



Connecticut Disability Advocacy Collaborative Bulletin

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

Empowerment! Opportunity! Justice!

August-September, 2009

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

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

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Because of two very important issues that have been dominating the news – one at the state level and one at the national level – the Bulletin this month will begin with a detailed look at both. Additional state and national news will follow on p. 6.

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Budget News

The only news is there is no news! Well, maybe a little..... 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. They finally agreed on large the budget deficit is but not on how the deficit is to be addressed. As of today (8-19-09) the Democratically-controlled legislature and the Governor are \$1 billion apart on the budget. The Governor has agreed to a minimal tax increase, while the Dems in the legislature want 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?

Two recent steps – there have been many others - taken by advocates are:

- New Haven Legal Assistance (Sheldon Toubman) and the Center for Medicare Advocacy (Judy Stein) have coordinated a letter-writing campaign to the Governor re: her decision to end the Medicare Part D "Wrap Around" program, blocking access to needed medications for thousands on Medicare and Medicaid or Medicare and ConnPACE. As of June 1 the state has ceased paying for non-formulary drugs not covered under the Medicare Part D plans of dual eligible enrollees. If implemented in the budget now being debated, the action would mean there would be no more state payments for drugs not covered for these low-income individuals through their Medicare Part D plans, leaving tens of thousands of people without access to necessary medications – although those drugs are covered for all other people on Medicaid.
- Mental health advocates have called upon the Governor to retract the 20% cut to CT's mental health providers she imposed on August 1. The magnitude of these cuts will have devastating, long-lasting consequences for people with psychiatric disabilities and their families. The Governor has also proposed:
 - Imposing Co-pays for Services in Medicaid
 - Imposing Co-pays for prescription drugs for people eligible for both Medicaid & Medicare
 - Restricting access to psychiatric medications by subjecting mental health related drugs to prior authorization
 - Eliminating already appropriated funding for 150 shovel-ready Supportive Housing units
 - 10% cuts to DMHAS Vocational and Rehabilitation Services

Other disability-related programs are at risk of being eliminated or slashed 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 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 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

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

National Health Care Reform Update

With much of the public discussion on health care reform focusing on the public option and “creeping socialism”, with rancorous town meetings taking place across the country, the Bulletin editors thought it would be most useful for disability activists to gain the perspective of the National Council for Independent Living and AARP. First from NCIL:

“While the loudest folks in the room have gotten the attention lately, their message does nothing to ensure that the healthcare and long-term care needs of people with disabilities are addressed. NCIL again encourages members to attend events to make our voices heard, because if we fail as a nation to reform the system, we’ll see another generation of our brothers and sisters locked in institutions; or locked in their homes without access to basic care and support that will allow them to gain employment or participate meaningfully. Another generation of people with disabilities will find inaccessible clinics and examination equipment, and doctors that treat us as second-class citizens incapable of self-directed lives, instead of valuing and respecting our rights and abilities.

If we don't get vocal and fight those who want to protect corporate financial interests at the expense of our right to affordable, non-discriminatory healthcare and long-term care, we will have only ourselves to blame. We must stand up for what is right, for what is needed, and for what will be one more step toward the freedom of Americans with disabilities. Again, NCIL would like to see the following in healthcare reform legislation:

- The language of the Community Choice Act, to allow anyone who is eligible for Medical Assistance the right to access Home and Community Based Services, and not be forced to accept long-term services and supports in a nursing home because that is what Medicaid unfairly mandates. This HAS NOT been included in any version yet!
- The language of the CLASS Act, which is a new long-term insurance option for people who are employed. If you pay into the system for a minimum of five years, and need assistance with 2-3 activities of daily living, you will get a cash benefit of roughly \$65 per day (this amount has not been determined, but the minimum is \$50/day and the highest estimates are \$75/day). You can use this cash benefit any way you'd like, and there is no lifetime limit or cap. This language has been included in House and Senate versions, and we'd like to ensure that it makes it into the final bill!
- The language of the Promoting Wellness for People with Disabilities Act, which mandates the U.S. Access Board to establish minimum accessibility standards for diagnostic equipment in medical and dental clinics and disability cultural competency training for healthcare and dental professionals. A few bits of this have been included in the House, but we need the full language to be included.
- Ending the two-year waiting period for Medicare for people with disabilities. This practice continues today, and healthcare reform is an excellent opportunity to end it. The House and Senate bills have provisions to expand coverage to people who may fall into this category. NCIL supports that provision, provided the quality of the options are equal to or better than Medicare, and that those who would not fit into the options for expanded coverage are allowed to be in Medicare as soon as they are eligible.

