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Summer  
2015



# The Center Connection

## HAPPY 25th BIRTHDAY AMERICANS WITH DISABILITIES ACT

### *Pushing Forward*

Twenty-five years ago, on July 26, 1990, 2,000 people with disabilities gathered on the South Lawn of the White House for the Americans with Disabilities Act (ADA) signing ceremony. The jubilant crowd heard President George H. W. Bush proclaim the often quoted words, "I now lift my pen to sign this Americans with Disabilities Act and say: Let the shameful wall of exclusion finally come tumbling down."

At the time of the ADA signing, I had just given birth to my daughter, Maddy. While I was not able to be on the South Lawn with so many of my friends and colleagues, I celebrated the historic event in Chicago, where Mayor Richard M. Daley, who committed to making Chicago the most accessible city in the country, hosted a local event. On that day at the White House, in Chicago and around the country, disability advocates felt as if, finally, we had done it. We passed a landmark civil rights law that would allow people with disabilities to participate in their communities and pursue employment opportunities on a level playing field. We did what so many told us couldn't be done.

Though we accomplished a monumental feat,

nothing about passage of the law was easy. There were barriers at every step. Despite the fact that there were no curb cuts, there was no access to bathrooms, there was no interstate TTY system of communication for people who were Deaf and Hard of Hearing, there was no emergency captioning and employers were free to discriminate based upon disability, Congress did not believe there was a history of discrimination. Without a history of discrimination, there would be no law.

Mobilizing the disability community, Justin Dart, Jr., vice chair of the [National Council on Disability](#) and the Martin Luther King of the disability rights movement, issued a call to action. Dart urged us to tell the world what discrimination looks like. Dart and his wife Yoshiko traveled around all 50 states collecting individual stories of discrimination. The community answered the call, giving Justin three large trash bags worth of testimonials, which he delivered during his testimony to Congress. As former Congressman Tony Coehlo said, in order to establish a record of discrimination, "We had to share the scar tissue of our lives, so Congress would understand how rampant discrimination was across our lives."

*(Continued on Page 2)*

In many ways, the law has changed the world. My daughter, just a few days old at the time Bush signed the law, has never known a world without the accessibility features we all now take for granted. Millions of young people with and without disabilities have grown up in a world without the physical barriers that separate us. Today, people with and without disabilities are riding the same buses, shopping at the same retail stores, drawing money from the same ATM machines and watching movies in the same theaters, making the world a better place for everyone.

The law has had enormous impact, but we can never take for granted the success we have achieved. Budget cuts, backlash and stigma all threaten to dismantle the rights everyone has come to expect. In 1999 and the early 2000s, a series of U.S. Supreme Court decisions removed a range of people with disabilities from ADA coverage, people that were included under the original intent of the law. All of these things remind us that the access, accommodations and opportunity we fought for could easily be dismantled.

Similarly, while there has been success, the promise of the Americans with Disabilities Act has not been realized in many ways. Just as millions of young people have never known a world without screen readers and bus lifts, they also have never known a world without catastrophically high unemployment rates for people with disabilities (in 2013, less than 20 percent of the working age disabled population was employed), without significant achievement gaps between disabled and non-disabled students and without unnecessary institutionalization of people with disabilities.

In 1990, many people played a pivotal role to get the law passed. Champions like Pat Wright, Congressman Tony Coehlo, Senator Tom Harkin, Senator Kennedy, Congressman Owens, Sylvia Walker, Michael Winter, Judy Heumann, Frank Bowe, Elizabeth Boggs, Lex Friedan, Bob Bergdorf, Chai Feldblum, Max Starkloff, Judi Chamberlin, Bonnie O'Day and many more. This year, as we celebrate

the 25th anniversary of the Americans with Disabilities Act, we need new champions who will lead the way toward the unfinished promise of the Americans with Disabilities Act. Today's children need to grow up in a world where people with disabilities have the opportunity to find work and to be successful at work, people with disabilities have the option to live with quality supports in affordable, accessible homes in integrated communities and people with psycho-social disabilities live in a world free of stigma.

