

Every Day is Independence Day

Winter 2010

Catskill Center for Independence

Good news from the first Biannual Statewide Voter Access Conference: Where do we go from here?

The Catskill Center for Independence and its Protection and Advocacy for Voter Access (Upstate PAVA) program Project HAVA, along with our sponsors New York State Independent Living Council (NYSILC) and New York Association of Independent Living (NYAIL), hosted a Voter Access Conference in Troy, NY earlier this month. Now that New York State has met most of the implementation requirements with the federal Help America Vote Act and passed some key pieces of state legislation on voter access, it is time to step up our efforts to ensure the rights of voters with disabilities get the fullest attention possible.

The theme of the conference was "Where do we go from here?" and provided attendees with opportunities for interactive discussions with seasoned advocates to hear about their successes and challenges in voter access achievements in their areas, a chance to learn about aspects of state and federal voter access legislation and current HAVA funding in New York and a mini polling site access training. Along with that every advocate went home with a toolkit developed by our Downstate PAVA partner, Center for the Disabled - NY (CIDNY) to use as they develop relationships with their home county election boards. But the highlight of the day came when Brad Williams, Executive Director of NYSILC presented the Catskill Center's Executive Director, Chris Zachmeyer, with an official certificate for the polling site access law which after nine long years of waiting in the wings becomes effective in New York State on December 15, 2010. Williams and Zachmeyer were co-writers of this bill many moons ago.



We had a near-capacity crowd!



Brad Williams presenting the polling site access law certificate to Chris Zachmeyer

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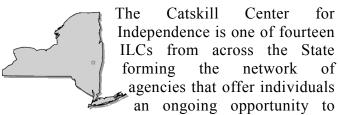


CCFI to Continue As a Participant in the Statewide Systems Advocacy Network

Charles Reichardt, Systems Advocate

The Catskill Center for Independence has once again been awarded a three-year, \$75,000 grant from the New York State Department of Education to continue its participation in the Statewide Systems Advocacy Network (SSAN).

As a grassroots advocacy network of Independent Living Centers (ILCs), the SSAN provides a forum for ILCs from across the state to work collaboratively to achieve successful outcomes on disability priority issues.



have their voices be heard by state officials on matters that are important to them as persons with disabilities. CCFI has implemented a local volunteer disability advocacy network consisting of more than 125 individuals, (with and without disabilities) that can be called to action at any time with the distribution of a single email or by making a few telephone calls. When combined with other local disability advocacy networks around the state, the impact has often been, and will continue to be, tremendous.

Are you just plain tired of the status quo? Have you wondered whether anyone is really listening? Can your voice be heard in your community, Albany or Washington? And do you want to do something that really counts and you can make a difference? If the answer is yes to any of these questions, then contact us at the Catskill Center for Independence and we will show you just how your voice can be heard. In concert with many others, you *can* make a difference in the lives of people where it really matters. Call us at the Catskill Center at: 432-8000, or visit our website at: www.ccfi.us for more information.

Our Newsletter on Tape/E-Mail

Would you like to receive our newsletter on tape or via email? There is no charge for either service, though it is helpful if those who are receiving the tapes return them if they are just planning to throw them away.

Please contact the Center at 607-432-8000, or you can e-mail us at ccfi.us if you would be interested in this service.

Money Follows the Person - An Identification of and Outreach to Nursing Home Residents Project

Pamela Levy, Project Coordinator



The MFP (Money Follows the Person) Demonstration Program promotes the belief that long-term care options, such as permanent nursing home placement, must be changed from being institutionally-based and provider-driven to "person-

centered" consumer directed and community-based.

Since the beginning of calendar year 2009, the number of participants transitioning from nursing homes has increased as solutions to barriers have been identified and technical assistance continues to be provided to help each state meet their transition goals. Nationwide, as of December 2009, almost 6,000 individuals have returned to their communities as a result of the MFP program.

In January 2010, Catskill Center for Independence (CCFI) was approved as a subcontractor to the Southern Tier Independence Center (under contract to the New York State Department of Health), to implement the MFP program. The Center's catchment area includes Nursing Home facilities in Cayuga, Chenango, Cortland, Delaware, and Otsego counties.

