



Connecticut Disability Advocacy Collaborative Bulletin

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

Empowerment! Opportunity! Justice!

July - August, 2009

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

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

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A slide show featuring activities from the September 27, 2008 Disability Convention and Expo is now on our web site: www.ct-dac.org . Check it out!

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Budget News

The only news is there is no news! Governor Jodi Rell and legislative leaders have been meeting behind closed doors, off and on, since the regular session of the General Assembly ended on June 3. The sticking point: a \$2.5 billion difference of opinion regarding how the budget deficit is to be addressed. The Governor is saying no tax increase, while the Democratically controlled legislature wants increased taxes levied against the state's wealthiest residents. So the primary issue at this point is do we cut services and programs further (the Democrats have already agreed to a number of cuts), or do we raise taxes?

Many disability-related programs are at risk of being eliminated or slashed. They include:

- eliminating state support for the Brain Injury Association of CT (BIAC)
- adopting a more restrictive definition of the term "medical necessity"
- eliminating or reducing funding for legislative commissions, including the Commission on Aging
- reverting to the historical practice of reducing State Supplement benefits by any cost-of-living increase in an individual's SSI benefit
- restricting participation in the state-funded levels of the Connecticut Home Care Program for Elders (CHCPE)
- reducing Medicaid/SAGA coverage for dental care
- eliminating funding for supportive housing
- eliminating limited vision and non-emergency transportation benefits under SAGA
- reducing state funding of the nursing home ombudsman program
- reducing state funding to the five Centers for Independent Living
- reducing coverage of medications, including coverage for dually-eligible individuals of non-formulary drugs, capping state coverage of Part D co-payments, requiring dually-eligible individuals and other ConnPACE participants to enroll in a "benchmark" Medicare D plan, adopting an asset test for participation in the ConnPACE program, and increasing the annual enrollment fee for participation in ConnPACE.

Whatever your priority issue(s), don't ignore this opportunity to influence the budget. Key legislative leaders include:

Speaker of the House Christopher Donovan, (860) 240-8500, 1-800-842-1902 or Christopher.Donovan@cga.ct.gov

House Majority Leader Denise Merrill, (860) 240-8500, 1-800-842-8267 or Denise.Merrill@cga.ct.gov

Senate President Donald Williams, (860) 240-8600, 1-800-842-1420 or Williams@senatedems.ct.gov

You can reach the Governor's office by calling: (860) 524-7397 or (800) 406-1527.

To find your local legislators go to <http://www.cga.ct.gov/asp/menu/CGAFindLeg.asp>. You may also call:

House Democrats: (800) 842-8267

House Republicans: (800) 842-1423

Senate Democrats: (800) 842-1420

Senate Republicans: (800) 842-1421

Illinois P&A Files Suit Against State to Halt Service Cuts

The Illinois P&A, which goes by the name Equip for Equality, filed a lawsuit in federal court on June 30 to block the service reductions being called for in the new state budget that went into effect July 1. The agency said that it was taking this emergency action in order to ensure that individuals with a wide range of disabilities are able to remain in their communities with basic supports and human services.

Does this quote from Equip for Equality Executive Director Zena Naiditch sound familiar: "The sweeping human service cuts that have been identified to balance the budget are unacceptable. If implemented, thousands of individuals will end up in institutions or homeless. The budget cannot be balanced on the backs of people with disabilities -- this action violates their human and civil rights. It is unethical, immoral and violates the ADA and other laws. It will turn back the clock on integration of people with disabilities and is not a lawful way to address budget problems."

Some Good Legislative News!

On June 9, Governor Rell signed into law P.A. 09-115, *An Act Concerning Health Insurance Coverage for Autism Spectrum Disorders*. Connecticut law now requires a group health insurance policy to cover the diagnosis of autism spectrum disorders and expands the requirements on insurers to cover treatment of these disorders. It requires insurers to cover behavioral therapy for a child age 14 or younger and certain prescription drugs and psychiatric and psychological services for children that are insured who have autism. The act permits a policy to set a certain annual dollar maximum for behavioral therapy coverage.

