



Connecticut Disability Advocacy Collaborative Bulletin

“Enhancing the effectiveness of disability activism by organizing and empowering individuals, families, groups, and organizations!”

Empowerment! Opportunity! Justice!

June - July, 2008

To include information in next month’s Bulletin please contact us!

Website: <http://www.ct-dac.org/contactus.htm>

Stan Kosloski, 860-614-8351 or StanKosloski@ct-dac.org

Jayne Kleinman, 203-631-4800 or JayneKleinman@ct-dac.org

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**The Disability Advocacy Collaborative presents the
2nd Disability Convention and Expo
Disability *Convention* and *Expo* 2008**

Saturday September 27

10 AM – 4 PM

At the Connecticut Expo Center

(Off of I-91, Exit 33, just north of Hartford)

- **Representatives from the major party Presidential campaigns will be invited as well as all five Congressional incumbents and their challengers; a panel of state representatives and senators will present their views on state level issues and offer tips on how to communicate effectively with your legislators**
- **Learn about your rights as a voter, including how to register to vote and what are the obligations of your town's polling places to ensure you can vote independently, in an accessible location**
- **Visit vendors carrying the latest in adaptive equipment and technology, such as wheelchairs and wheelchair ramps, augmentative and alternative communication devices, aids for independent living, wheelchair lifts, van modifications, and speech recognition captioning**
- **Get information on the many services available for children and adults with disabilities from state agencies and private agencies**
- **Talk with advocates from organizations that represent families that have children with disabilities, as well as adults with a wide range of disabilities - from physical to learning to intellectual to mental; people with visible disabilities and those whose disabilities are hidden will be in attendance to provide information and support**
- **Activities are being planned for children with and without disabilities, so plan to bring the kids and participate in fun activities for the whole family!**

Advocacy Groups Call on DSS to Reverse Intentional Discrimination in Impending Charter Oak Plan

Representatives of several state-wide disability and chronic disease organizations, including the Disability Advocacy Collaborative, have called on DSS Commissioner Michael Starkowski to reverse the intentional discrimination against individuals with disabilities under the Governor's health care plan known as Charter Oak. That plan has various limits of critical concern to individuals with such conditions:

- a limited drug benefit of only \$7500/year
- a benefit of only \$4000/year for medical equipment (e.g., hospital beds)
- lack of equal coverage for mental and physical health conditions, through limits specific to mental health conditions.

The plan not only has the effect of limiting access for people with chronic conditions—this was the purpose behind adopting these limits, as the advocates learned through the response to a Freedom of Information Act (FOIA) request for internal DSS documents. DSS's Charter Oak consultant, Steve Schramm, in an October 1, 2007 memo to the DSS Commissioner, sought to justify limitations on mental health benefits, durable medical equipment, and prescription drug coverage, explaining that these limitations were necessary "to avoid selection issues associated with the chronic users of those services. . . This is viewed as an incentive approach or negative plan design to avoid bad risk." The Schramm memo transparently explains that the "[p]oint to having limits on those kinds of services" is to discourage enrollment in Charter Oak by "chronic users of those services."

Throughout the months leading up to the issuance of a Request for Proposals in January of this year, the Governor or her office repeatedly referred to the Charter Oak plan as her plan for "universal health care" for adults and a plan for "everyone". These press releases touted that the plan would include a "full prescription package" and "no maximum annual benefits."

Despite the adoption by DSS of the October 2007 recommendation to adopt these limits to discourage individuals with chronic mental or physical conditions from joining the Charter Oak program, the Governor's Press Releases issued thereafter nevertheless continued to refer to the plan as one designed for "everyone", and even declared that it is specifically for the "*most vulnerable*."

Advocates for people with disabilities and chronic disease noted that they understand there are limited dollars available for new programs. However, James McGaughey, the Executive Director of the Office of Protection and Advocacy, noted that state law defines the protected class of "physically disabled" individuals as including "any individual who has any *chronic* physical handicap, *infirmity* or impairment" He said that it is "not permissible, under either our state constitution or statutes, for a state agency to allocate limited state funds in a way that specifically discriminates against people with mental or physical disabilities" and that "any limits

must not be designed to single these vulnerable individuals out for effective exclusion from a state program like Charter Oak.”