The anniversary gives us a platform to bring varied segments of our community together for a common goal. In Chicago, under the banner of ADA 25 Chicago, more than 160 organizations from the private, public and non-profit sector have committed to leveraging this 25th anniversary year to create more opportunities and make systemic change in education, employment, technology and community inclusion. With commitment initiatives like this in Chicago and around the country, I am confident that the full promise of the Americans with Disabilities Act will happen. Today, there is the expectation that students with disabilities will learn alongside their non-disabled peers, commuters with disabilities will ride the bus with non-disabled passengers and public spaces will be built to be accessible by all using Universal Design.

Around the world, the Americans with Disabilities Act is the model other countries follow when building a system of human rights protections for people with disabilities. The implementation, enforcement and model of the law has launched a paradigm shift with momentum that will not be reversed. This year, and in years to come, we will ride that momentum, filling in the gaps that still exist, fighting against the barriers that remain, ensuring that the promise of the law applies to all people with disabilities and extends to all sectors of society.



# Proposed Regulations Offer Guidelines for New State-Sponsored ABLE Accounts for People with Disabilities

WASHINGTON — The Internal Revenue Service today released [proposed regulations](#) implementing a new federal law authorizing states to offer specially-designed tax-favored ABLE accounts to people with disabilities who became disabled before age 26.

The Achieving a Better Life Experience (ABLE) account provision was signed into law in December 2014. Recognizing the special financial burdens faced by families raising children with disabilities, ABLE accounts are designed to enable people with disabilities and their families to save for and pay for disability-related expenses.

The new law authorizes any state to offer its residents the option of setting up an ABLE account. Alternatively, a state may contract with another state that offers such accounts. The account owner and designated beneficiary of the account is the disabled individual. In general, a designated beneficiary can have only one ABLE account at a time, and must have been disabled before his or her 26<sup>th</sup> birthday. The law provides what it means to be disabled for this purpose.

Contributions in a total amount up to the annual gift tax exclusion amount, currently \$14,000, can be made to an ABLE account on an annual basis, and distributions are tax-free if used to pay qualified disability expenses.

These are expenses that relate to the designated beneficiary's disability and help that person maintain or improve health, independence and quality of life. For example, they can include housing, education, transportation, health, prevention and wellness, employment training and support, assistive technology, and personal support services and other expenses.

In general, an ABLE account is not to be counted in determining the designated beneficiary's eligibility for many federal means-tested programs, or in determining the amount of any benefit or assistance provided under those programs, although special rules and limits apply for Supplemental Security Income (SSI) purposes.

The proposed regulations, available today for public inspection at [www.federalregister.gov](http://www.federalregister.gov), provide guidance to state programs, designated beneficiaries and other interested parties on a number of issues. For example, the proposed regulations explain the flexibility the programs have in ensuring an individual's eligibility for an ABLE account. They also indicate that the IRS will develop two new forms that ABLE account programs will use to report relevant account information annually to designated beneficiaries and the IRS — [Form 1099-QA](#) for distributions and [Form 5498-QA](#) for contributions.

Until the issuance of final regulations, taxpayers and qualified ABLE programs may rely on these proposed regulations.

The IRS welcomes comments. Comments must be received by Sept. 21, 2015, and may be submitted electronically, by mail, or hand delivered to the IRS. A public hearing is scheduled for Oct. 14, 2015, at the IRS Auditorium, 1111 Constitution Ave. NW, in Washington. See the proposed regulations for details on submitting comments or participating in the public hearing. More information can be found at [Tax Benefit for Disability: IRC Section 529A](#).

*Above article is an IRS News Release from IRS.gov*

## Statewide Independent Living Conference

New York Association on Independent Living (NYAIL) is hosting its 2015 statewide independent living conference on September 16-17, 2015 at the Hilton Garden Inn in Troy, NY. This year's theme is, "Back to the Future: Commemorating the 25<sup>th</sup> Anniversary of the Americans with Disabilities Act".

The conference provides an opportunity for more than 300 disability advocates, individuals with disabilities, friends and family members to connect with others from across the state to learn about the newest developments regarding the rights of people with disabilities and ways to ensure the necessary services and supports are available so that each individual's right to live in their community is realized.

