



Connecticut Disability Advocacy Collaborative Bulletin

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

Disability Rights is a Civil Rights Issue

September, 2005

Need this newsletter in an alternative format?

Please let us know.

If you want something to appear in the next edition, or have an article you would like us to include, please send it to us - jayne@kleinmanconsulting.com or skoslosk03@comcast.net — or Jayne Kleinman, 55 Corrigan Ave., Meriden, CT 06451, 203-631-4800.

ADDRESS CORRECTIONS AND REMOVALS: If you are not interested in receiving this Bulletin, or you would like this information sent to a different e-mail address, please e-mail Jayne Kleinman at jayne@kleinmanconsulting.com with your request.

This Bulletin is supported by a grant 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 Disability, and Communitas, Inc. serves as the project's fiscal agent. To all three we extend our appreciation.

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Calendar of Events

| <u><i>Date</i></u> | <u><i>Event</i></u> | <u><i>Location</i></u> | <u><i>Sponsor</i></u> | <u><i>Contact</i></u> |
|---|--|--|---|---|
| Sept. 8 – 7:00 pm | People First of CT | First Church of Christ – Court Street Middletown | People First of CT and Self Advocates Unlimited | Advozealot@aol.com |
| Sept. 8 7:30 pm | Disability Awareness - Kathy Buckley-4 time Amer.Comedy Nominee “America’s First Hearing Impaired Comedienne” | Trinity College (CART and interpreters available) | Trinity College “Themed Housing” group and the Office of Campus Life | haley.kimmet@ trincoll.edu |
| Sept. 13 3:00 - 5:00 pm and 6:00 - 8:00 pm | P&A Public Forums (see article below) | Middletown City Hall and Windham Middle School | Office of Protection and Advocacy | 1-800-842-7303, ext. 4360 (V/TTY), 860- 297-4360 (V) or 860- 297-4380 (TTY). |
| Sept. 14 – 9:30 am – 4:00 pm | Reverend Thomas Goekler, MM – (see article below) | Manchester Community College | MCC Institute on Disability and Community Inclusion & Communitas | 860-512-2789 or gducharme@mcc. commnet.edu |
| Sept. 14 3:00 - 5:00 pm and 6:00 - 8:00 pm | P&A Public Forums | Danbury Library and Groton Library | Office of Protection and Advocacy | 1-800-842-7303, ext. 4360 (V/TTY), 860- 297-4360 (V) or 860- 297-4380 (TTY). |
| Sept. 14 – 2:00 – 4 | Meeting of NW Partnership for Autism | UConn branch in Torrington | NW Partnership | 860-626-6800 |

| | | | | |
|--|--|---|--|---|
| pm | and related DD | | | |
| Sept. 15 3:00 - 5:00 pm and 6:00 - 8:00 pm | P&A Public Forums | Torrington Northwest Area Chamber of Commerce | Office of Protection and Advocacy | 800-842-7303, ext. 4360 (V/TTY), 860- 297-4360 (V) or 860- 297-4380 (TTY). |
| Sept 15 10 am – 12:00 pm | Health Care for All Meeting | 290 Pratt St. Meriden | Health Care for All Coalition | Gretchen Vivier gvivier@ccag.net |
| Sept. 16 | “Creating Inclusive Communities for Everyone” (see article below) 9:00 am – 4:00 pm | Farmington Marriott Hotel | UConn Center on Disabilities | 860-679-1500 (ask for Stan or Chris) |
| Sept. 19 – 8:30 am – 4:00 pm | Medicare Part D – What You Need to Know | Fantasia – 404 Washington Avenue – North Haven | Area Agency on Aging/ South Central Connecticut | 203-785-8533 or choicesscaa@snet.net |
| Sept. 20, 1:30-3:30 p.m. Sept. 22, 10 a.m. to noon, Sept. 27, 10 a.m. to noon Sept. 28, 10 a.m. to noon Sept. 29, 1- 3 p.m. | Medicare Part D Workshops (see article below) | Stamford. Middletown. Waterbury. Norwich. Hartford. | NAMI/CT | Alicia Woodsby at 860-882-0236 or 800- 215-3021. |
| Sept. 26-29 | Introduction to SRV (see article below) | Massachusetts - specific sites TBA | SRV Implementation Project & Mass. Alliance for Personal Action | Carl Cignoni – 413- 320-5367 or cvcignoni@msn.com |
| Sept. 27 | Thought Approaches to Difficult Behavior – Dave Yieter | Institute of Technology and Business Development (New Britain) | Council on Developmental Disabilities | ed.preneta@po.state. ct.us |
| Sept. 29 – 3 pm | Meeting of the Northwest Advocates for Disability Rights | St. John’s Episcopal Church | Independence Northwest | Chera Simpson 203-729-3299 |

OCTOBER—Disability Employment Awareness Month.