Jan VanTassel of Conn. Legal Rights Project said that, while the Governor is to be praised for attempting to address the serious problem of the uninsured, “it not only can’t but shouldn’t be done at the expense of people with chronic mental and physical conditions, as they are the least likely to be able to get other insurance-- which is why they are uninsured in the first place. We need to address the problem of the chronically ill uninsured by offering them real coverage—not simply move them from the ranks of the uninsured to the ranks of the fast-growing under-insured population.”

In light of the legal flaws with the plan, the advocates have urged DSS to remove the limits under the plan which were designed to keep the “most vulnerable” from actually being able to take advantage of the plan before implementation and particularly before contracts are signed with the three insurance companies DSS intends to contract with to administer the program.

Decision in Southbury Case

On June 4 Senior U.S. District Judge Ellen Bree Burns handed down a long-awaited decision in *Messier v. Southbury Training School*, a class action lawsuit filed in 1998 that sought decent care and community placement for the institution's approximately 600 residents. The Court will schedule a hearing to determine what remedy is appropriate in view of the violations of the residents' federal rights.

Lynn Warner, Executive Director of The Arc of Connecticut, hailed the decision, calling it "a momentous occasion and a clear validation of the rights of people with intellectual disabilities." The much-publicized case was tried to conclusion for 123 days between January and October 1999.

Justice For All reports that in the 113-page Memorandum of Decision and Order signed June 4, Judge Burns ruled that the plaintiffs (residents of Southbury Training School, The Arc of Connecticut, WeCAHR, and People First) established that the Department of Developmental Services had violated the statutory and constitutional rights of the residents. Further, the judge characterized Southbury as a segregated institution. She also held that the State of Connecticut failed to make independent professional judgments as to whether each resident could benefit from leaving the institution and failed to make community placements available for those who expressed the desire to leave the institution.

The Court noted that the State of Connecticut acknowledged that all of the residents of Southbury Training School could benefit from living in the community, and that many expressed the desire to leave the institution prior to and during the administration of Governor Lowell Weicker. The Court found, however, that, shortly after Governor John Rowland took office and appointed the current DDS Commissioner Peter O'Meara, the institution stopped gathering information about the residents who wished to leave and its administration stopped making professional judgments about whether each resident could leave. Further, the Court cited the State for failure to make resources available so that the residents could experience life outside

the institution contributed to the longstanding segregation of many residents. Judge Burns described the change in State policy as 1) an abdication of the State's duty under the United States Constitution to decide whether each class member would be better off leaving the institution and living in the community and 2) a violation of the rights of the residents secured by the Fourteenth Amendment to the U.S. Constitution, the Americans with Disabilities Act of 1990 and Section 504 of the Rehabilitation Act of 1973. Southbury Training School was in 1999, and remains today, one of the largest institutions for people with intellectual disabilities in the United States.

The Arc of Connecticut is located at 43 Woodland Street, Hartford, CT 06105. Its phone number is 860-246-6400.

Justice Department Settles CT Discrimination Case

In late May the Civil Rights Division of the U.S. Department of Justice (DOJ) reached a settlement that resolved a lawsuit alleging that a Windsor Locks landlord violated the Fair Housing Act by refusing to grant a tenant's requests for a reasonable accommodation.

The lawsuit, filed on Aug. 1, 2007, alleged that Mahmoud M. Hussein refused to grant a reasonable accommodation from his no-pets policy so that his tenant's minor daughter could work with an assistance dog to help with her cerebral palsy, seizure disorder, and depression. The lawsuit further alleged that Hussein retaliated against the mother and daughter after they attempted to exercise their rights under the Fair Housing Act by refusing to renew their annual lease and beginning eviction proceedings.

Under the consent decree, which is pending approval by the court, the defendant will pay \$115,000 in monetary relief, including \$102,000 to compensate the tenant and her daughter and \$13,000 in attorney's fees. Additionally, the defendant will attend fair housing training, implement a reasonable accommodation policy, and comply with notice, monitoring and reporting requirements.