If you are interested in being a conference sponsor or attending the conference, please contact the Center or NYAIL directly at 518.465.4650 or via email at [conference@ilny.org](mailto:conference@ilny.org). Sponsorships may be available to help defray conference costs.

## Summer Skin Care Tips

◆ Stay Hydrated

*Water keeps your skin moisturized*

◆ Use Sunscreen

*Make sure to reapply often*

◆ Ditch aerated drinks

*They are full of sugar. Instead drink water*

◆ Minimize alcohol and caffeine intake

*They will dehydrate you even more*

◆ Exfoliate

*Removes dead skin and improves blood circulation*



# Why do we call on the Long-Term Care Ombudsman?

By: Rebecca A. Bradley, Assistant Director NYS LTCOP Coordinator Broome/Delaware/Chenango Counties

You may have a loved one living in a Long-Term Care (LTC) Facility, or you yourself may be residing in one. During that time many questions or concerns can come up and it becomes uncertain who to turn to. The Long-Term Care Ombudsman Program (LTCOP) is always here to help. But the question still remains, what is an Ombudsman? An Ombudsman is a resident advocate. Someone who works 100% for the resident. If an issue, concern or even misunderstanding occurs within the facility, the Ombudsman can be called upon to assist with alleviating the situation.

Some of the issues an Ombudsman can advocate on are:

- \*Residents' rights
- \*Access to information
- \*Transfer/Discharge
- \*Medicare/Medicaid concerns
- \*Resident Care
- \*Policies and procedures
- \*Dietary concerns

Knowing who the LTC Ombudsman is for the facility you or a loved one is residing in is a phone call away. All LTC facilities must post Ombudsman posters so they are easily accessible to residents and resident families. Also residents and their families can request the Ombudsman be contacted on their behalf and asked to speak with them, or request the phone number for the Ombudsman Program. The Ombudsman will meet with any and all appropriate parties and work towards a resolution that provides peace of mind and continued quality of care for the individual. If you or someone you know has questions concerning the Ombudsman Program or questions about LTC facilities, please Contact Rebecca A. Bradley, LTC Ombudsman Program Coordinator for Broome, Chenango & Delaware Counties at Action for Older Persons, 607-722-1251.

## ***Working as a Social Security Disability Beneficiary***

So, what happens if I return to work while I'm receiving any type of Social Security Disability benefit (SSI, SSDI, CDB, DWB)? I lose my benefits immediately, right? WRONG!!

Social Security encourages individuals to successfully work their way off benefits and become financially stable. Therefore, they provide incentives to Social Security disability beneficiaries to accomplish this. One of the most common questions a social security disability beneficiary asks when he or she goes back to work is *"How much can I earn before it affects my benefits?"* The answer is not a simple dollar amount.

It is possible to come out ahead financially if you use work incentives provided by Social Security. Although you may not retain all of your Social Security benefits (in terms of the amount of cash benefit received, and, yes, you may eventually lose all of it), most people come out ahead financially by working and using work incentives. Also, contrary to popular belief, you most likely won't lose your health benefits immediately either. In fact, you may retain health coverage for a very long period of time. There are ways to extend health coverage of an individual with a disability who returns to work.

Working with someone who can help you understand and utilize the Social Security work incentives that are available to you will enhance your chances of returning to work and improve your overall financial outcome and stability. The Catskill Center for Independence has two individuals trained in the use and application of the work incentives available to Social Security Disability beneficiaries who want to successfully return to work and improve their overall financial circumstances. Each individual's situation is unique and needs to be reviewed in order to help you find out what options are available to YOU specifically. If you are interested in learning more about Social Security work incentives please contact the Center today to find out more.

*Denise Burroughs, Vocational Services Specialist*

# Suicide Prevention is Everyone's Business

National Suicide Prevention Week is the Monday through Sunday surrounding World Suicide Prevention Day, which is observed on September 10 each year to promote worldwide action to prevent suicides. Various events and activities are held throughout the week to raise awareness that suicide is a major preventable cause of premature death.

