



Connecticut Disability Advocacy Collaborative Bulletin

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

Empowerment! Opportunity! Justice!

May 2007

Need this newsletter in an alternative format? Please let us know.

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This Bulletin is supported by a grant that the Disability Advocacy Collaborative has received from the Connecticut Council on Developmental Disabilities. In addition, in-kind support is being provided by the UCONN Center on Disabilities, and Communitas, Inc. serves as the project’s fiscal agent. To all three we extend our deep appreciation.

This month the Bulletin will be somewhat abbreviated due to lots of advocacy work on the crisis which has developed with the PCA Waiver. See the announcement below for details, contact your local legislators today, and plan to attend the Press Conference and Rally on May 9.

Press Conference and Rally

Wednesday, May 9, 2007

Press Conference: 10:30 am – Room 1E – Legislative Office Building (LOB)

Rally: to follow at State Capitol

The PCA Waiver is capped!

People with personal assistance needs may be forced to go into a nursing facility to get supports they need!

This is a counter-productive public policy!

The legislature must add 250 slots to the state budget to cover the need over the next two years!

Let your voice be heard now!

FACT: Average annual cost of individuals using services under the PCA waiver - \$24,756

FACT: Average cost of one year in a nursing facility - \$109,000

FACT: 75 individuals currently on PCA waiver waiting list, and over 190 individuals in the pipeline

FACT: 250 new slots needed to address waiting list over a twelve month period

FACT: between 1999-2006 there was a 24% increase in the number of nursing facility residents under 65!

FACT: Money Follows the Person (MFP) will not address the PCA waiver crisis (an individual must be in a nursing facility at least six months to be eligible) or provide services for people already living in the community.

**PLAN TO ATTEND THE PRESS CONFERENCE AND RALLY,
AND MAKE A CALL TO YOUR LEGISLATOR TODAY! TELL
THEM TO ADD 250 SLOTS TO THE PCA WAIVER!**

For more information contact the CT Association of Centers for Independent Living
at 860-656-0430 or gwaterhouse@cacil.net

Do You Know Who your State Legislators Are?

If you want to become active in legislative advocacy, you will need to know who your local legislators are. So check out: www.cga.ct.gov/maps/townlist.asp and click on your town. If more than one representative is listed in your town, call your local town or city hall and give them your address so that they can tell you which representative is yours.

You may also reach your legislators (toll free) at the State Capitol:

Senate Democrats: (860) 240-8600 or (800) 842-1420

Senate Republicans: (860) 240-8800 or (800) 842-1421

House Democrats: (860) 240-8500 or (800) 842-1902

House Republicans: (860) 240-8600 or (800) 842-1423

Update on Disability Advocacy Collaborative Activities

To get involved with a Regional Advocacy Network, or to find the date of the next meeting of the Network in your area, contact the following:

Northwest -- contact: Bill Knight (lackerman01@snet.net)

Southwest --contact: Carol Kana (pkana@snet.net)

Danbury Area -- contact Pam Arturi (parturi@abilitybeyonddisability.org)

North Central -- contact: Candace Low (clow@independenceunlimited.org)

Waterbury Area --contact: Mike Valuckas (mike.valuckas@independencenorthwest.org)

Northeast Area -- contact: Carolyn Newcombe (cnewcombe@charter.net)

May 5 Rally for Universal Quality Health Care!

The Universal Health Care Foundation of Connecticut is urging citizens with and without disabilities to attend a rally they are organizing on Saturday, May 5 from 11 am – 1 pm at Bushnell Park in Hartford. The Foundation suggests two reasons for attending: 1. There is a crying need for universal health care, as we see with folks who have limited incomes which are not low enough, or have such incomes but are not in the "right" categorical group, as well as with people across the state who are unable to get health insurance and are one accident or medical condition away from financial disaster. 2. The general

message coming from this rally is that fixing our broken health care system should be a priority. The rally should also help push the generally very positive health care agenda adopted by the legislature's Appropriations Committee which directly benefits low-income individuals needing access to quality health care, including those who are already enrolled in state assistance programs which do not deliver the coverage promised on paper. For more information go to www.healthcare4every1.org.

120 ADAPT Activists Arrested

On Monday, April 30, 120 of the 500 ADAPT activists from across the nation were arrested in and outside the House Rayburn Office Building on Capitol Hill. Arrests were made in the offices of Rep. John Dingell (D-MI) and Rep. Joe Barton (R-TX) as well as inside a hearing room of Rayburn and outside Rayburn's entrance. We are not aware of whether Connecticut ADAPT member Claude Holcombe was among those arrested.

Activists were in Rayburn in efforts to have Reps. Dingell and Barton set a hearing date on the calendar for the Energy and Commerce Committee for the Community Choice Act and to have them sign on as co-sponsors of the legislation. Leaders of ADAPT met the previous week with the Democratic National Committee (DNC) and were scheduled to meet with the Republican National Committee (RNC) on May 1, all in efforts to help move the Community Choice Act through Congress.