The federal Fair Housing Act prohibits discrimination in housing based on race, color, religion, national origin, sex, disability and familial status. More information about the Civil Rights Division and the laws it enforces is available at www.usdoj.gov/crt. Individuals who believe that they may have been victims of housing discrimination can call the Housing Discrimination Tip Line (1-800-896-7743), email the Justice Department at fairhousing@usdoj.gov, or contact the U.S. Department of Housing and Urban Development at 1-800-669-9777. [Justice for All – 6-04-08]

Upcoming Events

The Connecticut Chapter of the **National Spinal Cord Injury Association** will hold its Annual Picnic on Saturday, June 21 from 12:30 – 3:00 pm at the Chauncey Conference Center and Pavilion at Gaylord Hospital. Representatives from Independence Technologies will be present to demonstrate the IBOT wheelchair. Friends and family are welcomed and food will provided

by Season's Catering. For more information contact 203-284-1045.

Parents with Cognitive Disabilities: Come hear what's working on a national level to support parents with cognitive disabilities, and help create Connecticut's plan to address the service needs of these families. The event will be held on Tuesday, June 24, 2008 from 8:30 a.m. until 4:00 p.m. at Amarante's Sea Cliff in New Haven.

The intended audience for the conference is Bureau Chiefs, Area Directors, Program Directors, Program Supervisors and Supervisors in State departments, and Executive Staff in private agencies. Guests will include the Thortons, parents with cognitive disabilities who have been interviewed on 60 Minutes. For more information contact wendy.kwalwasser@ct.gov.

The **Western Connecticut Association for Human Rights (WeCAHR)** will hold its Annual Meeting Thursday, June 26 from 7:00 – 8:30 pm at the Terryville Mansion in Danbury. Interested persons can call 203-792-3540 for more information.

The July state meeting of **People First** will be held on Thursday, June 26th at 7:00 pm at the Clarion Hotel in East Windsor. The agenda will include a review of Judge Ellen Bree Burns's decision on community placement for the people at Southbury Training School that was issued on June 4. This will be the last meeting that Jean Bowen will attend as an advisor to People First of Connecticut. Laura Hastillo of Manchester will take over effective July 1.

The **Board of Education and Services for the Blind** has announced that the agency is still accepting nominations for the 2008 Awards of Excellence. There are six nomination categories including awards for students, small and large businesses, entrepreneurs who are blind, consumers, teachers, and community boards and foundations. The nomination submission deadline is June 27. An awards ceremony will be held in October in conjunction with White Cane Safety Day in Connecticut. Specific information about the nomination process is available on the agency website (www.ct.gov/besb).

The next event in the **Council on Developmental Disabilities'** series on Life Threatening Public Policy will be held on June 27 from 10:00 am – 2:00 pm and the topic is "Constructive Responses to Life Threatening Public Policy". The workshop will be held at the Institute of Technology and Business Development, Central Connecticut State University in New Britain. To register for the event, call 418-6157, or toll free 1-800-653-1134, or e-mail ed.preneta@ct.gov. There is no cost to attend.

The next event in the series will be held on Friday, September 19, from 2:00 - 4:00 pm and is entitled "Culture Of Death". It will also be held at the Institute of Technology and Business Development at Central Connecticut State University.

On June 28 the **Trumbull Parents of Students with Learning Differences** will offer a one day workshop for parents on *Understanding Special Education*. The workshop will run from 8:00 am - 6:00 pm, and will require two hours of preparation. It will be held at the Helen Plumb Building, 571 Church Hill Road in Trumbull. The trainers are NCPS teacher Vivian Birdsall and

SPED*NET New Canaan director, Anne Eason, Esq. The workshop will include prizes, food, fun, and extensive materials. CEUs are available for educators and everything is FREE! Questions on the curriculum? Contact Anne Eason at 966-9709 or Anne@spednet.org. General questions on the course, location, or Turmbull Parents of Students with Learning Differences - contact Alice Ferreira at alice.c.ferreira@healthnet.com.

In July the **Benhaven Learning Network** will present a three part series for parents who have children on the autism spectrum entitled “Behavioral Challenges at Home and in the Community”. The series will be offered on July 9, July 16, and July 30 from 10:00 am – 12:00 pm and parents are urged to attend all three sessions. The training will take place at the Benhaven School, 125 North Plains Industrial Road in Wallingford. The fee for the series is \$75.00 (includes all three sessions, handouts and refreshments). Please call Stacy Hultgren 203-234-1996 x 336 if you have questions.