Early screening of mental illnesses and access to treatment—as well as the elimination of stigma, born of ignorance and fear, keeps too many people from seeking help. Every year, more than 30,000 Americans take their own lives. Suicide is the eighth-leading cause of death in the United States, and the third among our youth, ages 15 to 24. Most suffer from treatable mental illnesses: biological imbalances in the brain, which distort rational thinking and can lead to tragic choices. The majority suffer from some form of depression.

## Know the Warning Signs

- Threats or comments about killing themselves, also known as suicidal ideation, can begin with seemingly harmless thoughts like “I wish I wasn’t here” but can become more overt and dangerous
- Increased alcohol and drug use
- Aggressive behavior
- Social withdrawal from friends, family and the community
- Dramatic mood swings
- Talking, writing or thinking about death
- Impulsive or reckless behavior



## Speak up if you're worried!

If you spot the warning signs of suicide in someone you know, you might wonder if it's a good idea to say anything. What if you're wrong? What if the person gets angry? In such situations, it's natural to feel uncomfortable or afraid. But anyone who talks about suicide or shows other warning signs needs immediate help—the sooner the better.

## In an Emergency, Contact:

- Call 911
- National Suicide Prevention Hotline: 1-800-273-TALK (8255)
- Psychiatric hospital walk-in clinic
- Hospital emergency room
- Urgent care center/clinic

Article comprised of information from [www.nami.org](http://www.nami.org), [www.afsp.org](http://www.afsp.org) and [www.helpguide.org](http://www.helpguide.org)

Pamela Levy, Assistant Director

## A Great Day's Work



Story  
Submitted by  
Don Wyckoff,  
Architectural  
Barrier  
Consultant

A gentleman called the Center quite distressed, asking if we knew where he could get a mobility scooter for little money. He said that as his disease progressed he's been forced to exclude himself from family and friend functions, as he could not walk long enough to participate as he once did. I could hear the sadness in his voice when he told me he wasn't able to play with his kids, or join them in the neighborhood. He said "life seems too pointless if I can't be a part of their active lives."

I informed him that while very rare, we did indeed have a scooter which was recently donated by a very compassionate community member who'd recently lost her husband. I could hear that he needed to compose himself to ask "How much is the scooter?"

"Free!" I said happily..... followed by silence. "Are you serious?" he asked in what was obvious disbelief. "YEP, I'm serious, c'mon down and bring a vehicle large enough to carry it."

When he came to the Center, I could tell that he was so incredibly relieved and he thanked me many times. He said, "You're my hero!" as we loaded it in his car. It was at that point that I informed him that it wasn't me, but a kind woman who selflessly donated the machine to our Center as she knew it would help someone.... Those are the heroes. These moments are only possible due to the generous donations we receive from people like yourself. If you can, please donate your used, unwanted assistive devices to help us help others.

# Useful Links

NY Connect Resource Guide: <http://www.co.delaware.ny.us/departments/ltc/resdir.htm>

If you or someone you know has a disability and would like their opinions heard you can take this survey:

<https://www.surveymonkey.com/r/MW7ZCD9>

Directory of Independent Living Centers: <http://www.ilru.org/projects/silc-net/silc-directory>

New York Association on Independent Living: <http://www.ilny.org/>



Don't forget to check us out on:

Web: [www.ccfi.us](http://www.ccfi.us)

Facebook: <https://www.facebook.com/CatskillCenter23>

Twitter: <https://twitter.com/CatskillCenter1>

YouTube: <https://www.youtube.com/user/catskillcenter1>



## Navigator News

Even though our Open Enrollment for 2015 has formally ended, we are still assisting many consumers in Schoharie County each week as they enroll in Child Health Plus and Medicaid. Our Open Enrollment was very successful as we re-enrolled/renewed most of our existing consumers and were able to enroll about 100 new families this year. It is amazing to be part of helping families get health care coverage that they can afford!