The Community Choice Act provides an alternative to nursing homes and institutions for people with disabilities. It will fundamentally change the long term care system and the institutional bias that now exists. Building on the Money Follows the Person concept, the Community Choice Act establishes a national program of community-based attendant services and supports for people with disabilities, regardless of age or disability. This bill would allow the dollars to follow the person, and allow eligible individuals, or their representatives, to choose where they would receive services and supports. Any individual who is entitled to nursing home or other institutional services will now be able to choose where and how these services are provided.

To learn more about the Community Choice Act, visit: www.adapt.org/casaintr.htm.

MIG Begins Database of Volunteers A Request from Cathy Ludlum

The Medicaid Infrastructure Grant is a five-year, multimillion dollar federal grant focused on identifying and reducing barriers to employment for people with disabilities and the aging population. Our workgroups continue to create strategies around the transition from school to work; stakeholder education; transportation; and recruitment, hiring, and promotion. During April, our major thrusts have included the development of a state-of-the-art web site, and planning for our second annual Employment Summit which will take place on June 27.

As representatives of the Medicaid Infrastructure Grant travel around the state, doing presentations and networking, people frequently say, "This is so exciting! Is there a way

I can help to move this project along?” Until recently, our response has been vague. There is much that needs to be done, but we didn't have a way of mobilizing the people who want to give of their time and energy.

In the last few weeks, we have developed a Volunteer Interest Inventory (please see below), and begun developing a database of volunteers. We can now start matching up people with immediate and long range volunteer assignments.

If you want to get involved right away, consider these two possibilities:

1. We are seeking people with disabilities, especially hidden disabilities, and their employers for a Success Stories video being put together by our public relations firm, Mintz and Hoke.
2. With the Employment Summit less than two months away, we are seeking volunteers to help us with the logistics, such as staffing the registration table, running the microphone back and forth during the question-and-answer session, and general gofer. There may be other needs as well.

For questions about volunteering, please contact Cathy Ludlum at cathyludlum@cox.net or 860-649-7110. For more general information about the Medicaid Infrastructure Grant, please contact Amy Porter at amy.porter@ct.gov or 1-800-773-4636.

Cathy Ludlum
MIG Consultant

IDEA 2004 – Regulations and Implications

The Klebanoff Institute of Special Education at the University of Connecticut and the University of Connecticut A.J. Papanikou Center for Excellence in Developmental Disabilities are sponsoring a workshop on the IDEA regulations on May 9 from 9:00 am – 3:00 pm at the Connecticut Grand Hotel in Waterbury. More detailed information is available at www.uconnucedd.org.

“The Great West Hartford Disaster”

The West Hartford Advisory Commission on Persons with Disabilities is holding a town meeting entitled “ARE YOU PREPARED? IF NOT, GET PREPARED!” on Wednesday, May 9, 2007 at 7:00 p.m. The meeting will be held at the Town Hall, Town Council Chambers, West Hartford. The program will include what you need to know to be prepared for a disaster with an emphasis on people with disabilities and those who are elderly. Speakers include Scott Slifka, Mayor of West Hartford, Chief William Austin, West Hartford Fire Department, Barbara Carpenter, Town Councilwoman and Therese Nadeau, Disaster Preparedness Expert. For information call: Sharon Denson 860-232-3204.

PATH and Community Building Workshop

MARC, Inc. of Manchester will present a PATH and Community building workshop featuring David and Faye Wetherow from CommunityWorks, British Columbia. The workshop will take place May 14-16 from 8:30 a.m. to 4:30 p.m. each day at the Super 8 Motel & Conference Center at 20 Taylor Street in Manchester.

At the heart of helping people with disabilities move toward lives of self-determination, companionship and contribution are effective skills in organizational and person-centered planning, strategies for developing personal support networks, and patterns of inquiry that invite vision, build commitment and encourage collaboration. The workshop is an intensive practice-based training based on the internationally recognized work of Jack Pearpoint, Marsha Forest, John O'Brien, Judith Snow, Joseph Schaeffer, and David and Faye Wetherow. Participants leave inspired, energized, and with tools that they can immediately put into use at work and in their personal lives. Each participant gets their own personal PATH completed and helps two other participants complete their PATHs. For more information call Kevin Zingler at MARC at (860) 646-5718 or email kzingler@marcct.org.

Effective Strategies for the Education of Children with Autism and Related Disabilities

Connecticut FEAT will host a conference on Saturday, May 19- 8:30 AM—3 PM at the University of Connecticut, Waterbury Campus. The Keynote Address: “Are We There Yet? Building the Road from Scientifically Based Research to Effective Educational Policies for Children with Autism” will be delivered by Mary Beth Bruder, Ph.D. For more information contact the CT FEAT Information Hotline (860) 571-3888 or go to www.ctfeat.org.