The **Connecticut Parent Advocacy Center** invites all parents to join them for an afternoon of food and fun at their Annual Friends and Family Summer Picnic. The event will be held on Saturday, July 12 from 12 noon to 4:00 pm at Camp Harkness in Waterford (301 Great Neck Road). Among a variety of activities, this year's picnic will feature Children's Yoga and a Traveling Touch Tank from the Mystic Aquarium! To RSVP please call CPAC at 800-445-2722 or email them at cpac@cpacinc.org. You can also register online at www.cpacinc.org.

Disability Advocacy Collaborative Regional Contacts

To get involved with one of the Collaborative's Regional Advocacy Networks, contact the following:

Northwest — contact: Bill Knight (lackerman01@snet.net) – meetings are held at the Litchfield Arc

Southwest –contact: Carol Kana (pkana@snet.net) – meetings are held at the Norwalk Police Department

Danbury Area – contact Dale Brown (dbrown@wecahr.org) – meetings are held at Ability Beyond Disability in Bethel

North Central — contact: Candace Low (clow@independenceunlimited.org) – meetings are held at 151 New Park Avenue in Hartford – next meeting June 30 at 10 am

Waterbury Area –contact: Mike Valuckas (mike.valuckas@independencenorthwest.org) – contact Mike for information about next meeting

Northeast Area – contact: Carolyn Newcombe (cnewcombe@charter.net) – meetings are held at the Mansfield Senior Center – next meeting July 29 at 6 pm

Bridgeport Area – contact: Tony LaCava (tlacava@drcfc.org) – meetings are on the third Thursday of the month at various sites

What's New with Connect-Ability

Connect-Ability – Connecticut's Medicaid Infrastructure Grant – has upgraded its web site [<http://www.connect-ability.com/>] in recent weeks. Several key elements have been added:

- The Youth section now features a blog where Connect-Ability's teen correspondents share their stories, perspectives, and dreams. As young people prepare to transition into the world of work or higher education, they now have access to inspiration and support in the words of the eight bloggers, who can respond to their questions and comments.
- The Transportation section now includes two new items. Under Public Transportation Options, click on the word "video" to see "Opening Doors," a five-minute film that shows people with disabilities using public transportation and gives an overview of the equipment and services now available. On the same page, click on "Train" to see the two-page "Tips for First-Time Train Users," which gives information and encouragement to try out this important transportation resource.

Connect-Ability Also Chooses Local Level Pilots

Ten organizations and non-profit agencies have been awarded funding by Connect-Ability to help them prepare strategic plans that may result in the awarding of up to \$200,000 each. The funding will allow the entities to implement creative ways to help people with disabilities join the workforce. The following is a list of the successful bidders, and the priority areas and communities they will serve:

- Oak Hill/New England Assistive Technology Center will focus on Recruiting, Hiring and Promoting people with disabilities in Hartford, East Hartford, West Hartford, Bloomfield, Windsor, Wethersfield, New Britain, Farmington, and Avon.
- Padres Abriendo Puertas/Parents Opening Doors will focus on School to Work Transition in Hartford and New Britain.
- The Workplace, Inc. will focus on School to Work Transitioning in Ansonia, Beacon Falls, Bridgeport, Darien, Derby, Easton, Fairfield, Greenwich, Monroe, New Canaan, Norwalk, Oxford, Seymour, Shelton, Stamford, Stratford, Trumbull, Westport, Weston, and Wilton.
- The Connecticut Association of Centers for Independent Living will focus on Recruiting, Hiring and Promoting people with disabilities in the Windham region including Ashford, Chaplin, Columbia, Coventry, Hampton, Lebanon, Mansfield, Scotland, Willington, and Windham.
- Futures, Inc. will focus on School to Work Transitioning in Hartford.
- Capitol Region Education Council will focus on School to Work Transitioning in the Bloomfield and Rocky Hill public schools.
- Bristol Community Organization, Inc. will focus on School to Work Transitioning in Bristol and Plymouth.
- Workforce Alliance will focus on School to Work Transition and Recruiting, Hiring and Promoting people with disabilities in Bethany, Branford, Chester, Clinton, Cromwell, Deep River, Durham, East Haddam, East Hampton, East Haven, Essex, Guilford, Haddam, Hamden, Killingworth, Madison, Meriden, Middlefield, Middletown, Milford, New Haven, North Branford, North Haven, Old Saybrook, Orange, Portland, Wallingford, West Haven, Westbrook, and Woodbridge.
- City of New Haven Department of Services for Persons with Disabilities will focus on School to Work Transitioning in New Haven County.