A Project Coordinator and Community Transition Facilitator work closely with Administrators,

Continued on next page



discharge planners, social workers, nursing home residents and their supports to provide objective

home and community-based information that will assist in the residents' decision of whether or not to return to their communities. Information includes resources for exploration in the areas of Personal Care Services, Adult



Care Facilities, home modifications, housing searches and many other county-specific service options. Nursing Home residents are encouraged to self-identify needs and program staff can work in conjunction with each individual's team until discharge.

If you would like more detailed information on this outreach project, please contact the Center at (607) 432 - 8000.

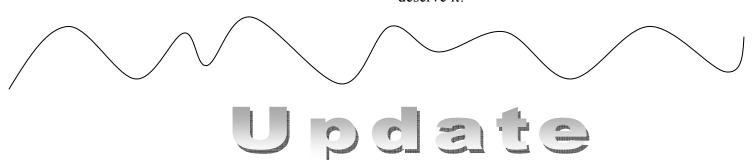






The Catskill Center for Independence would like to thank Rina Riba for her six years of dedicated work for the Center. Your wisdom, your humor and your smile will be missed greatly!

May your retirement open the door to a whole new world of enjoyment, adventure, and happiness. You deserve it!



The Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) Waiver programs continue to grow, with more participants selecting the Catskill Center for Independence as their Service Coordination Provider. The Center is still accepting referrals for the Waiver Programs. For questions or to request more information please contact Selena Granata at (607) 432-8000 or selenagranata@ccfi.us.



What is "PABSS"?

(Hint: For people who receive SSDI and/or SSI)

Laurene M. Reichardt,
Disability Programs Manager/Community Work
Incentive Coordinator

People with disabilities who are seeking to become employed often times face daunting challenges in getting a job and remaining employed. Dealing with day-to-day challenges associated with a disability can make

even a part-time job difficult to keep. When people with disabilities also have to face disability-related barriers when getting and keeping a job, it can make a person discouraged enough to say, "To heck with it – I'm staying at home on Social Security and not going to work!"

If people with disabilities face challenges when seeking and keeping employment there are many places to turn to for help. One of the best kept secrets is assistance from Protection & Advocacy, or P&A. In New York State, the Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD) is the state agency that oversees the provision of P&A services. There are several types of protection & advocacy services including:

- Protection & Advocacy for Persons with Developmental Disabilities (PADD)
- Protection & Advocacy for Individuals with Mental Illness (PAIMI)
- Protection & Advocacy for Individual Rights (PAIR)
- Protection & Advocacy for Beneficiaries of Social Security (PABSS)
- Protection & Advocacy for Persons with Traumatic Brain Injury (PATBI)
- Protection & Advocacy for Assistive Technology Program (PAAT)
- Protection and Advocacy for Voter Access (PAVA)

This article will specifically discuss Protection & Advocacy for Beneficiaries of Social Security or PABSS.

Under Federal law (the Ticket-to-Work and Work Incentives Improvement Act) the Commission on Quality of Care and Advocacy for Persons with Disabilities has been given the responsibility of establishing and providing PABSS services to people with disabilities who are on Social Security Disability Insurance (SSDI) benefits, or to people who receive Supplemental Security Income (SSI), and who want to get a job, keep a job, or regain a job. According to the NYS COCAPD website:

"The PABSS advocacy program will work to identify and remove barriers to employment and assist eligible individuals working towards self-sufficiency. The Commission and its regional service offices will investigate complaints of inappropriate or inadequate services and assist individuals with disabilities in decision-making, technical assistance and dispute resolution." (http://cqc.ny.gov/advocacy/protection-advocacy-programs/pabss)

While the PABSS services do include providing legal assistance, these services are provided only to people with disability-related employment issues; there is no cash assistance provided through these services. The Social Security website on PABSS states, "...although Protection & Advocacy services are free, P&A providers cannot take on every case." (http://www.socialsecurity.gov/work/PandA.html).

At this website, Social Security has also provided a useful chart explaining what PABSS covers and what it does not:

Areas that PABSS may NOT help you with:

- Issues Not Related to the Employment of the disabled beneficiary
- Social Security Disability Determination
- Personal Injury
- Criminal Defense
- Attempts to Obtain Guardianship



- Property and Probate Issues
- Malpractice
- Direct Cash Assistance

Areas that PABSS may help you with:

- Special Education and Transition
- Health Care
- Disability Benefits and Work Incentives
- Rights and Conditions of employment
- Vocational Rehabilitation and preparation
- Wage and Hour Issues
- Transportation
- Housing
- Assistance



If you are someone with a disability who is receiving SSDI, SSI or both, and you have issues with employment that you need assistance with; PABSS may be the answer for you. For further assistance and/or to be connected with the PABSS provider that serves your area, contact the Catskill Center for Independence at 607-432-8000, or e-mail us at ccfi@ccfi.us, or call the Work Incentives Planning & Assistance phone line at 1-866-724-8666.