Jonathan's Dream: A Playground for All Kids

Since October of 1996, Jonathan's Dream has provided Hartford-area children of all abilities with a fun, free place to play. The 25,000-square-foot playground, located in West Hartford at the Greater Hartford Jewish Community Center, remains as vibrant 10 years later as it was when it debuted as a model play place for children with and without disabilities”.

“Jonathan’s Boundless Dreams Day” will be held on Sunday May 20 from 1:00-4:00 at the playground in West Hartford to celebrate the 10th Anniversary. Go to www.boundlessplaygrounds.org for more information.

Southwest Advocacy Network Presents ADA Workshop

A.D.A IN ACTION: HOW TO MAKE IT WORK FOR YOU

WHAT: issues of the Americans with Disabilities Act at work, at home, in your town hall, in your community.

WHEN: Thursday, June 7, 2007, registration 9:30 a.m. - Program 10 a.m.-3 p.m.

LOCATION: Tully Health & Fitness Center (Auditorium) - 32 Strawberry Hill Court, Stamford, Ct. 203-355-4567

COST: \$10 (includes lunch)

Presenter: Stan Kosloski, Former State A.D.A. Coordinator and current Project Director of the Connecticut Disability Advocacy Collaborative.

To register, please send a check for \$10 to Carol Kana, 42 Wescott St. - Riverside, Ct. 06878, made out to "Disability Advocacy Collaborative", NO LATER THAN JUNE 1, 2007.

For further information, please contact Carol Kana at 203-637-4304, or email her at pkana@snet.net. If you need an accommodation to attend the training, or you need written materials in an alternate format, please contact Carol by May 22, 2007.

"We Belong" to Hold a Gala Celebration on June 7

A "Gala Celebration", sponsored by "We Belong", will be held on June 7 from 6:30 to 8:30 at **The Westport Library**, located at the Arnold Bernhard Plaza, 20 Jesup Road, Westport - 06880. The event will feature an update on the PJ Case Settlement with Attorney David Shaw. Awards will also be presented to local heroes who promote excellence in the promotion of inclusion. We Belong is a network of individuals from Fairfield County who are interested in inclusive education for students with disabilities. Check www.spednet.org/IFC.htm for more info, or contact Eva Greenwald at (203) 554-4462, or evagreenwald@sbcglobal.net.

CWDN 10th Annual Meeting

The Connecticut Women and Disability Network (*"Dedicated to the Empowerment of Girls and Women with Disabilities"*) invites Women and Girls to their 10th Annual Meeting, Saturday June 9, 10:00 am – 3:00 pm. In addition to celebrating friendships and relaxing, there will also be a panel discussion: "Exploration of Alternative Therapies: *Taking care of yourself!!*" The meeting will be held at Camp Hemlocks, 85 Jones Street, Hebron. For more information call 860-228-9496 Ext. 200 or contact Pat Guerard at 860-342-0116, or pguerard@sbcglobal.net.

**SUPPORT COMMUNITAS TEAM MARATHON
FOR THE LONG WALK ~ 2007**

George Ducharme, Pat Beeman and friends will again be conducting two half-marathon walks (13.1 miles) during 2007 as fund-raisers for Communitas. Last year, contributions in support of the walks helped Communitas raise over \$3,000. All –and we do mean all – of the money you donate is used to make a significant difference in the lives of children and adult with disabilities and their families. No dollars donated are used for administrative or overhead expenses. Every dollar spent reflects the mission for which Communitas was founded 19 years ago ... promoting and actively supporting positive, inclusive communities.

These half-marathon fundraisers are a metaphor for the day-to-day struggles of many with whom Pat and George walk. This year (2007), they have dedicated their training and two walks (one on June 3rd in South Dakota, the second on September 8th in Manchester, Vermont) to all of the ordinary people who live lives, often with very difficult and challenging circumstances, filled with the same hopes and dreams that all of us share. They again ask for your assistance in 2007. Please pledge or contribute your tax-deductible donation today, encourage one friend to do the same and register your support for George, Pat and other Communitas walkers and rollers as they continue the Long Walk to Freedom and Participation. One dollar (or more, if you can) a mile will go a long way.

Please make checks payable to Communitas, Inc. and mail to Communitas, Inc., P.O. Box 358, Manchester, CT 06045. For more information call 860-512-2789 or email George at gducharme@mcc.commnet.edu

National Transportation Week – May 13-20

CDAC Calls on You to “Try Another Way!”

National Transportation Week provides an opportunity for the transportation community to join together for greater awareness about the importance of transportation. National Transportation Week also focuses on making youth aware of transportation-related careers. During the week of May 13, “Try Another Way.” At least once use a different mode of transportation than you generally do. Walk or roll, ride a bike, ride the bus or train, share a ride, or offer a ride. For more information about National Transportation Week go to www.ntweek.org.