140 Attend Olmstead Event

The year 2009 marked the 10 year anniversary of the historic Olmstead Supreme Court decision, and the Disability Advocacy Collaborative, in conjunction with a cross section of the disability community, held a commemorative event on June 18 at the State Capitol in Hartford. Over 140 disability rights supporters attended the event, including Lois Curtis from Georgia, one of the lead plaintiffs in the case. Preceding the afternoon events, thirty individuals, led by ADAPT leader Claude Holcomb, marched two miles in the rain from a Hartford nursing facility to the State Capitol to demonstrate the continued need to help people move out of institutional settings and into the community.

Five Recognition Awards were made to acknowledge four individuals and one organization that have “lived out” the integration principles of Olmstead. Phyllis Zlotnick, Peg Dignoti, Jan VanTassel, and state Senator Jonathan Harris received individual awards, and Communitas, Inc. received an organizational award. Claude Holcomb was the recipient of a special award given the veteran advocate by the Office of Protection and Advocacy.

MFP After Seven Months

The State’s Money Follow the Person program (MFP) is up and running, and almost 700 referrals have been screened since the program opened for business in December. Eligible persons include anyone who has been in a nursing facility or other institutional setting for at least six months. Twenty Transition Coordinators and five Housing Specialists are available to help individuals plan and implement a strategy to move themselves out of the facility and into the community. Independent living centers and Area Agencies on Aging are assisting individuals in making the transition from a facility to a home.

Application to the program can be made by calling 1-888-99CTMFP (888-992-8637) or by e-mail mfp@ct.gov. Additional information may be obtained at www.ct.gov/moneyfollowtheperson .

MFP is designed to revolutionize the way federal Medicaid money is spent in Connecticut, rebalancing expenditures so that individuals needing in-home care can receive that care in their own home rather than in an institution.

People First Statewide Meeting

A meeting of people First of CT will be held on Thursday July 23rd from 7:00 - 9:00 pm at The Arc of Meriden/Wallingford (200 Research Parkway – Meriden). This is an important meeting as this is the first time People First will be conducting nominations for officers at a statewide meeting. The election itself will be held at the October Statewide meeting.

For more information contact Leslie Simoes at the Arc of CT at lsimoes@arcct.com.

POWERFEST 2009: Future Generations

Powerfest 2009, a statewide inclusive youth transition festival, will be held at the University of Bridgeport on Saturday, October 3, from 10:00 am – 6:00 pm. The event is sponsored by the CT Council on Developmental Disabilities, the Disability Resource Network, the Department Of Public Health, and the Statewide Independent Living Council. The target audience is youth 14-24. The primary purpose of the event is to prepare young people for adult life.

Conference topics include: advocacy, education and vocational pursuits, community and socialization, transportation, recreation and leisure, independence, rights and responsibilities, inspiration and motivation, self-esteem and self-direction and empowerment. The event has been planned and directed by youth with disabilities.

Details and registration material are available at www.ct.gov/ctcdd. Pre- registration is required. Registration forms should be mailed in by September 3 to Angela Spino, CT Council on Developmental Disabilities, 460 Capitol Avenue, Hartford, CT 06106. If you require any special accommodations and/or need assistance with accessible transportation, please contact Angela at 860-418-8709 or angela.spino@ct.gov. There is no cost to attend.

The CT DD Council Presents Free Special Ed Training

Patti Carrin and Angela Spino of the Council on Developmental Disabilities will present free trainings on “Special Education and Community Inclusion Toolkits” on four dates and in four locations:

Thursday, July 23 - 10 am – 1 pm - United Community and Family Services - 47 Town Street, Norwich, CT 06360

Wednesday, July 29 - 10 am – 1 pm - Chauncey Pavilion-Gaylord Hospital - Gaylord Farm Road, Wallingford, CT 06492

Thursday, July 30 - 10 am – 1 pm - Tully Center-Stamford Hospital - 30 Shelburne Road, Stamford, CT 06902

Tuesday, August 4 - 6 pm – 8:30 pm - Chauncey Pavilion-Gaylord Hospital - Gaylord Farm Road, Wallingford, CT 06492

Registration is free, but space is limited to 25 people per session! Contact Michael Fuller at michael.fuller@ct.gov or by phone at (860) 509-7279 to register.

