



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

July, 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.

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Calendar of Events

<u>Date</u>	<u>Event</u>	<u>Location</u>	<u>Sponsor</u>	<u>Contact</u>
The Brain Injury Association of Connecticut has moved to 333 East River Drive, Suite 106, East Hartford, CT 06108, 860-721-8111				
July 6 5:15-7:00	Introduction to the Disability Advocacy Collaborative	Groton Town Hall Annex	CT Disability Advocacy Collaborative	jjk1009@hotmail.com
July 12 5:15-7:00	Introduction to the Disability Advocacy Collaborative	Hamden Senior Center	CT Disability Advocacy Collaborative	jjk1009@hotmail.com
July 14	People First of CT Statewide Meeting	American Legion Hall, Willimantic	People First of CT	Advozealot@aol.com
July 14 10:00 - 12:30	P.A.T.H.S. Transportation Forum	NW Chamber of Commerce, Torrington	UCONN Center on Disabilities	jkleinman@uchc.edu
July 14 2005	CT Family Support Council	SERC – Middletown	CT Family Support Council	jtcarroll@cox.net
July 19 1:00-3:30	P.A.T.H.S. Transportation Forum	Newington Senior and Disabled Ctr.	UCONN Center on Disabilities	jkleinman@uchc.edu
July 21	End of Session Wrap-up	Old Judiciary Room State Capitol	CT Elder Action network	<u>Commission.aging@po.state.ct.us</u> 860-424-5910
July 25 2005 - 6:00	New Britain Annual (15 th) ADA Anniversary Celebration	Walnut Hill Park - New Britain	New Britain Comm. on Persons with Disabilities	NBCOPWD@juno.com

July 26 10:00 am	Out & About: Celebrating the Spirit of the Americans with Disabilities Act	Legislative Office Building Room 1D, Hartford	CT DD Network and ADA Coalition of CT	jjagger@uchc.edu
July 25-28	Youth Leadership Forum	UConn campus, Storrs	CT YLF	www.ctdol.state.ct.us/ ylf/default.htm
July 28 4:45-7:00	P.A.T.H.S. Transportation Forum	Hamden Senior Center	UConn Center on Disabilities	jkleinman@uchc.edu
Aug. 8-12	Junior Wheelchair Sports Camp	St. Joseph's College, West Hartford	Hospital for Special Care	860-267-2457 860-832-6220
Aug. 16 1:00-3:30	P.A.T.H.S. Transportation Forum	Bridgeport North Branch Library Comm. Center	UConn Center on Disabilities	jkleinman@uchc.edu
Sept. 8 7:30	Kathy Buckley-4 time Amer.Comedy Nominee "Amer's First Hearing Impaired Comedienne"	Trinity College (CART and interpreters available)	Disability Awareness Quad and the Office of Campus Life	Haley.Kimmet@ Trincoll.edu
Sept. 16	"Creating Inclusive Communities for Everyone"	Farmington Marriott Hotel	UConn Center on Disabilities	860-679-1500 (ask for Stan or Chris)
OCTOBER—Disability Employment Awareness Month.				
Oct. 15 8:30 -3:00	People First Conference	Bristol Clarion Hotel	People First of CT	Advozealot@aol.com
Oct. 23-26	White House Conference on Aging	Washington, D.C.		www.whcoa.gov
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. 12	Adult employment and advocacy	Hartford	Nonverbal Learning Disorders Assn.	<u>NLDA@nlda.org</u>
Nov. 17-20	"Reclaiming Freedom: A Call to Action"	Hartford	National Assn. for Rights Protection and Advocacy (NARPA)	narpa.org/narpa 334-491-6277
Sept. 16, <u>2006</u>	Disability Advocacy Collaborative Convention	CT Expo Center Hartford	Disability Advocacy Collaborative	<u>jjk1009@hotmail.com</u> 203-238-9391

15th ADA Anniversary Celebrations

Out & About: Celebrating the Spirit of the Americans with Disabilities Act

The Connecticut Developmental Disabilities Network, in collaboration with the ADA Coalition of Connecticut, is hosting a celebration of the fifteenth anniversary of the signing of the Americans with Disabilities Act. The event will recognize some of the organizations and towns that have gone above and beyond the requirements of the law to make their programs accessible and useable to persons with disabilities. The recognition ceremony will be held at 10:00 o'clock in the morning on July 26, 2005 in room 1D of the Legislative Office Building in Hartford. (The Developmental Disabilities Network is a partnership of the Connecticut Council on Developmental Disabilities, the Connecticut Office of Protection & Advocacy for Persons with Disabilities, and the University of Connecticut A.J. Pappanikou Center for Excellence in Developmental Disabilities Education, Research and Service.)