| | | | | |
|-----------------------------------|--|---|--|---|
| Oct. 1 10:00 am – 4:00 pm | 2 nd Annual Autism Spectrum Resource Fair | Southern CT State University | CT Autism Spectrum Resource Center | Lois Rosenwald at ASRC - 203-248-5222. |
| Oct. 1 9:30 am | “Walk and Roll” Benefit for Communitas and MCC Institute on Disability and Community Inclusion | Manchester Community College | MCC Institute | jjakiela@mcc. commnet.edu |
| Oct.5 – 11:00 am – 2:00 pm | Multi-Cultural Community Services Fair | Elks Lodge 346 Main St. - Danbury | Greater Danbury Mental Health Authority | Cindy at 203-778-2216 ext. 344 |
| Oct. 15 8:30 am - 3:00 pm | People First Conference | Bristol Clarion Hotel | People First of CT | Advozealot@aol.com |
| Oct. 19-21 | ABCD Leadership Forum (see article below) | Four Points Sheraton in Meriden | Northeast Assets Leadership Project & CAN | 860-571-8463 ryan@ctassets.org |
| Oct. 29 | Disability Collaborative meets the folks from New Jersey | TBD | Disability Advocacy Collaborative | Jayne Kleinman jjk1009@hotmail.com |
| Nov. 4 | “Children Who Can’t Be Cured...Continuing the Conversation of End-of-Life Care” | Four Points Sheraton Hotel, Meriden | CT Dept. of Soc. Services and CT Children’s Medical Center | ctceol@harthosp.org 860-545-7823 |
| Nov. 9 – 8:30 am – 12:30 pm | Life, Works, and Words of Jean Vanier | Manchester Community College | MCC Institute on Disability and Community Inclusion & Communitas | 860-242-3304 or mmek2@aol.com |
| Nov. 17-20 | Conference - “Reclaiming Freedom: A Call to Action” | Sheraton Hartford | National Assn. for Rights Protection and Advocacy (NARPA) | narpa.org/narpa 334-491-6277 |
| Nov. 19 | Adult employment and advocacy conference | Hartford | Nonverbal Learning Disorders Assn. | NLDA@nlda.org |
| Dec. 11-14 | White House Conference on Aging | Washington, D.C. | US Administra- tion on Aging | www.whcoa.gov |
| Sept. 16, <u>2006</u> | Disability Advocacy Collaborative Convention | CT Expo Center Hartford | Disability Advocacy Collaborative | jjk1009@hotmail.com 203-238-9391 |

A Special Request

Those of you who are regular readers of the Bulletin know that we usually put local and state news first followed by what we feel are major developments at the national level. This month we make an exception to that practice to share an appeal from Justice for All, ADAPT, and ILRU of Houston:

“The Centers for Independent Living in Biloxi, Mississippi and New Orleans have been gravely affected by the hurricane. In fact the Biloxi, MS center was totally destroyed. Many of you are asking how you can help. Here is what we have learned from colleagues in those states.

Sending money is the first priority. Sending supplies to those centers is helpful too but NOT RIGHT NOW, because they can't get through the water.

Here are the suggested options for right now:

- 1) Send a check or credit card payment to the Red Cross and designate it for Hurricane Relief, or designate it for people with disabilities in the Biloxi/Hattiesburg or New Orleans areas.**
- 2) If you want to send money for the CILs that are dealing with this disaster directly, here are your options:**

For the Biloxi Center, mail the check (payable to LIFE of Central MS and designated for the Biloxi Center) to:

**LIFE of Central Mississippi
754 North President Street, Suite 1
Jackson, MS 39202**

For the centers in Louisiana (make checks payable to Resources for Independent Living - this is a branch of the N.O. center - and designate for the New Orleans center) and mail to:

**Resources for IL
11931 Industriplex Blvd. Suite 200
Baton Rouge, LA 70809**

We have also learned from Mack Marsh of the Shreveport Center that they would also appreciate supplies if there is any way to get those supplies to the centers. His list includes: manual wheelchairs, hospital beds, adult diapers, bed pads, catheters and other supplies. The address for the Baton Rouge center is shown above, addresses for the Shreveport and Lake Charles centers follow:

**Southwest LA Independence Center, Inc.
Mitch Granger**

**1202 Kirkman, Suite C
Lake Charles, LA 70601**

**New Horizons, Inc.
Jerry Kidwell
9300 Mansfield Road, Suite 204
Shreveport, LA 71118**

Feel free to forward this information to other people interested in the needs of people with disabilities affected by this disaster.”

Napoleon Dynamite?

About 10 million people in the United States are reported to have a medical diagnosis that includes mental retardation (preferred term: intellectual disability). Children with this diagnosis were given the right by federal law to be included on typical school campuses for their education as far back as 1974. A pen, which has a connection to the movie “Napoleon Dynamite” and is now being sold in stores throughout the country, could create a volatile and dangerous environment for students with disabilities. The pen contains a number of recorded phrases, including one that says "You Are Retarded!".