Workforce Alliance to Sponsor a “Working Breakfast”

The Workforce Alliance, one of Connect-Ability’s local level pilot programs, is co-hosting a working breakfast for employers with four Chambers of Commerce, with special guests Ted Kennedy and Joyce Bender. The event will be held on Tuesday September 22 from 7:45 – 9:30 a.m. at the Crowne Plaza Hotel, Cromwell.

Ted Kennedy Jr., an influential disability advocate, is Executive Director of Facing the Challenge, a nonprofit advocacy office for disability-related issues. He is also a teaching fellow on disability policy at Harvard University’s Kennedy School of Government.

Joyce A. Bender is the CEO and Founder of Bender Consulting Services, Inc., a firm that provides consulting services to businesses and competitive employment opportunities for people with disabilities. She is the host of "Disability Matters with Joyce Bender", a radio show on VoiceAmerica.

There is no charge for this breakfast. RSVP to info@workforcealliance.biz or call 203-867-4030 ext 249 to reserve a seat.

The CT DD Council Seeking Public Comment

Prior to making any decisions on specific 2009 initiatives to continue in 2010, or new 2010 initiatives, the CT Council has identified the following categories as priorities for funding:

Education
Employment
Housing and Independent Living
Inclusive Communities
Transportation

The CT Council may identify specific initiatives following its September 22 meeting.

The period for comments will conclude on August 3. Comments may be returned to the CT Council on Developmental Disabilities, 460 Capitol Avenue, Hartford, CT 06106. Comments may be e-mailed to Ed Preneta at Ed.Preneta@ct.gov.

LTC Plan Seeks Input

The State Office of Policy and Management and the state Long Term Care Planning Committee are seeking input as they develop the state's 2010 Long Term Care Plan. The recommendations and action steps provided in this Plan are put forward to improve the balance of the long-term care system in Connecticut for individuals of all ages and across all types of disabilities. While this Plan maps out the need for long-term care over the next twenty five years, the recommendations address current needs as well as future demands.

The draft plan makes sixteen recommendations for improving the state long term care service system. These recommendations are reflective of a system of care, and as such, they must be viewed as both interrelated and interdependent.

Advocates are encouraged to take advantage of this opportunity to influence the state's long term care system. To obtain a copy of the draft Plan and a Feedback Form contact Barbara Wolf at barbara.wolf@ct.gov. Public input is due to Barbara by Friday, August 7 by email, or by fax to 860-418-6495.

Pfizer Launches Program for the Unemployed

Pfizer has launched a new program, called MAINTAIN (Medicines Assistance for Those who Are in Need), which is designed to help recently unemployed Americans and their families who have lost their insurance and who are taking Pfizer medicines to continue treatment at no cost for up to one year. The program will be open for enrollment through December 31, 2009 and applies to eligible Americans who have become unemployed since January 1, 2009. Eligibility requirements of the MAINTAIN program include: loss medicine for at least 3 months prior to unemployment and enrolling in the program; lack of prescription drug coverage; and can attest to financial hardship. Those who qualify will receive their Pfizer medicines at no cost for up to 12

months or until they become re-insured (whichever occurs first). Over 70 Pfizer primary care medicines will be made available.

To apply call 1-866-706-2400 or go to: www.PfizerHelpfulAnswers.com.

Training For Non-Profit Leaders Offers Scholarships

The following planning retreat may be of interest to Executive Directors of non-profit disability organizations: The UConn Nonprofit Leadership Program has announced that scholarships are now being offered for those interested in attending the Facing Change: Nonprofit Executive Director Planning Retreat this summer and fall. Because many small nonprofits wishing to participate in the retreat are coming up against financial constraints, several Connecticut foundations are providing scholarships to support attendance to this strategic planning and skill-development retreat.