- The Arc of New London County will focus on School to Work Transitioning in Norwich, Waterford, and Lisbon.

Advocates are encouraged to contact the grant recipients in their area and get involved now in the planning stage of the initiatives.

Long Time Advocate Retires

Jean Bowen, a founder of People First of Connecticut, has announced her retirement as advisor effective June 30. Jean has been one of a handful of advocates who have persevered for the long term, in Jean's case thirty years, to make the world better for people with disabilities. Here are the words Jean used when she announced her retirement to People First members:

"People First has faced many challenges over the years and has achieved so much. I have been proud of our work together and all that you have accomplished.

It is time for me to move in another direction and so I am submitting my resignation to take effect in 30 days. Many of you know of my concern and interest in helping our communities develop supportive housing and home ownership for first time homebuyers. I will pursue this with the Dream Homes Community Center in Danbury.

I know that you will want to have input as you should into the process of who shall become your advisor. But there is a lot of work to do in the next few months to implement the objectives of training and conference. I have recommended to WeCAHR that Laura Hastillo serve as the Interim Advisor. Laura has years of advocacy and advisor responsibilities and is enthusiastic and highly regarded by our members and advisors.

It has been rewarding work for me to enhance the self advocacy movement in our state and nationally. You are a success in every way and have showed the world that people with disabilities can speak for themselves and advocate for social change."

ADACC Annual Meeting

The ADA Coalition of Connecticut (ADACC) has announced that its Annual Meeting, Luncheon & Awards Presentation will be held on Thursday, October 30, 2008 from 11:30 am - 3:00 pm at the Crowne Plaza Hotel in Cromwell. The cost to attend is \$35/person and for table sponsors the cost is \$350. Join the Americans with Disabilities Act Coalition of Connecticut as they honor state residents who have helped further the cause of the ADA. Contact Project Director Lisa Caron by e-mail at adacoalition@sbcglobal.net or by phone at 860-297-4383 for more information.

Hartford Stage to Offer Audio Descriptive Events

Beth Rival and fellow members of the Connecticut Chapter of the National Federation of the Blind have been working with Hartford Stage Company to offer audio descriptive performances of events held at its theater in Hartford. *A Midsummer Night's Dream* will be presented in the

audio descriptive format on Sunday, September 14th at 2 pm and 7:30 pm and *Resurrection* on Sunday, November 2nd also at 2 pm and 7:30 pm.

For more information contact Jenima Manson at 860-520-7244 or JManson@hartfordstage.com .

Interested in a Career in the Arts?

The Connecticut Commission on Culture and Tourism (CCT), in partnership with Young Audiences Arts for Learning Connecticut (YAC), the state's VSA arts affiliate, will be holding a statewide forum on careers in the arts for people with disabilities. The forum will be held on November 15 at the Carol Autorino Center for the Arts and Humanities at St. Joseph College in West Hartford.

The purpose of the day-long forum is to assess the educational and career development needs and barriers for Connecticut artists and arts administrators with disabilities, promote dialogue and networking among artists with disabilities and arts/service organizations, and stimulate community leadership and interagency coordination.

Since January 2008, CCT and YAC have convened a statewide advisory committee whose members have helped to identify artists with disabilities, artists interested in working with those with disabilities, as well as to reach out to organizations, agencies, institutions, and groups. In March, advisory committee members hosted focus groups to begin collecting information from artists and organizations.

In an effort to continue to solicit input and build an inclusive database, CCT and YAC are asking all interested artists and individuals to complete a Call for Artists-Artist Find survey by July 1, 2008. To get a copy of the survey contact Susan Docker at susan.docker@ct.gov.