Connecticut Student Speaks Out About Health Care

The Connecticut winner in the national essay contest sponsored by the Campaign for Children’s Health Care, ages 14 to 18, was Sarah Ports, 17, from Lebanon. Excerpts from her essay are as follow: “Once again, I am left sitting all alone under the giant oak tree,

missing out on all the fun my friends are having. ... A couple weeks after that, I got *very* sick. It was a lot worse than the other time, and I didn't even have fun watching TV. I was like that for almost a week, until my fever got so high that my parents decided that they had to take me to the hospital. You see, we don't have any health insurance, because my parents have their own business. They say that if they got a different job, then we would be able to afford to go to the doctor, but they like what they do, so I don't want them to have to change. ... When a doctor finally examined me, he told my parents that I had a very bad case of Rheumatic fever. He said I must have had strep a couple weeks before, and this was the result of it going untreated. ... None of this would have happened if we had had medical insurance, or gotten some antibiotics when I had the strep throat. But it happened, so I try not to dwell on that. It has given me a great ambition for my life. I want to see a day when everybody in the USA can go to a doctor when it is needed, no matter what. This should never have to happen to another kid, ever again”.

To read Sarah’s essay in its entirety or to learn more about the Campaign send an email to info@childrenshealthcampaign.org go to www.childrenshealthcampaign.org. [*Families USA*, April, 2007]

Consumer Health Action Tip Sheets Available

Tip sheets on how to get good health care are available from the Connecticut Consumer Health Action Network. To obtain a copy call 203-772-2817 or 1-888-873-4585. You can also go to their website at www.cthealthpolicy.org/action.

Disability Rights Bus Travels Across Nation Coming to Connecticut October 14 - 16

"The Road to Freedom" bus is traveling to 80 cities in its year-long tour to raise awareness of ADA. The tour, which has already traveled an estimated 3,500 miles to sixteen cities, will end in Washington, D.C. on November 15. The bus tour was inspired by Justin and Yoshiko Dart's historic trips across America in the late 80s fighting for the passage of ADA.

A primary purpose of the Tour is to gather support for the ADA Restoration Act. U.S. Supreme Court decisions over the last ten years have served to weaken several provisions in the ADA, most notably the definition of who is covered. The proposed law will restore individuals to its protection that were originally meant to be included.

The ADA Restoration Act is not about new legislation. It’s about “putting teeth” into what we already have. Go to www.adawatch.org/ to fully understand the many issues involved.

30th Anniversary of the 504 Sit-Ins

Thirty years ago, sit-ins were held in Washington D.C., Eugene, Oregon, New York, Los Angeles, and San Francisco to protest HEW (Department of Health, Education, and

Welfare for you young ‘uns) Secretary Joseph Califano's refusal to sign meaningful regulations for Section 504. In San Francisco, the demonstrations went on for almost a month, becoming the longest sit-in of a federal building in history. The historic demonstrations were successful and the 504 regulations were finally signed. For more details about the 504 demonstration, visit the 504 20th Anniversary page on DREDF's website: www.dredf.org/504site/504home.html.

Alzheimer’s Affects a Growing Segment of the Population

In an updated review of the most common nervous system disorders in the United States, the Fisher Center for Alzheimer’s Research Foundation found that 67 out of every 1,000 elderly Americans carries a diagnosis of Alzheimer’s disease, a figure substantially higher than previous estimates. The findings were published in the January 30 issue of *Neurology*, the scientific journal of the American Academy of Neurology. According to the article “Current, accurate estimates of the numbers of people affected by neurological disorders are needed to understand the burden of these conditions on patients, families, and society, to plan and carry out research on their causes and treatment, and to provide adequate services to people who suffer from these illnesses.” For more information about Alzheimer’s go to www.alzinfo.org.

Election Day is Tuesday, November 6, 2007!

Connecticut residents in all 169 municipalities in CT will be voting for their community leaders in the election this year. These leaders will have a significant impact on the programs and services available. Start learning and getting involved now! Contact your Town Hall, the Registrar of Voters or the League of Women Voters (www.lwvct.org/). You can also contact Elanah Sherman at the Office of Protection and Advocacy Elanah.Sherman@po.state.ct.us, 860-297-4322 or look at [Your Rights as a Voter with a Disability](#) on the P&A website at www.ct.gov/opapd/.

The League of Women Voters is a nonpartisan political organization which encourages informed and active participation in government and works to increase understanding of major public policy issues and to influence public policy through education and advocacy. They work to increase voters' knowledge of candidates and issues. Contact them by calling call (203) 288-7996, e-mailing LWVCT@lwvct.org. or go to their website at www.lwvct.org/.