Advocates are suggesting that if a derogatory statement like this had been directed at some other marginalized group - ethnic, cultural or religious – there would have been hell to pay. They suggest that socially conscious citizens seek to remove these pens from the stores immediately and do not let them get into the hands of students. The pens will only increase segregation and discrimination of individuals with cognitive disabilities.

Should you want to actively oppose the distribution of these pens, you may sign on to a petition at: www.ipetitions.com/campaigns/stop_napoleon/

Disability Advocacy Collaborative Update and Meeting Dates

On the heels of six successful Introductory Meetings held by the Disability Advocacy Collaborative during June and July, follow up meetings are being arranged. Three regions will meet during September (all meetings are at 5 pm) and anyone interested in becoming involved is invited to attend:

- North East Region – September 14 – at the Mansfield Senior Center
- South East Region – September 28 at UCP of Eastern Connecticut
- South Central Region – September 15 at Hamden Senior Services Center

During August meetings were held with Jean Bowen and Pat Tomka from WeCAHR in Danbury and with Chera Simpson from Independence North West in Naugatuck. WeCAHR will work with the Collaborative in developing a Collaborative network in the Danbury area and Independence North West will assist in the greater Waterbury area. We appreciate the support provided by Jean, Pat, and Chera.

Also in August a follow up meeting was held with individuals who volunteered to sit on an “interim steering committee” for the North Central area (i.e., Greater Hartford). The group agreed to develop a mailing list of advocacy organizations and individual advocates in the area. In addition, the group agreed to host a large scale meeting of all interested parties in late October (tentatively set for October 27). The purpose of the meeting will be to identify a limited number of issues the North Central regional network will work on over the next year. An electronic survey will also be prepared to get input from interested individuals who cannot attend the meeting.

In the fall of this year, and the winter and spring of 2006, additional coalition building and self-advocacy meetings and workshops will be held throughout the state to build the local advocacy networks. The Collaborative is looking for organizations and individuals who want to get involved in this initiative, including folks who want to take a leadership role. Anyone interested should contact Jayne Kleinman at the address listed at the top of this Bulletin.

Meet the Folks from New Jersey

On Saturday, October 29 representatives from the New Jersey DD Council will visit Connecticut to share their experiences organizing Disability Conventions. The Connecticut Collaborative will host a statewide Disability Convention at the Connecticut Expo Center in Hartford in September of 2006 and want to benefit from the New Jersey DD Council’s experience. The New Jersey representatives will meet with the Collaborative’s Steering Committee in the morning and will share their experience with any interested individuals from the regional networks in the afternoon. So save the afternoon of October 29th for an opportunity to learn from others who have been there, and done that.

Reminder: Two Inclusion Related Conferences This Fall

On September 16, 2005 “Creating Inclusive Communities for Everyone,” a conference hosted by the UConn Center on Disabilities, will take place at the Marriott Hotel in Farmington. The central question for conference participants is “How can I help build a welcoming, accessible, and inclusive community that supports all its residents to be full participants?”. Call Chris Gaynor or Stan Kosloski at 860-679-1500 for more information.

And on October 19-21, the Northeast Assets Leadership Project will sponsor a leadership forum at the Four Points Sheraton Hotel in Meriden. Jody Kretzmann, Co-director of the Asset Based Community Development (ABCD) Institute at Northwestern University in Chicago, and Mike Green, faculty member at the ABCD Institute, are among the speakers. A track dedicated to those interested in the ABCD basics will be offered, as well as “advanced labs” for experienced practitioners. For more information, e-mail or

call John Walker (207-799-2580) or jwalker3@maine.rr.com or Greg Ryan (860-571-8463) or ryan@ctassets.org.

P&A Public Forums

The Office of Protection and Advocacy for Persons with Disabilities (P&A) is an independent state agency that promotes, protects and defends the civil and human rights of people with disabilities. Every year, P&A develops priorities in response to the needs of people with disabilities. These priorities determine the issues that receive special attention during the year.

P&A will be holding a series of five public forums throughout the state from September 13 - 15, 2005. The information gathered at these forums will be used to assist in shaping the agency's priorities and long range strategic planning.

| Location | Date | Times | Address |
|---|--------------------|--------------------------|---|
| Middletown City Hall | September 13, 2005 | 3 – 5:00pm 6 – 8:00pm | 245 DeKoven Drive Middletown, CT 06457 |
| Windham Middle School | September 13, 2005 | 3 – 5:00pm 6 – 8:00pm | 123 Quarry Street Willimantic, CT 06226 |
| Danbury Library | September 14, 2005 | 3 – 5:00pm 6 – 8:00pm | 170 Main Street Danbury, CT 06810 |
| Groton Library | September 14, 2005 | 3 – 5:00pm 6 – 8:00pm | 52 Newtown Road Groton, CT 06340 |
| Torrington-Northwest Area Chamber of Commerce | September 15, 2005 | 3 – 5:00pm 6 – 8:00pm | 333 Kennedy Drive, Suite 101 Torrington, CT 06790 |

A sign language interpreter has been reserved for each event. Requests for interpreters or other accommodation (material in large print, assistive listening system, etc.), must be received three business days before the event. Please note that a survey is available online at: www.ct.gov/opapd for people who are unable to attend a forum but want to give input. The deadline for submitting completed surveys is September 30, 2005.