New Britain Annual ADA Anniversary Celebration

On Monday, July 25, 2005, at the Darius Miller Memorial Band Shell in Walnut Hill Park in New Britain, there will be a free performance by "Sister Funk" from 7:00 P.M. to 9:00 P.M. At 7:45 P.M. Mayor Timothy T. Stewart will present an official Proclamation and lead a cake cutting ceremony to honor the 15th anniversary of the signing of the ADA. A qualified interpreter will be available.

As part of this year's ADA Anniversary Celebration, the video, "Community Inclusion: Keeping Our Eyes on the Prize, Overcoming Barriers and Developing Strategies that Support Real Choices in Community Living" will be shown. Disability organizations and commercial vendors who sell products to people with disabilities are invited. For more information contact New Britain Commission on Persons with Disabilities at (860) 826-3368 or via fax/T.D.D. ((860) 826-3367. The Commission's email address is: NBCOPWD@juno.com. (In the event of inclement weather this event will take place the following night, Tuesday, July 26, 2005, 7:00 P.M. to 9:00 P.M.).

ADA Anniversary

Andy Imparato, President and CEO of the American Association of People with Disabilities (AAPD), is distributing an ADA Anniversary Statement of Solidarity that was developed jointly with the National Council on Independent Living's Civil Rights Committee and Board of Directors. The goals of the statement are to help frame media coverage of the ADA anniversary on July 26, and to demonstrate the unity and common vision of many organizations across the disability, aging, and civil rights communities.

Imperato is circulating the statement for sign-ons from national, state and local non-profit, non-partisan advocacy organizations. Any organization wishing to sign onto the statement should send an e-mail indicating that desire to ImparatoA@aol.com. He asks that groups sign-on by July 15 and plans to circulate the document with the sign-ons to date a couple of times between now and the anniversary so folks can track progress.

To view the statement go to www.aapd-dc.org. **To learn about other ADA events around the country go to the AAPD website.**

Celebrate the ADA – Support Disability Rights

On Saturday, July 23rd, in Washington, DC, and cities throughout the United States, ADAPT will be hosting Fun Runs for Disability Rights. The purpose of the event is to recognize all disability rights warriors, disability rights achievements, the continuing need for aggressive advocacy, and to celebrate the 15th Anniversary of the Americans with Disabilities Act. Yoshiko Dart, widow of Justin Dart, her family and friends will be joining the Fun Run.

For information call: 512/442-0252. Donations may be sent to Fun Run for Disability Rights - 1339 Lamar Sq Dr - Suite 101 - Austin, Texas 78704 (All donations are tax-deductible).

Disability Advocacy Collaborative Update and Meeting Dates

The first four Introductory Meetings held by the Disability Advocacy Collaborative over the last two weeks proved a rousing success, and two additional meetings are upcoming (see below). The purpose of the meetings is to introduce advocates to the Collaborative, explain its purpose and goals, the importance of the development of regional advocacy networks, as well as a Disability Convention tentatively set for September 16, 2006. The involvement of all disability advocacy groups, family organizations, and individual advocates is sought.

During the fall of this year, and the winter and spring of 2006, regional coalition building and self-advocacy workshops will be held throughout the state to build the six regional networks. The Collaborative is looking for individuals who want to get involved in this initiative, including folks who want to take a leadership role at the regional level.

Here is the schedule of the remaining introductory meetings, each of which will run from 5:15 - 7:00 pm. Light refreshments will be provided.

<u>South East Region – July 6</u> Groton Town Hall Annex Long Point Road Groton	<u>South Central Region – July 12</u> Senior Center Activity Room Miller Complex 2901 Dixwell Avenue Hamden
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Sign language interpreters have been scheduled for all forums, but will be canceled if we do not receive a request for an interpreter at least 72 hours before the event is scheduled.

If you need an interpreter or any other accommodation (e.g., materials in alternative format) please call Jayne Kleinman at 203-631-4800, or e-mail her at jjk1009@hotmail.com. Out of respect for those of us with chemical sensitivities, all meetings are fragrance free.

AND OTHER DATES

Save September 16, 2005 and September 16, 2006!

Two important dates to remember: 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. Funded under the Real Choice Systems Change Grant, the conference will help participants (i.e., community leaders, advocates, elected officials and ADA Coordinators) develop inclusion strategies and initiatives to use in their own towns and communities. Call Chris Gaynor or Stan Kosloski at 860-679-1500 for more information.