ADA Restoration Act Headed to Passage?

On Wednesday, June 18 by a vote of 27 to 0, the House Judiciary Committee unanimously passed HR 3195, the ADA Restoration Act, introduced by former Judiciary Committee Chairman Jim Sensenbrenner (R-Wis), and Majority Leader Steny Hoyer (D-MD). Additionally, the House Education and Labor Committee also marked-up the bill, where it passed overwhelmingly by a vote of 43 to 1.

Disability, civil rights and employer groups have been working hard to secure support for the negotiated language of the Restoration Act that now has the endorsement of more than 50 national and 60 state and local disability groups, the U.S. Chamber of Commerce, the Society for Human Resource Management, the National Association of Manufacturers, the Human Resource Policy Association, and a growing list of companies, including McDonalds, General Motors and Honeywell.

Advocates had worked very hard to counter any efforts in either committee to attach an ADA notification requirement to the bill, a cause that was championed in prior Congresses by

Representative Mark Foley of Florida and that is strongly opposed by the disability-civil rights employer coalition working to enact the ADA Amendments Act. They are also working hard to secure White House and Senate Republican support for the negotiated bill.

Wouldn't it be neat if the bill was signed into law on July 26, the date of the 18th anniversary of the passage of the ADA?

Competitive Bidding Likely to Be Delayed

Five years ago, Congress passed a law to require competitive bidding among companies that provide home medical equipment to Medicare beneficiaries. Now, the Democratic-controlled Congress is set to order a delay of the bidding process, at the behest of equipment suppliers and groups representing Medicare beneficiaries. What happened is, by some accounts, a classic Washington story. The change in direction has come about because of widespread complaints about how the bidding process has been set up and because medical equipment dealers and their clients - Medicare beneficiaries - are a potent political force.

But CMS says that forcing suppliers to bid for Medicare business based on price will wring substantial savings out of a program that has long been associated with fraud. Users of home medical equipment, especially those with severe disabilities that use highly sophisticated wheelchairs for mobility, may lose relationships with equipment providers that know their needs well and that they have spent years cultivating.

On June 12, Rep. Pete Stark, D-Calif., the chairman of the Ways and Means Subcommittee on Health, introduced legislation (HR 6252) with the subcommittee's ranking Republican, Dave Camp of Michigan, that would delay the bidding process for 18 months and force CMS to give suppliers more assistance submitting bids.

But will this delay ultimately be of benefit to people with disabilities, the end users of the equipment being provided?

Brain Injury Settlement in Massachusetts

Thousands of people with brain injuries may soon be able to move out of nursing homes and other institutions under a settlement filed yesterday between the state and a group representing people with brain injuries. The settlement resolves a class action lawsuit filed more than a year ago by the Westborough-based Brain Injury Association of Massachusetts, which charged the state with violating federal law by not providing community-based services to people with brain injuries. The lack of such services means people who would prefer to live independently cannot, and in some cases are warehoused in nursing homes and other institutions.

About 8,000 people with brain injuries now live in nursing homes and rehabilitative facilities, according to the association. At least a quarter of them, or about 2,000 people, could transition to living in the community if the state provided adequate service.

Yesterday's settlement, however, doesn't mean those with brain injuries can move out just yet.

While attorneys for the association hope the deal will be approved by a judge by the end of July, the association's Executive Director Arlene Korab said the first step in the process will be an educational one. "There will be a huge educational process, through nursing facilities, to make everyone aware this is going to be happening," she said. People with brain injuries who want to leave those institutional settings, she said, will then undergo a clinical assessment to determine whether they can safely move into a community setting. Those who are able to could then move home and live with their parents or move into small group homes, Korab said.

Court of Appeals Rules Paper Money Discriminates Against Blind

A ruling in May by a federal appeals court in Washington found that because different denominations of paper money are indistinguishable by touch, the government is discriminating against blind people. The decision could force the Treasury Department to make significant changes to currency, such as printing different-sized bills for different amounts or giving them raised markings.

