



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

June 2006

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Update on Disability Advocacy Collaborative Activities

Advocacy Training Workshops!

The Collaborative has sponsored Advocacy Training workshops in Norwalk and Willimantic over the last six weeks, with another workshop scheduled for the Waterbury area on June 28 (in conjunction with Independence Northwest and the Northwest Activists for Disability Rights). Carol Kana from Greenwich has emerged as a leader of the Norwalk area advocacy network, and Varian Salters, Patty Hope, Dexter Eddy, and Bill Powers are providing leadership in the Mansfield area.

Between 20-25 individuals attended the workshops in Norwalk and Willimantic, which featured interactive presentations by Betty Gallo, a respected lobbyist who has represented a variety of disability and other non-profit organizations at the state legislature for a number of years. Both workshops offered people with disabilities and families the opportunity to learn skills that will allow them to effectively represent their own interests and needs within the community in which they live and/or at the state level with the state legislature and state agencies. In addition to developing personal leadership skills, the workshops explained how town governments work; who the key decision-makers within communities are; and how budgets get made. For people interested in state level advocacy, the workshops explained how our state legislature works; how to prepare and give testimony; and the best ways to contact your legislator.

Larry Robinson, VISTA Volunteer, is working with Pat Tomka from WeCAHR and self-advocate Chad Sinanian to organize a regional advocacy network in the Danbury area. An organizational meeting was held in May which brought together 25 individuals interested in creating a stronger advocacy presence in the greater Danbury area.

Other organizing efforts continue in the northwest and southeast corners of the state, and in the Hartford area, New Haven area, and Bridgeport area.

Disability Convention 2006

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Exhibitor packets were mailed out to businesses and private non-profit organizations who want to showcase their goods and services at the September 16 Disability Convention. There are a variety of options available to service providers and advocacy organizations.

If you want to make sure you get a vendor packet, e-mail Jayne Kleinman at jjk1009@hotmail.com or call 203-631-4800.

Greg Smith, nationally known motivational speaker who hosts the "On a Roll" radio show will join us for the day, courtesy of the Self Determination/Family Support Planning Committee. We are attempting to make arrangements to broadcast his show that day from the Connecticut Expo Center, site of the Convention.

Special note: watch for the Collaborative's official web site, to be up and running by July 1!

Connecticut's 2006 Legislative Session A Summary of Outcomes for Mental Health

Alicia Woodsby, Public Policy Coordinator for NAMI-CT (National Alliance for the Mentally Ill – Connecticut Chapter) has compiled a summary of legislative action during the recently concluded session of the state General Assembly. Here are the two introductory paragraphs from her report:

“Overall, there were many positive steps for mental health this legislative session. Several new areas of funding and programming were added that address the criminalization and unnecessary incarceration of people with serious mental illnesses. Furthermore, significant progress was made for raising the age in Connecticut Courts to 18 years old.

In addition, the legislature provided funding and statutory language to continue the Medicare Part D wrap around into the next fiscal year, as well as language to allow for a Medicaid waiver and/or state plan amendment to divert or discharge people with serious mental illnesses who are inappropriately placed in nursing homes.”

To obtain a copy of the report contact Alicia at 860-882-0236, 800-215-3021, or by e-mail at publicpolicy@namict.org .

In addition to Alicia's report, Beth Leslie, Legislative Liaison for the Office of Protection and Advocacy, has updated the P&A web site (www.ct.gov/opapd), listing bills that passed this session that affect people with disabilities. To obtain the text of these and other bills, visit the General Assembly's Internet site at www.cga.ct.gov/ .

NAMI-CT is looking for Volunteers!