DD Council Workshops

Another reminder: the Connecticut Council on Developmental Disabilities is offering a series of workshops that may be of interest to parents, adults with disabilities and advocates:

Tuesday, September 27, 2005

"Thoughtful Approaches To Difficult Behavior." This workshop is a follow-up to the Council's May 2005 workshop on "Restraints." Time: 10:00 a.m. to 4:00 p.m. - Tuition: FREE - Registration Deadline: September 20, 2005 - Limited to 75 participants.

Presenter: Dave Yeiter currently offers workshops on approaches to difficult behavior in the New Hampshire human service system. He has over 30 years of experience in the fields of mental health and developmental disabilities.

Tuesday, October 25, 2005

"Adaptive Strategies For Families Who Have Children With Impairments For Working With Schools." This workshop will focus on assisting families to build better relationships with their school systems. Time: 10:00 a.m. to 2:00 p.m. - Tuition: FREE
Registration Deadline: October 18, 2005. Limited to 50 participants.

Presenters: Ed Wilson has worked in human services for 17 years, the last 7 years working with families, students and school systems in Massachusetts. Carl Cignoni has worked in the field for 30 years in a variety of roles, currently with children in schools, in direct service, with families, and in planning with school systems in Massachusetts.

Tuesday, November 1, 2005

"Carrying A Big Stick: Issues Of Power And Control That Lead To Violence In Human Services." This workshop is a follow up to the Council's May 2005 workshop on "Restraints." Time: 10:00 a.m. to 4:30 p.m. - Tuition: FREE – Registration
Deadline: October 26, 2005. Limited to 50 participants.

Presenter(s): Marc Tumeinski is the Training Coordinator of the SRV Implementation Project in Massachusetts and he is a service worker. He supports people with physical and intellectual impairments at home, school and work.

For more information contact Ed Preneta at the DD Council at: ed.preneta@po.state.ct.us

Medicare Part D – What's Up?

A series of workshops on the new Medicare Part D program are being sponsored this month by the Connecticut chapter of the National Alliance on Mental Illness, or NAMI. In October, counselors will be available to help people with mental illness navigate the complex changes.

"We are very concerned about the state's lack of outreach and education for people with disabilities who will be impacted by this major change in how they receive their prescription drugs," said Sheila Amdur, NAMI-Connecticut's chairwoman for public policy.

The following workshops are scheduled:

Tuesday, Sept. 20, 1:30-3:30 p.m., Laurel House, Stamford.

Thursday, Sept. 22, 10 a.m. to noon, Lee Auditorium, Merritt Hall, Connecticut Valley Hospital, Middletown.

Tuesday, Sept. 27, 10 a.m. to noon, Village at East Farms, Waterbury.

Wednesday, Sept. 28, 10 a.m. to noon, Southeastern Mental Health Authority, Norwich.

Thursday, Sept. 29, 1-3 p.m., Hartford Medical Society, Hartford.

People interested in attending can register by calling Alicia Woodsby at 860-882-0236 or 800-215-3021.

Advocates are also invited to attend a one-day training on Monday, September 19 from 8:30 am – 4:00 pm at Fantasia in North Haven. The sponsor is the Agency on Aging of South Central Connecticut, and the trainers will be from the federal Centers for Medicare and Medicaid Services, the Center for Medicare Advocacy, Inc., and the Social Security Administration. The cost is \$15. For more information call 203-785-8533 (choicesscaa@snet.net).

NARPA's Annual Rights Conference Coming to Hartford!

The National Association of Rights Protection and Advocacy will be holding its annual conference in East Hartford from November 17-20, 2005. This is a national conference and not to be missed. Entitled "Reclaiming Freedom: A Call to Action!", the conference will feature the following presenters:

Judi Chamberlin, Psychiatric survivor and activist since 1971
Author, *On Our Own: Patient-Controlled Alternatives to the Mental Health System*, Co-Founder of the National Empowerment Center

Professor David Cohen, Ph.D., Florida International University
Author, Researcher, and Expert on Psychiatric Medications

Peter Cubra, J.D., Children's Rights Attorney
Founder, Advocacy, Inc. - Albuquerque, NM

Aaryce Hayes, M.S.W., Advocate
Advocacy, Inc., Texas

Mark Davis, Advocate, Bisexual/Gay/Intersex/Lesbian/Transgender/Questioning Rights
20-year veteran of the consumer/survivor movement

In addition, there will be over 30 workshops presented by renowned advocates and activists. For more information contact NARPA via the web at www.narpa.org or call 334-491-6277.

