



**NCIL** **25**  
Celebrating Years of  
Independent Living

**National Council on Independent Living**

Legislative and Advocacy Priorities

Summer 2008

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Dear Advocates and Allies,

I am pleased to announce the release of the summer edition of National Council on Independent Living's 2008 Policy Priorities. This publication will introduce you to a sample of the many legislative issues NCIL is currently pursuing in order to secure full equality for people with disabilities in our great nation.

NCIL is the oldest cross-disability, national grassroots organization run by and for people with disabilities. NCIL's membership includes people with disabilities, Centers for Independent Living, Statewide Independent living Councils, and other disability rights organizations. As a membership organization, NCIL advances independent living and the rights of people with disabilities through consumer-driven advocacy.

I would like to draw particular attention to issues surrounding Independent Living Funding, discussed on page 12 of this publication. 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 would also like to draw your attention to the *ADA Restoration Act* and the *Community Choice Act*, two bills that NCIL members and Americans with disabilities nationwide feel are essential to the civil and human rights of people with disabilities. I am very proud of our community's hard work to bring these bills to Congress. Together we will see the passage of our legislation, the restoration of our civil rights and a world in which people with disabilities are truly valued equally and participate fully.

Sincerely,

A handwritten signature in cursive script that reads "John A. Lancaster". The signature is written in black ink on a light-colored background.

John A. Lancaster  
Executive Director, National Council on Independent Living

# Civil Rights and the Americans with Disabilities Act

## ***ADA Amendments Act, formerly known as ADA Restoration Act***

*HR 3195 (passed) and S 1881*

Eighteen years ago, Congress passed the *Americans with Disabilities Act (ADA)* with overwhelming bipartisan support. However, in recent years a number of Supreme Court decisions have significantly reduced the protections available to people with disabilities in employment settings.

Courts are quick to side with businesses and employers, deciding against people with disabilities who challenge employment discrimination 97% of the time, often before the person has even had a chance to show that the employer treated them unfairly. Courts have created an absurd Catch-22 by allowing employers to say a person is too disabled to do the job but not disabled enough to be protected by the *ADA*. People with conditions like epilepsy, diabetes, HIV, cancer, hearing loss, and mental illness who manage their disabilities with “mitigating measures,” such as medication, prosthetics, hearing aids, etcetera, are viewed by the Courts as too functional to have a disability and are thus denied the *ADA*’s protection from employment discrimination.

People denied a job or fired because an employer mistakenly believes they cannot perform the job or because the employer does not want people with disabilities in the workplace are also denied the *ADA*’s protection from employment discrimination.

NCIL has been working with a broad coalition of disability organizations who are helping House Majority Leader Steny Hoyer (D-MD) and Representative James Sensenbrenner (R-WI) enact legislation, the *ADA Amendments Act*, formerly known as the *ADA Restoration Act*, which would enable Americans with disabilities utilizing the *ADA* to focus on the discrimination that they have experienced rather than having to first prove that they fall within the scope of the *ADA*’s protection. With this bill, the *ADA*’s clear and comprehensive national mandate for the elimination of discrimination on the basis of disability will be properly restored and the *ADA* can rightfully reclaim its place among our nation’s civil rights laws.

On Wednesday, June 24, the US House of Representatives passed the *ADA Amendments Act!* House Majority Leader Steny Hoyer (D-MD), who played a leading role in passage of the *ADA* in 1990, and Rep. James Sensenbrenner, long-time disability advocate, sponsored the bill along with more than 240 cosponsors.

On the other side of Capitol Hill, Senators Tom Harkin (D-IA) and Arlen Specter (R-PA) sponsored companion bill *S. 1881*. Senator Ted Stevens (R-AK) recently cosponsored the bill, but we need more Senators to show bipartisan support for ending employment discrimination against people with disabilities by cosponsoring the legislation.

At Congress’ request, disability advocates and representatives of the business community worked to reach agreement on these core issues to restore the *ADA*. NCIL Executive Director John Lancaster and the *ADA* / Civil Rights Subcommittee are pleased to have participated in these efforts.

NCIL urges the Senate to pass and President Bush to sign a bill that will restore the *Americans with Disabilities Act* to the original intent of Congress, which covered people with disabilities regardless of mitigating measures, and ensured the right of people with disabilities to address employment discrimination.