NAMI-CT (National Alliance for the Mentally Ill – Connecticut Chapter) is looking for parents, consumers and teachers who are willing to be members of teams to present a two hour in-service workshop to elementary, middle and high school teachers to share the following information:

1. identification of early onset mental illness in children and adolescents
2. skills to help children in the classroom
3. linkages to help connect families to community- based services

Interested parties are invited to be part of this dynamic new program, called *Parents and Teachers as Allies*:

- Parents should have a child or adolescent who is currently or was recently enrolled within the public school system (elementary, middle or high school) and be willing to share the challenges of accessing the proper educational support services for their children.
- Consumers should have experienced early onset mental illness that challenged their ability to perform effectively in an academic environment and be willing to tell their story about those challenges
- Teachers should be able to articulate the challenges they face in the classroom from a learning and disciplinary perspective. NAMI-CT would especially appreciate the perspective of teachers who may have a child themselves with mental health needs. A “train the trainer” is being planned for early July.

Please call Louise Pyers, Children’s Outreach Coordinator before June 21st if you are interested and/or would like additional information: 1-800-215-3021.

Candidate Education Trainings

NAMI-CT is also co-sponsoring a series of Candidate Education Trainings this month with the Keep the Promise Coalition, the Reaching Home Campaign, African-Caribbean American Parents of Children with Disabilities (AFCAMP), and FAVOR, Inc. This training is a wonderful opportunity to learn how to educate candidates for public office about mental health issues.

The regionally based training schedule is as follows:

Region 1: June 20, 2006 from 10 -12 pm at Laurel House- 1616 Washington Blvd., Stamford, CT 06902

Region 2: June 21, 2006 from 1-3 pm at Merritt Hall at CT Valley Hospital- Silver St., Middletown, CT 06457

Region 3: June 22, 2006 from 1-3 pm at Southeastern Mental Health Authority- 401 W. Thames St. Building 301, Norwich, CT 06360 (multi-purpose room)

Region 4: June 27, 2006 from 1-3 pm at Hartford Medical Society- 230 Scarborough St., Hartford, CT 06105

Region 5: June 28, 2006 from 1-3 pm at The Drop-In Center- 95 Thomaston Ave., Waterbury, CT 06702

For more information contact Cathleen Anderson-Baker at: Phone: 877-402-2299 x 5969 or by E-mail: keepthepromise@clrp.org .

News from People First

The members of People First who attended a statewide meeting in April developed ideas and phrases for an organizational mission statement. The ideas and concepts were put into the following language by the People First Board of Directors:

“People First of CT is a statewide self-advocacy organization that believes that all people should be treated as equals and be respected for what they can do. We advocate for ourselves and educate people about self-advocacy and People First of CT. We stand behind closing institutions and encourage people with disabilities to live more independent lives.”

Local People First Chapters are encouraged to review and make any final comments to their Board representative before the June 22nd Board meeting. Members will be asked to adopt the mission at the July 27th statewide meeting.

Nine self-advocates from Connecticut attended the 8th national self advocacy SABE conference on Memorial Day weekend in Atlanta, GA. Members visited the Dr. Martin Luther King Center and participated in a march to the Capitol and a rally in support of freeing individuals from institutions. Lois Curtis was honored for the impact she made when she sued the state of Georgia because she wanted to live in the community. Her case ultimately went to the United States Supreme Court and resulted in the Olmstead Decision, which helps people to move from institutions to the community.

Chad Sinanian of Danbury was elected Secretary of SABE and he will now serve as an officer and a member of the Executive Committee. One thousand individuals came to the conference, and from all reports it was the best ever. Quentin Hughes III carried the Connecticut state flag in the opening ceremony. Chad and Quentin were joined by Carol Grabbe, Varian Salters, Bill Berry, Christine Biesewicz, Jean Bowen, Dale Brown and Leslie Simoes.

Future People First meetings:

- June 22 - Board of Directors, The Arc of Southington - 6-8 pm
- July 27 - Statewide meeting, First Church of Christ, Middletown - 7:00 pm
- Sept. 16 – Disability Advocacy Collaborative Convention, Expo Center, Weston Street, Hartford - 10 am – 4 pm
- Oct. 28 - People First of CT state conference, Clarion Inn, Bristol 8:00 am – 4:00 pm – Cost: \$25.

New Parent Support Group Forms

A new parent support group has formed in the Waterbury area for parents raising children with developmental delays and other special needs:

WHEN: First Wednesday of every month
(first meeting was on Wednesday, June 7th)
TIME: 10:00 a.m. – 12 Noon
PLACE: Central Park in Waterbury
inside Kid's Play Gym
(side entrance of Salvation Army)
74 Central Avenue

Interested parents will get to meet other parents who share similar experiences, receive information about family services and supports, learn more about child development and parenting, and socialize in a relaxed environment. Workshops are being planned on transition services, respite care, and other shared concerns. Light refreshments are provided for parents/caregivers and children.

The support group is being sponsored by the Family Support Network-Northwest Region and the Connecticut Lifespan Respite Coalition. For more information contact: Alice Buttwell - (860) 350-6025 or e-mail: alicemmbb@aol.com , or Joy C. Liebeskind (203) 272-9058 e-mail: SJSJL@cox.net .

Hats off to New Haven

The City of New Haven, first recognized at the local level, has been selected by the National Multiple Sclerosis Society to receive its Employer of the Year Award. On Tuesday, May 30, 2006, Lisa Gerrol, the President of the Greater CT Chapter of the National Multiple Sclerosis Society, presented a plaque to Mayor John DeStefano, Jr. in recognition of the City's efforts to provide accommodations and opportunities for employees diagnosed with MS.

Michelle Duprey, head of the city's Department of Services for Persons with Disabilities, has work tirelessly to redress the obstacles people face, having pushed the city to expand its resources for disabled individuals. She and her colleagues are to be congratulated for bringing this honor to the City of New Haven.

DMR to Sponsor Forum

Public Act 06-92 (HB 5478), An Act Concerning the Department of Mental Retardation, passed the Connecticut State Legislature this session, requiring DMR to solicit input regarding a name change for the Department. Ideas are sought from clients and families receiving services provided by the department, advocates, and other interested parties. DMR is required to submit a report of findings and recommendations, including the cost of any recommended name change, to the Governor, the Office of Policy and Management and the Public Health Committee of the state General Assembly not later than January 1, 2007. There is a new link on the DMR website with information about this issue - www.dmr.state.ct.us/NameChange.htm

There will be opportunity this fall for statewide public input in a public forum format at the Legislative Office Building in Hartford. The forum is tentatively scheduled for Thursday, September 7, 2006 in Room 1D at the LOB.

Additional details will follow on the website as they become available.

Opportunity for Families to Participate in Planning the Medical Home Initiative

Dick Edmonds, Bureau Chief of the State Department of Public Health, is inviting families on the Connecticut Family Support Council to attend the Medical Home Advisory Council (MHAC) meetings. Reimbursement of expenses is available for those families who are not able to obtain reimbursement from an employer to attend.

Molly Cole (mcole@favor-ct.org or 860-563-3232) and Richard Antonelli (860-545-9333) are co-chairing the MHAC should you want to further discuss the purpose and mission of this Council. To get on the email list for announcements of future meetings, send your contact information to Dorothy Pacyna, Department of Public Health, at Dorothy.Pacyna@po.state.ct.us .

Latinos with Disabilities: Breaking Barriers

A bilingual conference entitled “Breaking Barriers through Multicultural Awareness” will be held Thursday, June 22, 2006 from 8:00 am – 3:30 pm in the Student Center at Central Connecticut State University in New Britain. The conference is designed for individuals with disabilities, parents and family members, advocates, human service workers, teachers, students, and employers. Workshop topics include special education, communication across cultures, self-advocacy, family dynamics, and social security benefits, with an emphasis on promoting cultural awareness among people with disabilities and those who serve them.

The keynote speaker will be Kathleen Martinez, Executive Director of the World Institute on Disability in California and an internationally known disability rights leader.

For more information, or to register, contact Padres Abriendo Puertas at 860-297-4378.

CAHS Sponsors Food Stamp Workshop

The Connecticut Association of Human Services (CAHS) invites interested persons to a series of workshops on the federal Food Stamp Program during the month of June. The workshops are being co-sponsored by the United States Department of Agriculture (USDA). Attendees will be provided with updated information about: program eligibility rules, income guidelines, where and how to access the programs, and much more.

Regional USDA officials and local DSS officials will be present. The Food Stamp workshop will be immediately followed by a special Kids Count report release.

This free workshop will be offered on the following dates and times at the locations listed:

- Tuesday, June 27, from 8:30 a.m. - 12:30 p.m. at Gateway Community College- 60 Sargent Drive, in New Haven.
- Wednesday, June 28, from 8:30 a.m. – 12:30 p.m. at the Timexpo Museum in Waterbury-175 Union Street
- Thursday, June 29, from 8:30 a.m. - 1:00 p.m. at the City Hall Annex-999 Broad St., in Bridgeport. (Note: The Bridgeport event will be co-hosted by the Bridgeport Social Services Department.)

For more information contact Tracy Helin, CAHS, 110 Bartholomew Avenue, Suite 4030, Hartford, CT 06106, E-mail thelin@cahs.org or call (860) 951-2212 ext. 236.

"Come and See" Leadership Training

Interested in learning how to increase the numbers of parents and potential leaders involved in your community? Want to learn how to become a more effective leader in bringing about effective change for families and children in Connecticut?

The Discovery Community Initiative is offering a training opportunity to help parents, providers and community leaders within Discovery Communities understand the power of the one-on-one conversation tool to build community and increase capacity for parent involvement and action. Participants will receive hands-on training in how to conduct one-on-one interviews, as well as learning about the tools and strategies needed to engage others from your community more fully into your organizing initiatives. To find out if you live in a Discovery Community go to:

www.democracyinaction.org/dia/track.jsp?key=127922965&url_num=5&url=http://www.discovery.wcgmf.org/communities.html .

This training, which will be a dynamic and interactive learning experience, is being held on Friday, June 16th from 9:00am-3:00pm at the Unitarian Society of New Haven, 700 Hartford Turnpike in Hamden.

Interested? Contact Ann Pratt, Director of Connecticut Parent Power, with questions: (860) 209-1234, or prattworks@earthlink.net . Stipends are available to help with childcare and transportation expenses.

News from the U.K.

Justice for All sends along an article from the Daily Mail in the United Kingdom re: the ethical storm over abortions that has been renewed as it appears that termination of life is being carried out for minor, treatable birth defects. Here are some excerpts:

”Late terminations have been performed in recent years because the babies had club feet, official figures show. Babies are being aborted with only minor defects. Other babies were destroyed because they had webbed fingers or extra digits. Such defects can often be corrected with a simple operation or physiotherapy.

The revelation sparked fears that abortion is increasingly being used to satisfy couples' desire for the 'perfect' baby. Campaigners warned we are turning into a society that can no longer tolerate imperfection. Ethical groups fear parents are opting for abortions because they are not told of the support and help available if they continued with the pregnancy.

Figures from the Office for National Statistics show that between 1996 and 2004, 20 babies were aborted after 20 weeks because they had a club foot. It is one of the most common birth defects in Britain, affecting one in 1,000 babies each year. That means around 600 to 700 babies are born annually in the UK with the problem, which causes the feet to point downwards and in severe cases can cause a limp.

However it can be corrected without surgery using splints, plaster casts and boots. Naomi Davis, a leading Pediatrician at Manchester Children's Hospital who specialises in correcting club feet, said: 'I think it is reasonable to be totally shocked that abortion is being offered for this. It is entirely treatable. I can only think it is lack of information.'

Figures also show that four babies were aborted since 1996 because they were found to have webbed fingers or extra digits, which can be sorted out with simply surgery. In 2004 it emerged a baby was aborted at 28 weeks after scans showed it had a cleft palate. Curate Joanna Jepson tried to ensure criminal charges were brought against the two doctors involved but the authorities last year decided against prosecution. She however vowed to continue in her fight to make terminations illegal after 24 weeks and to ensure cleft palates were not included within the term 'serious handicap' and used to justify late abortions.

Ms. Jepson reacted angrily to news of the club foot abortions. 'The law was not designed for this,' she said. 'Actions like these are fostering a disposable attitude to human life and I'm extremely concerned it is going on. I am appalled that the medical profession is allowing or even suggesting abortions for these conditions.'

Sue Banton, founder of the group Steps for parents of children with foot disorders, said last year one couple decided to terminate a pregnancy at 25 weeks after discovering their baby would have a section of foot missing. 'We gave them other families to talk to, but they just didn't want to know,' she said. 'It is terrible. I know lots of perfectly nice people with this condition and you just can't imagine them not being here.'

Pippa Spriggs from Cambridge, whose son Isaac is celebrating his second birthday in July, was dismayed when a scan showed her baby had a club foot. 'Abortion certainly was not openly advised but it was made clear to me it was available,' she said.

Julia Millington, of the Alive and Kicking Campaign, said: 'It is all about our perceptions of perfection. Increasingly things are moving along the lines where nothing is good enough. It seems we can no longer tolerate any imperfection. Babies are at the mercy of ultrasound scans and what they may disclose.' “

Know Any Artists??

VSA Arts and Volkswagen of America are seeking artwork from young artists with disabilities, ages 16-25, living within the U.S. Entitled "Destination Anywhere", the initiative challenges artists to consider the picture plane as a destination, a place where the viewer might take a trip they never expected. Fifteen finalists will be awarded a total of \$60,000 during an awards ceremony on Capitol Hill and artwork will be displayed in a nation-wide touring exhibit that will debut at the Smithsonian Institution in Washington, D.C.

Artwork may illustrate a destination. Abstract work that relates to feelings or emotions, or an experience of living with a disability and its role in shaping or transforming the destination is also encouraged. Art must be an original work that has been completed in the last three years. Eligible media includes: paintings, drawings, fine art prints, photography, computer generated prints, and mixed media. Artwork must be presented in two dimensions and should not exceed 60 inches in either direction. There is no fee to apply.

Visit www.vsarts.org/VWcall for additional information and entry instructions or contact Jennifer Colaguori, Visual Arts Coordinator, at jenniferc@vsarts.org or 800-933-8721 ext. 3885. Alternative formats of the call for entries are available upon request.

NCD Releases Report on Airline Kiosk Systems

In late May the National Council on Disability (NCD) released a Position Paper on Access to Airline Self-Service Kiosk Systems, calling on the U.S. Department of Transportation (DOT) to adopt an updated Air Carrier Access Act (ACAA) standard for accessible design applicable to these kiosk systems. The report also asks DOT to initiate settlement negotiations with covered air carriers and airports to bring their kiosk systems into full compliance.

According to NCD chairperson Lex Frieden, "U.S. air carriers and airports have obligations under federal accessibility laws and regulations to provide cross-disability access to their kiosk systems. Those carriers and airports operating kiosk systems not in

conformity with the Americans with Disabilities Act's standard for accessible design, which is also ACAA's standard, are out of compliance."

"Advances in information technology (IT) have enabled the airline industry to improve the quality and efficiency of its services delivery while reducing operating costs. But the airlines would leave travelers with disabilities out of the IT loop, failing to offer them the same benefits and convenience of service available to other travelers. The airlines' resistance to providing customer services through fully accessible kiosks and Web sites disregards the capacity of accessible IT to empower people with disabilities to do for themselves," Frieden concluded.

Although no airline-kiosk vendor serving the U.S. market has included accessibility among its product features, vendors confirm that they foresee no significant technical obstacles to development and deployment of fully accessible kiosk systems using existing access technology. A leading authority on accessibility technology estimates that the costs of access hardware and software modifications for a fully accessible system would not exceed one to two percent of the overall cost. However, the airline industry has yet to acknowledge the need for such a product.

For more information, contact Mark Quigley at 202-272-2004 or 202-272-2074 TTY. The full report can be found at www.ncd.gov/newsroom/publications/2006/kiosk.htm .

Please relay this Bulletin to your membership including those who do not have e-mail access. Suggest your membership without e-mail 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.

If you want something to appear in the next edition please send it to us – jjk1009@hotmail.com or skoslosk03@comcast.net — or Jayne Kleinman, 55 Corrigan Ave., Meriden, CT 06451, 203-631-4800.

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person). The best time to call either in CT or in Washington, D.C. is early in the morning.

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