Autism Spectrum Resource Fair

The Autism Spectrum Resource Center (ASRC) has announced its 2nd Annual Autism Spectrum Resource Fair which will be held on Saturday, October 1, 2005, at Southern Connecticut State University in New Haven. The Resource Fair will run from 10:00 am to 4:00 pm. Exhibitors will be present from camps, schools, recreation programs, after school programs, summer programs, social skills programs and more. They will also have a large book store and food on site. Organizers expect there to be at least 1000

professionals and families attending, since that was the number that went through last year.

ASRC will also be offering a large display bulletin board to advertise: parent assistors, advocates, ABA providers, and tutors. For more information contact Lois Rosenwald at ASRC - 203-248-5222.

Health and Wellness Fair

The NEAT (New England Assistive Technology) Marketplace and the Connecticut VNA have joined together to offer a health and wellness fair on Wednesday, October 5, 2005 at the NEAT facility, corner of Coventry and Holcomb Streets in Hartford. The event will run from 9:00 am – 2:30 pm and will feature vendor booths, health screenings, legal advice, and information about a wide variety of health issues. For more info, call NEAT at 860-243-2869 (website: www.neatmarketplace.org).

MCC Institute on Disability and Community Inclusion

Several events of interest to people with disabilities and families are being offered by Communitas and the Manchester Community College Institute on Disability and Community Inclusion over the next several months:

- On Wednesday, September 14 (9:30 am – 4:00 pm) Father Thomas Goekler, MM will lead a discussion on “Urban Issues from Hartford to Honduras: Economics, Gangs, and Local Response” (am session) and “Globalization: the View from the Street – Real Stories of Real People” (pm session)
- On Saturday, October 1 (9:30 am) the annual “Walk and Roll” fundraiser will take place on the campus of Manchester Community College (includes the Kristen DeBonee 5 K race and a 1 mile Fun Walk)
- On Wednesday, November 9 (9:00 am – 12:30 pm) Father Joseph “Cal” Gengras will present “The Heart has its Reasons – A Personal Focus on the Life, Works, and Words of Jean Vanier”

For information on any of the above events contact George Ducharme at 860-512-2789 (gducharme@mcc.commnet.edu).

P.A.T.H.S. Forums

(Plan for the Achievement of Transportation Coordination in Human Services)

As readers of the Bulletin know from past articles, the University of Connecticut Center on Disabilities has conducted seven forums for individuals with disabilities around the State on transportation. These forums have provided an opportunity for consumers to help identify what programs/services work well; to identify the gaps/barriers/obstacles experienced by people using various local bus services and specialized transportation

services; to determine needs for training and customer service; and to establish priority areas for action. A report on the findings is currently being compiled.

The long term plan for the project, funded by the Council on Developmental Disabilities, will be for people with disabilities to become transportation partners with other organizations and individuals to ensure the interests of people with disabilities are represented in the DOT State Action Plan. The Connecticut Department of Transportation (ConnDOT) has received a grant from United We Ride (an interagency Federal national initiative that supports States in developing coordinated human service delivery systems) and is presently in the process of selecting a transportation consultant.

To receive a copy of the report or for more information please contact Jayne J. Kleinman, M.S., CRC, Transportation Project Facilitator, University of Connecticut Center on Disabilities, 263 Farmington Avenue - MC 6222 - Farmington, CT 06030-6222, phone: (860) 679-1575, fax: (860) 679-1571, TTY: (860) 679-1502, Toll free: (866) 623-1315.

Olmstead Coalition Reorganizes

The Olmstead Coalition, so effective in promoting community integration following the 1999 U.S. Supreme Court decision, has reorganized and is seeking participation from Connecticut activists who are interested in pursuing the goal of full inclusion. For more information call Carrie at the Disability Network of Eastern Connecticut (860-823-1898).

NFB Seeks Donations

The National Federation of the Blind (NFB) is seeking donations for its Imagination Fund . The Imagination Fund was established with the goal of providing support for the work of the Jernigan Institute and local Federation chapters and affiliates throughout the United States, including Connecticut. This year the Imagination Fund campaign will elicit the help of hundreds of volunteers from around the country to share progress and ask for assistance. Contributions to the Imagination Fund will ensure that the initiatives of the Institute are advanced and that NFB state affiliates have the support needed to reach out to individuals who are blind in local communities.

For more information contact NFB at:
1800 Johnson Street
Baltimore, MD 21230
410-659-9314, ext. 2408
e-mail: imenchero@nfb.org
web site: www.nfb.org

SRV Events in Massachusetts

The SRV Implementation Project and the Massachusetts Alliance for Personal Action are offering several events for human services workers over the next several months. The

events will lay out a helpful framework for service workers to use in implementing relevant and effective service in the lives of vulnerable, socially devalued people. Three 4-day workshops on "Introduction to Social Role Valorization" will take place in Massachusetts on September 26-29, 2005, February 6-9, 2006, and April 3-6, 2006. A practicum with SRV using the PASSING tool will be held November 13-18, 2005. This 5 ½ day event, done in teams, will give participants an opportunity to work with the ideas of SRV to craft a vision of good service, and is particularly helpful for those designing services and/or assessing service quality. For more information call Carl Cignoni at 413-320-5367 (cvcignoni@msn.com) or Jack Yates at 508-946-9718 (yatessns@aol.com).

Wanted: Website Manager/IT Consultant

The Americans with Disabilities Act Coalition of Connecticut is seeking a consultant to maintain the organization's website and participate in grant work involving website accessibility for persons with disabilities. Skills required include ability to design, update and maintain ADACC's website. Must possess ability to work cooperatively with various organizations, grantors, and Project Director. Hours TBD. Compensation negotiable. Please send resume to Lisa Caron, Project Director at adacoalition@sbcglobal.net, or mail to ADACC – 60B Weston Street – Hartford, CT 06120.

Connecticut Company launches Web Site

On the 15th anniversary of the Americans with Disabilities Act, the People With disabilities Broadcasting Corporation (PWdBC) announced the formal launch of its website and the initial stage of creating and maintaining a powerful new disability media presence.

Central to PWdBC's mission is the creation of the first 24-hour TV channel "of, by and for people with disabilities . . . and everyone else." PWdBC is in exploratory conversations with a number of media companies to make this channel a reality. Howard Renensland, PWdBC Founder and President, is an accomplished actor, writer, director, and teacher, and has an adult daughter who was born with disabilities.

A PWdBC press release notes that few characters with disabilities appear in television and film. Actors with disabilities portray just a handful of these. Perhaps more importantly, people with disabilities are not represented in the creative processes behind the camera, making accurate portrayals of people with disabilities rare.

PWdBC will work toward correcting this imbalance by becoming the first mainstream media entity to design all programs to be accessible and available to everyone, to give a voice to this growing population, and to foster the employment and training of a large number of talented people with disabilities in the entertainment and information industries.

For more information, contact:
Howard Renensland, Founder & President
PWdBC, People With disabilities Broadcasting Corporation
Post Office Box 685, Wilton, CT 06897
203-216-1300
howard@pwdbc.org
www.pwdbc.org

Medicaid Commission Releases Report

On September 1, 2005 the Medicaid Commission recently appointed by President Bush delivered its first report to the Secretary of Health and Human Services Michael Leavitt. The report makes cost cutting recommendations and precedes what is expected to be a major funding crisis for individuals who depend on Medicaid for their medical care support. The report can be found on the Commission's website at: www.cms.hhs.gov/faca/mc/details.asp.

A brief summary of each of the final recommendations is listed below:

- (1) Allowing states to establish pharmaceutical prices based on the Average Manufacturer Price (AMP) rather than the published Average Wholesale Price (AWP). Additionally, reforms should be implemented to ensure that manufacturers are appropriately reporting data. Estimated savings are \$4.3 billion over five years.
- (2) Providing Medicaid managed care health plans access to the existing pharmaceutical manufacturer rebate program currently available to other Medicaid health plans. States should have the option of collecting these rebates directly or allowing plans to access them in exchange for lower capitation payments. Estimated savings are \$2 billion over five years.
- (3) Moving the start date of the penalty period for persons transferring assets for Medicaid eligibility from the date of the transfer to the date of application for Medicaid or the nursing home admission date, whichever is later. Estimated savings are \$1.4 billion over five years.
- (4) Increasing the look-back period from 36 months to five years for transfer from personal assets of Medicaid applicants during a period of time prior to application. Applicants are prohibited from transferring resources during the look-back period for less than fair market value. Estimated savings are less than \$100 million over five years.
- (5) Allowing states the flexibility to be able to increase co-payments on non-preferred drugs beyond nominal amounts when a preferred drug is available, to encourage beneficiaries to fill the least costly effective prescription for treatment. States should be given the ability to develop effective tiered co-pay structures to encourage cost-effective drug utilization where appropriate for all beneficiaries, regardless of income. All co-payments for the preferred drug list should become enforceable. States should be given broad authority to waive co-payments in cases of true hardship or where failure to take a preferred drug might create serious adverse health effects. Estimated savings are \$2

billion over five years.

(6) Changing the law so that managed care organizations (MCOs) are treated the same as other classes of health care providers with respect to provider tax uniformity requirements. Specifically, states would be required to tax all managed care organizations, not just those with Medicaid contracts, in order to meet the uniformity requirements. States should be prevented from guaranteeing that tax revenues paid to states by MCOs be returned. Estimated savings are \$1.2 billion over five years.

ADA Watch and Judge Roberts

What follows are excerpts from a letter that calls on the Senate Committee on the Judiciary to consider the impact on disability rights during the Judge Roberts Supreme Court confirmation process. Individuals or organizations that wish to sign on to the letter should contact ADA Watch Coordinator Jim Ward at jimward@adawatch.org.

“On behalf of the undersigned disability, aging, civil rights and social justice organizations, we write to you regarding the nomination of John G. Roberts to be an Associate Justice of the U.S. Supreme Court. As the nomination and confirmation process now begins to unfold, we strongly urge you to consider the extraordinary impact that Judge Roberts, if confirmed, will have on the lives, liberties, and constitutional rights of the tens of millions of Americans with physical, mental, cognitive, and developmental disabilities.

...For example, Reagan Administration documents demonstrate Roberts role in attempting to undermine the Equal Employment Opportunity Commission (EEOC) and that Roberts uncritically passed along demands that the administration repeal a requirement of government contractors to hire the handicapped.

...In Board of Education v. Rowley, 458 U.S. 176 (1982), an 8-year-old student who was deaf sought to have a sign language interpreter provided to assist her in school. The trial court ruled that federal law required the state to provide an interpreter for her. The appeals court affirmed. Roberts, while at the Justice Department, wrote a memo to the Attorney General criticizing these decisions. Roberts stated that the lower courts, in an exercise of judicial activism, used the vague statutory language to overrule the board and substitute their own judgment of appropriate educational policy.

.... Our concerns are illustrated by Mr. Roberts' 2000 television interview, in which he declared that the Rehnquist Court was not "conservative" enough. Roberts, of course, later convinced the Rehnquist Court to eliminate ADA protections for millions of Americans with disabilities especially those with epilepsy, diabetes, mental illness and work-related injuries.

.... In Toyota Motor Manufacturing v. Williams, 534 U.S. 184 (2002), Roberts successfully argued to the Supreme Court that a woman who had developed severe bilateral carpal tunnel syndrome and tendonitis from working on the assembly line

at an auto manufacturing plant could not prevail in a suit against her employer for failing to accommodate her disability. Roberts argued that she was not a person with a disability because she was not sufficiently limited in major life activities outside of her job. Roberts brief greatly distorted the extent of the woman's limitations. As a result of Roberts distortions, the Rehnquist Court held that the test for coverage under the ADA is a narrow one that must be strictly applied, and it articulated a more stringent test than the test set forth by Congress in the law itself.

.... Indeed, Judge Roberts has a long history of advocating for the weakening of legal protections for children and adults with disabilities under the ADA, Section 504 of the Rehabilitation Act, Child Welfare Act, and education law, as well as the legal under-pinnings of such laws including Congress commerce power. Attached, please find an overview compiled by the Bazelon Center for Mental Health Law entitled "John Roberts Problematic Record on Disability Rights".

<http://bazelon.org/issues/disabilityrights/judicialnominees/roberts.htm>

.... Based on his record, we are concerned that the ADA, a bipartisan law that seldom attracts public attention similar to the hot-button issues often debated in the context of Supreme Court confirmation hearings, might be further weakened should Judge John Roberts be confirmed.

.... We call on the Senate Judiciary Committee to allow testimony from representatives of the disability community and to fully examine Judge Roberts' record and views in regard to the Americans with Disabilities Act (ADA) and disability rights protections generally."

Sit-in in Tennessee Continues

The sit-in in the Tennessee Governor Bredesen's Office has passed the seventy day mark. A rally Saturday, August 27 called for a legislative special session to reverse the destructive cuts to the TennCare program (Tennessee's Medicaid program) pursued by the Bredesen Administration. Advocates are asking lawmakers to use the special session to examine the options that the governor has ignored. For example, Tennessee has no real options to nursing homes.

The governor responded by saying he did not support taxes to solve the TennCare problem.

The activists that have occupied the governor's office for seventy-one days now have questioned the Governor why many cost-saving proposals and efficiency techniques were never attempted to solve the problems with TennCare.

In addition, advocates report that although the governor's cuts will reduce the state of Tennessee's portion of the state healthcare bill, the cuts will also trigger a loss of \$1.2 billion in federal funding. They say the tremendous loss of resources will cost Tennessee



over 14,000 jobs and cannot be considered “saving” money.

MEDICAID FUNDING IS A BIG ISSUE IN EVERY STATE IN THE UNION! CONNECTICUT ADVOCATES MUST PAY ATTENTION TO WHAT HAPPENS IN TENNESSEE!

Youth Advisory Committee Recruiting

The National Council on Disability (NCD) has announced a nationwide search for new members for the Youth Advisory Committee (YAC). NCD is an independent federal agency, made up of 15 executive members appointed by the president, and their responsibility is to make recommendations to the President and Congress on issues affecting Americans with disabilities. The YAC is an advisory committee of youth with disabilities ranging in age from 16-25. NCD is recruiting members from cross disability sectors, diverse cultures and in under represented areas of the country. The YAC ensures that NCD's policy recommendations and activities gives consideration to the perspectives of young people with disabilities.

The recruiting process will close September 18, 2005 (i.e., e-mails by 12 midnight & postal mail marked by this date). To submit an application, send three documents - a resume, a letter of recommendation, and a cover letter pointing out your leadership experiences and your disability oriented experiences - to: youth@ncd.gov; if using postal mail, please send documents to: YOUTH-YAC Recruiting, National Council on Disability 1331 F Street, Suite 850, Washington, DC 20004. If you have further questions please feel free to contact Isaac Huff, YAC Chair at: I_Huff@superaleja.org or Rebecca Hare, YAC Vice-Chair at harer@iel.org. To read more about the YAC's past work, check the NCD Website at: www.ncd.gov.

Community-Based LTC - A Comparison

In July, Justice for All published “Community-Based LTC - A Comparison, Information Bulletin # 89”, noting that for the first time, the FY 2004 Medicaid expenditures compare community based long-term care ("LTC") expenditures by State and by category. LTC expenditures are made up of two categories - institutional versus community based expenditures. Obviously, the higher the percentages in the community, the more integrated the services. Bulletin #89 and back issues of other Information Bulletins are available online at www.stevegoldada.com with a searchable Archive at this site divided into different subjects. Or contact Steve Gold directly by writing to stevegoldada@cs.com.

Medicare Part D -The New Prescription Drug Bill

The new law known as the Medicare Modernization Act, or the MMA, will take effect January 2006, and many seniors and individuals with disabilities are concerned, and rightly so. The website of the National Senior Citizens Law Center includes articles such as:

- how Medicare Part D affects low-income seniors and people with disabilities;
- fundamental changes for the poorest Medicare beneficiaries;
- paying for Part D prescription drug costs;
- how to appeal adverse decisions; and
- choosing a Medicare Part D Plan.

Although Medicare Part D is referred to as a voluntary program, it is not really voluntary for the lowest income populations. As Medicare Part D takes effect, low-income persons will have their existing Medicaid drug coverage replaced completely by Medicare Part D private plans, with a new cost structure and new drug formularies. If you are looking for information about Medicare Part D go to www.nslc.org/issues_health_medicareD_con.htm.

The stated purpose of the Medicare drug benefit is to assist the senior population and individuals with disabilities in paying for their medications, not make paying for them more difficult. A survey released on August 16 by AARP (American Association of Retired Persons), showed that drug prices have been inflated substantially. Many are attributing this surge to the pending expansion of the Medicare plan to include prescription drugs this coming January.

CMS Again Fails to Address the In Home Restriction on Power Mobility Devices

The Centers for Medicare and Medicaid Services (CMS) announced an interim final rule that eliminates the requirement that a physician transcribe patient information onto a separate form - a "certificate of medical necessity" or CMN - when prescribing a power mobility device (PMD). Instead, the rule, which goes into effect on October 25, 2005, states that clinical documentation from a patient's medical record is to be submitted with a written prescription to the supplier of a PMD. The announcement also included regulations on the Medicare Modernization Act's face-to-face physician examination requirement when prescribing a PMD, as well as new provisions which allow physicians other than specialists in physical medicine, orthopedic surgery, neurology, or rheumatology to prescribe PMD's. Unfortunately, these new regulations do not address the in-home restriction. In fact, the wording used in the press releases and regulation reinforce CMS's stance that a mobility device must be necessary for use in a patient's home. The regulations are effective on October 25, 2005 and public comments will be accepted until November 25, 2005.

This summer over 100 members of Congress signed bipartisan letters to Health and Human Services Secretary Michael Leavitt requesting modification of Medicare's in-home restriction. The letters asked the Secretary to modify the restriction on mobility devices to improve access to the community.

Community for All Tool Kit: Resources for Supporting Community Living Available

A tool kit has been developed at the request of volunteers, advocates, self-advocates, and professionals concerned with preserving the remarkable progress made towards the inclusion of people with cognitive, intellectual and developmental disabilities into the mainstream of community life. To fight disinformation and segregation, this tool kit provides the philosophy, policy and research rationale that directs community supports and services for all people with disabilities. Topics include: Developmental/Psychiatric Disabilities, Model Communities, Physical Disabilities, Transition/Diversion from Institutions. For more information go to: www.hcbs.org/moreInfo.php/nb/doc/1345.

Please relay this Bulletin to your membership including those who do not have e-mail access. Suggest your membership go to the library and go onto www.kleinmanconsulting.com to view or print a copy. If you would like to see previous issues of the Bulletin, read about the background of the Collaborative or if you would like to be added to the mailing list, you may also go to www.KleinmanConsulting.com.

How can you find your federal Representatives and Senators? Go to www.congress.org and find the box under the heading “Write Elected Officials.” Type in your Zip code and press the “Enter” key. Then, when the names of your elected officials come on the screen, click on the word “Info” under the name of the elected official you want to contact. The telephone number will be listed on the page that comes up next. You may also call the U.S. Capitol Switchboard at 1-888-818-6641.