A three-judge panel of the U.S. Court of Appeals for the District of Columbia issued the 2-1 ruling in a lawsuit by the American Council of the Blind. The government has been fighting the case for about six years and could appeal the ruling. Officials said Tuesday they were reviewing the decision.

Even while fighting the lawsuit, the government has taken some steps to modify U.S. currency for individuals with visual disabilities. The redesign of the \$5 bill introduced in March features a giant "5" in purple on one side of the bill to help those with vision problems.

The Treasury considered printing different sizes of bills but ran into opposition from makers of vending machines. In fighting the lawsuit, government lawyers said it could cost billions to redesign vending machines, but the court rejected that argument, noting that one proposed solution would be to leave \$1 bills unchanged.

Kathy Austin, with the Chicago-based Guild for the Blind, notes that the new currency may become an advantage to those who aren't blind or visually disabled such as waiters or bartenders who work in low light or bank tellers who often dispense cash quickly.

"Many things initially designed for people with disabilities do come to help the general public," said Austin. "Most people think of curb cuts. Initially designed for wheelchairs, they also help moms with strollers, or those with canes and walkers."

And as the population continues to age, Austin bets more and more people will be in need of the added help.

A Life of Quality

Harriet McBryde Johnson, a tenacious, well-known Charleston disability and civil rights attorney, died suddenly Wednesday, June 4. She was 50. Lawrence Downes wrote a tribute that captures the essence of this beautiful woman.

[By Lawrence Downes, June 12, 2008] - In *Parting the Waters*, his history of the early civil-rights movement, Taylor Branch recounts how a teacher of Gandhian resistance, James Lawson, would tell his students not to curl passively into fetal balls when segregationists came to beat them up. It only made them more brutal. This was a way to get livers kicked in and backs broken, he said, recommending that resisters try to maintain eye contact with those beating them.

I thought of that when I learned of the death of Harriet McBryde Johnson, who looked at the world with an unflinching, sometimes withering, gaze. What many saw when they looked at her was a scrawny woman with a twisted spine who got around with a power wheelchair and lots of help. What she saw was a world that refused to make room for the severely disabled, one that looked at people like her, if it looked at them at all, with horror, hostility, condescension and pity, a sentiment she hated.

Ms. Johnson was an eloquent defender of the rights of the disabled. She came to wide attention through *The New York Times Magazine*, in essays she wrote about her confrontations with the philosopher Peter Singer over his defense of killing disabled infants at birth. Ms. Johnson, an atheist, was unmoved by religious appeals to life. Instead, her rebuttal boiled down to a simple: How dare you?

How dare you decide that certain people with limitations are nonpersons with no right to exist? How dare you presume to define quality of life, for me or anyone else, to set the value of a disabled life lower than yours, or to conclude that such a life lacks the potential for happiness and dignity because you cannot imagine how it could? The disabled certainly suffer. But everyone does, Ms. Johnson argued, and if the disabled face extra hassles and indignities in life, well, remedies for those things are all possible, and should be provided.

Instead, the world is run by and for the nondisabled, and those who don't measure up are infantilized, ignored and stockpiled in institutions that Ms. Johnson called the disability gulag. She feared being sent to it in her later years. Ms. Johnson was enraged by injustice, but not susceptible to hatred or despair.

To her, Mr. Singer was a monster, but she realized that the unenlightened also included many of her own friends, colleagues and relatives. She decided that "It's not in my heart to deny every single one of them, categorically, my affection and my love".

Website Launched to Capture Air Travel "Horror Stories"

Justice for All reports that a new website was recently launched by consumer advocates seeking to obtain better services at airports throughout the country (www.howwasyourflight.com/). Airline passengers face many problems when flying, from stranded flights, to a growing list of fees, to safety and security concerns and disability discrimination. The online site includes U.S. airline information and captures air traveler complaints and "horror stories," and airline rankings

- such as best time, worst time, and most complaints -- and includes many “how-to” tips for new equipment and services found at airports. Consumers with disabilities are encouraged to take a passenger survey, or submit complaints or travel horror stories, and to send photos or videos of situations or circumstances illustrating problems or solutions for accessibility.

The initiative is a project of the Reaching Higher Coalition, a coalition of community groups, clergy, elected leaders, and airport workers who are committed to improving standards in the U.S. airline industry. They can be reached via an email to info@howwasyourflight.com.