NCIL also supports the following:

- No Pre-existing conditions exclusions. Insurance companies will be prohibited from refusing coverage because of medical history.
- No Annual or Lifetime Caps on Coverage. Insurance companies will be prevented from placing annual or lifetime caps on coverage.
- Coverage for Durable Medical Equipment, Prosthetics, and Orthotics (DMEPOS). These products will be included in any new health plans.
- Increased Medicaid provider reimbursement rates. More providers will serve Medicaid clients when their reimbursement rates match those of Medicare providers.”

- Statement by the National Council on Independent Living

Debunking Health Care Myths (From an AARP Alert)

The following Myth/Fact analysis was published by AARP:

“FACT #1: Medicare will not be ended, and no benefits or services will be cut. AARP's position on this could not be clearer. And we have sent this message loud and clear to Congress. While the current proposals include savings in Medicare by cutting out fraud, abuse, waste, and inefficiency, we're standing up and making sure benefits for Medicare recipients are not only fully protected, but are improved.

FACT #2: No legislation currently in Congress would mandate the rationing of care. Period. Our staff has read all of the legislation circulating in Congress and there are no provisions in these bills that would ration care for our members. None. If any ever did, we would vigorously fight to stop that legislation.

FACT #3: There is no provision of any piece of legislation that would promote euthanasia of any kind. The rumors out there are flat out lies. Right now Medicare does not cover counseling for end-of-life care. The portion of the bill in question would simply provide coverage for optional end-of-life consultations with doctors, so that the patient can be aware of all of the treatment options on the table. It is not mandatory and it has nothing to do with euthanasia.

FACT #4: We have not endorsed President Obama's plan. In fact, we haven't endorsed any plan. We are supporting reform of our health care system, something that AARP has pushed for many years. We're working closely with Republican and Democratic members of Congress to lower health care costs and to ensure quality affordable coverage for older Americans – and we want reform legislation passed and signed by the president this year.

So what is AARP fighting for in health reform?

1. Stopping insurance companies from charging older Americans unaffordable premiums because of their age.
2. Ending the practice of excluding people from insurance because of pre-existing conditions.
3. Holding down health costs and making insurance coverage more affordable for all Americans.
4. Making prescription drugs more affordable by narrowing the Medicare doughnut hole, bringing generics to market faster, and allowing Medicare to negotiate better drug prices.”

House Committee Publishes Reform Rebuttal

To clarify the misconceptions about health care reform proposals, the House Education and Labor Committee has published "Health Care Checkup: A Line-by-Line Rebuttal to False E-Mail". The rebuttal can be accessed at <http://edlabor.house.gov/blog/2009/08/health-care-checkup-a-line-by-.shtml>.

CACIL to Receive Mini-Grant

The National Council on Independent Living (NCIL) has announced that the Connecticut Association of Centers for Independent Living (CACIL) is one of five states that will receive a \$4,000 mini-grant. CACIL was selected because of their proposal for collaboration, education and exchange of information and resources between independent living community and the aging community.

The finalists were selected by a panel of public and private sector experts in aging and disability, long-term supports, and research and program development. NCIL has awarded these mini-grants for the second year in a row because of the strong belief that the aging and disability communities need to be full and committed partners in the expansion of information, resources and services. NCIL also believes that such grants strengthen the role of the Center for Independent Living in establishing or enhancing ADRCs.

CACIL Organizes Community Freedom Fund

CACIL, in conjunction with the state's five independent living centers and five Area Agencies on Aging, has created a Community Freedom Fund to assist people with disabilities and elders move from nursing facilities back to the community. The "Fund" will assist in obtaining the necessities of life including: furniture, bedding, cooking utensils, food, cleaning supplies and other supports and services needed to live in the community. The fund can be found on the internet at www.cacil.net/communityfreedomfund/.

NC Disability Advocacy Network to Plan Focus Group

The North Central Disability Advocacy Network is planning a fall Focus Group on the topic of Visitability. The meeting will take place on Monday, August 31 from 10:00 – 11:30 am in Suite 11 at 151 New Park Avenue in Hartford. Visitability means that if three items were included during the construction phase of single family houses – one no-step entrance, 36" wide hallways, and one bathroom that is large enough for a wheelchair on the ground floor – then individuals who use wheelchairs can more readily visit family and friends. Interested persons should call Denise at (860) 523-5021 v/TTY to arrange accommodations. An interpreter will be provided.

The NC Disability Advocacy Network is facilitated by Independence Unlimited, where Candace Low is Executive Director. Sue Salters is the staff person assigned to the Network, which is affiliated with the Disability Advocacy Collaborative.

And News from SW CT

The SouthWest Disability Advocacy Network is hosting their yearly advocacy seminar on Wednesday, October 21 from 10:00 am – 3:00 pm at the Tully Center in Stamford. The topics for the seminar include self-advocacy, federal legislation, and the recently passed ADA Amendments Act. Contact regional coordinator Carol Kana at pkana@snet.net for more info.

Veterans Stand Down

The 2009 Veterans Stand Down will be held on September 18 from 7:00 am to 3:00 pm at the Connecticut Department of Veterans Affairs in Rocky Hill. The day-long event provides support services to assist veterans in need. More than 30 government agencies and private organizations will offer services and assistance to veterans including food, clothing, job counseling, housing referrals, social service assistance, and dental and mental health screenings. Free transportation will be provided. Last year close to 1,000 veterans attended the Stand Down.

Visit www.ct.gov/ctva for more information on the Stand Down.

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.

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.

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.

News from BIAC

As it fights to retain its state funding, BIAC became affiliated with its 30th support group on Tuesday, July 28. It will debut on 9/2/09 in Danielson and will meet on the 1st & 3rd Wednesday of every month from 1:30 to 3 p.m. One of the facilitators, Denna Niedzwiecki, was a past employee of BIAC in the early 1990's as a Community Educator.

Interested readers should refer to the support group listing for the specifics on location, time, and contact person for all of the groups at www.biact.org/about.html.

News from DNEC

The Deaf Focus Group that is sponsored by DNEC will be having a holiday dinner at Golden Palace in Uncasville on Thursday, December 17 at 6 pm. Dinner will be \$7.00 per person and DNEC will pay the rest. The Golden Palace is located behind Chili's at 2173 Norwich/New London Tpke in Uncasville. The party is open to the deaf community, ASL students, and interpreters, as well as family and friends. Contact Linda Fafard for more information via Videophone at 860-237-3445 (VP) or Lfafard@dnec.org or Text 860-639-0897(T).

DNEC is also sponsoring an ASL level Part 1 Sign Language class that will be held every Monday starting September 22 for eight weeks from 6:00 pm - 7:15 pm. Classes will be held at the DNEC office at 238 West Town Street in Norwich. The cost is \$75. The class will be 10 contact hours (1 CEU) and the deadline to register is September 15, 2008. For more information please contact 860-823-1898 x21.

LDA to Sponsor Workshop Series

For more than 20 years, the Learning Disabilities Association (LDA) of Connecticut has provided parents and professionals the training they need to be fully knowledgeable and engaged at IEP (individualized education program) meetings and as parent advisors. This fall they are offering "What You Need to Know about Special Education: Seminars for Parents and Professionals". Each of these seminars will be held on Thursdays, from 9:30 a.m. to noon, at the LDA-CT offices, on the fifth floor of 999 Asylum Avenue, Hartford. The fees are: \$300 for members attending all 12 seminars; \$350 for non-members attending all 12 seminars; and \$50 for anyone attending individual seminars. To register you may either [download, print, and mail this brochure \(PDF\) with your payment](#) or use PayPal, LDA-CT's provider of secure credit card transactions.

More info can be found at www.ldact.org. You may also call 860- 560-1711.

KTP Offers Annual Legislative Advocacy Trainings

The Keep the Promise Coalition will again offer training workshops for individuals wishing to sharpen their legislative advocacy skills. "Essentials of Legislative Advocacy" will be offered on Thursday, Oct. 1st & Thursday, Oct. 8th from 8:30 a.m.- 3:30p.m. at the Legislative Office Building, 300 Capitol Avenue in Hartford. A box lunch will be provided. And a "Legislative Leadership" workshop will be held on Thursday, Dec. 3rd & Thursday, Dec. 10th from 8:30 a.m. -

3:30 p.m., also at the Legislative Office Building. Lunch vouchers to the LOB Cafeteria will be provided. There is a \$10 fee to help cover cost of book and lunch for each series.

and Celebrates Ten Years of Legislative Advocacy

The Keep the Promise Coalition will celebrate 10 years of legislative advocacy on Thursday, November 5 from 11:30 a.m. - 3:00 p.m. at the St. Thomas Seminary, 467 Bloomfield Avenue in Bloomfield. There will be well-deserved awards presentations, a delicious lunch, and awesome entertainment. Invitations will be sent out in October.

The Keep the Promise Coalition is located at 241 Main Street, 5th Floor, Hartford. Its phone numbers (for Cheri and Maura) are 860-882-0236 and 1-800-215-3021 (toll free), and its Fax is 860-882-0240. You may also reach them by e-Mail at: keepthepromise@namict.org and their Website is www.ctkeepthepromise.org.

What is Recovery.gov?

www.recovery.gov is a website that allows ordinary citizens to see how the money from the American Recovery and Reinvestment Act (ARRA) is being distributed and managed within the state. Within days after the signing of the legislation, federal agencies started distributing funds. As the agencies report data to www.recovery.gov, you can see how Connecticut, our Congressional districts, and even federal contractors that receive ARRA funds are benefitting from the stimulus package. Information will be displayed visually, through maps, charts, and graphics.

It's Official!

U.S. Finally Signs U.N. Convention on the Rights of Persons with Disabilities

The United States signed a U.N. convention aimed at ensuring equal rights for the world's 650 million individuals with disabilities, a pact that the former Bush administration refused to endorse. In a ceremony at U.N. headquarters, U.S. Ambassador Susan Rice inked the pact, billed by the United Nations as the first human rights treaty of the 21st century. It came into force last year. The 32-page U.N. Convention on the Rights of Persons with Disabilities outlaws all forms of discrimination at work on the basis of disability, including in hiring, promotion and working conditions. It requires equal pay for work of equal value. It also calls on signatory states to promote the employment of individuals with disabilities, including through "affirmative action" programs that favor them.

Valerie Jarrett, a senior adviser to Obama, told the gathering the signing was a "historic step toward advancing our global commitment to the fundamental human rights for all persons with disabilities." She also announced the creation of a senior-level position at the State Department to develop a strategy to promote the rights of individuals with disabilities around the world.

NCD Releases Report, and Seeks Public Input

On Wednesday, August 12 the National Council on Disability (NCD) released its report “Effective Emergency Management: Making Improvements for Communities and People with Disabilities”, calling on federal, state, and local authorities to make sweeping changes in emergency management practices for people with disabilities.

NCD’s first evaluation of government work in this area was published in a 2005 report “Saving Lives: Including People with Disabilities in Emergency Planning”. That report laid out a scenario of a major hurricane striking the Gulf Coast and outlined steps that the federal government should take to include people with disabilities in emergency preparedness, disaster relief, and homeland security. Hurricane Katrina struck four months after the report was published. As a result of NCD’s work, the 2006 Homeland Security Appropriations bill’s Post-Katrina Emergency Management Reform Act (H.R. 5441) required Federal Emergency Management Agency (FEMA) to employ a National Disability Coordinator and to interact, consult, and coordinate with NCD on a list of eight other activities.

NCD is also gathering public input for a study of emerging issues and trends affecting the lives of people with disabilities. Information gathered will be used in the development of NCD's next annual progress report to the President and Congress. The purpose of this public consultation is to gather input to inform NCD's assessment of the status of the nation in achieving policies that guarantee equal opportunity for all individuals with disabilities, and empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

To obtain the emergency management report, and for more information about the public input options, go to: www.ncd.gov/whatsnew.htm. Re: public input, you must send your suggestions to NCD by September 15 in one of two ways:

Email to: ncd@ncd.gov and type "Emerging Trends" in the subject line.

Or by U.S. mail to:
National Council on Disability
ATTN: Emerging Trends Committee
1331 F Street NW, Suite 850
Washington, DC 20004

DisabilityInfo.gov is Now Disability.gov

The redesigned site includes new social media tools that will enable you to more easily share, organize and receive important disability-related information, as well as suggest new resources to add to Disability.gov. Visit [How to Use this Site](#) for an overview of what Disability.gov now offers at disabilityinfo@dol.gov.

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> .

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.