Election Day 2010: Limping along in Lima

Helen Benlisa, Project HAVA Director

Having been working on voter access issues for over 5 years now, I have seen a range of interpretations of accessibility features; some have been honest attempts and others downright dangerous and



scary. In the early days at this job I often puzzled over why, when we have these carefully developed legal standards and requirements, there are so many different "interpretations"? The fact remains that because this is a civil rights issue, nothing changes unless the civil body demands a change. There are no accessibility police, not much in the way of oversight and pitiful little in the way of general

education about access issues. But Election Day 2010 afforded me even more insight into the importance of an accessible environment, including accessible polling places, and revved my engine of accessibility advocacy a little higher.

On Election Day eve, my comrade in access and I drove to a rural county in the western part of the state so we could start early the next morning on our tour of duty, surveying polling sites accessibility. Our mission is to see how the county election boards are coming along with ensuring voters of all stripes can get into the polls and cast their ballots. My ordeal began after we settled in for the night at an historic hotel in Lima; what it lacked in modern conveniences it made up for by brimming with stories of the past and even boasted a spirit or two. Our rooms were on the second floor, so after traipsing up the grand staircase (no elevator, but who cares - we had ghosts to chase!!) we searched all the nooks and crannies hoping to "make contact". We weren't lucky on that account, so after one last perusal of the family photos on display and final good-night visit to the slightly scary street-side balcony, we were off for a good nights' sleep. Or so I thought.

After settling in, I started to feel a little twinge in my hip, a nagging ache that I chalked up to too much driving and not enough walking. But I thought, "I've felt this before" and it usually goes away after resting and stretching. Well, it didn't go away. It expanded and deepened and flared and roared to the point where I would rather have all my teeth pulled - twice - without the benefit of Novocain or give birth ten times in a week. I would rather have experienced just about anything else but this! I was in the most excruciating pain of my life to date and I hope I never have to go there again.

As trying and traumatizing as it was, it opened my eyes to reality I haven't had to personally face before...the reality where everything instantly changes and there is no stopping it, no fixing it right away and very limited ways of dealing with the immediacy and enormity of it all.

There was no relief from this pain: I couldn't do the most basic life functions let alone complex ones without making an already bad situation worse. I could only gather from the type of pain and its



location in my body it was a pinched nerve or something very much like it; it had turned my left hip and thigh into my own personal war zone.

Standing still was impossible, as was sitting, walking, bending, or moving in any way imaginable. Somehow I managed to get through the necessary morning activities, but not without screaming, crying and carrying on. When I got to the top of the stairs, I cried some more. My left leg could not bear weight and neither could my derrière, so sitting my way down was out of the question. I hobbled down the stairs by a combination of leaning on the banister, dragging the bad leg and supporting myself with the good one. If it wasn't so incredibly painful, it would have been funny.

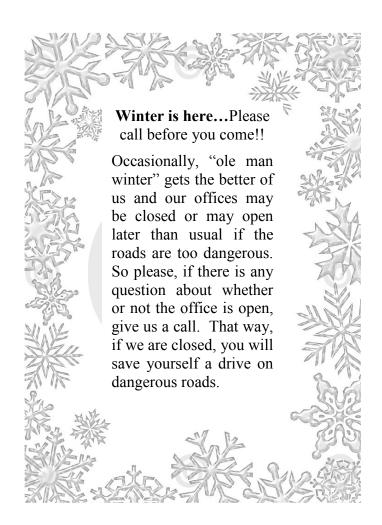
Well, after much gnashing of teeth, we managed to start our day. Sitting semi-reclined in the car was an improvement, but the throbbing-twinge-ing-searing pain continued. There would have been no way I could have operated a motor vehicle in that state, thankfully my comrade had that covered. After breakfast we got started on our tour: 4 counties to cover, a meeting with a reporter - not a thing you want to pass up in this business - limited daylight and now, limited mobility. As my partner was entering polling site addresses into the GPS, I thought I'd try to stretch and walk it out. I limped along a parking area and lo and behold, at the end of the drive was a chiropractor's office. It was a sign...the universe had led me here. Not one to sneeze at such cosmic directives. I went inside and begged them to do whatever was possible because I couldn't not work that day. We only have so many election days during the year!