Autistic and Proud: A Movement Takes Hold

As its name suggests, the Autistic Self-Advocacy Network aims to help people with the disability represent themselves, instead of relying on families and care providers to speak for them. They share a credo with other disability groups: "Nothing about us without us."

The case for moving from Asperger's to activism was made clear last year, when the Child Study Center at New York University released a series of ads about "psychiatric disorders." Designed to look like a ransom note, each ad claimed a condition such as depression, bulimia or autism was holding a child hostage. "We have your son. We are destroying his ability for social interaction and driving him into a life of complete isolation," read one. It was signed "Asperger Syndrome." After a public outcry, NYU canceled the campaign.

Ari Ne'eman was among those offended by the school's approach to raising public awareness. He's the president of the Autistic Self-Advocacy Network and has been diagnosed with Asperger's. "We found these ads extremely offensive because they reinforced perceptions of people with disabilities as not being full people, as being somehow kidnapped and not fully present in our own bodies." Ne'em describes Asperger's and autism as disabilities - but with a twist. "We're disabled by society," he says. "What disables us is, for instance, an education system that's only designed to meet the needs of one kind of student, or societal prejudices which say that autistic people will never be able to live in a community."

Click here to read the entire [article](#). [Reported on NPR – 6-2-08]

Excerpts from Steve Gold’s Information Bulletin # 248 (5/08)

Steve Gold reports on recent GAO report: “How can so many State officials "miss" seeing and reporting deficiencies in nursing homes, year in and out, that put people with disabilities and the elderly in "actual harm or immediate jeopardy"? It should not be that difficult for States to inspect and monitor nursing facilities and to report accurately how these facilities are "treating" residents. When States "miss" these deficiencies and therefore do not report them, the nursing facilities cannot be held accountable for failing to make corrections or improvements.

The recent U.S. Government Accountability Office report, "Federal Monitoring Surveys Demonstrate Continued Understatement of Serious Care Problems and CMS Oversight Weaknesses"(the eighteenth such GAO report since 1998), once again showed that nursing facilities apparently can do whatever harm they want to residents, and the State inspection

officials, who are supposed to monitor these facilities and report deficiencies, ignore these wrongdoings and do not report extremely serious deficiencies.”

Steve ends his latest bulletin with this challenge: “Elderly and Disability Advocates: What actions are you taking to ensure your State inspection surveys do not” miss” such deficiencies? In your State, what are the consequences when State inspectors "miss" deficiencies year in and year out? Are your newspapers or editorial boards aware of these incredible percentages?”

Items to check out:

- Percentages of Surveys with MISSED Deficiencies at the "Actual Harm or Immediate Jeopardy" level. Connecticut has 6% rating while the overall the percentage is 15%. To view the list for all 50 states go to www.stevegoldada.com/stevegoldada/archive.php.
- Percentages of Surveys with At Least One MISSED Deficiency at the "Potential for More than Minimal Harm" level. Connecticut is at 50%. Overall the nation has 68.3%.

To contact Steve Gold directly, write to stevegoldada@cs.com or call 215-627-7100. Back issues of other Information Bulletins are available online at <http://www.stevegoldada.com> .

Advisory Committees Search

The National Council on Disability (NCD) is compiling a list of people who would like to be considered for membership when vacancies occur on NCD advisory committees. NCD has three advisory committees: Cultural Diversity, International Watch, and Youth. The Cultural Diversity Advisory Committee provides advice and recommendations to NCD on issues affecting people with disabilities from culturally diverse backgrounds. International Watch shares information on international disability issues and advises NCD on the development of policy proposals that will advocate for a foreign policy that is consistent with the values and goals of the Americans with Disabilities Act. The Youth Advisory Committee provides advice to NCD on various issues, such as NCD's planning and priorities. All advisory committee members are appointed for two-year terms by the NCD chair. Advisory committees meet by teleconference, and there is no cost to the advisory committee member.

For more information about NCD advisory committees, please go to www.ncd.gov/newsroom/advisory/advisory.htm .
Send your letter of interest by email to ncd@ncd.gov .

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