The schedule of retreats:

- August 5 - Leading in a Changing Environment
- August 6 - Managing Resources: High Impact in Tumultuous Times
- August 7 - Decision Making for Alliances, Collaborations and Mergers
- November 6 - Outcome Session, Assessing Your Organization's Path

Contact Program Manager Linda Friedman at 860-486-9318 or linda.friedman@uconn.edu about scholarship funds.

Council for Persons with Disabilities Looking for Members

A little over twenty years ago, the CT Council for Persons with Disabilities was created to address the need for an advisory body to the Commissioner of the Department of Social Services (DSS). The relevant statute is Connecticut General Statutes (Sec. 17b-606). The role of the Council is to advise DSS in carrying out its duties as lead agency for services to persons with physical and mental disabilities and as coordinating agency for the delivery of such services by all state agencies. The Council is comprised of individuals who applied and were specifically appointed because of their personal background, and their desire to advocate and be the voice for persons with disabilities in the State of Connecticut.

If you are interested in learning more about the Council, or want to apply for membership, contact Susan Roarabaugh, Co-Chair, at roarabaugh@sbcglobal.net.

Partnership Presentation

The North Central Aging and Disability Partnership is presenting a unique legal rights workshop on September 17 from 1 – 4 pm at the NEAT Center, 120 Holcomb Street, Hartford. The Partnership includes Independence Unlimited, the North Central Area Agency on Aging, and Connecticut Community Care, Inc.

The workshop is entitled “Improving Access to Health Care – Your Legal Rights” and will identify common physical, attitudinal, and communication barriers in medical settings, share information about legal rights in medical settings, and then present creative solutions and advocacy strategies. It will be conducted by Candace Low, Executive Director of Independence Unlimited.

For more information, to RSVP, or to arrange accommodations, contact Denise at 860-523-5021 (voice/TTY).

Kristin Debonee Walk “N” Roll

The Annual Kristen Debonee 5K Walk”N” Roll will be held on October 3 at 10 am at Manchester Community College. All proceeds from the event will benefit Communitas, Inc., an organization that has provided significant support to the Collaborative over its four year history.

Registration for the Walk “N” Roll will take place between 9:30 – 10 am in the AST Building (Tower). There is a \$5 registration fee. A one mile Fun Walk will also be held, and the event will take place rain or shine.

For further information contact Joan Jakiela at 860-512-2705 or by e-mail at jjakiela@mcc.commnet.edu.

Health Care Reform Legislation Moves Forward

Just about every national disability organization is working with members of Congress and their staff to ensure that health care reform efforts meet the needs of people with disabilities. Here is a quick review of where things stand:

Health Care Reform Legislation in the Senate: On June 9, Senators Ted Kennedy (MA) and Christopher Dodd (CT) announced the "Affordable Health Choices Act" which is currently being debated in the Senate Health, Education, Labor and Pensions (HELP) Committee. At the same time, Senator Max Baucus (MT) is leading a bi-partisan effort in the Senate Finance Committee to create a separate budget neutral health care reform bill. Both committees have jurisdiction over health legislation in the Senate, and the end goal is to combine both the HELP and Finance versions into one Senate bill.

Health Care Reform Legislation in the House: The House of Representatives is moving health care reform legislation through three committees that have jurisdiction over health issues: Energy and Commerce, Ways and Means, and Education and Labor. Those three committees released their combined health care reform proposal on June 19. Health care reform efforts in the House are being lead by Congressmen Henry Waxman (CA), Pete Stark (CA), and George Miller (CA), all chairmen of their respective committees or subcommittees.

Common Themes in the Legislation: While Senate and House legislation will initially differ in detail, there are common themes:

- Establish a National Health Exchange
- Require individuals to obtain health insurance
- Make subsidies available to help pay for coverage
- Address gaps in Medicare Part D prescription drug coverage
- Eliminate pre-existing condition discrimination
- Remove lifetime caps in insurance policies

Points of Disagreement in the Legislation: Some differing points include the inclusion of long-term care provisions, a pathway for the approval of generic biologic drugs, the specifics of a public plan, and provisions mandating employer coverage. Those factors could impact the ability of Congress to pass legislation by the August recess.

National Disability-Related Initiatives Cause Concern Among Advocates

A number of disability rights organization, including ADAPT, have expressed outrage at the Obama administration's selective endorsement of one piece of proposed long term care legislation while refusing to support a companion measure aimed at eliminating the institutional bias in Medicaid for aging or disabled lower income people. President Obama, with strong support from over 80 national disability and aging organizations, had co-sponsored the legislation when he was a U.S. Senator.

The Obama administration is supporting Sen. Ted Kennedy's "CLASS Act," which would allow middle class Americans to set aside money from their paychecks in anticipation of the expenses they will likely face for long-term services and supports as they age, or acquire a disability. After paying into the fund for at least five years, workers or their non-working spouses could draw on the fund for long-term services and assistance, either in a nursing home or in the community. Workers who wish could opt out of the program, an outcome more likely in tough economic times or in cases where low worker-wages barely cover individual or family survival expenses.

ADAPT notes that while supporting the CLASS legislation the administration has ignored a companion bill that would include lower income disabled and older people in reform of long term services and supports, and health care reform. A multitude of other national disability and aging organizations in Washington, including ADAPT, has gone on record in support of Sen. Kennedy's CLASS Act only if it is paired with a "fix" for Medicaid addressing lower income and non-working people, similar to provisions contained in the Community Choice Act (CCA). CCA inserts the concept of "personal choice" into the law, adding language that mandates states to pay for help in a person's own home the same way the law mandates them to pay for nursing homes. Current law can force people with disabilities and who are aging into nursing homes in order to receive services that can just as easily be delivered in the community. Research has demonstrated that community-based assistance is almost always less expensive.

Because the CLASS Act does not address the Medicaid “institutional bias,” people who use up the benefits they save under the act will still face having to move to nursing homes to keep getting assistance, unless they can afford to stay in their own homes because of other resources they have.

Hate Crime Bill Moves Forward

The Leadership Conference on Civil Rights has announced that national hate crimes legislation has passed the U.S. House of Representatives and was on the agenda of the U.S. Senate when this edition of the Bulletin was being written. The bill, referred to as the Matthew Shepard Hate Crimes Prevention Act, would provide significant improvements to our current hate crimes prevention laws.

This bill expands the coverage of existing hate crime laws to include crimes not only based on race, color, religion, and national origin, but also bias-motivated crimes based on the victim's actual or perceived sexual orientation, gender, gender identity, or disability. It also provides the federal government jurisdiction to prosecute hate crimes in states where current law or local law enforcement action are inadequate. This increased protection will help groups that continue to be subjected to bias-motivated violence and intimidation.

Hate crimes cut across every community. Passing this bill will ensure that all people have the right to be safe and free from physical harm and intimidation. The Matthew Shepard Hate Crimes Prevention Act sends a clear message that Americans do not have to live in fear.

For more information, read the Leadership Conference on Civil Rights Education Fund's latest report, “[Confronting the New Faces of Hate: Hate Crimes in America 2009](#)”, which documents the continuing serious nature of hate crimes in the United States.

College Scholarships for Students with Disabilities

The American Association on Health and Disability (AAHD) has created the AAHD Scholarship Program to support students with disabilities who are pursuing higher education. Preference will be given to students who plan to pursue undergraduate/graduate studies in public health, health promotion, or disability studies, to include disability policy and disability research. As 2009 is the first year of the scholarship program, funds are limited and scholarships will therefore be competitive. Scholarships will be limited to under \$1,000, and the deadline to apply is October 15.

For more info go to <http://tinyurl.com/quu22e> .

Funding for Respite Care at Risk!

Forty nine national and 250 state and local organizations from 32 states have written the U.S. Senate re: funding for the Lifespan Respite Care Act (PL 109-442). The legislation authorizes funding at a level of \$71.1 million, but the Senate is considering funding the initiative at a \$2.5

million level.

The organizations letter states “Despite its widely supported enactment in 2006, the program received only \$2.5 million in FY09. While we appreciate your leadership on this issue, states are reluctant to apply for funds because of the limited dollars currently available. The Lifespan Respite Care Act is the only federal law which mandates respite services for families, rather than offering it as an optional service, the only federal program which could help ensure respite quality or choice, and the only federal program which requires that funds be used for respite start-up, training and coordination. As the only federal program to address basic accessibility and affordability issues for families regardless of age or disability, it serves a critical and unique purpose.

For families and individuals who may not qualify for any public or private respite funding, including children with severe disabilities, teens with serious emotional and psychological conditions, and adults with Multiple Sclerosis, ALS, traumatic brain injury, spinal cord injuries, cancer, Alzheimer’s and many other chronic physical and mental health conditions, these programs may be holding out the only helping hand. For our wounded veterans returning home from war with traumatic brain injuries and other polytraumas, Lifespan Respite systems could be the lifeline their families must turn to in their new roles as life-long family caregivers.

We urge you to fully fund the program at \$71.1 million and thank you for your ongoing leadership on this issue.”

Accessible Technology Bill Introduced

On Friday afternoon, June 26 Rep. Ed Markey (D-MA) introduced comprehensive legislation to ensure that people with disabilities have access to Internet-based telecommunications and video programming technologies. The bill, the Twenty-first Century Communications and Video Accessibility Act of 2009 (H.R. 3101), would:

- require that mobile and other Internet-based telecommunications devices and equipment be fully hearing aid compatible, have accessible user interfaces, and offer people with disabilities use of a full range of text messaging and other popular services that are currently largely inaccessible;
- provide people who are deaf-blind with vital but costly technologies they need to communicate electronically;
- establish a process and time table for the provision of real-time text capability;
- clarify existing relay-to-relay, Lifeline and Linkup service requirements to ensure their relevance to the real world communications needs of people with disabilities;
- restore the Federal Communications Commission's modest video description rules and unambiguously establish the FCC's current and ongoing authority to expand such regulations;
- require emergency announcements and similar information to be accessible to people with

disabilities through audible presentation of on-screen alerts;

- ensure that video programming offered via the Internet will be both captioned and described;
- call for all devices that receive and playback video programming to employ accessible user interfaces and allow ready access to captioning and description; and
- strengthen consumers' ability to enforce their rights to communications and video accessibility through the establishment of a clearinghouse of information about service and equipment accessibility and usability, a meaningful FCC complaint process that holds industry accountable for their accessibility obligations, and judicial review of FCC action to ensure FCC accountability.

DOJ Releases New Guide on Accessible Meetings

The Department of Justice (DOJ) recently published new ADA guidance on conducting accessible and inclusive meetings. The 28-page guide, “Accessible Information Exchange: Meeting on a Level Playing Field,” covers access to meeting sites as well as presentations, printed materials and other forms of communication. Information is provided on how to evaluate the accessibility of meeting rooms, parking, routes and entrances, and restrooms. This guidance also covers the layout of meeting spaces, accessible circulation and seating, provision of printed materials in accessible formats, and making audible communication accessible through assistive listening systems, real-time captioning, and sign language interpretation. The guide is available on DOJ’s website at www.ada.gov/business/accessiblemtg.htm.

HUD to offer Housing Assistance

The U.S. Department of Housing and Urban Development joined President Obama’s commemoration of the tenth anniversary of the Supreme Court’s Olmstead decision last month by announcing that it will offer rental assistance to 4,000 non-elderly families with disabilities, including 1,000 vouchers specifically targeted to those transitioning out of nursing homes and other care facilities. The announcement coincided with the tenth anniversary of the Supreme Court’s ruling in *Olmstead v. L.C. & E.W.* which affirmed the rights of individuals with disabilities to live independently. To commemorate this landmark decision, President Obama declared 2009 the Year of Community Living.

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

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

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

**For four years the Collaborative was supported in a number of different ways by Communitas, Inc.
To George, Pat and Bev we extend our deep appreciation.**