Our next Open Enrollment for Qualified Health Plans will be in November 2015 for enrollment effective January 1, 2016. Currently we are enrolling businesses in SHOP plans for their employees and individuals in Child Health Plus and Medicaid on a year-round basis. If you have lost your health care coverage within the last 60 days or will be losing it shortly, we can still enroll you in a Qualified Health Plan now, so give us a call.

I would like to welcome aboard my colleague, Jason Gaughan, who will be handling the Navigator duties several evenings per week as well as alternate Saturdays. Jason has already enrolled several families and is off to a great start helping Schoharie County residents enroll in health care coverage on the NYS Marketplace. It is wonderful to have Jason's positive attitude and knowledge in our Navigator program.

We will both be doing some outreach this summer in hopes of making even more families and businesses aware of our free services and the plans that are available to them. If you know of a business or group that would like us to meet with them to discuss our program as well as answer questions about the New York State Marketplace and the Affordable Care Act, please contact me at 607-725-7256 so that we can set up a date and time. It is the goal of Catskill Center for Independence to educate and assist as many consumers as we can and help them enroll in affordable health care!

*Debbie Martin, IPA Lead Navigator*

# Awareness Ribbons Guide



We have a new logo at the Catskill Center which is comprised of many awareness ribbons. Each ribbon represents different disability groups. We will be featuring these ribbons in our newsletters with the specific group each represents.



(Orange)

- Leukemia
- Lupus
- Melanoma
- Kidney Cancer
- Multiple Sclerosis
- Prader-Willi Syndrome
- Reflex Sympathetic Dystrophy Syndrome (RSDS)
- Complex Regional Pain Syndrome (CRPS)
- Self-Injury Awareness



(Black & White)

- Rare Disease
- Carcinoid and Neuroendocrine Tumor
- Ehler-Danlos Syndrome



(Light Blue)

- Acute Respiratory Distress Syndrome (ARDS)
- Addison's Disease
- Alopecia
- Arthritis
- Behcet's Disease
- Chronic Fatigue Syndrome
- Colitis
- Colon Cancer
- Chron's Disease
- Epstein-Barr Virus
- Erb's Palsy
- Graves Disease
- Gullian Barre Syndrome
- Huntington's Disease
- Hyperaldosteronism
- Histiocytosis
- Ichthyosis
- Prostate Cancer
- Rectal Cancer
- Restless Legs Syndrome
- Reye's Syndrome
- Scleroderma
- Short Bowel Syndrome
- Shprintzen Syndrome
- Thyroid Disease
- Trisomy 18



(Gold)

- Childhood Cancer
- COPD
- Embryonal Rhabdomyosarcoma
- Pediatric Cancer



(Blue & Yellow)

- Down Syndrome
- Cushing Syndrome

## GO GREEN!

If you would prefer to stay environmentally conscious and receive your newsletter electronically, please feel free to contact us at (607) 432-8000 or send an email request to [ccfi@ccfi.us](mailto:ccfi@ccfi.us).



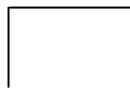


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Membership Drive

The Catskill Center for Independence believes that individuals with disabilities have the same basic rights as other members of society: The right to independently determine their own destiny; to participate freely and equally in all aspects of society; and to contribute to and share in community living. If you share in these beliefs we encourage you to become a dues-paying member of the Center. We need your knowledge, experience and input to assist us in developing Center programs and activities to better meet the needs of our community. To become a Center member, simply detach and return the form below along with you check for \$10.00 (annual dues) to us.

*You do not need to become a dues-paying member of the Center to receive Center services!!!*

\_\_\_\_\_

o Yes, I wish to become a dues-paying member of the Center. Enclosed is my check for \$ \_\_\_\_\_ (annual dues)

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip Code: \_\_\_\_\_ Telephone: \_\_\_\_\_

Please make checks payable to:  
 Catskill Center for Independence (Membership)  
 P.O. Box 1247  
 Oneonta, NY 13820

*A copy of the Center's annual report may be obtained upon request from our organization or from the NYS Attorney General's Charities Bureau,  
 Attn: FOIL Officer, 120 Broadway, New York, NY 10271*

**\*All contributions are tax deductible**