# Healthcare and Ending the Institutional Bias

## ***Community Choice Act***

*HR 1621 and S 799*

NCIL strongly endorses the *Community Choice Act of 2007* because it will help bring an end to the shameful institutional bias in this country. Currently, every state that receives Medicaid is required by law to provide nursing facility services, but community-based services remain optional, leaving them open to funding cuts year after year as institutions remain prosperous. As a direct result, millions of seniors and people with disabilities are forced into institutions to receive medical or personal assistance services. *The Community Choice Act* requires states to offer community-based supports for Medicaid-eligible consumers who want to stay in or return to their homes and communities. It will provide a real alternative to institutional care that many states lack, as well as saving Medicaid billions of dollars.

The average cost of a private nursing home room is \$75,000, yet the cost of a full-time home health aide only \$39,500 per year. When totaled, the savings to states and the federal government (simply by allowing people to receive services in their homes) will allow for expanded healthcare services and the elimination of lengthy waiting lists on which people currently sit for years at a time, waiting to receive services anywhere but in an institution.

*The Community Choice Act* will provide people with disabilities the opportunity to choose where and how they receive personal assistance services, which is invariably in their homes among family and friends, and within their communities. Senator Tom Harkin (D-IA) and Representative Danny Davis (D-IL) introduced the *Community Choice Act*. The Senate version is currently in the Finance Committee, which has ordered the bill to be scored by the Congressional Budget Office. The House bill is currently in Energy & Commerce Subcommittee on Health.

There is now evidence that the Congressional Budget Office report from 1997 was inaccurate and the legislation will actually cost one tenth of the original estimate by CBO, proving the Community Choice Act is a cost-effective initiative as well as the right thing to do. For further information, please see the University of California San Francisco (UCSF) report entitled "Estimating the Expense of a Mandatory Home- and Community-Based Personal Assistance Services Benefit Under Medicaid". LaPlante, MP, Kaye, HS, & Harrington, C. (2007).

## ***Ending the Medicare Waiting Period Act***

*HR 154 and S 2102*

NCIL supports elimination of the 24-month Medicare waiting period. If a person qualifies for Social Security Disability Insurance, they are by definition disabled and usually in need of medical attention. This bill will immediately eliminate the two year waiting period for those that need immediate, life-saving medical attention. For those without a life-threatening condition, the waiting period will be eliminated within 10 years of enactment. Currently, there are about 600,000 Americans with significant disabilities who have no insurance and go without healthcare. Many go into debt, are forced into personal bankruptcy, or die while waiting the required two years for their Medicare coverage to begin after they are deemed eligible for Social Security Disability. Twelve percent of people in the Medicare waiting period die each year while waiting for coverage to begin. This practice must stop. Death and illness do not wait on bureaucracy. NCIL commends Representative Gene Green (D-TX) and Senator Jeff Bingaman (D-NM) for introducing the *Ending the Medicare Waiting Period Act of 2007*. The House bill is currently in the Ways and Means Committee's Subcommittee on Health and the Senate version has been referred to the Finance Committee.

## **Healthcare and Ending the Institutional Bias**, continued

### ***CLASS Act: Community Living Assistance Services and Supports***

*HR 3001 and S 1758*

The CLASS Act would assist people with disabilities who are employed and in need of long term assistance or supports by providing a flexible cash insurance benefit that could be used creatively to purchase services, supports and technology. NCIL applauds the creative approach of the bill in addressing issues around long term care services. We believe an insurance program that is affordable, available nationwide, and not tied to poverty and unemployment is a laudable goal and a much-needed piece of the long term service puzzle. Senator Edward Kennedy (D-MA) and Representative Frank Pallone (D-NJ) introduced the CLASS Act. The Senate Bill has been referred to the Health, Education, Labor and Pension (HELP) Committee and the House bill has been referred to the Committee on Energy and Commerce, the Committees on Ways and Means, and the Committee on Rules.

### ***Promoting Wellness for People with Disabilities Act***

*HR 3294 and S 1050*

NCIL applauds Senator Tom Harkin (D-IA) and Representative Nita Lowey (D-NY) for introducing the *Promoting Wellness for People with Disabilities Act of 2007*. Health and wellness are important to all individuals, especially people with disabilities. Accessible medical examination equipment is crucial and access to healthcare must be unbiased. This legislation is the first to address the need for establishing accessibility standards for medical diagnostic equipment such as examination tables, examination chairs, weight scales, mammography equipment, X-ray machines, and other equipment commonly used for diagnostic purposes by medical professionals. *HR 3294 and S 1050* require medical and dental schools, along with their residency programs, to increase training to improve competency and clinical skills in providing care to patients with disabilities, including those with intellectual disabilities. Currently, few medical schools provide education for their students in treating people with disabilities and providing accommodations to ensure access to quality care. *The Promoting Wellness for People with Disabilities Act* also creates a small grant program to prevent secondary conditions and promote healthy lifestyles for people with disabilities. The Senate bill is currently in the Health, Education, Labor and Pension Committee and the House version has been referred to the Committee on Education and Labor's Subcommittee on Health, Education, Labor and Pension.

## **Harmful CMS Regulations**

The Centers for Medicaid and Medicare Services is critical to people with disabilities for healthcare. CMS has proposed regulations to curb fraud and abuse without regard to adverse impact on people with disabilities. NCIL supports the following legislation to delay implementation of CMS regulations:

### ***The Medicare Durable Medical Equipment Access Act***

*HR 1845 and S 1428*

Representative John Tanner (D-TN) and Senator Orrin Hatch (R-UT) introduced this bill, which was created in response to CMS implementation of the Medicare Durable Medical Equipment, Prosthetics, Orthotics and Supplies (DMEPOS) Competitive Bidding Program. The Competitive Bidding Program reduces the number of Medicare suppliers who can sell durable medical equipment such as power wheelchairs, walkers and oxygen. NCIL feels this program will hinder access to durable medical equipment for people with disabilities who rely on it to live independently. This program will be implemented across the country by 2010 if we do not stop it now. S 1428 is currently in the Committee on Finance and its House counterpart is in the Ways and Means Committee's Subcommittee on Health.

## **Healthcare and Ending the Institutional Bias**, continued

### ***Medicare Independent Living Act***

*HR 1809 and S 2103*

*The Independent Living Act of 2007* will eliminate an incorrect and devastating interpretation of the “In-Home Rule” by the Centers for Medicare and Medicaid Services (CMS). Medicare’s mobility device benefit has never been generous. In fact, Medicare will only provide wheelchairs and scooters to those beneficiaries who need them to eat, bathe, groom, dress, or use the bathroom *inside* their home. In many communities, CMS takes a hard line on the issue and insists that if the provided medical device is used outside the home, the recipient is no longer entitled to the device.

The current rule prevents beneficiaries from living independently by returning to work or school, regaining self-sufficiency, accessing their place of worship, the voting booth, and the homes of family and friends. Medicare continues to pursue such myopic and irrational policies that genuinely harm beneficiaries in the name of reducing fraud and abuse. NCIL denounces CMS for its continued refusal to address Medicare’s restrictive “In-Home Rule” policy, which was originally meant to define durable medical equipment as devices provided outside an institution, hospital, or nursing home which therefore warranted separate reimbursement under Medicare Part B. Instead, it is interpreted by CMS to restrict coverage only to mobility devices that are used exclusively within the beneficiary’s home. NCIL commends Representative James Langevin (D-RI) and Senator Jeff Bingaman (D-NM) for introducing this needed legislative fix. The House bill is currently in the Ways and Means Committee’s Subcommittee on Health and its Senate counterpart has been referred to the Committee on Finance.

### ***Medicare Access to Complex Rehabilitation and Assistive Technology Act***

*H.R. 2231 S. 2931*

*The Medicare Access to Complex Rehabilitation and Assistive Technology Act* exempts complex rehabilitation equipment and assistive technology from the Medicare Competitive Bidding Program. The bill defines complex rehabilitation equipment as “medically necessary adaptive seating, positioning, and mobility devices and speech generating devices that are evaluated, fitted, configured, adjusted, or programmed to meet specific and unique needs”. The bill is currently in the House Subcommittee on Health and its lead sponsor is Representative Thomas Allen (D-ME). The Senate version is in the Committee on Finance and its lead sponsor is Senator Olympia Snowe (R-ME).

### ***A Bill: To Temporarily Delay Application of Proposed Changes to Medicaid Payment Rules for Case Management and Targeted Case Management Services***

*H.R. 2231 S. 2931*

NCIL is very concerned about new Case Management and Targeted Case Management (TCM) regulations. Funds designated for TCM services help people transition from school to adult life or from an institution to the community. CMS is cutting transition services eligible for funding from 180 to 60 days, far less than the amount of time needed for a successful transition. NCIL believes CMS is going well beyond Congressional intent and that implementation of the proposed regulations will harm access to nursing home transition services for people with disabilities nationwide. This goes against the New Freedom Initiative and the *Olmstead Decision*. Representative Keith Ellison (D-MN) and Senator Norm Coleman (D-MN) recognized this and together introduced *HR 5173 and S 2578*. This bill would focus only on delaying the implementation of section 6052 of the *Deficit Reduction Act of 2005*, which clarifies the Medicaid definition of covered Case Management and Targeted Case Management (TCM) services. In the House, this bill is currently in the Ways and Means Committee’s Subcommittee on Health and the Senate bill is in the Committee on Finance.

# Employment and Economic Empowerment

Stagnant Employment Patterns of People with Disabilities: The high incidence of U.S. poverty caused by disability is unacceptable on moral and economic grounds. The time has come to better serve the needs of Americans with disabilities. NCIL calls on the President, Presidential and Congressional candidates, and Members of Congress to refocus and address the chronically stagnant, low employment rates of Americans with disabilities.

In the short term, Congress should:

- Ask the federal Office of Personnel Management to both prioritize implementation of federal Schedule A rules, and conduct all effort needed to make the federal government a model employer of Americans with a disability.
- Ask Representative Henry Waxman (D-CA) to conduct oversight hearings on the low use of Schedule A, and other employment supports promoting government employment of people with disabilities.
- Encourage local, federally funded employment services in their state or District to support and provide outreach for the 2008 re-launch of Social Security's New Ticket to Work Program for its disability beneficiaries, in the works for over four years.
- Pass the ADA Restoration Act!

**NCIL Employment Policy:** NCIL believes the U.S. can and will decouple the conflicting goals of today's Social Security disability benefit programs. *Providing supports to help people maintain paid work would be separate from providing income when people are physically or mentally unable to work.*

An employment support *insurance* program would provide health coverage through new models of Medicare, benefits planning services, and referrals to employment support services. The Employment Support Insurance (ESI) would be similar to the social insurance model that SSDI uses now, with FICA payroll deductions. ESI would provide sound transition between looking for work, employment, and having to go on SSI or SSDI. For those unable to work, the current SSDI program would maintain its earnings replacement components under an Earnings Replacement Insurance (ERI) program. Medicare health coverage would be available right away in the 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. Potential beneficiaries would choose application for the ESI or ERI depending on needs. This two-plan model protects life-saving aspects of current systems while addressing gross deficiencies.

Tax code reform could keep what works, and fix what is broken by combining, simplifying, and expanding existing tax credits under a new disabled access credit. The new credit would have one definition for access, that is, the definition for reasonable accommodation in the ADA. This definition would also apply for revised versions of the Work Opportunity Tax Credit, making more employers eligible for the credit. The EITC would also be expanded.

National public policy on employment is stuck in a morass of confusing program rules and conflicting advocacy positions. *"There is a terrible tension between eligibility to get benefits versus getting employment help."* Designs for two-plan models, reinforced with tax reform, would address today's mind-bending process of proving an inability to work before getting work incentives. NCIL believes the U.S. can and will decouple the conflicting goals of the Social Security disability benefit programs by using coherent win-win state, federal and private partnerships.

# Accessible, Affordable, Integrated Housing

## ***The Federal Housing Finance Regulatory Reform Act***

Bill Numbers Not Yet Assigned

NCIL supports the creation of a national housing trust fund because it would lead to the creation of more affordable housing across the nation and be a small step toward addressing the shortage of affordable housing in nearly all regions of the country. A national housing trust fund would increase the supply of affordable housing through production, preservation, and rehabilitation. It is expected that much of this would affect rental housing. Since the funding would come from a portion of the profits of Freddie Mac and Fannie Mae, the funds will be considered federal, and thus subject to Section 504 standards as well as the *Fair Housing Act* as amended. Because of deep income targeting requirements, a national housing trust fund would increase the number of affordable and accessible units available to extremely low-income Americans with disabilities (including those living on fixed incomes). Advocates need to be aware that although the *National Affordable Housing Trust Fund Act (HR 2895 and S 2523)* passed the House of Representatives and was introduced in the Senate by John Kerry (D-MA) in 2007, NCIL is currently focusing efforts on the *Federal Housing Finance Regulatory Reform Act of 2008*, which as of the printing of this document does not yet have a bill number. Unlike previous bills relating to the National Housing Trust Fund, this bill does not have any requirements on accessibility. Ask your Senator to add a clarification that the funds will be considered federal funds (and bound to follow Section 504), and to add the following section:

To the extent the dwelling unit is not required under Federal law to comply with standards relating to accessibility for persons with disabilities, the dwelling unit complies with such basic visitability standards as the Secretary shall by regulation provide.

Please alert your Representative to the *Federal Housing Finance Regulatory Reform Act of 2008* and ask them to work to resolve differences between what emerges from the Senate and *HR 2895*. Reiterate that they must ensure that the funds will be considered federal funds, and that any units not required to be accessible be required to be visitable.

## ***Section 8 Voucher Reform Act (SEVRA)***

*HR 1851 and S 2684*

Introduced by Representative Maxine Waters, the *Section 8 Voucher Reform Act* passed the House on July 12, 2007. *HR 1851* has been referred to the Senate. 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. *SEVRA* is intended to simplify the rules concerning the Section 8 Rental Assistance program. There are too many provisions and changes to include in this summary, and while NCIL supports many of the reforms, we remain very concerned that some changes will have a negative impact on people with disabilities. Our concerns include reductions in income adjustments for unreimbursed medical expenses, replacing the Earned Income Disregards for people returning to work after receiving benefits for at least 12 months, the elimination of child care deductibles, and the expansion of the unproven Moving to Work program, recently renamed the Housing Innovations Program in the Senate draft bill. Please see NCIL's position paper at [www.ncil.org/news/SEVRA.html](http://www.ncil.org/news/SEVRA.html) for full details. NCIL believes that while this bill is well-intentioned and may very well achieve many of its stated goals, the people who can least afford it will be impacted negatively by the work disincentives in the current version of *SEVRA*. Our analysis is that some people with disabilities receiving housing assistance will see their portion of the rent increase. While NCIL is pleased to see funds designated to affordable housing, we remain concerned about supporting the bill in its current form. We urge members of Congress to improve *SEVRA* by addressing our concerns.

# Transportation: Free to Choose, Free to Travel

## ***Over-the-Road Bus Transportation Accessibility Act***

*HR 3985*; Senate Bill Number Pending

*HR 3985* would address the problem of private inter-city bus companies without stations, known as curbside carriers, which willfully ignore the ADA. These companies, which use high-floor "over-the-road" buses and offer budget fares along the Eastern seaboard and across the country, do not provide accessible buses and have frequently discriminated against people with disabilities with other clear-cut violations of the *Americans with Disabilities Act (ADA)*, such as denying transportation to people with guide dogs or requiring them to sit in the last row of the bus. Specifically, *HR 3985* amends Federal transportation law to add as a condition of registration that motor carriers of passengers comply with specified accessibility requirements. The bill directs the Secretary of Transportation and the Attorney General to enter into a memorandum of understanding to delineate the specific roles and responsibilities of the Department of Transportation and the Department of Justice, respectively, in enforcing carrier compliance with such requirements. On April 24<sup>th</sup>, the Senate Committee on Commerce, Science, and Transportation approved *HR 3985*, which the House approved in late 2007. NCIL urges lawmakers to support this measure.

***Free to Choose, Free to Travel:*** Transportation is a critical issue for persons with disabilities, often affecting the opportunity to live independently. Experts agree that the lack of accessible transportation options is one of the most significant barriers facing people with disabilities. Without accessible and affordable transportation, people with disabilities are prevented from attending school, maintaining employment, traveling within the communities of their choice, and fully participating in the American Dream. Therefore, it is the policy of the National Council on Independent Living to seek a federal standard that requires all taxi fleets to be wheelchair accessible by January 1, 2013 and that the Access Board develop and adopt a minimum standard for universal accessible design of all taxicabs.

While efforts have focused on public bus and train travel, experience has shown that accessible public transit is not always the most convenient, cost effective, or time sensitive solution. People with disabilities are part of the general public and want the very same travel options available to everyone else. Taxicabs represent a personal travel option. Yet when it comes to honoring the equal access intent of the *Americans with Disabilities Act*, America's taxicab fleets come up woefully short.

Currently, many Americans with disabilities are limited to medical transportation. Such practice is unfair, unjust, prohibitively expensive and contrary to the spirit of *ADA's* integration mandate. The passage of legislation smoothing the way for the acquisition of wheelchair accessible vehicles will maximize community integration and participation for many of our citizens who currently live without such opportunity. Affordable and accessible taxicab services will ensure that seniors and people with disabilities will age in place, providing greater opportunities to live independently in their existing homes.

To develop legislation around the intent of this policy, we invite all stakeholders in the transportation industry, disability community and government to join with us in structuring legislation to ensure equal access to taxi transportation. Such an action is not without precedent. Federal, state, and local government regulation currently provides safety, access and price controls within the taxi industry. Requiring equal access to taxi fleets for those using mobility devices is no different than government limiting the age of a vehicle that can be used, the fee that can be charged or stating that no taxi operator or company may discriminate against serving passengers based on their race, religion, sex, or ethnic origin. Equal access to America's private transportation fleets is a matter of fundamental fairness whose time has come. NCIL urges Congress to conduct an oversight hearing on accessible transportation, including access to taxi cabs.

## **Available and Accessible Technology**

NCIL is a strong advocate for the use of assistive technology as tools for independence. We believe the principles of inclusion, consumer control, and peer support apply to the use, development and delivery of technology usable and available by all citizens. NCIL believes that people with disabilities are best served by being exposed to technology, having the opportunity to experiment with technology, and being able to acquire technology by making an informed choice and accessing resources to pay for technology. NCIL believes that vigilance is needed to insure that developing technologies are inclusive and accessible. We support legislation and efforts that develop and enforce access standards in emerging and existing technology.

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

NCIL supports funding of the *Assistive Technology Act* as authorized by Congress because it assists consumers in learning about, experimenting with, and acquiring assistive technology in pursuit of their independence. The *Assistive Technology Act* sets the minimum state grant award at \$410,000. Currently, 75% of the programs funded under the *Assistive Technology Act* are funded below the minimum. Of the 75% of the programs receiving less than the minimum, the average state grant program allotment is under \$370,000.

By supporting the *Assistive Technology Act* as authorized and increasing funding for the state assistive technology programs and their collaborators, Congress can ensure that the continuum of services is available to consumers in an integrated manner and better enable them to make decisions that meet their needs and life circumstances.

**Ensuring Accessible Telephones and Television:** Legislative and regulatory safeguards are needed that will ensure full access by people with disabilities to the new high-speed broadband, wireless and new digital technologies. Our nation is moving from analog communications to more versatile digital technologies. More and more devices enter the marketplace that connects television, the Internet, phone and other services. Few of these are designed with disability in mind and there is danger that people with disabilities will be left behind. These new technologies can provide people with disabilities new opportunities for greater independence, integration, and privacy, but only if designed to be accessible to and usable by people with disabilities.

### ***The Twenty-first Century Communications and Video Accessibility Act***

Representative Markey (D-MA), chairman of the House Subcommittee on Telecommunications and the Internet, has published draft legislation, "*The Twenty-first Century Communications and Video Accessibility Act*," which includes many simple, mostly software-oriented steps forward to ensuring people with disabilities are not left behind with new technologies. These objectives were recommended in the 2007 report by the National Council on Disability, "The Need for Federal Legislation and Regulation Prohibiting Telecommunications and Information Services Discrimination," available at: <http://www.ncd.gov/newsroom/publications/2006/discrimination.htm>

NCIL members ask for support of the principles of accessibility found in this bill when introduced. The cost of retroactive accessibility and continuing to build inaccessible infrastructures results in extraordinary and unnecessary burdens. Nothing about us without us!

## The Independent Living Program

Centers for Independent Living are non-residential, community-based, non-profit organizations that are designed and operated by individuals 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 address discrimination and barriers that exist in society through direct advocacy. These barriers are sometimes architectural, but more often reflective of attitudes and prejudices that have been reinforced for generations. They have deterred people with disabilities from working, leaving many in poverty and unjustly detained in institutions. It is logical to recognize that with increased opportunities, individuals with disabilities will reclaim their civil rights and participate in their communities in ways their non-disabled counterparts take for granted.

During fiscal years 2004 – 2006, Centers for Independent Living:

- Attracted over \$520 million through private, state, local and other sources annually;
- Moved 8,381 people out of costly nursing homes and institutions, saving states and the Federal government well over \$160 million; and
- Provided the core services of advocacy, information and referral, peer support, and independent living skills training to over 3 million individuals with disabilities.

In that same period, Centers provided other services to over 659,000 individuals with disabilities in their respective communities that include:

- Services to over 56,000 youth with disabilities;
- Assistance to over 169,000 people in securing accessible, affordable, integrated housing;
- Transportation services to over 106,000 people with disabilities who currently live without affordable, accessible transportation;
- Personal assistance services to over 163,000 people with disabilities;
- Vocational and employment services to 105,000 people with disabilities; and
- Assistance with Assistive Technology for 114,000 people with disabilities.

In addition to the direct services they provide, CILs seek ways to broadly change traditional service delivery in their communities and throughout the nation, including reformation of the long term care system. For over 30 years, Centers for Independent Living have sought community-based programs to assist people with all types of disabilities to remain in or return to their homes and communities. When such services are delivered in an individual's home, rather than a costly nursing facility or other institution, the invariable result is tremendous cost savings to Medicaid, Medicare and state budgets while enabling people with disabilities to become more independent, financially self-sufficient, and less reliant on long term government supports.

The success of system change activities performed by CILs will assist people with all types of disabilities to gain the civil rights guaranteed by our constitution to live and work independently in society.

## **The Independent Living Program**, continued

Independent Living Research Utilization (ILRU) found in a 1999 study (before additional responsibilities were added) that each Center needs a base funding of \$250,000 to fully carry out the responsibilities assigned them. That figure would be significantly higher today. Yet, current funding (under the Rehabilitation Act) provides only \$73.3 million to support hundreds of Centers throughout the country. The average grantee receives approximately \$218,000, which often includes funding for one or more satellites. Due to three consecutive years of funding cuts, Independent Living is now funded below the base levels of 2003.

In addition, CILs often identify and implement needed services in their communities that remain unfunded. NCIL estimates that to meet the current demand, appropriations for the IL Program will need to increase by \$100 million. Increased funding could be reinvested from the billions currently spent to keep people with disabilities out of the mainstream of society. Considering the amount of money that could be saved simply by supporting Centers in their mission to reintegrate people with disabilities unjustly detained in nursing homes and other institutions, this solution is both morally sound and financially necessary.

Recommendations: Centers for Independent Living urgently need two actions:

- Change the formula for distribution of Title VII Part C funds to bring greater equity in funding for the development and expansion of Centers for Independent Living across America. The new formula would divide all new Part C funds so that 50% of the funds are split evenly among the states and territories and the other 50% is distributed according to the percentage the state's population represents (relative to the national population); and
- Increase funding in Title VII Part C funds by at least \$100 million.

## **Reauthorization of the *Rehabilitation Act***

NCIL supports many of the provisions that were included in the Senate-passed *Workforce Investment Act* Amendments, S. 1021, from the 109th Congress. Based upon the recent trend in conservative interpretations of the *Rehabilitation Act*, it is imperative that the following provisions be included in a reauthorization.

Suggested amendments for CILs:

- Carryover - Would allow Centers to carry over Part C funds not spent during the first year into a second year. Section 17(a)(1) of the Rehabilitation Act of 1973, as amended does not allow the opportunity to carryover Title VII C funds from one fiscal year to the next, as Congress intended.
- Grandfathered Centers - Centers that receive Part C funding would not need to re-compete for their grants if they received one prior to the first year of the reauthorization. Centers receiving Part C funds would be grandfathered into the system if they received funds "the previous year" (assuming they met the standards and assurances).
  - Amends 722 (e)(1)(A) of the law to permit entities which fulfill the definition of Center for Independent Living to assume that status and retain their funding under Part C. 722 (e)(1)(A).

## The Independent Living Program, continued

- Funding Formula Change – *S 1021* included legislation championed by Senator Bob Bennett (R-UT) and Representative Michael Simpson (R-ID) that would enable every new Part C dollar to be shared among all of the states and territories. States with the largest populations would always receive more funding proportionally.
  - Amends Section 721 of the Rehabilitation Act of 1973 (42 23 U.S.C. 796f). The current formula is based primarily on population, “an amount bearing the same ratio to such remainder as the population of the State bears to the population of all States. . . not less than . . . one-third of one percent of the sums made available for the fiscal year” There are 24 minimum-funded states.
- Fifth Core Service – Subject to increased appropriations, NCIL supports a fifth core service be added to transition people from nursing homes into the community and from schools into independent living and employment.
  - Although it is generally agreed that most Centers are already providing these types of services, recent budget cuts have inhibited CILs’ ability to offer transition as a “core service.” The additional service will also be addressed in the State Plan for Independent Living and in the Standards for CILs.
  - Amends Title VII, Section 704 and Section 725 to add Promoting Full Access to Community Life as a core service.

SILC Protections - There are several clarifications regarding SILC activities that were included in *S. 1021* and should be included in the reauthorization:

- Chairperson of the SILC – In the 109th Congress, both the Senate and House bills confirmed that the Council shall select a chairperson from among the voting membership of the State Independent Living Council (SILC). An exception for governors who lack veto authority was removed from *S. 1021* in 1998.
  - Amends Section 705(b)(5)(A) to delete “Except as provided in subparagraph (B)” and deletes this subparagraph in its entirety.

The function of the Statewide Independent Living Council should be clarified to include:

- Provide advice and assistance to the Designated State Unit regarding the performance of its responsibilities under this title;
- Facilitate the improvement and coordination of services provided to individuals with disabilities by Centers for Independent Living, the Designated State Unit, other government agencies, and community organizations;
- Conduct resource development activities to obtain funding from public and private resources to support the activities described in this subsection or to support the provision of independent living services by Centers for Independent Living, and;
- Perform such other functions, **including but not limited to systems advocacy**, consistent with the purpose of this chapter and comparable to other functions described in this subsection, as the Council determines to be appropriate.
  - Amends Section 705 to clarify the authority and functions of the SILC.

## Legislation NCIL Supports:

- *HR 3195 / S 1881, ADA Amendments Act*, formerly known as the *ADA Restoration Act*
- *HR 1621 / S 799, Community Choice Act*
- *HR 154 / S 2102, Ending the Medicare Waiting Period*
- *HR 1809 / S 2103, Medicare Independent Living Act*
- *HR 3001 / S 1758, Community Living Assistance Services and Supports, (CLASS Act)*
- *HR 3294 / S 1050, Promoting Wellness for People with Disabilities*
- *HR 5613, HR 5173 / S 2578 Legislation to stop Harmful CMS Regulations* (please see page 7)
- *HR 1845 / S1428 Durable Medical Equipment Access Act of 2007*
- *HR 1424 / S 558, Mental Health Parity & the Paul Wellstone Addiction Equity Act*
- Full funding of all community transportation provisions of the *Safe, Accountable, Flexible, and Efficient Transportation Equity Act: A Legacy for Users (SAFETEA-LU)*
- *HR 1592, Local Law Enforcement Hate Crime Prevention Act (LLEHCPA)*
- Reauthorization of the *Rehabilitation Act* and Increased funding for Title VII Part C funds by at least \$100 million – for a total of \$175 million
- *HR 2895 / S 2523, National Affordable Housing Trust Fund Act of 2007*
- Full Implementation of *HR 5441, the Department of Homeland Security Appropriations Bill of 2007*, enacted last year, which contains the *Post Katrina Emergency Management Reform Bill*
- Full implementation of the *Help America Vote Act of 2002 (HAVA)*
- *HR 1427, Federal Housing Finance Reform Act of 2007*
- *H.R. 3774 / S. 2148, Senior Executive Service Diversity Assurance Act*
- *S 427, Affordable Housing Expansion and Public Safety Act of 2007*

## Legislation NCIL Opposes:

- Cuts to or “flat funding” of programs that enable people with disabilities to live, learn, work, and play in their communities.
- Any paper audit trail or other means of independent vote verification requirement that restricts people with disabilities’ access to vote privately.
- *H.R. 2839, Developmental Disabilities Assistance and Bill of Rights Act of 2000*: NCIL opposes any bill which would put the health, welfare, and security of individuals with disabilities in jeopardy.



**The National Council on Independent Living**

1710 Rhode Island Ave, NW / Fifth Floor ▪ Washington, D.C. 20036

voice: (202) 207-0334 ▪ fax: (202) 207-0341 ▪ tty: (202) 207-0340

website: [www.ncil.org](http://www.ncil.org) ▪ email: [ncil@ncil.org](mailto:ncil@ncil.org)