receive long-term services and supports:

- Arkansas
- California
- Louisiana
- Maryland
- Minnesota
- New York
- Rhode Island
- Washington

This is a tremendous step forward and NCIL members are working to expand the number of states that are selecting this option.



It is clear, however, that not every state will adequately implement the Supreme Court's *Olmstead* decision and assure that people with disabilities have the right to live and receive services in the most integrated setting. That is why NCIL strongly endorses developing legislation that addresses Medicaid's institutional bias and 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 addresses Medicaid's institutional bias and 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. It is clear that Medicaid and the systems for providing long-term services and supports will be examined during this Congress.



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.



NCIL strongly supports reform of long-term services and supports in order to take the pressure off Medicaid, so that it can better serve the needs of people with disabilities and low income communities. Such a program should also help assure that people with disabilities who work are able to get and keep the long-term services and support they need to be independent. Without such a program, 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 plan that addresses these concerns, but cautions that we must not pursue public policy that assures individuals served in such a program have the opportunity to live in the community while Medicaid recipients are relegated to nursing facilities and other institutions.

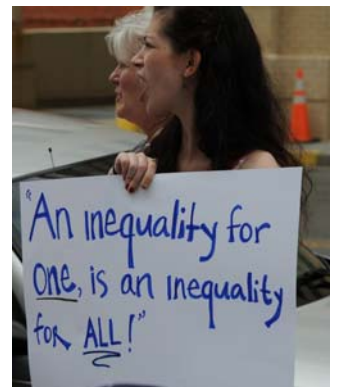
Prohibiting Discrimination Based on Disability in Healthcare

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.

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;
- discrimination in organ procurement practices, including proposed protocols that 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.



Competitive Bidding

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 a lack of local providers and delays in deliveries, which have lengthened hospital stays and driven up costs.

From a policy and legislative standpoint, NCIL has supported a number of measures over the past few years aimed at ending the CMS Competitive Bidding program, and will likely support similar measures in the 113th Congress. Although legislation can eliminate the dangers created by this program, it will never pass unless members of the House and Senate understand that it is actually reducing access and support for their constituents with disabilities. Members of Congress are not hearing about the issues that people with disabilities are experiencing under this program, which is why NCIL's focus is encouraging our members and individuals who are suffering as a result of this program to contact their lawmakers and tell them what is really happening.

As this program 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.

Civil Rights and the *Americans with Disabilities Act*

Several bills presented in the 112th Congress would have, if passed, prevented the Department of Justice from enforcing regulations to increase access for people with disabilities to swimming pools, lakes, recreation centers, and resorts. New challenges to the *ADA* are being promoted by the hotel industry and other lobbyists in an attempt to roll back the rights of people with disabilities.

The challenges to full implementation of the *ADA* Standards 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 accessibility requirements set forth in the *ADA* 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. Tell Congress: *don't roll back our rights!*



The *Violence Against Women Act*

On March 7, 2013 President Obama signed the *Violence Against Women Act of 2013* into law. *VAWA* passed in the Senate by a vote of 78-22 and in the House by a vote of 236-138. NCIL is very pleased that Congress passed the Senate's version of *VAWA*, which is inclusive and encompasses prevention, protection, and services for all victims.

NCIL's Violence and Abuse Task Force wrote language for the legislation and lead a national advocacy outreach campaign to achieve this five year reauthorization. This law includes updated provisions that protect the rights of LGBT persons, immigrants, and Native Americans. It also included new language that represents an opportunity for people with disabilities. A specialty grants section will provide funding to CILs across the nation through their state partnerships with Domestic Violence programs. These funds will allow CILs to provide technical assistance to first responders, law enforcement, shelter staff members, and others on how to assist people with disabilities. The bill will also provide states with funds to provide accessible shelters or find alternative protection for victims with disabilities.



While celebration of this victory is currently underway, the Friends of *VAWA* National Coalition, which NCIL helped create, will continue its work. Plans are being made to roll out an advocacy campaign in early fall for the legislative work on the next reauthorization of *VAWA*.

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.



Mental Health

Mental Health has a new prominence after December's mass shooting at Sandy Hook School in Newtown, Connecticut. NCIL recognizes that mental illness diagnosis is common - half of Americans can expect a diagnosis during their lifetime. NCIL also recognizes that people with disabilities, including those diagnosed with mental illness, are more likely to become victims than perpetrators of violence.



As a result, NCIL appreciates efforts to address gun violence. However, the evidence does not support profiling or other discrimination based on disability as a solution. NCIL opposes any legislation that continues or strengthens lists of people with mental illness and any deprivation of liberty based on disability rather than criminal activity.

Substance Abuse and Mental Health Services Administration (SAMSHA)

The Substance Abuse and Mental Health Services Administration (SAMHSA) of the Department of Health and Human Services is overdue for reauthorization. While bills, including *H.R. 5466*, were introduced in the 111th Congress to amend the *Public Health Service Act* to reauthorize SAMHSA and its programs, none of the bills passed nor was the administration reauthorized in the 112th Congress.

NCIL supports reauthorization with the following provisions:

- 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*.

ADA Notification Act

New forms of an *ADA Notification Act* may be introduced in the new Congress, and have 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.

These bills would create a disincentive for businesses to comply with the ADA. Businesses would be encouraged to continue denying access to individuals with disabilities until they receive a notice that someone intends to sue.

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.

NCIL supports legislation that protects consumers from abuse or civil rights violations, such as the following bills from the 112th Congress:

- *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.



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.

Housing Funding

Housing affordability continues to be a serious challenge for many households with a person with a disability across the country, and funding has not kept up with the increasing number of people seeking housing assistance. In the face of the increasing cost of and heightened need for housing assistance, funding has been stagnant - or worse. With sequestration and other budget-cutting initiatives, there are threats of severe cuts to housing assistance programs.



NCIL opposes cuts to housing assistance to low-income households, and urges increased funding to meet the large number of unassisted households who have extremely low income. As members of Congress discuss funding levels for the 2014 budget, we encourage them to bear in mind that funding housing assistance has tangible benefits in the form of decreased homelessness and its associated costs and increased housing stability for children, which results in improved outcomes in academics and health.

Common Sense Housing Investment Act of 2012

Formerly *H.R. 6677*

Congress created the National Housing Trust Fund (NHTF) in 2008 with initial funding intended to come 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 principally for extremely low income Americans, which disproportionately includes households with a member who has a disability.

There is currently a proposal by the National Low Income Housing Coalition (NLIHC) to fund the NHTF through a reform to the Mortgage Interest Deduction that homeowners receive if they itemize on their tax returns. Currently the deduction, estimated by OMB to cost more than \$100 billion, is the largest housing subsidy, yet disproportionately benefits households who least need a subsidy.

The reform, as introduced during the last session by Representative Ellison of Minnesota, *HR 6677*, the *Common Sense Housing Investment Act of 2012*, would create a 20% nonrefundable tax credit on the interest paid by homeowners who have mortgages up to \$500,000 on their primary residence and one other house. The Mortgage Interest Deduction itself would be phased out through 2017 as it is replaced by the tax credit. This means more homeowners (maybe as many as 17 million more) with mortgages would benefit because those who do not file itemized tax returns would get a tax break too.

The bill would lower the cap on mortgage eligibility for the tax break from \$1 million to \$500,000, creating an estimated \$27 billion in savings, which would be directed in the following way: \$15.4 billion / year to the National Housing Trust Fund; \$7.7 billion / year to the Section 8 program; \$2.5 billion to the Public Housing Capital Fund; and \$1.4 billion to the Low Income Housing Tax Credit (LIHTC) program. The additional funding to the LIHTC program would provide an incentive to developers to create more funding toward units serving extremely low income households.

Mr. Ellison intends to reintroduce his bill in the new Congress.

Inclusive Home Design Act

Formerly *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.

Housing Fairness Act of 2013

H.R. 285

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 for education and enforcement. It also would put in place stronger reporting requirements for HUD.



Moving to Work

(Incorporated into various bills)

Moving to Work (MTW) is an unproven pilot program involving a small number of Public Housing Authorities (35) 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. In previous sessions, bills have proposed a MTW-style expansion called "Housing Innovations Program" that would double the number of eligible agencies. Another bill 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 opposes any expansion until a thorough evaluation has taken place on the impact on tenants, particularly those with disabilities.

Employment and Economic Equity



Cornell University research has found that in 2011, 33.4% of working-age (21-64) people with disabilities were employed, compared with the 75.6% of people without disabilities. Moreover, 27.8% of working-age Americans with disabilities lived in poverty, compared to 12.4% of those without disabilities.

Social Security Disability Programs: NCIL's Challenge to Congress

Social Security must start supporting paid work and stop being the barrier to it. Many disability experts agree that Supplemental Security Income (SSI), and Social Security Disability Insurance (SSDI) remain the single most pervasive deterrent to the productivity and economic well-being of Americans with disabilities. *There is a terrible tension between eligibility to get benefits versus getting employment help.*¹

After decades of research, discussion, and false starts at structural reform, a national focus has emerged to replace federal disability policy on disability benefits with new programs commensurate with our expectations that we be productive and engaged in self-managing careers that are backed by consistent and more efficiently run disability services.

White House & Congress: Work with NCIL in 2013!

NCIL youth, along with other NCIL experts, are going to lead a direct, focused, safe, and productive dialog with policy makers to replace Social Security's disability programs with a federal policy agenda that supports productivity, paid work, health and well-being, and wealth building for individuals and families living with disability. In coming weeks, NCIL will share specific reform directions to assist the Congress and the Administration with designing policy and programs to meet this policy agenda.

NCIL members, in policy partnership with the World Institute on Disability (WID), have recommended since 2006 that Congress assess structural reform to Social Security's dysfunctional disability programs. This year, NCIL requests a direct dialog on how we can replace them.

The dialog is not new or limited. It is pervasive across the country. Talk to any family or individual living with and managing the high costs of disability. This year, we ask that the dialog on how people get disability benefits, why we get them, and when we get them, take center stage in the Congress. As requested of the Congress and the Administration back in 2007:

*"Congress and the Administration should take action to evaluate the impact of modernizing the Social Security definition of disability by defining disability in a manner that acknowledges the interaction between the person's impairment and the environment and does not require the individual to prove their inability to engage in substantial gainful activity."*²

Momentum for Change

There have been promising but faltering starts towards a new dialog, including Social Security's White House-approved Social Security Work Incentives Simplification Pilot (WISP). WISP proposes simplified work rules for Social Security disability beneficiaries, a core reform principle. WISP proposes to retain benefit and health coverage eligibility indefinitely after work begins.

This Spring, the Social Security Advisory Board, private think tanks, and economists are convening

conferences on reform of Social Security's disability programs. NCIL believes that reform must be solidly grounded in understanding who the people are who use Social Security disability programs, and understanding the mainstream expectations in the *Americans with Disabilities Act (ADA)*. NCIL requires that youth and adult disability beneficiaries be at the center of the reform dialog and initiatives.

Congressional Action Steps for Republicans, Democrats, and Independents

The NCIL initiative is about building something new and improved, not taking something away. With this in mind, NCIL proposes initial steps for Congress to take immediately:

- Assign specific, legislative staff to work with NCIL to improve proposals generated by NCIL members in partnership with other disability organizations such as the World Institute on Disability
- Assign staff to work with White House experts on such initiatives
- Request ad hoc GAO research on employment and disability when needed to support this dialog and legislative initiative

Target Populations for a New Federal Policy on Disability Benefits:

- Working Americans with disability, and / or not on Social Security disability benefits, who may be at risk of applying for federal disability benefits
- SSI and SSDI youth under 30 and their families
- Older SSI and SSDI working age adults with longer breaks and time away from the workforce

Near Term Legislation: The 2013 *ABLE Act*

H.R. 647 and S. 313

NCIL supports passage of the *ABLE Act*, which will create a new subsection (f) within Section 529 of the Internal Revenue Code. Well known, uncontested research shows that living with a long-term disability means having routine, higher, out of pocket costs (Fremstad, 2009). The bill will allow individuals and families to save more private funds in an ABLE Account to better support our health and well-being, our employment, our independent living, and our self-sufficiency over time.

NCIL recommends adding the following policy to the new *ABLE 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.*

End Notes:

1. William P. Molmen, General Counsel, Integrated Benefits Institute, San Francisco
2. Recommendation 31 above is cited from: Final Report to the President and Congress,; *Building on the Ticket: A New Paradigm for Investing in Economic Self-Sufficiency for People with Significant Disabilities*, 2007, Final Report of the Panel, Social Security Ticket to Work and Work Incentives Advisory Panel.

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:

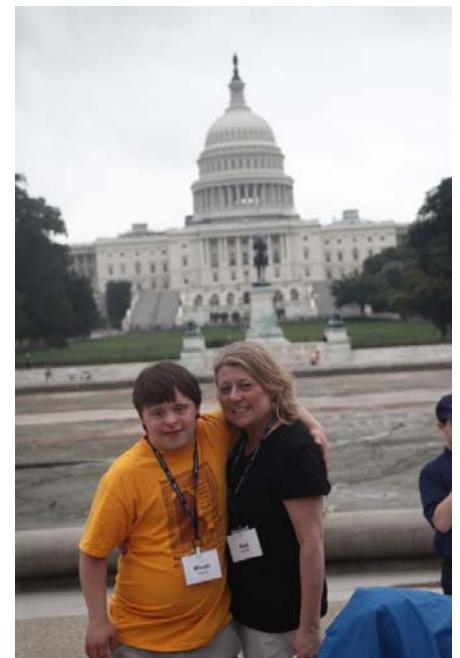
- Empowerment of students with disabilities with information about education rights, services and expectations
- Integration of academic instruction, school activities, and planning to promote successful transition from school to adult life
- Accountability standards focused on improving the graduation 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
- Requirements for disaggregation of assessment data and use of the data to improve educational opportunities

Stop Restraint and Seclusion

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

Legislation is needed to make it clear to schools that continued use of these dangerous, harmful and unnecessary practices must end.

See page 11 of this booklet for a list of NCIL-supported legislation from the 112th Congress that would protect students and young people with disabilities from abuse or civil rights violations.



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 Life Blood of Society

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 systems that connect our cities, regions, and rural areas. NCIL strongly supports and advocates the integration of individuals with disabilities into society through the design of universally accessible transportation systems and pedestrian safety initiatives.

NCIL demands that all new and innovative public and private transportation systems that transfer passengers with disabilities be universally accessible. Given the wide variety of pedestrian transportation options, pedestrian safety and 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 societal and community integration, involvement, and participation by individuals with disabilities:

- **Rural passenger transportation systems, including transportation systems between one municipality and another, must be of universal and accessible design:** NCIL strongly supports increased availability and access to affordable and accessible rural transportation options that connect municipalities to one another. In order to maximize continuity and efficiency of such a transportation system, a coordinated plan is required. Within such a coordinated plan, this rule of accessibility must also apply to small airplanes and any other method of passenger transportation.
- **Livable communities:** Safe and accessible rights-of-way are essential elements of community life. All pedestrians must be able to travel in safety with accessible rights-of-way. It is of equal imperative to maximize accessibility and safety for pedestrians as it is for passengers.
- **Private transportation services:** Legislation is needed to increase the number and availability of accessible vehicles within the private transportation industry, including taxis, limousines, shuttle service, car rentals, buses, trains, etc.

Increased investment in the current transportation system alone will not solve the problems that affect the lack of continuous, seamless, accessible and affordable transportation services. Americans, especially individuals with disabilities, are negatively affected on a daily basis by the lack of accessible and affordable transportation. Americans with disabilities demand transportation options that are affordable and accessible. We must embrace innovative ideas that serve to enhance and maximize community integration, connectivity, and independence.

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.

When America honors the equal access intent of the *Americans with Disabilities Act* by ensuring accessible and affordable public and private transportation systems, people with disabilities will have the same travel options available to everyone else, allowing them to attend school, maintain employment, attend social and faith functions, travel within the communities of their choice, and fully participate in the American Dream.

Toward maximizing accessible transportation within the private transportation industry, 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.

Allowing Local Control of Federal Transit Funds Act

Not Yet Introduced in the 113th 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 113th Congress

The *Safe, Accountable, Flexible, Efficient Transportation Equity Act (SAFETEA)* authorizes funds for highways, highway safety & transit programs, and paratransit, including fixed route and demand-responsive services. Reauthorization of this legislation is critical for the provision of equal access to public and private 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 must 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. Simultaneously, DOT must not make the same mistake by neglecting to include mobile devices and apps. It is imperative that we ensure access to the most advanced and accessible communication technologies.

Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (CRPD) is an international treaty adopted by the United Nations in 2006. The CRPD was inspired by U.S. leadership in recognizing the rights of people with disabilities through its own *Americans with Disabilities Act*. As of February 2013, the treaty has 156 signatures and 128 ratifications. The CRPD has been a vital framework, particularly to the developing world, for creating legislation and policies that embrace the rights and dignity of all people with disabilities.



Status of the CRPD in the United States

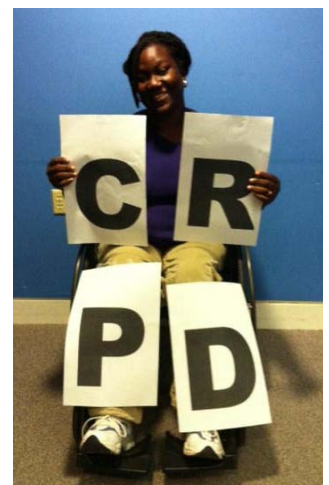
The United States signed the treaty in 2009 and transmitted it to the U.S. Senate for their advice and consent in May of 2012. The U.S. International Council on Disabilities (USICD) has led the community's call for ratification (expressed by over 375 disability, faith, business, and veteran organizations), rallying Senate support, and working with leaders like Senator Bob Dole to ensure bipartisanship and secure the 2/3 Senate vote needed. In July, the CRPD was voted successfully out of the Senate Foreign Relations Committee (SFRC).

On December 4, 2012 the United States Senate considered the ratification of the CRPD but fell short of the super-majority vote required, much due to falsehoods spread by the opposition. A strong opposition effort, led by the Home School Legal Defense Association, arose just before the July hearing in the SFRC, falsely claiming that the ratification of the CRPD would harm parental rights and require serious changes in U.S. law. Despite amendments (RUDs) adopted at the SFRC hearing to quash the opposition's concerns, the opposition movement added former Senator Rick Santorum as its main spokesperson and efforts remained determined to overcome the treaty's chances at ratification. The vote in December, with Senator Kirk (IL) being absent, required 66 votes in favor to succeed. The official vote count was 61-38, signaling a loss by a mere five votes. The nays included Senator Moran (KS) who previously had announced his sponsorship of the treaty.

In reaction to the failed vote, Senate Majority Leader Reid committed to bringing the treaty up again in 2013. For the 113th Congress, the treaty has returned to the Senate Foreign Relations Committee (SFRC) with the original nine recommended RUDs from the Administration. Republican Senator Lugar (IN) has left the Senate, making Senator Corker (TN) the new Republican Ranking Member of the Committee. Senator Kerry has been appointed Secretary of State and the new SFRC Chairman is now Senator Menendez (NJ).

American Disability Community's Role

Grassroots support will continue to be vital in order to ensure widespread Senate support to ratify this landmark treaty. NCIL supports the U.S. ratification of the CRPD, and is actively working with USICD to raise awareness and understanding of this treaty. Together, the disability community has renewed their call for U.S. ratification and is working on a stronger, even more robust campaign in 2013. 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, Esmé Grant, at egrant@usidc.org or visit 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 113th 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:

- *Stop Child Abuse in Residential Programs for Teens Act (formerly H.R. 3126 and S. 1667)*
- *Ending Corporal Punishment in Schools Act (formerly H.R. 3027)*
- *Keeping All Students Safe in School Act (formerly H.R. 1381 and S. 2020)*
- *Positive Behavior for Safe and Effective Schools Act (formerly H.R. 3165)*
- *Achievement through Prevention Act (formerly S. 541)*
- *Common Sense Housing Investment Act of 2012 (formerly H.R. 6677)*
- *Inclusive Home Design Act (formerly H.R. 5781)*
- *Housing Fairness Act of 2013 (H.R. 285)*
- *The Achieving a Better Life Experience Act (H.R. 647 and S. 313)*
- *Allowing Local Control of Federal Transit Funds Act (not yet Introduced in the 113th Congress)*
- *Assistive Technology Act (not yet Introduced in the 113th Congress)*
- *Community Choice Act (not yet Introduced in the 113th Congress)*

Reauthorization of:

- *Workforce Investment Act (H.R. 798)*
- *Workforce Investment Act Draft Senate HELP Committee Legislation (bill number not yet assigned)*
- *Safe, Accountable, Flexible, Efficient Transportation Equity Act (not yet Introduced in the 113th Congress)*

Ratification of:

- *Convention on the Rights of Persons with Disabilities*

Legislation NCIL Opposes:

- *ADA Notification Act (not yet Introduced in the 113th Congress)*
- Any legislation that:
 - Attempts to abolish the National Housing Trust Fund
 - Creates lists of people with mental illness and any deprivation of liberty based on disability rather than criminal activity
 - 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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