Patched up and functioning well enough to cope, we got about our business, surveyed several sites, met with that reporter and got an article printed in the next days' paper. But it drove home the awareness of how inaccessible our environments are to folks who may not have the moves of Fred Astaire or Ginger Rogers. I was thankful to lean on handrails along ramps or use the curb cuts so I didn't have to

lift my leg more than an inch off the ground. I was relieved to enter through automatic doors so I didn't have to counter-balance the weight of the door with my body. And I was indignant at establishments that made no effort whatsoever at making the environment accessible.

Our findings were about what they usually are: not a single polling place we visited was fully accessible. There are no good reasons why this lack of access should continue, only excuses. And excuses do not hold up under the law.

So, am I going to work harder at driving the legal issues about access home to our election officials? Am I going to advocate, advocate, advocate for accessible environments everywhere because it is simply right and proper and long overdue? You bet I am.





Hi my name is Selena Granata and I am the service coordinator for the Hello! TBI and NHTD waiver programs at the Center. I have worked for 20 plus vears in human services and have a Masters Degree from SUNY Binghamton. I live in Oxford, NY and have been enjoying my scenic drive to Oneonta this fall. I have three grown children and a 3 year old granddaughter that keeps me busy. My husband and I live in our 150 year old home with our 2 dogs Coco, a 4 lb poodle and CZ a 100 lb. Rottweiler, but Coco is the boss. I enjoy cooking, reading and traveling to anyplace that has a beach; I love the ocean. I have had the pleasure of meeting many of the individuals on the waivers and look forward to working with them.

Coping with Disability as We Age: Aging Gracefully and Gratefully with a Disability

Denise A. Burroughs, Vocational Services Specialist

According to statistics on the World Web as gathered by Cornucopia of Disability Information (CODI), State University of New York at Buffalo, approximately one in five persons have a disability, and one-third of disabled Americans is age 65 or older. Additionally, although there are many different types of disabilities, most occur later in life. "Fewer than 15 percent [of disabled Americans] were born with their disability". Given these statistics,

disability". Given these statistics, it seems apparent that many of us will need to learn to cope with some form of disability as we age.

Doing so gracefully, and if at all possible, gratefully as well, is really a matter of our mindset and how we choose to perceive and live with our disability.

One of the major tenets of the Life Skills Approach is that "how you perceive your disability may become one of your most significant treatments and...is totally in your control. Even if the symptoms stay the same, the quality of your life can be affected and that is not insignificant". In other

words, although coping with a disability can be difficult and may require significant adjustments in our lives, how we choose to view those necessary adjustments can and will undoubtedly have a tremendous impact on our quality of life. Personally, I have seen someone become disabled and have to use a wheelchair in her fifties. This individual decided that this was tantamount to a life-in-prison sentence. Yet, I believe that had she viewed her disability as an opportunity for growth and self-reflection, she may not have viewed her circumstances as imprisonment.

I, myself became disabled at age 24 due to a stroke. I can attest from personal experience that I needed to relearn how to do many things I once took for granted. Something as simple as getting into and out of a car now represented a challenge of sorts and even taking a single step without my left knee snapping back required considerable thought. As I have gotten older, and have accepted my limitations, I have begun to view these challenges as learning opportunities rather than burdens. I believe they have increased my opportunity to learn patience with myself and in certain situations. I have also found it helpful to be thankful for that which I do have rather than resent that which I do not.

I do not mean to sound "Pollyanna - ish" here. Make no mistake about it: having a disability can at times be downright aggravating, frustrating and difficult. The loss of an ability we once had also represents a very real loss. Nonetheless, we each choose how to deal with that loss, aggravation, frustration and difficulty.

By viewing a disability as an opportunity for growth, and as a means to cultivate personal qualities in which we may be lacking, it is possible to not only grow old with a disability gracefully, but gratefully as well. The Life Skills Approach sums up this philosophy rather nicely: "How you deal with a disability defines the quality of your life, limitations are a creation of your mind and not your body. Learn to focus on your strength and not your weakness and turn dealing with a disability into an opportunity of personal growth."