And on September 16, 2006, the Disability Advocacy Collaborative will host a Disability Convention at the CT Expo Center in Hartford. The date and location is tentative but the event isn't. Contact Jayne Kleinman at jjk1009@hotmail.com or 203-631-4800 for more information.

Free Summer Camp for Children with Disabilities

The Ivan Lendl Junior Wheelchair Sports Camp is offered FREE-OF-CHARGE to children ages 7-18 who have with physical disabilities. Instruction in sports (e.g., tennis, basketball, and track and field) is offered by experienced athletes with disabilities. The camp will be held on August 8th-August 12, 2005 (9 am – 4 pm) at St. Joseph College, West Hartford, CT. To register call 860-267-2457.

State Legislation

The state General Assembly concluded its regular session and a special session in June. It was a session of mixed results for people with disabilities. One bill that fortunately did not pass: Substitute Senate Bill 818, as amended by strike-all Senate Amendment A. The language of this amendment threatened to undermine the longstanding direction of Connecticut's policy regarding accessible housing for people with disabilities. The Office of Protection and Advocacy and access advocates expressed their significant concerns regarding bill, with positive results.

The legislature's Office of Fiscal Analysis has produced a very helpful summary of the state budget that was passed by the general Assembly. You can access it on the legislative website at this link: <http://www.cga.ct.gov/ofa/>

Here are some of the important measures passed into law this year, as shared with us by Beth Leslie, legislation liaison for the state Office of Protection and Advocacy:

AN ACT CONCERNING AN INCREASE TO THE UNEARNED INCOME DISREGARD FOR STATE SUPPLEMENT RECIPIENTS. To allow recipients of the state supplement to the federal Supplemental Security Income Program to receive federal cost-of-living increases without incurring a corresponding decrease in the state supplement benefits.

AN ACT CONCERNING THE EXPENDITURES OF THE DEPARTMENT OF SOCIAL SERVICES This is one of the "budget implementer" bills. It is 117 pages long and has 104 separate sections. One section is worth mentioning: Section 56 prohibits towns from treating DMHAS community residences that house six or fewer persons receiving mental health or addiction services and necessary staff persons paid for or provided by the Department of Mental Health and Addiction Services in a manner different from any single family residence. This language is similar to anti-discrimination language that allows DCF and DMR to have community residences in towns without having to fight for the right to live in the community.

AN ACT CONCERNING VOTER REGISTRATION, CERTAIN NOMINATING PROCEDURES, CAMPAIGN ACCOUNTABILITY, A VOTER GUIDE, PUSH POLLING AND ELECTRONIC VOTING MACHINES. To require any new voting machine to be constructed so as to produce an individual, permanent, voter-verified paper record for each elector casting a vote on the machine.

AN ACT CONCERNING REVISIONS TO THE DEPARTMENT OF MENTAL RETARDATION STATUTES. To extend benefits to Department of Mental Retardation self-advocates, update the birth-to-three local interagency coordinating council statute and make technical changes to the Department of Mental Retardation ombudsman and the State of Connecticut-Unified School District #3 statutes. To require the Office of Protection and Advocacy for Persons with Disabilities and the Department of Mental Retardation to develop and implement an updated agreement on how they will investigate allegations of abuse and neglect against people with mental retardation and provide them protective services.

AN ACT CONCERNING HOSPITAL PATIENTS' RIGHTS. To establish a patients' bill of rights for any person admitted as a patient to any hospital in the state.

AN ACT CONCERNING THE EMERGENCY USE OF CARTRIDGE INJECTORS. To broaden the scope of immunity from liability for negligence for the emergency use of cartridge injectors under the Good Samaritan law and to require before or after school programs, day camps and day care facilities to provide staff trained in the use of cartridge injectors.

AN ACT IMPLEMENTING THE RECOMMENDATIONS OF THE LEGISLATIVE PROGRAM REVIEW AND INVESTIGATIONS COMMITTEE RELATING TO

POPULATIONS IN STATE ELDERLY AND DISABLED HOUSING PROJECTS. To provide an inventory of accessible housing units and services for the elderly and disabled persons, and provide funding for additional units for these residents.

AN ACT CONCERNING THE APPOINTMENT OF TEMPORARY CONSERVATORS. To revise the procedures for appointing a temporary conservator. This bill restricts the powers of temporary conservators and requires additional court oversight of their activities. It restricts the probate court's authority to appoint them and requires it to hold a hearing within 72 hours of making an ex parte (without advance notice and a hearing) appointment.

AN ACT CONCERNING MINOR REVISIONS TO THE EDUCATION STATUTES. The bill also expressly requires local and regional boards of education that loan assistive devices to public school students to do so for free, and allows boards to prescribe rules and regulations for the care and use of the devices. The same requirements already apply to books, supplies, material, and equipment for school instructional needs. Under current law and the bill, an "assistive device" is a customized, modified, or off-the-shelf item, product system, or piece of equipment that people with disabilities can use to increase, maintain, or improve their functional capabilities.

AN ACT CONCERNING THE PENALTY FOR CRUELTY TO PERSONS. To ensure that a person who abuses another person who is elderly, blind, disabled or mentally retarded receives appropriate punishment. This bill sets graduated penalties for the crime of cruelty to persons, which is currently punishable by a fine of up to \$ 500, imprisonment for up to one year, or both. It imposes stiffer penalties for more serious, intentional misconduct.

AN ACT MAKING PERMANENT THE ACQUIRED OR TRAUMATIC BRAIN INJURY GROUP HOME PILOT PROGRAM. To establish the acquired or traumatic brain injury group home project permanently.

AN ACT CONCERNING THE STATE'S LONG-TERM CARE POLICY. To improve long-term care in the state by providing that the state's long-term care plan shall be guided by the principle that individuals with long-term care needs shall have the option to choose and receive long-term care in the least restrictive, appropriate setting.

The Bulletin editors thank OP&A's Beth Leslie for supplying the above information. To receive a copy of her final report on the outcome of this year's session of the State legislature write to at beth.leslie@po.state.ct.us.

Federal Legislative Update

The U. S. Congress will adjourn for the July 4th recess on July 1 and be in their home districts through July 11. This is a good time to contact your legislators about what is important to you.

Update on P.A.T.H.S. Forums and Meeting Dates
(Plan for the Achievement of Transportation Coordination in Human Services)

As reported in last month's issue of "The Bulletin," the University of Connecticut Center on Disabilities, under a grant from the Council on Developmental Disabilities, is sponsoring a series of forums on transportation. Two successful forums were held Groton and Manchester. There will be four more forums in July and August in Bridgeport, Torrington, Newington and Hamden.

Thursday, July 14, 10:00 – 12:30, Torrington, Northwest Chamber
Co-sponsors: WeCAHR, Independence Northwest, Litchfield ARC

Tuesday, July 19, 1:00 – 3:30
Newington Senior & Disabled Center
Co-sponsor: Independence Unlimited

July 28, 4:45 – 7:00
Miller Hamden Library/Senior Center, Hamden

August 16, 1:00 - 3:30 North Branch Library Community Center, Bridgeport
Co-sponsor: Disability Resource Center of Fairfield County

Jayne Kleinman, Project Coordinator, is interested in hearing from people with disabilities who use various local bus services and specialized transportation services, in order to help shape the DOT State Action Plan for a coordinated human service transportation system. Interested parties are invited to contact Jayne at jkleinman@uchc.edu, or call her at 860-679-1575.

OTHER TRANSPORTATION NEWS

Federal Transit Administration Releases Report On Coordinated Human Service Transportation

On June 13, the National Council on Disability (NCD) released its report "The Current State of Transportation for People with Disabilities," stating that improvements have been made in transportation for people with disabilities, but more remains to be done. The report was developed with the input of individuals with disabilities and transportation professionals from around the country.

According to NCD the purpose in undertaking this project was to develop a better understanding of access to transportation and mobility for people with disabilities, including access to traditional public transportation systems, private transportation services, alternative transportation initiatives, and the pedestrian environment; to identify transportation barriers as well as promising practices and models; and to develop

recommendations in keeping with the goals of President Bush's New Freedom Initiative to "expand transportation opportunities for people with disabilities."

The report highlights industry best practices and successful initiatives that can serve as models for communities for enhancing transportation and mobility for people with disabilities. This report also sets forth a variety of recommendations for service improvements and for additional research that will lead to greater options for the six million Americans with disabilities who have difficulties obtaining the transportation they need to live independent and productive lives.

Among the problems noted in the report: buses sometimes leave commuters with disabilities waiting at stops; many drivers are not trained in how to handle wheelchairs; bus drivers do not always announce stops; major gaps exist for those who live in rural areas or rely on paratransit — a supplemental system of transporting people from their home to work, appointments or transit centers. The ADA requires public transportation needs to be accessible to people with disabilities, but it doesn't address rural areas that don't have public transportation. For more information go to www.ncd.gov.

“United We Ride” Annual Report Released

Under the leadership of the Federal Transit Administration (FTA) of the U.S. Department of Transportation, the Civil Rights Division of the U.S. Department of Justice is working in collaboration with federal agencies from across government to enhance a streamlined approach to human service transportation service delivery. There are 62 federally funded programs under FTA, collectively serving senior citizens, low-income individuals, and people with disabilities. In implementing Executive Order 13330, signed by President George W. Bush on February 24, 2004, the Interagency Coordinating Council on Access and Mobility (CCAM) has been established and has been working to minimize duplication of services, to promote collaboration across funding streams, and ultimately to facilitate a seamless approach to human service transportation that covers the three named constituencies.

On May 24, 2005, Transportation Secretary Norman Mineta announced the release of its 2005 Annual Report under this coordinated initiative called "United We Ride." To view the full report, read more about coordinated transportation, and see the text of the Executive Order, visit: <http://www.UnitedWeRide.gov>

Help Wanted: Meeting Assistant

The Connecticut Council on Developmental Disabilities is looking for a person to serve on a per diem basis as a Meeting Assistant to help Council members with developmental disabilities at Council meetings and events.

The Meeting Assistant will help one or more Council members with developmental disabilities organize Council meeting materials, understand issues and generally participate in Council decision-making. The Meeting Assistant may also meet with one or more Council members with developmental disabilities prior to Council meetings to help them prepare for Council meetings and events.

Council meetings are generally held from 10 a.m. to 2 p.m. on the 2nd Tuesday of January, March, June, September and November. An overnight Retreat is usually held on a Friday-Saturday in May, and Council Members also participate on one of the Council's standing committees and attend at least one site visit evaluation of Council grantees during the year. Meeting Assistants will be paid at the per diem rate of \$50 per weekday. To apply to be a Meeting Assistant send a letter expressing your interest and experience that you feel is relevant to: Connecticut Council on Developmental Disabilities, 460 Capitol Avenue, Hartford, CT 06106, Attn: Meeting Assistant.

Nonverbal Learning Disorders Association (NLDA)

The Nonverbal Learning Disorders Association (NLDA) represents individuals with learning disabilities whose condition is similar but not the same as Aspergers Syndrome. NLDA encourages effective identification and intervention, fosters research, and protects the rights of learning disabled individuals. They seek to accomplish their goals through awareness, advocacy, empowerment, education, and service. The organization includes individuals with learning disabilities, their families and associates, and those who provide professional care and intervention.

NLD is a neurological disorder which originates in the right hemisphere of the brain. Assets may include early speech and vocabulary development which includes reading, spelling and verbal ability and auditory retention. Difficulties typically occur in motor skills such as visual spatial information, inability to comprehend nonverbal communication and difficulty adjusting to transitions and novel situations.

The Connecticut affiliate of the Nonverbal Learning Disabilities Association will be conducting an adult employment and advocacy conference on Nov. 12 in Hartford. For diagnosis criteria or more information contact the Connecticut affiliate of NLDA: 2446 Albany Avenue, West Hartford, CT 06117; by e-mail: NLDA@nlda.org; or by phone: 860-570-021.

“Valedictorian Has the World at Her Fingertips”

Courtney Tabor, a former participant in Connecticut's Youth Leadership Forum”, recently was named RHAM high school class valedictorian. Courtney, who is blind, has a computer called a Braille Note, provided with assistance from RHAM. In a recent article in the *Hartford Courant*, Brittany Oat describes her interview with Courtney: “With her guide dog Meeka [a graduation present] she was interviewed with a computer screen glaring from the corner of her bedroom with the instant messenger ready to be signed on. A monotone voice from the speakers tells Tabor when her friends come online ...”
[*Hartford Courant*, June 20, 2005]

Supreme Court Rules!

The Supreme Court, expanding the scope of the ADA, ruled on June 6 that foreign cruise lines sailing in U.S. waters must provide better access for passengers in wheelchairs. The 6-3 decision is a victory for disabled rights advocates, who said inadequate ship facilities inhibited their right to "participate fully in society."

"With this decision the Supreme Court has told the cruise lines that we are entitled to what every other passenger receives -- access to emergency equipment and the full range of public facilities," said Douglas Spector of Houston, one of the disabled passengers suing the cruise lines.

"The statute is applicable to foreign ships in the United States waters to the same extent that it is applicable to American ships in those waters," Justice Anthony Kennedy wrote for the majority. Kennedy noted that cruise lines need not comply with Title III of the ADA to the extent it creates too much international discord or disruption of a ship's internal affairs, under a provision of the statute that calls only for "readily achievable" modifications. "It is likely that under a proper interpretation of 'readily achievable' Title III would impose no requirements that interfere with the internal affairs of foreign-flag cruise ships," Kennedy concluded.

Historic Settlement in Nationwide Disability Discrimination Lawsuit

On June 8 the Equal Rights Center (ERC), the American Association of People with Disabilities (AAPD) and the United Spinal Association announced what is by far the largest settlement of a lawsuit challenging defects in the design and construction of multi-family housing under the Fair Housing Act and the Americans with Disabilities Act.

The settlement requires the survey of 71 apartment complexes developed by the Archstone-Smith Trust and located in 16 states around the country, which contain approximately 36,000 apartment units, about 12,000 of which are covered by the settlement. At their expense, Archstone agreed to retrofit features of the complexes that operated as barriers to the full use and enjoyment of these facilities by people with disabilities. Archstone-Smith Trust is the seventh largest developer of apartment complexes in the United States. Although surveys of the properties have not concluded, the cost of remediation is estimated to exceed \$20 million. Archstone will also pay \$1.4 million in damages and attorneys fees and litigation expenses.

The Consent Decree also requires, for the 3-year period it is in effect, that Archstone-Smith Trust will certify that its future construction of apartment complexes will comply with the accessibility requirements of the Fair Housing Act and the ADA and to educate its personnel on the design and construction requirements of those laws.

A copy of the Consent Decree is available at www.cmht.com or www.washlaw.org.

News from our Neighbor to the North

On Monday, June 13, 2005 Health and Human Services Secretary Mike Leavitt announced a new Medicaid program that will give elderly and disabled Vermont residents more options to remain in their homes and communities and out of institutions.

The Vermont Long Term Care Plan, administered under a Section 1115 waiver of current Medicaid rules, will establish a unique triage system to evaluate the appropriate type of care for enrollees who may be at risk of institutionalization. The assessment would determine what kind of services the Medicaid program would provide. Those determined to be in the highest tier of need would be offered a traditional nursing facility or whatever expanded services were needed to keep them in their own homes. Those in the second tier who need fewer or less intensive services, could still receive nursing home or home-based care, but would be served in the order of greatest need. The second tier beneficiaries would continue to receive acute care and other supportive services. The program will expand community-based services to 950 older and disabled individuals who are at risk of institutionalization but would not yet qualify for services without this demonstration.

It is hoped that the new program will provide important evidence on how to end the institutional bias in Medicaid, to allow people with a disability to live in the community when they prefer to do so, without increasing Medicaid costs.

The demonstration will include about 4,500 Medicaid recipients who are age 65 and older and adults with physical disabilities. The state will add resources each year to the long-term care system, equivalent to a minimum of 100 additional Home and Community Based slots. To assure high quality services are being delivered to all participants in the new program, a quality assurance program and an independent advocacy system, the State and Local Long Term Care Ombudsman Program, will be available to persons in the new program.

Medicaid is a state/federal partnership program that provides health care benefits to over 53 million low-income Americans including children, the elderly and persons with disabilities. Nearly \$300 billion dollars was spent on Medicaid services in 2004.

Public Support for Medicaid

Justice for All reports that the nation's Governors have their work cut out for them in convincing the public to accept fundamental changes in Medicaid.

Nearly three-fourths of individuals polled by the Henry J. Kaiser Family Foundation opposed cuts in state Medicaid programs to help balance state budgets, even though two-thirds said their state was in fiscal crisis or had major budget problems, according to the survey released June 29.

When asked about reforms similar to those proposed by the National Governors Association to trim Medicaid's runaway costs, 54 percent opposed charging higher co-payments and deductibles for services such as doctor's visits, 65 percent opposed limiting the prescription drugs Medicaid covers, and 55 percent objected to curtailing elderly people's ability to transfer wealth and assets to qualify for taxpayer-funded health care.

"This poll shows that Americans across the political spectrum value the role Medicaid plays in our health care system," said Diane Rowland, executive vice president of the foundation. "Much of the political debate surrounding Medicaid these days focuses on controlling costs, but proposals to cut funding for the program or scale back the coverage it offers do not appear to be popular with the public."

The survey also indicates that 74 percent of the public considers Medicaid a "very important" government program, behind only Social Security (88 percent) and Medicare (83 percent).

Medicaid News from Steve Gold

In order to understand the current Medicaid debate, Steve Gold has published an Informational Bulletin explaining how the program has changed since 1990. He did this so disability advocates could understand how disability-specific interests fit into the broader picture. All of the following is based on national data, but it is possible to do the same analysis for the State of Connecticut. All the data is from www.Medstat.com and from www.hcbs.org/moreInfo.php/

The disability focus is on the Medicaid's expenditures for Community-Based Long Term Care, which is only one (very small) part of the Medicaid program. In contrast are the expenditures for Institutional-based Long Term Care - those services for persons with disabilities which are provided solely in the institutions.

Back issues of other Information Bulletins are available online at <http://www.stevegoldada.com> with a searchable Archive at this site divided into different subjects.

More on Medicaid

Congress isn't the only battleground in the fight to preserve Medicaid. Several states are considering deep cuts and ambitious restructuring of state Medicaid programs. Perhaps the most critical of these is Tennessee, where Governor Phil Bredesen has proposed the largest cutback of state public health programs in the history of our nation. Governor Bredesen's plan would strip 323,000 Tennesseans of their health coverage, including 97,000 with chronic conditions and high health care costs. His plan would also saddle 396,000 enrollees, no matter how sick they are, with arbitrary limits on their health care. One concern is that some of these beneficiaries will become sicker, and some may even

die, as a result of losing coverage.

Why is this important to those of us living in Connecticut? Governor Bredesen has made no secret of his desire to export his vision of Medicaid to the rest of the nation. Although several states are considering cutting and "restructuring" Medicaid, Bredesen's plan to reform TennCare (Tennessee's state Medicaid program) is so far the most far-reaching and would do the most harm to a state's Medicaid recipients. Furthermore, Bredesen is touting his plan as a model for national Medicaid reform. The Governor's vision of national Medicaid reform would impose onerous cost-sharing requirements and arbitrary limits on health care services for beneficiaries, among other things.

To find out more about what's happening in Tennessee, visit the Tennessee Health Care Campaign's Web site at www.tennicare.org/

AND MEDICARE NEWS

Medicare – Want to Be Heard?

“Are you struggling to pay for your prescription drugs or get the health care you need?” Work with the Medicare Rights Center to bring your story to the ears of policymakers, the press and the public in an effort to expose the shortcomings of the American health care system. To learn more about how to be heard, go to www.medicarerights.org/hiddenlives.html.

Medicare In-Home Restriction “puts people in prison”

An article dated June 23 from *Asclepios: Your Weekly Medicare Consumer Advocacy Update*, reports that the Centers for Medicare and Medicaid Services' (CMS) have an antiquated interpretation of “in the home” that turns people's homes into prisons. “CMS's interpretation is out of step with the past 30 years of changes in disability law and policy.” To demonstrate this point, the update includes the following examples:

- the Rehabilitation Act of 1973, which prohibits discrimination against people with disabilities by executive agencies, programs receiving federal financial assistance and the U.S. Postal Service;
- the 1990 Americans with Disabilities Act (ADA), which “provide[d] a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities”;
- The U.S. Supreme Court's 1999 landmark ruling in *Olmsted v. L.C.*, which found that the ADA requires the most integrated community-based settings for individuals with disabilities whenever possible. (The Court had ruled: “unjustified isolation is properly regarded as discrimination based on disability”); and finally
- President Bush's New Freedom Initiative, which promotes opportunities for Americans with disabilities to learn and develop skills, engage in productive

work, make choices about their daily lives and participate fully in their communities.

Frustrated after years of CMS's resistance, a wide array of consumer groups are now preparing a lawsuit challenging the 'in the home' requirement. Of the 1,019,000 people with Medicare classified as permanent wheelchair users between 1994 and 1997, 14 percent—roughly 140,000—would have been good candidates for a more functionally advanced wheelchair than Medicare's 'in the home' standard would allow. The groups will encourage CMS to modify its interpretation of the "in the home" language to better suit the "real-life" needs of people with mobility impairments.

The Medicare Rights Center (MRC), which authored the article, is the largest independent source of health care information and assistance in the United States for people on Medicare. A national nonprofit founded in 1989, MRC helps older adults and people with disabilities get good, affordable health care. For more information write them at: MRCAdvocacyUpdate@medicarerights.org.

Medicare Demonstration Project for Day Care Services

The Centers for Medicare & Medicaid Services (CMS) have announced plans for a demonstration project that will allow some Medicare beneficiaries to receive medical adult day care services under the home health benefit. According to CMS "this demonstration will permit Medicare to assess whether providing medical adult day care services through the home health benefit will improve patient outcomes and provide the opportunity for some respite for beneficiaries' caregivers." Home health agencies will partner with medical adult day care facilities to provide adult day-care services to Medicare beneficiaries as a substitute for a portion of home health services that would otherwise be provided in the home. The demonstration is authorized by Section 703 of the Medicare Prescription Drug, Improvement and Modernization Act of 2003. [Medicare News, June 2005]

Alert from CCD on Social Security

The Consortium for Citizens with Disabilities (CCD) in Washington, DC has created a Task Force on Social Security, with the goal to prevent privatization of this critical program. Here are excerpts from an action alert, which CCD distributed June 28th:

The Issue: The President and others are aggressively promoting changes in Social Security to include private accounts to replace guaranteed benefits. Both the House and Senate have been holding hearings about Social Security reform. The next few months are critical for the outcome of these proposals.

Background: CCD is planning grassroots activities to oppose privatization. To ensure success, we will work closely with our local chapters and members and other interested groups and coalitions that oppose privatization. For more

information about how various changes would affect people with disabilities, be sure to read the CCD Fact Sheets and PowerPoint presentation posted at www.c-c-d.org, click on Social Security Task Force.

What You Can Do: During the Fourth of July recess, you may see Members of Congress at public events, parades, informal gatherings or in their district offices. The recess began Friday, July 1 and runs through Sunday, July 10. This is an excellent time to talk about how the Social Security program must continue to provide guaranteed benefits for eligible people with disabilities and their family members.

The Message: Any changes in the Social Security program must follow four principles:

- Preserve it as social insurance for everyone who is eligible.
- Keep its current structure based on payroll taxes that guarantees monthly benefits adjusted for inflation.
- Protect children and spouses - both with and without disabilities who depend on Social Security benefits when their worker spouse or parent retires, dies or becomes disabled.
- Restore its financial stability to meet the future needs of eligible individuals.

CCD's Social Security Task Force Grassroots Coordinator is Rhoda Schulzinger, and she can be contacted at: rschulzinger@verizon.net

Californians Defeat Assisted Suicide Bill

Californians with disabilities and many others opposing AB 654, the bill to sanction doctor-assisted suicide in California, hailed its defeat on Thursday, June 2. This action all but ends the imminent threat of doctor-assisted suicide in California.

Following the bill's defeat, proponents announced they would try to amend the assisted suicide language into an Assembly bill already in the State Senate. The amended bill was expected to die in the Senate.

"At the end of the day proponents couldn't find 20 votes to publicly support this bill," noted Laura Remson Mitchell of the California Disability Alliance. "When legislators realized this bill was not about the right to die, but was in fact about undermining our healthcare system and doctors assisting in their patients' suicide, support evaporated as it always has."

VA Resources and Benefits Available

A recently released Directive from the Veteran's Administration spells out the vast array of VA resources and benefits available to any veteran with a spinal cord injury or disease. The Directive sets the guidelines for training of VA staff who work with SCI patients, the

staffing, composition, and training competencies of staff who work at the 20 VA SCI Centers around the country, and the qualifications for members of SCI Teams at every VA Medical Center. The Directive also describes services available to people unable to get out of their homes, durable medical equipment, yearly evaluations, training of spouses/care-givers, and much more. To read VA Directive 1176.1, go to "Google" and type in "VHA Directive 1176.1".

Need a Computer?

The Computers to Work program offers pre-owned computers to people with disabilities. All computers are installed with a full suite of Microsoft Office, including Power Point, Word, and Excel. To qualify for a system, please submit a letter detailing your disability and whether you plan to use your computer for educational or employment purposes, to: Open Doors Organization, Attn.: Judson Paschen, 2551 N. Clark Street, Suite 301, Chicago, IL 60614 (e-mail: jud@opendoorsnfp.org). Open Doors is dedicated to creating a society in which all persons with disabilities have the same consumer opportunities as those without disabilities says Founder and President Eric Lipp. "We aspire to teach businesses how to succeed in the disability market, while simultaneously empowering the disability community."

Nominations of Athletes with Disabilities Invited for Casey Martin Award

To honor professional golfer Casey Martin's extraordinary achievement and to communicate its significance for others facing barriers to participation in sports, Nike, Inc. has created the Casey Martin Award to recognize achievements made by individuals with disabilities fighting for the right to compete in sports. The application deadline is July 8, 2005.

Each year Nike will honor an individual for their courage in pursuing their sport of choice on or off the field despite challenges or barriers, whether physical, mental, societal, or cultural. Along with the individual recognition, the recipient will be able to direct a grant award of \$25,000 to a qualified nonprofit organization of his or her choice. To be eligible to receive the nonprofit award, the recipient organization must be a 501(c)(3) entity in good standing with the IRS. Recipient organizations can be local, national, or international in scope and provide direct service, education, or public policy support to individuals or organizations serving the disabled community. For complete nomination guidelines and an application form, as well as information on previous award recipients, see the Nike Web site: www.nike.com/.

Barrier Free Travel

For information about online booking for people with disabilities and for access to news, resources and industry updates go to at BarrierFreeTravels.com. