

Disability Advocacy Collaborative Bulletin Board

Disability Rights is a Civil Rights Issue

July 2004

Please relay this information to your membership including constituents who do not have e-mail access. Make this available in large print, tape and for others who have difficulty accessing information. This bulletin is available online at www.kleinmanconsulting.com/bulletin.html.

If you want something to appear in the next edition send it to me at jayne@kleinmanconsulting.com or jjk1009@hotmail.com —Jayne Kleinman - 55 Corrigan Ave., Meriden, CT 06451, 203-238-9391

Calendar of Events

<i>Date</i>	<i>Event</i>	<i>Location</i>	<i>Sponsor</i>	<i>Contact</i>
July 21, 2004 9:30- 12 :30	“Moving Forward: Expanding Coverage through 1115 Waivers” (the large category in which all waivers fit).	Lyceum, 227 Lawrence St., Hartford	CT Permanent Commission on the Status of Women	(860) 240-8300 jsolomon@ctkidslink.org
July 26, 2004 10AM – 1PM	ADA Anniversary Your Right to Vote	Legislative Office Building, Hartford	DD Council, P&A, UConn A.J. Pappanikou Center	Ann Dandrow at 860-679-1592 or adandrow@uchc.edu
July 26, 2004 6PM-9PM	14 th Annual Ability/Disability ADA Celebration	Darius Miller Band Shell, Walnut Hill Park, New Britain	New Britain Commission on Persons with Disabilities	NBCOPWD@juno.com (860) 826-3355
Sept. 18, 2004	2004 Americans with Disabilities Convention (presidential candidates invited)	Atlantic City, New Jersey	NJ Council on DD	skosloski03@comcast.net
Sept. 18, 2004 noon- 3:00 PM	WeCAHR Family Celebration and Picnic	Harrybrooke Park, New Milford	WeCAHR	203-792-3540 advozealot@aol.com
Sept. 20-23, 2004	Social Role Valorization Training	Central CT State University	DD Council and SRV Project of Worcester, MA	Yvette Johnson at (860) 418-8709, or yvette.johnson@po.state.ct.us
Oct. 30, 2004	People First of CT Annual Conference	Bristol Radisson Inn	WeCAHR	203-792-3540 advozealot@aol.com

In This Issue

	<i>Page</i>
Calendar of Events	1
Inaugural event of the Disability Advocacy Collaborative — if you haven't registered to vote yet do it now!	2
Connecticut Votes	3
Disability Advocacy Collaborative (background and future goals)	3
Your non-profit organization can register voters!	5
If you rely on government assistance to pay for housing, this law may protect you.	5
Use your home to stay at home—more about reverse mortgages	6
Understanding the new Medicare discount card (and why we need to change the legislation). In two years you will be responsible for \$5,000 after not a great deal of help.	6
Social Role Valorization Training	6
Articles of interest – “Suing to get out in the world,” “The process of making the world better is not an easy one,” “The way we live now: stairway to justice”.	7
Legislative issues to watch for (transportation, Personal Assistance Services, Cash and Counseling, the Family Opportunity Act, and Money Follows the Person bill — look for updates in the next issue of the Bulletin.	8
Resources	8
Connecticut Votes Calendar	9
Disability Advocacy Collaborative sign up sheet	11

The Inaugural Event of the Disability Advocacy Collaborative 41% to 51% - a Goal to be Obtained! June 24, 2004

Eighty individuals attended the inaugural event of the newly formed Disability Advocacy Collaborative, a voter education workshop held at the Radisson Inn in Cromwell on June 24, 2004. The eighty in attendance represented a wide range of disabilities, including parents and family members as well as adults with disabilities.

Two panel discussions took place, and they included representatives from the Office of the Secretary of State, Democracy Works, two presenters from the Office of Protection and Advocacy, the League of Women Voters, the Genesis Social Club in Manchester, and State Rep. David McCluskey. Carolanne Curry from the Women's Campaign School at Yale University moderated both panels. Cathy Cook (Rep. State Senator) was unable to attend.

The immediate challenge put forth to the organizations in attendance was to develop local campaigns to register people to vote; the secondary challenge was to encourage people to vote in November. The Collaborative is considering another event in the fall to further promote the importance of voting.

According to the National Organization on Disability, 41% of eligible voters with disabilities voted in the 2000 Presidential election, compared to 51% of the general adult population. If 51% of adults with disabilities vote this November, over a million additional votes will be cast, enough to possibly determine the outcome of the election, which is predicted to be as close a race as the election four years ago.

Organizer Stan Kosloski singled out Katie Martin from the Keep the Promise Coalition, Wayne Delusso from NAMI/CT, and Jayne Kleinman for their extraordinary efforts to make the workshop a success.

At the end of the day a sheet explaining the purpose of the Collaborative (why it was founded) was distributed along with a tear-off for individuals and organizations to fill out if they are interested in becoming members (see below). So far the Collaborative has had active participation by the Keep the Promise Coalition, the Arc of Connecticut, NAMI/CT, the ADA Coalition of Connecticut, the Brain Injury Association, the Connecticut Women and Disability Network, the Disability Resource Center of Fairfield County, the State Independent Living Council (SILC), the Connecticut Association of Centers for Independent Living (CACIL), People First, Advocacy Unlimited, the Office of Protection and Advocacy, the Council of Developmental Disabilities, and WeCAHR. The Collaborative anticipates there will be many more organizations who will express an interest in joining over the next month or two. Over ninety organizations have been identified as potential members.

Connecticut VOTES!

A calendar of registration drives follows this newsletter with dates, times and locations. Volunteers are needed at these events. If you are interested please contact Chris Santoro or Minaren S. Bozeman at Democracy Works at (860) 727-1157.

Disability Advocacy Collaborative

An Introduction

Starting in the late summer and early fall of 2003, a small group of individuals began meeting to determine the feasibility of developing a collaborative advocacy initiative in the state of Connecticut. The thinking was that with the early retirement of a number of state government disability leaders there may be a window of opportunity to make a real impact on state government. By joining forces, it may be possible to undertake a group effort to

encourage reform of the various disability “systems”. In addition, the state legislature’s Program Review and Investigations Committee was considering a proposal at that time to merge several disability agencies into one super-agency.

After several meetings over the next four months there were larger group meetings with individuals and organizations who shared an interest in enhancing disability services. The initial window of opportunity had passed, but there was still interest in developing an organization of some kind that would:

- Improve communication between and among the various advocacy organizations
- Create a more unified voice among disability advocacy groups, which would result in a stronger political power base
- Enhance support for broad based advocacy issues
- Educate the legislature
- Organize candidates’ forums during which individuals running for office would be asked to go on record re: their position on key disability issues
- Include youth and elders in disability advocacy strategies
- Include individuals with disabilities not currently involved in disability advocacy, with an emphasis on grass roots organizing and leadership development
- Encourage passion and enthusiasm in the promotion of disability rights

The above bullets identify the objectives of what has become called the Disability Advocacy Collaborative.

After the series of meetings noted above, a decision was made to get the Collaborative started by identifying an activity that could be undertaken that would get the new entity off and running. The theme of voter education and voter registration became the overall goal of the Collaborative for the first year.

At this time the Collaborative is loosely formed and evolving. We would love to have you or your organization join with us to make systems change a reality in Connecticut.

The vision for the Collaborative is to concentrate on voter education and voter registration this year, and devoting Year 2 (2005) on cross-disability self-advocacy/empowerment training. The big event, the primary goal, would be a large scale disability convention in the fall of 2006, the next year we will elect state constitutional officers (i.e., Governor, Attorney General, Treasurer, Comptroller, Secretary of State).

If you or your organization have not yet indicated an interest in being a part of the Collaborative, please give us an idea of your degree of support by either filling out the questionnaire at the end of this Bulletin, or mail to my address listed at the beginning of this Bulletin. Thank you.

Jayne Kleinman

Your non-profit organization may be able to register voters!

Most nonprofit organizations are tax exempt under section 501(c) (3) of the Internal Revenue Code and therefore cannot engage in partisan political activity. But many organizations do not understand that they can register voters as long as voter registration activities are conducted in a non-partisan way. In fact, the National Voter Registration Act of 1993 encourages all nongovernmental entities to offer voter registration services. Nonpartisan means not influenced by, affiliated with, or supportive of the interests or policies of any political party or candidate.

As long as your organization is not engaging in partisan activity, you CAN: register voters, encouraged registered voters to vote, and drive voters to the polls. You CANNOT: make statements in support or opposition to a particular candidate or party. (CABHN FEVER, June, 2004)

For more information about the do's and don'ts of voter registration for non-profit organizations, contact Americo Santiago at Democracy Works, 860-727-1157 or at americo@democracyworksct.org.

If you rely on government assistance to help you pay for housing, This CT law may protect you!

Connecticut is one of only a handful of states that have made it illegal to refuse to rent to a person who relies on government assistance to pay for housing. This law protects anyone who pays for housing with any lawful source of income. Various forms of assistance qualify as a "lawful sources of income" under Connecticut law, including: Federal housing subsidies such as Section 8 housing vouchers, State housing assistance such as the Rental Assistance Program (RAP) and the Rental Assistance Program (T-RAP) -- similar to the Section 8 Security Deposit Guarantee.

Connecticut Legal Services (CLS) is now focusing on enforcing the law--particularly in Fairfield and New London counties. CLS attorneys hope to file several complaints against landlords who practice discrimination. CLS believes that the problem of denial of housing to government-assistance participants is more widespread than it may appear.

People who feel they may have been victims of discrimination, or their caseworkers or advocates, should contact David Stowe at the Bridgeport CLS office at (203) 336-3851, or toll free at 1-800-809-4434. Mr. Stowe can also be reached at dstowe@connlegalservices.org.

Use your home to stay at home!!

The National Council on the Aging, with the support of both the Centers for Medicare and Medicaid Services (CMS) and the Robert Wood Johnson Foundation, is laying the groundwork for a powerful public-private partnership to increase the use of reverse mortgages to help pay for long-term care. The ultimate goal of the *Use Your Home to Stay at Home* program is to increase the appropriate use of reverse mortgages so that millions of homeowners can tap home equity to pay for long-term care services or insurance. Reverse mortgages are a special type of loan allowing people aged 62 and older to convert equity in their home into cash while they continue to live at home for as long as they want. For a fact sheet on reverse mortgages, please go to www.ncoa.org.

Understanding the Medicare Act of 2003

Starting June 1st seniors (65 and older) who receive either Part A or Part B Medicare and disabled adults eligible for Medicare have been able to purchase discount cards from private sponsors. The sponsors can change their formularies and prices at any time however there is a “lock-in period for the Medicare recipient which means that if the medication they are taking is no longer on the formulary of the sponsor they will be responsible themselves. **(WHAT???)**.

In 2006 the “gap” you are responsible for is over \$5,000 (see below). Contact the Center for Medicare Advocacy, Inc. www.medicareadvocacy.org or call 860-456-7790 for more **information**.

In 2006 Medicare will cover 25% co-insurance up to \$2250 per year in out-of-pocket expenses. The “donut hole” as it is referred to starts after \$2250 in incurred expenses. From this point, the beneficiary is responsible for the full cost of prescriptions until the \$3600 out-of-pocket spending cap is reached. The \$3600 out-of-pocket does include the already-paid deductible (\$250 in 2006) and co-insurance (\$500 in 2006), leaving the beneficiary responsible for \$2850 in the doughnut hole in 2006. Only deductibles and co-pays toward drugs on a plan's formulary count toward the out-of-pocket limit. Beneficiaries would have to incur a total of \$5100 in such expenses to reach the out-of-pocket cap. **(Does this sound right to you? Many legislators were unaware of this when they signed off on the bill.)**

Social role valorization training available!

Participants will learn about vulnerability and social devaluation and examine service delivery actions and policies, challenge personal beliefs and assumptions, renew personal commitments and learn positive service delivery strategies. Sponsored by the DD Council and the SRV Project of Worcester, Mass. Contact Yvette Johnson at <yvette.johnson@po.state.ct.us> for more information.

Articles of interest

“Suing to get out in the world -- San Franciscans break out of nursing homes to live on their own”

“On a sunny day two years ago, 70-year-old Jesse Fitchett packed everything he owned in a plastic bag, put on his Giants baseball cap and said goodbye to his friends in San Francisco’s Laguna Honda nursing home. Then Fitchett—partially paralyzed and in a wheelchair—rolled out the door of the big, grim building, an early recruit in the growing rebellion against nursing homes. ... Fitchett and other residents of Laguna Honda, one of the country’s largest nursing homes, had no options either, until they made a federal case of the issue and sued the city of San Francisco, which runs the 1,065 bed facility. Experts say their class action suit, one of the first of its kind in the country, may mark the beginning of a whole new movement. ... In 1999 the U.S. Supreme Court reinforced disability rights laws, ruling that if a disabled person prefers to live in the community, and care services would cost the same or less than a nursing home, restricting him to an institution is isolating and discriminatory.

Once he was out, Fitchett took satisfaction from the small pleasures of his new life. For more than two years he navigated the streets of San Francisco in an electric wheelchair, window shopping in Union Square or mingling with the tourists enjoying the bay and the flash of color of the shops along Fisherman’s Wharf. “I like to go to the wharf and watch the people,” he said in an April interview, “Sometimes I have a hot dog and then just sit there and turn my face up to the sun.” ... This sparkling city by the Bay was the birthplace of the independent-living movement. ... Now older Americans have begun to use these disability laws to rejoin the world. The case also broke new ground by setting up a system for assessing the wishes of nursing home residents. “It may seem very basic,” says Gershon, who represented the plaintiffs, “but to ask these older people what they want—that’s very novel.” (AARP Bulletin/June 2004/)

“The process of making the world better is not an easy one”

Ragged Edge Online’s Cal Montgomery: “Even imagining the kind of world you’re shooting for is hard to do.” Read Cal Montgomery’s exploration into “Harry Potter and the Allure of Separatism” online at <http://www.raggededgemagazine.com/focus/potter0604.html>.

“The Way We Live Now: Stairway to Justice”

Harriet McBride Johnson – NY Magazine story on the Lane Supreme Court Decision – “Monday, May 17, was an interesting day for civil rights. As the first same-sex marriages were performed in Massachusetts and people everywhere observed the 50th anniversary of Brown v. Board of Education, the U.S. Supreme Court delivered another important civil rights victory in Tennessee v. Lane. (Although it was a squeaker). {The facts in Lane involved access to a courthouse for a person who uses a wheelchair. The second plaintiff, a court reporter who uses a wheelchair, can’t work in a number of courtrooms because of

architectural barrier}. For many decades, long flights of stairs made statements about the grandeur and power of the law. They reflected prevailing assumptions about the abilities of the people who would be participating in public life. By design, they were humbling, even disempowering. Ramps, elevators and appropriate use of government spaces have the opposite effect. For people with disabilities, it is impossible to conceptualize equal protection without them.”

For a complete copy of the article go to www.jfanow.org.

Legislative issues to speak up about!

Support Transportation Bills—Congress has sent to a House/Senate Conference Committee two transportation authorization bills. The process of coming up with final bill language will probably take several months. Call Maureen McCloskey of PVA (202-416-7696) or go to Maureenm@pva.org for more information.

Look for updates in August—Public hearings were recently held to update of the state’s PCA waiver option, and CT’s participation in the Cash and Counseling service moved one step closer to reality in June with an “inverse site visit” with the Robert Wood Johnson Foundation.

The Family Opportunity Act (FOA) and the Money Follows the Person (MFP) legislation have stalled. Call, fax and send e-mails to Congress, President Bush and Dr. Mark McCellen and Dennis Smith at the Center for Medicaid/Medicare Services and ask them to find the means necessary for this legislation to pass. For more information go to www.jfanow.org.

Resources

Infoline--Infoline can be reached at 2-1-1. They offer confidential, free human service assistance.

Conservation and home improvement loans as well as energy assistance are available to qualified applicants. If you know someone who to wants explore this further contact www.chif.org--The Connecticut Housing Investment Fund, Inc. (CHIF).

If you're a senior 60 or over with questions about your rights as a consumer, call the Consumer Law Project for Elders hotline, M-F, 9am-5pm, 1-800-296-1467.

The Connecticut Alliance for Basic Human Needs (CABHN) is a statewide network of individuals, community groups and organizations which supports and promotes advocacy on low-income issues. For more information contact the Legal Assistance Resource Center of CT or CABHN at 80 Jefferson Street, Hartford, CT 06106. -- (860) 278-5688.

New Hours at Statewide Legal Services!

If you are low income and think you have a legal problem, help is available. Call between 5 p.m. and 7 p.m. on Tuesday and Thursday and the wait is shorter. **NEW HOURS: Mon. & Wed. – 9 AM-4 PM Tues. & Thurs. - 9AM-7PM Fri. - 9AM- 3 PM.** Call 860-344-0380 in the Middletown/Hartford areas. The toll free number is 800-453-3320. Se habla Espanola.

Want to Write an Article?

These are just a few of the advocacy issues I would like to feature but I need your help. Let me know of your interest in any of the following:

- **Transportation**
- **Voting**
- **Medicaid/Saga/Medicare cuts**
- **Housing opportunities (or lack thereof)**
- **Closed captioning**
- **Children with disabilities and their families**

How to find your legislators: Go to <http://mygov.governmentguide.com>

<h2 style="margin: 0;">Connecticut VOTES! - Connecticut VOTA!</h2> <p style="margin: 0;">A coalition to promote vote education, voter registration and voter participation</p>
--

Please call Chris Santoro or Minaren S. Bozeman at Democracy Works (860) 727-1157).


CT VOTES! Voter Registration Drives ~ Volunteers Needed!!

DATE	EVENT	TIME	LOCAT ION	TOWN	ORGANIZATION	CONTACT PERSON
Friday, July 16 th	Jazz Festival	6pm	Bushnell Park	Hartford	Democracy Works	Chris Santoro (860) 727- 1157
Friday, July 16 th	Dave Matthews Band	6pm	Meadow s Music Theater	Hartford	Democracy Works	Chris Santoro (860) 727- 1157
Saturday, July 17 th	Jazz Festival	1pm- 9pm	Bushnell Park	Hartford	TBA	Chris Santoro (860) 727- 1157
Saturday, July 17 th	Arts & Craft Fair	12pm- 7pm	Town Green	Guilford	National Council of Jewish Women	Margie Hirshfield (203) 288-

						6733
Saturday, July 17 th	Dave Matthews Band	6pm	Meadow s Music Theater	Hartford	TBA	TBA
Sunday, July 18 th	Jazz Festival	11 am	Bushnell Park	Hartford	Americans with Disabilities Act Coalition of Connecticut, Inc.	Elanah Sherman (860) 297- 4383
Thursday, July 15 th	3 rd Thursday Street Festival	4:30p m- 9pm	Main Street	Willimant ic	One CT East Working Families	Gabe Fonceca (860)523- 1699
Thursday, July 22 nd	2004 Tall Ships Challenge	1pm- 9pm	New London Waterfro nt	New London	PRFAA	Jarssymar Rosario (860) 522- 2434
Friday, July 23 rd	2004 Tall Ships Challenge	9am- 9pm	New London Waterfro nt	New London	PRFAA	Jarssymar Rosario (860) 522- 2434
Saturday, July 24 th	2004 Tall Ships Challenge	9am- 9pm	New London Waterfro nt	New London	PRFAA	Jarssymar Rosario (860) 522- 2434
Sunday, July 25 th	2004 Tall Ships Challenge	9am- 5pm	New London Waterfro nt	New London	PRFAA	Jarssymar Rosario (860) 522- 2434
Saturday, July 24 th	Connecticut Carnival	11 am	Bushnell Park	Hartford	TBA	TBA
Thursday, August 4 th	Gospel Fest	4:30p m- 7:30p m	Goff Street Park	New Haven	TBA	TBA
Saturday, August 7 th	Cove Beach Fireworks	12pm- 9pm	Cove Beach	Stamford	TBA	TBA
Saturday, August 14 th	2 nd Annual Stamford Carnival	1pm-9 pm	Columb us Park	Stamford	TBA	TBA
Thursday, August 19 th	3 rd Thursday Street Festival	4:30p m- 9pm	Main Street	Willimant ic	One CT East Working Families Party	Debbie Noble (860) 278- 5688 x12
Saturday, August 21 st	19 th Annual Keney Park Parade	12:00 p.m.	Keney Park	Hartford	TBA	TBA
Saturday, September 11 th	9 th Annual LEVAS (Lift Every Voice and Sing) Gospel Festival & Fair	11am- 9pm	Bushnell Park	Hartford	TBA	TBA
Thursday, September 16 th	3 rd Thursday Street Festival	4:30p m- 9pm	Main Street	Willimant ic	One CT East Working Families Party	Debbie Noble (860) 278- 5688 x12

Saturday, September 18 th	CT Pride Festival Connecticut	11am -6pm	Bushnell Park	Hartford	Democracy Works	Minaren Bozeman (860) 727- 1157
Saturday, September 25 th	African American Day Parade	1pm- 9pm	Keney Park	Hartford	Democracy Works	Minaren Bozeman (860) 727- 1157

***Volunteers not needed**

Voter Registration Volunteers are needed at these events, if interested please contact

:

**Disability Advocacy Collaborative
7 Shadow Lane
Cromwell, CT 06416
skosloski03@comcast.net**

I/we are interested in becoming a participant in the Disability Advocacy Collaborative _____

Name	Organization	Address	Phone	e-mail address

I/we are interested in the work of the Collaborative and would be willing to assist but not join at this time. Please keep me informed of future developments_____.

Name	Organization	Address	Phone	e-mail address

My/our specific area of expertise is

Other thoughts or comments:
