



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

February 2006

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Please let us know.

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>Date</u>	<u>Event</u>	<u>Location</u>	<u>Sponsor</u>	<u>Contact</u>
Feb. 8	First Day of 2006 Legislative Session	Legislative Office Building		
Feb. 11 – 11 am – 3 pm	“Valentine’s Day Dally” with dining and dancing	Durham Firehouse	Brain Injury Association	860-721-8111
Feb. 16 – 9:30 am	"Making Women Visible Day - Economic Security for Women – a Symposium on Women’s Issues"	Legislative Office Building	Permanent Commission on the Status of Women	PCSW – 860-240-8300 pcsw@cga.ct.gov
Feb. 16 - 9:00 - 10:30 am	Meet and Greet Your Legislator	Legislative Office Building	Family Support Council	Karen Zrenda (888-842-1937) or Laura Knapp (877-743 - 5516).
Feb. 17 – 10:30 am	Press Conference on Autism Spectrum Proposal	Legislative Office Building Hartford	Autism Spectrum Resource Center	Lois Rosenwald - 203-248-5222 or ct-asrc@sbcglobal.net
Feb. 18 – 9 am – 1 pm	Developing Play Skills in Children with Autism Spectrum Disorder	ACES – 205 Skiff St. – Hamden	Autism Spectrum Resource Center	Lois Rosenwald - 203-248-5222 or ct-asrc@sbcglobal.net
Feb. 22	Paternal Rights Forum	Old Judiciary Room – State Capitol	CT Civil Rights Council & Divorced Men’s Association of CT	John DiBiase Jr. – jdibiasejr@aol.com 203-630-1338
March 7 – 10 am – 12 noon	Cash and Counseling Forum	Legislative Office Building – Hartford	DD Network	Jessica Jagger jjagger@uchc.edu
March 14 10 am	Meeting of Long Term Care Planning Committee	Rm 310 – State Capitol	LTCPC	David Guttchen – 860-418-6318 david.guttchen@po.state.ct.us
March 23 10 am -5 pm	Strangers in the House: The Dilemma of Living with In Home Services	Institute of Technical and Business Development – CCSU	DD Council	Ed Preneta 860-418-6157 or ed.preneta@po.state.ct.us

April 8 - 9 am – 3:30 pm	Life After High School: How Do We Prepare?	Institute of Technical and Business Development – CCSU	The Autism Spectrum Resource Center	Lois Rosenwald - 203- 248-5222 or ct-asrc@sbcglobal.net
April 19 10 am – 5 pm	Insights into Lives of Students with Impairments	Institute of Technical and Business Development – CCSU	DD Council	Ed Preneta 860-418-6157 or ed.preneta@ po.state.ct.us
April 20 – 10 am – 12 noon	Home Supports for Children who are Medically Fragile	Old Judiciary Room – State Capitol	DD Network	Jessica Jagger jjagger@uchc.edu
May 3	Last Day of 2006 Legislative Session	Legislative Office Building Hartford		
May 31 10 am – 5 pm	Frailty in Old Age	Institute of Technical and Business Development – CCSU	DD Council	Ed Preneta 860-418-6157 or ed.preneta@ po.state.ct.us
Sept. 16	Disability Advocacy Collaborative Convention	CT Expo Center - Hartford	Disability Advocacy Collaborative	Jayne Kleinman jjk1009@hotmail.com 203-238-9391

Disability Advocacy Collaborative Update

So much is going on within the Disability Advocacy Collaborative network that bullets will be used to update readers. Areas of activity are focused on 1) the development of a series of regional advocacy networks, and 2) the planning for the Disability Convention on September 16, 2006:

Regional Advocacy Networks:

- Larry Robinson began with the Collaborative as a VISTA Volunteer in early January; Larry is working to organize an advocacy network in the Stamford/Greenwich area, and support organizing efforts by WeCAHR in the Danbury area, the Northwest Activists for Disability Rights (NADR) in both the Waterbury area and the Torrington/Litchfield area, and the Disability Resource Center in Stratford for the Bridgeport area
- Collaborative staff met with Betty Gallo (Betty Gallo and Company – a lobbying firm) to design a self advocacy workshop that will be offered in 4-6 regions of the state in May and June

- The first meeting of disability activists – individuals with disabilities and families - in the Stamford/Greenwich area will be held in Greenwich on Friday, February 24 at 10 am in the Greenwich Town Hall
- The northeast network will meet on Monday, February 27 (4 pm) to plan a self-advocacy event in the Mansfield area for May or June
- A two part self-advocacy initiative is being planned for southeastern Connecticut, with leadership provided by DNEC, UCP of Eastern Connecticut, the town of Groton, and CCCI; the first activity will be a presentation on self-advocacy basics on the evening of March 21 (6:30-8:30 pm), to be followed by a session featuring people who are making a difference in their community on April 4 (also 6:30-8:30 pm).
- The New Haven area network is working to plan a advocacy workshop for people with disabilities and families, with the goal of encouraging people to get involved in a political campaign, and possibly running for office in the future; the City of New Haven Office of Disability Services, the Disability Resource Office at SCSU, and a number of other disability organizations and individuals are participating in planning the event
- The Hartford area network is working on developing a web site for the Collaborative, and will be offered the opportunity to host a self-advocacy training event in June

Convention Planning:

- The State Independent Living Council will join efforts with the Collaborative to plan and implement a Candidates' Forum during the afternoon of the Disability Convention
- A most gratifying meeting was held on February 3 with a number of service providing agencies to solicit their input and support for the Convention
- The Collaborative operates with guidance from a Steering Committee that has undertaken the planning for the Disability Convention; a number of committees have been created to ensure all aspects of the Convention are covered:
 - Candidates Forum Committee – will work in collaboration with the SILC to invite and include candidates for Governor, other state constitutional officers, the U.S. Senate seat, and local candidates for the state General Assembly
 - Vendors and Agency Committee – booths will be made available at the convention for both vendors (private businesses that provide disability related equipment and services) and public and private agencies that provide services to people with disabilities and families
 - Public Relations Committee – to plan a public relations campaign to encourage attendance at the Convention
 - Transportation Committee (see article below)
 - Volunteers Committee – to ensure that the necessary supports are available within the Expo Center to ensure the smooth running of the Convention

- Fun Activities Committee (needs a Chair – anyone interested?) – to plan fun activities for the Convention to make the event attractive to family and children with disabilities
- Fund-raising Committee – you know what that means!

Special Request

The Collaborative is looking for individuals to serve as regional transportation coordinators to facilitate participation in the Convention by people without their own means of transportation. Also needed is a volunteer Statewide Coordinator to coordinate regional efforts. Please contact Jayne Kleinman if you want to be involved with this critical effort by sending her an email (jjk1009@hotmail.com), writing her at 55 Corrigan Ave., Meriden, CT 06451 or calling her at 203-631-4800.

A Pilot Program for Adults with Autism Spectrum Disorders

Senator James Amann will hold a press conference on February 17, 2006 to announce his support for legislation that calls for a pilot program to provide a coordinated system of supports and services for adults with autism spectrum disorders (ASD) without mental retardation. A Legislative Breakfast will be held at 8:30 am and the press conference is set for 10:30 a.m. Both activities will take place at the Legislative Office Building on Capitol Avenue in Hartford.

The pilot program, which will last for two years, is slated to serve up to fifty adults with ASD, who do not have mental retardation, as defined in section 1-1g of the General Statutes. The introduction of this legislation represents a critical step forward in addressing the service and support needs of adults with ASD.

If you would like to attend either the breakfast or press conference, please confirm by calling Lois Rosenwald at 203-248-5222 or by email ct-asrc@sbcglobal.net. The Connecticut Autism Spectrum Resource Center (ASRC) is organizing the event and would like to get an idea of the number of people they may expect so they can make preparations.

Protection and Advocacy Legislative Initiatives

The State Office of Protection and Advocacy for Persons with Disabilities (P&A) is seeking legislative support for a proposal that would ensure that public school students (K-12) with print disabilities receive their instructional materials at the same time as other students, and in formats that are of the highest quality. A print disability is any disability that makes reading printed material difficult or impossible. Students with visual impairments typically have print disabilities, but students with cognitive and physical impairments may have them, too.

Right now, neither state nor federal law adequately addresses the instructional materials needs of students with print disabilities. (The 2004 reauthorized Individuals with Disabilities Education Act, or IDEA, includes new sections that address these needs, but the provisions are extremely weak.)

If you are interested in learning more about the issue or in joining us in P&A's legislative efforts, please contact Elanah Sherman at 860-297-4322 (V), 860-297-4380 (TTY), 800-842-7303 (V and TTY) or elanah.sherman@po.state.ct.us .

P&A has also submitted proposals that would:

1. allow the Executive Director of P&A to create an Accessibility Access Board. The Executive Director would determine the membership. The Advisory Board could advise the Director on accessibility matters including those related to government programs and services, transportation and housing.
2. require the Department of Correction to report all suicides of inmates and prisoners to P&A, and forward related information to P&A in a timely manner.
3. put the Fatality Review Board, which was created by Governor Rowland's Executive Order 25, into the P&A statute; also require the Department of Mental Health and Addiction Services to report the deaths of all clients that occur in DMHAS hospitals and DMHAS-contracted hospital beds.

The Connecticut Family Support Council Hosts a "Meet and Greet"

The Connecticut Family Support Council is extending an invitation to executive branch agencies, state legislators, community leaders, parents of children with disabilities (all disabilities) and friends in the community to join them for a "Meet and Greet" on Thursday, February 16, 2006. The event will take place from 9:00 - 10:30 am in the Second Floor Atrium of the Legislative Office Building, 300 Capitol Avenue in Hartford.

The Council envisions a comfortable exchange over coffee and pastries - allowing parents to personally meet and greet their legislators and community leaders - foregoing a formal agenda. The 2005 Connecticut Family Support Council's Annual Report, which highlights Council's priorities and recommendations for 2006 in relation to supports for families of children of all disabilities, will be made available.

Family Support is important! Let the numbers of parents in attendance speak to this! Share your concerns and stories with those who can make a difference. Questions? Contact Karen Zrenda (888-842-1937) or Laura Knapp (877-743 - 5516).

Long Term Care Advisory Council Seeks Comprehensive Analysis

The State Long Term Care Advisory Council announced its 2006 legislative priorities to a packed house at the Legislative Office Building in Hartford on February 6, 2006. The

primary goal of the Council this year is to obtain funding for a comprehensive analysis of the state's long term care needs. The analysis called for would 1) assess consumers' long term care needs, desires, and preferences, and 2) plan for optimal use of public and private long term care funding. Assessment and planning for future needs should gauge present and future consumer needs and assess the financial viability, capacity, and performance of the service network.

Other priorities include the creation of a state-funded home care pilot for persons under age 65 not eligible for existing PCA waivers; an expansion of the statewide respite care program by increasing funding and eliminating the restriction that makes people under 65 who are on Medicaid ineligible; mandating criminal background checks on all direct care workers who provide long term care services, and provide adequate funding for the entire long term care continuum which is at risk of further erosion.

For more information, contact Julie-Evans Starr, Co-Chair of the Long Term Care Advisory Council (860-240-5201, or by e-mail at coa@cga.ct.gov).

Arc/CT's Legislative Priorities

Peg Dignoti, Executive Director of the State Arc, reports the following legislative priorities:

- Support Funding for the Waiting List of the Department of Mental Retardation: The Settlement in the Arc/CT vs. DMR lawsuit requires funding for 150 individuals from the Emergency or Priority 1 Waiting List and 100 people from the Planning List (Priorities 2 and 3) each year for five years.
- Support wage increases for employees of private community agencies: Direct support staff employed by private agencies under contract with DMR are paid approximately 40% less than State employees doing comparable work. The Arc/CT will also support a rate adjustment for low-rate agencies and a cost-of-living increase for non-wage cost increases in fuel, transportation, etc.
- Change the name of the Department of Mental Retardation to the Department of Developmental Disabilities: People who have intellectual disabilities intensely dislike the term "mental retardation" and while The Arc, the State Department of Education and many other public and private agencies have stopped using it, DMR has not. The Arc will join with People First of Connecticut in seeking statutory changes for all references to DMR, and will also seek legislation requiring the use of respectful and people-first language (PFL) in all Connecticut statutes and regulations.
- Support mandatory audio or visual taping of interrogations in capital cases: People with intellectual disabilities can easily misunderstand or be misled into making false confessions to serious crimes; electronic recording of interrogations can help determine the validity of the confession.

- Support establishment of a Trust fund to hold proceeds from the sale or lease of properties formerly used to house or care for people with intellectual disabilities: The Trust Fund could be used to provide services and supports to people who used to live in state facilities and institutions who need additional supports and to people who are on the Waiting List for services because their families supported them at home all their lives.
- Support repeal of the law that provides a financial incentive to school district planning to construct segregated educational facilities: Current State law authorizes school construction grants for “cooperative regional special education facilities” in an amount equal to 95% of the cost of “purchasing, constructing or reconstructing appropriate facilities to be used primarily for children requiring special education...” in violation of State and Federal laws.
- Ensure adequate funding to implement the Federal District Court-approved Settlement in the “P.J. v. Board of Education” case: Support increased opportunities for administrators, regular and special educators, and parents to learn more about inclusive education and provide adequate funding for implementation of this landmark decision. (Arc/CT was a plaintiff in the P.J. case)

Renewed Attempt to Keep People with Disabilities Out of Elderly Housing

Jan VanTassel, Executive Director of the Connecticut Legal Rights Project, reports there will be another attempt this legislative session to limit the housing choices available to people with disabilities by restricting their access to state funded elderly housing. Although not the first choice for many people with disabilities, state elderly/disabled housing is often the only viable option. The legislature’s Program Review and Investigations Committee found that only a small number of negative incidents in elderly projects involved residents under the age of 62. The staff of the committee concluded that these incidents could be addressed with better management techniques and enhanced services for all tenants.

Our elected officials must be urged to address the real problem – the lack of affordable, accessible housing – and not the symptom. To get involved or find out more, contact Jan at 860-262-5042 or jvantassel@clrp.org.

NAMI-CT’s Legislative Priorities

Alicia Woodsby of NAMI-CT (National Alliance on Mental Illness – CT Chapter) has announced a series of 2006 legislative priorities developed by NAMI-CT. These include:

- Maximize federal revenue for mental health services and reinvest money “saved” back into the mental health system

- Decriminalize youth and adults with serious mental illness
- Reduce the number of people with serious mental illness being placed in nursing homes and provide the services needed to sustain community living
- Raise the age of adulthood in Connecticut to 18 years old

Alice can be reached at 1-800-215-3021 or by e-mail at publicpolicy@namict.org

Pilot Program for Persons with Disabilities Between 18-64

Many individuals with disabilities between the ages of 18 to 64 are not covered by current Medicaid waivers or state-funded programs. They need help with activities of daily living and may have limited family support, have cognitive impairment, and/or have needs that change over time. The existing Connecticut Home Care Program for Elders is only available to those 65 and older, and the Medicaid Personal Care Assistance (PCA) Waiver requires that individuals have the ability to self-direct their own care.

The pilot program being requested will be limited to fifty adults and not cost more than \$250,000, and will be offset in the long run by keeping people with disabilities out of institutional settings, where care is much more expensive. In addition, costs for individual participants in the pilot program to live in the community will be capped at 50% of the cost of nursing home care.

According to the MS Society and Alzheimer’s Association, 7,436 people under age 65 received care in a Connecticut nursing facility during state fiscal year 2003. Many people who have cognitive and other significant impairments, could live in the community with the right services and supports and help managing their care. People with chronic illnesses and disabilities caused by such diseases as Huntington’s Disease, Parkinson’s Disease, ongoing strokes, Alzheimer’s Disease, Multiple Sclerosis and HIV/AIDS are likely to be helped by this program. It could help people get out of nursing homes as well as those who are at risk of institutionalization.

“JF” Deadlines for 2006

The 2006 state legislative session begins Wednesday, February 8, and ends May 3. Beth Leslie, Legislative Liaison for the Office of Protection and Advocacy for Persons with Disabilities, shares with Bulletin readers the JF deadline for committees of the state General Assembly. The "JF Deadline" is the date by which each committee must report out bills or resolutions for further consideration by other committees or the full General Assembly.

Aging - March 9	Commerce - March 16
Banks - March 9	Insurance and Real Estate - March 16
Children - March 9	Planning and Development - March 17
Housing - March 9	Environment - March 20
Public Safety and Security - March 9	Public Health - March 20
Veterans Affairs - March 9	Human Services - March 21

Program Review and Investigations - March 10 Transportation - March 13 Energy and Technology - March 14 General Law - March 14 Higher Education and Employment Advancement - March 14 Legislative Management - March 15	Labor and Public Employees - March 21 Education - March 24 Government Administration and Elections - March 24 Judiciary - March 27 Appropriations - April 4 Finance, Revenue and Bonding - April 6
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Beth Leslie can be reached at the Office of Protection and Advocacy for Persons with Disabilities - 60-B Weston Street - Hartford CT 06120 Phone (860)297-4369 - TDD (860)566-2102 - Fax (860)566-8714 – E-mail: beth.leslie@po.state.ct.us .

Justice Department to Investigate CVH

From the Hartford Courant: “The U.S. Department of Justice is investigating whether the state's largest public psychiatric hospital protects patients from harm and uses seclusion and physical restraints properly. The Justice Department's civil rights division began an investigation of Connecticut Valley Hospital on Dec. 15, and federal investigators will inspect the Middletown campus in mid-March.

The hospital had been staggered by three suicides in a 15-month period, including two in 10 weeks. An investigation by the state Department of Public Health found that serious breakdowns in basic nursing preceded two of the suicides. In those cases, nurses failed to respond to telltale behavior by two patients with a history of suicide attempts. One of the nurses was a "traveling nurse," a temporary employee who had been found incompetent at her job but was still placed in a supervisory position.”

P&A Brings Suit Against State

On Monday, February 6, the State Office of Protection and Advocacy for Persons with Disabilities (P&A) filed suit against three state agencies, claiming violations of the Americans with Disabilities Act. The suit accuses Connecticut of violating federal law by forcing hundreds of psychiatric patients to live in nursing homes, often in segregation, when community-living alternatives would better suit them. P&A was joined in the lawsuit by the Bazelon Center for Mental Health Law.

Although the lawsuit focuses on patients at three Connecticut nursing facilities, OPA Executive Director James McGaughey said the implications extend far beyond those individuals and places. "Institutionalizing people when they want to live in the community, and it is possible for them to live in the community with the proper supports, is a violation of their civil rights," he said.

About 3,000 of the state's approximately 27,000 nursing home residents have been diagnosed with serious mental illness.

DDC/SRV Training Opportunities

The Connecticut Council on Developmental Disabilities and the Social Role Valorization (SRV) Implementation Project, Worcester, Massachusetts, are pleased to announce the following Spring 2006 SRV training events:

Thursday, March 23, 2006: "Strangers in the House: The Dilemma Of Living With In-Home Services." Families and individuals who receive in-home support services typically face a major dilemma of trying to maintain the integrity of their home and family lives despite inescapable disruption of service worker presence in the home. This dilemma can quickly become intolerable. This workshop offers insights, practical advice and strategies for managing the issues involved. If you use in-home supports, this workshop is for you.

Time: 10:00 a.m. to 5:00 p.m.

Tuition: FREE

Registration Deadline: March 9, 2006

Wednesday, April 19, 2006: "Insights into the Lives of Students with Impairments." This workshop is for educators, related personnel and school administrators. Continuing Education Units (CEUs) will be explored. This workshop will explore countering the negative stigma of impairment and "special ed" and building positive identities.

Time: 10:00 a.m. to 5:00 p.m.

Tuition: FREE

Registration Deadline: April 5, 2006

Wednesday, May 31, 2006: "Frailty in Old Age: Understanding Vulnerability and Supporting Elders in Valued Roles." In a culture that increasingly devalues elders, people who are older are especially vulnerable to being denied access to the good things in life. Being old and having a disability is double jeopardy. This workshop examines the common life experiences of elders in today's culture, with a particular emphasis on the harm that gets done to people who are older who are segregated and congregated and obstacles people who are older face in acquiring or maintaining a typical life. This workshop is for anyone caring for people who are older.

Time: 10:00 a.m. to 5:00 p.m.

Tuition: FREE

Registration Deadline: May 17, 2006

Location: All training will be held at the Institute of Technical and Business Development, Central Connecticut State University, 185 Main Street, New Britain. Directions will be provided to registrants. Materials, parking, refreshments and lunch will be provided.

Registration: Advanced registration required. Registration will not be accepted at the door. Send your name, agency affiliation (if any), address, telephone and e-mail (if any) to:

CT Council on Developmental Disabilities

460 Capitol Avenue
Hartford, CT 06106-1308

Accommodations: With your registration, please let us know if you will need sign language interpreters, taped materials, dietary foods or other accommodations.

Further Information: Ed Preneta (860) 418-6157 or ed.preneta@po.state.ct.us

An Update on HAVA Implementation in Connecticut

The following article is provided by Elanah Sherman of the state Office of Protection and Advocacy for Persons with Disabilities:

The Help America Vote Act (HAVA) was passed in 2002. Although many people believe that it deals exclusively with accessibility, the law actually responds to a wide range of voting issues, including voter identification policy, provisional ballot voting, etc. In terms of disability, the law addresses five major areas:

- 1) It authorizes funding for Protection and Advocacy agencies across the country to work on enhancing access to the vote;
- 2) It provides funding for states to increase access at their polling places;
- 3) It requires that individuals with disabilities be represented on the state HAVA Committee;
- 4) It requires that, by January 1, 2006, each polling place offer the opportunity for people with disabilities, including those with visual disabilities, to vote privately and independently;
- 5) It provides funding for research on accessible voting technology.

According to the Secretary of the State's Office, former-Governor Rowland would not authorize the Secretary to apply for funding to improve polling place access (Point 2, above), so Connecticut has been unable to help municipalities fund their modification needs.

Although in many ways HAVA implementation has gone smoothly in CT, there have been some unexpected glitches, unfortunate disappointments and unhappy surprises, especially in the area of voting machine purchase. The original expectation was that the state would comply with the machine requirements of HAVA by having at least one disability-friendly, non-lever machine at every polling place by the 2006 elections. (See Point 4, above.) However, according to the Secretary of the State, the manufacturer of the selected machine had misconstrued its certification status, thus becoming ineligible for transacting with the State and throwing the entire purchasing process back to its beginnings. That is where we are now.

In Connecticut, we are fortunate to have Registrars who are, for the most part, committed to providing maximum access to people with disabilities and who are well educated on the legal requirements. Most polling places offer decent to exemplary structural accessibility, with the most common compliance problems being in the areas of parking,

exterior door width (too narrow), and exterior door pressure weight (too heavy); one also frequently finds a lack of directional signage when the accessible voting entrance is different from the main voting entrance.

In future issues of the Bulletin, Elanah will provide more detailed information on the ups and downs of the State's journey toward full compliance with the HAVA. In the meantime, please call her if you want additional information on HAVA or if you would like to arrange a workshop on disability-related voter rights.

Ms. Sherman can be reached at 860-297-4322 (V), 860-297-4380 (TTY), 800-842-7303 (V and TTY), or elanah.sherman@po.state.ct.us .

Are You Eligible to Hire Your Own Personal Assistant through the State's PCA Waiver Program?

Under the C-PASS project, the University of Connecticut Center on Disabilities has developed an instructional guide for employers (i.e., persons with disabilities) who hire personal assistants. The guide covers a wide variety of topics including: the hiring process, funding options and tax considerations, effective communication, being an assertive employer, and other areas of importance for people to know in hiring and managing personal assistants. Staff at the Center are reaching out to interested, motivated individuals to become part of testing these materials.

Personalized training sessions will be conducted in your home to teach you the skills you need to hire and manage your own assistants. This training will take between seven and ten visits. There will be a telephone interview before and after the training to help evaluate the effectiveness of the guide, materials and teaching techniques.

Please contact Therese Nadeau, Project Specialist (860-679-1591), tnadeau@uchc.edu, or TTY (860-679-1502) by March 1, 2006 if you would like to be a part of this project.

Consumer Energy Help: Staying Warm this Winter

AARP Connecticut has multiple copies of their brochure "Consumer Energy Help: Staying Warm this Winter" available by calling 1-866-295-7329 (toll free). Those of you that fall in the "mature" category can also ask them about membership in AARP, which is open to anyone 50 and over. You might also visit their website to view the benefits of membership at www.aarp.org/.

Autism Spectrum Resource Center Offers Workshop

TOPIC: Developing Play Skills in ASD Children

PLACE: ACES Staff Development/Administration Building – 205 Skiff Street – Hamden, CT.

Date: February 18, 2006 Snow Date: March 25, 2006

Time: 9 am to 1 pm

Presenter: Megan McCullough

Ms. McCullough graduated from Fairfield University with a B.A. in Psychology. She began working with Giant Steps School in 1993 as the Play and Social Communication Specialist. Giant Steps Connecticut is a private school for children with Autism Spectrum Disorders and other neurological impairments. In her role at the school, she has developed a play and social communication curriculum. Ms. McCullough has gone on to receive her Master's in Special Education, and has completed her sixth-year degree in Education Administration. She currently is in the position of Academic Coordinator at Giant Steps.

For more information call the Autism Spectrum Resource Center at 203-248-5222.

Important Transportation Updates

Here is an update on three important transportation initiatives currently underway in the state of Connecticut:

- \$5 million per year for two years has been appropriated by the state General Assembly to implement Sec. 13b-38bb of the General Statutes. The funds are to be used to expand demand-response transportation services for people who are elderly or disabled. The funding was appropriated for FY 2006 (beginning July 1, 2005), and FY 2007 (beginning July 1, 2006). Fifty percent of the funds have been appropriated on the basis of the population of persons age sixty and over and fifty percent on the basis of the municipality's square mileage. [Find out more about your community with regard to population size, government structure and contact information by going to www.ct.gov/ctportal/cwp/view.asp?a=843&q=257266 and clicking on your town.]

C.G.S. 13b-38bb requires that municipalities apply to the state for the funds through a designated Regional Planning Organization (RPO) or a transit district. To locate which Planning Organization you belong to, go to www.opm.state.ct.us/igp/RPOs/rpo.htm. The municipality must work with this regional body to determine how to use the funding most effectively in that municipality and its surrounding region. If a municipality chooses not to apply for its share of funding, that portion will be returned to the Special Transportation Fund. In order to be certain that state funds will not be used to supplant municipal funds, the municipality must certify their maintenance of effort annually.

The goals as stated in the statute are to provide a uniform funding source available to all municipalities in the state, provide new transportation services to enhance access to the community for seniors and people with disabilities where

transportation services do not exist, expand transportation services to enhance access to the community in areas where transportation is already available, and to encourage efficient use of scarce resources through coordination.

Coordination models may include 1) informal arrangements and a voluntary process whereby providers plan their services to avoid duplication of services provided by other agencies, or 2) formal coordination through a lead agency model whereby one agency takes on the responsibility for providing transportation for several other agencies.

Applications are due to Regional Planning Organizations by February 24 with recommendations sent to ConnDOT by March 10. Municipalities in the midst of their budgeting process can send a letter of intent that they will make the funds available for their match on July 1st. Since the funding being used is from the 7/1/05 – 6/30/06 fiscal year, it is hoped that the full \$5 million will be carried over past June 30, and the \$5 million available for FY '07 (7/1/06 – 6/30/07) can be carried over to FY '08.

Readers of “The Bulletin” are encouraged to contact your local chief elected officials (Mayor or First Selectman) to determine their plans and ask to be involved. Regional Planning Offices can also provide more details about the grants.

- On January 31 the Aging Services Division of the Connecticut Department of Social Services hosted an information forum at the Legislative Office Building. Kathy Freund described the ITNAmerica model in Portland, Maine. [ITN stands for Independent Transportation Network.] The program was put in place after Ms. Freund’s son was injured eighteen years ago by an elderly man who thought he hit a dog. Functioning much like a taxi service, eligible senior citizens can purchase a ride – at a cost of \$7.50 – to anywhere they want to go. The cost can be lowered if you share a ride, or schedule trips in advance. Should an individual donate their car to the service, they get credit for future rides when they need to go shopping, visit relatives, or go to the doctor. The program is available 24/7 and 1000 people benefited from the service last year, using it to take 15,000 rides. No tax dollars are used, and the effort is sustained by donations from citizens and private businesses. Four other states plan to develop a similar model.

At the forum, state Senator Jonathan Harris from West Hartford reported that an appropriation of \$100,000 was included under “Connecticut Transportation Grants for Municipalities” to go to four municipalities this year with populations over 25,000 to implement a similar project in Connecticut. An RFP from the Department of Social Services will be published in the next few months with funds available June 1. Applications will be processed by the Department of Social Services.

The entire proceedings of the forum were recorded by CT-N (the Connecticut Network: the State Public Affairs Network). To view the program, including broadcast times and archives, go to www.ctn.state.ct.us/index.asp.

- The Connecticut Department of Transportation is continuing efforts to engage a consultant to assist them in implementing the federal United We Ride project in Connecticut. You may go to the United We Ride website (www.unitedweride.gov/) to learn more about the program. As a part of the initiative, ConnDOT will conduct a meeting with Governor Rell and other State Commissioners to get “buy in” from the top down. Future meetings will be held to discuss transportation barriers and the value of coordination, to strategize how improved service can be obtained.

P.A.T.H.S. Forum Reports on Website

The University of Connecticut Center on Disabilities, under a grant from the Council on Developmental Disabilities, (Plan for the Achievement of Transportation Coordination in Human Services) sponsored seven forums during 2005.

To view the reports and also to see the “Consolidated Findings From Regional Forums On Transportation,” “Maps Of Disability Related Transportation” and “Examples of local and regional best practices,” click on the following link
http://uconnuidd.org/projects/paths_publications.html

Connecticut Writer Extraordinaire!

Joan Seliger Sidney is writer-in-residence at the University of Connecticut’s Center for Judaic Studies and Contemporary Jewish Life and Lecturer in the Department of English. She is the author of “Body of Diminishing Motion – Poems and a Memoir”, published in 2005. Her work has been described as “a portrait of life with Multiple Sclerosis that is fresh and sensitive, and very much needed. Wielding her art in a brave and unflinching way, she provides a wonderfully nuanced and emotionally true account of living with an unpredictable but relentless enemy bent on sabotaging communication within her brain”. The publication can be obtained through CavanKerry Press.

Joan lives in Storrs, Connecticut, with her husband. She has four adult children.

An Exhibit at P&A

Richmond Jones, an accomplished photographer who has been published and exhibited in both this country and Canada, will have his exhibit “Portraits from Southbury Training School” on display at the Office of Protection and Advocacy in Hartford through March 28, 2006. In creating this exhibit, Jones sought to provide a humanistic alternative to other artists whose images of people with intellectual disabilities tended to foster distance rather than commonality. Jones’s portraits, in contrast, create a sense of shared humanity.

Elanah Sherman (860-297-4300 – elanah.sherman@po.state.ct.us) is coordinating this exhibit at P&A.

City of New Haven Awarded Employer of the Year at National Level

The City of New Haven, first recognized at the local level, has been awarded Employer of the Year by the National Multiple Sclerosis Society. The National Multiple Sclerosis Society, Greater Connecticut Chapter presented to the City of New Haven the Employer of the Year award at its annual meeting in October. The City of New Haven subsequently received recognition at the national level in the organization's "more than 100 employees" category.

The City of New Haven has provided a variety of resources and accommodations to individuals diagnosed with multiple sclerosis, including flexible work schedules, specialized telephones, and accessibility modifications to workspace and assistive technology through its Department of Services for Persons with Disabilities, headed by Michelle Duprey.

For more information about multiple sclerosis and its effects, please contact the Greater Connecticut Chapter at 860.953.0601 or visit www.ctnmss.org.

Disability Policy Specialist Job Opening

The Connecticut Council on Developmental Disabilities is hiring a "Disability Policy Specialist" to begin on April 28, 2006. The position has a starting salary of \$43,312 plus a full fringe benefits package. This is a full-time state position funded under the federal Developmental Disabilities Act. Parents who have children with developmental disabilities are encouraged to apply.

Applicants must be committed to, and willing to promote, the full and unconditional inclusion of people with disabilities, regardless of severity of disabilities, in valued roles and non-segregated environments in neighborhoods and communities.

This position is being advertised through February 2006. Interviews will be held during March 2006. Three (3) references will be requested for applicants chosen for interviews.

Applicants should send a brief resume with a one-page cover letter to Edward T. Preneta, Director, Connecticut Council on Developmental Disabilities, 460 Capitol Avenue, Hartford, CT 06106-1308, or e-mail to ed.preneta@po.state.ct.us or fax to (860) 418-6003. Resumes and cover letters must be received by the Council Office no later than 4:30 p.m., Friday, March 3, 2006. Further information about the Council can be found on the Council's Web site at <http://www.ct.gov/ctcdd>.

Medicaid Commission Meeting

News from Justice for All: When the Medicaid Commission met in Washington, DC, last week to begin their deliberations on making recommendations to the Administration and to Congress on the future of the Medicaid program, their focus was on eligibility populations. This was consistent with a schedule that had been adopted in October for the next five meetings of the Commission:

- * January meeting - Considering fiscal constraints, who should be served and why?
- * March meeting - How do we get the best quality acute and preventive care for our public dollars?
- * May meeting - How do we get the best quality long-term care for our public dollars?
- * July meeting - What are the tools to making our dollars go farther? How do we improve the infrastructure for quality care?
- * September meeting - What are the tools to making our dollars go farther: information technology, fraud and abuse and financing?

At the present time, about one-third of Medicaid's budget goes to long-term care. So it is certainly understandable that the Commission should especially consider recommendations involving long-term care, which it will begin to do at its March meeting. At the recent White House Conference on Aging that meets every ten years, long-term care was the target of many of the recommendations from that conference. Also, on December 15, 2005, the National Council on Disability (NCD) released its report on "The State of 21st Century Long-Term Services and Supports."

It is possible for anyone to make public comments during the Commission's meeting, as well as to submit in writing any proposals or testimony for the Commission's consideration. For example, ADAPT submitted a proposal to the Medicaid Commission very early in its deliberations entitled "Programmatic/Cost Efficient Medicaid Changes to End the Institutional Bias." This proposal focuses on "how Medicaid's long-term services and support system can more effectively serve more people with disabilities and older Americans in the community by reforming the institutional funding bias that has existed since 1965 and without block granting or arbitrarily capping Medicaid funding." A member of ADAPT will be testifying at the March meeting.

Written submissions to the Commission should be sent to Stacie Maass, Executive Director of the Medicaid Commission, 200 Independence Avenue, SW, Washington, DC 20201, phone (202)401-5879, Stacie.Maass@hhs.gov.

For more information regarding Medicaid Commission issues, please see: www.aapd.com/News/commission/indexmedcomm.php

NCD Conducting an Employment Study

The National Council on Disability is currently conducting a study that will gather information from a wide range of sources and stakeholders regarding the issues that persons with disabilities encounter in seeking and maintaining employment. Rutgers University Program for Disability Research is facilitating this discussion for NCD via an online bulletin board. The purpose of this online discussion is to inform policy and program recommendations for employment opportunities for individuals with disabilities. This study will result in a comprehensive report and set of policy recommendations, to be provided the National Council on Disability, by June 1, 2006.

The online discussion is located at www.ncdadaemploymentstudy.com . If you have questions at any time about this research project, you may contact the project director, James Schmeling, at: Program for Disability Research - Rutgers University - 303 George St. Suite 405 - New Brunswick, NJ 08901 - Tel: 319-335-8458 - E-mail: james-schmeling@uiowa.edu.

Report on State Strategies to Help Keep Consumers Out of Nursing Facilities

The Kaiser Commission on Medicaid and the Uninsured has published a report on tactics used by states to divert nursing facility admissions. Policies and practices in eight states are described although "best practices" are not identified. Four of the states examined (Maine, Oregon, Vermont and Washington) have made large scale changes to their Medicaid long-term care (LTC) systems to invest at least half of their Medicaid LTC budget on home and community-based services (HCBS). The other four states studied (Indiana, Nebraska, New Jersey and Pennsylvania) have made more incremental changes, spending a smaller proportion of Medicaid LTC funding on HCBS. The report suggests that despite these different approaches, there are seven key elements to the successful diversion from nursing facilities. These are; philosophical commitment and legislative direction, fast eligibility determinations, making community care available immediately, procedures to track and manage placements, assuring financing for HCBS, accessible and affordable housing, and information about the options for care for professionals and consumers. For more information, go to: [_www.kff.org/medicaid/7402.cfm_](http://www.kff.org/medicaid/7402.cfm).

Applications Solicited for the Ed Roberts Postdoctoral Fellowship in Disability Studies

The Ed Roberts Postdoctoral Fellowship in Disability Studies is now open for applications. The postdoctoral program is funded by the National Institute on Disability and Rehabilitation Research. The goal of this program is to train postdoctoral and professional scholars, in any discipline, to be leaders in disability studies and rehabilitation research and mentorship. Based at the University of California, Berkeley, a San Francisco Bay Area Consortium of universities, research institutes, and disability

agencies will recruit people with advanced professional degrees who want to broaden their theoretical outlook and their disability research methodological skills. For more information, go to www.pascenter.org/news/news_home.php?id=51.

WID Calls for Stories and Artwork on Abuse

The World Institute on Disability (WID), a nonprofit research, training and public policy center, is seeking stories, poetry, artwork and cartoons about people with disabilities who have faced physical and emotional abuse. Stories and artwork that exemplify challenging, stopping or interrupting abuse and mistreatment at the hands of providers, caregivers, personal assistants, medical and other kinds of service providers and helpers are sought.

These pieces will be compiled and issued as “CAPE: Curriculum on Abuse Prevention and Empowerment”, a training guide for people with disabilities, family members and services providers. Funded by the National Institute on Disability Rehabilitation and Research, the book will be widely distributed via CD ROM, print and the web, in English and Spanish.

Submissions of written pieces may be up to 750 words in length (three double-spaced pages). Pieces longer than 750 words will not be considered. Please submit manuscripts electronically or on paper, double-spaced in 12-point type.

Please note: Submissions cannot be returned. Keep your own copy. Authors and artists of selected pieces will receive a copy of the volume on CD ROM and in print. WID will seek commercial publication of this volume, and if this effort is successful, authors and artists of selected pieces will receive a small honorarium. The deadline for submission is **March 15, 2006**. Items should be sent to: Marsha Saxton, CAPE, World Institute on Disability, 510 16th Street, Oakland, CA 94612, marsax@wid.org.

Disability & Emergency Preparedness Resources Interactive Map Website

A unique web-based tool has been developed that provides access to an accessible, interactive clearinghouse of regional, state, and local disability-related emergency management resources. As a service to first responders, emergency managers and people with disabilities, the National Organization on Disability’s Emergency Preparedness Initiative (EPI) is providing regional, state, and local disability-related emergency management resources. Interested parties have access to a map, and if you click on your state you may view a list of links to disability & emergency preparedness resources in your area. For more information go to www.hcbs.org/moreInfo.php/nb/doc/1491.

Disability Statistics Website

Cornell University has developed a variety of graphs and charts, tables, and written descriptions that provide a comprehensive view of key disability statistics in the U.S. The disability statistics are based primarily on data from the 2000 Census. To view the 2004 Disability Status Reports - available in PDF or HTML and listed by state - go to: www.ilr.cornell.edu/ped/disabilitystatistics/. For more general information go to www.hcbs.org/moreInfo.php/nb/doc/1494 .

Help Eliminate the Twenty-Four Month Medicare Waiting Period

The Medicare Rights Center (offices in New York and Washington, DC) has persevered in its efforts to eliminate the 24 month Medicare coverage waiting period and has recently embarked on a national media project to bring the issue to light. The goal is to raise awareness of the lasting damage caused by the waiting period by recording the personal experiences of individuals who are currently in the waiting period or who recently got Medicare coverage after having gone through the two-year wait. If you or someone you know might be willing to participate in this project by sharing their story please contact the Center at hkreamer@medicarerights.org.

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.

If you want something to appear in the next edition 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.

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. The best way to contact your Member of Congress is via phone (or ideally in person). The best time to call either in CT or in Washington, D.C. is early in the morning.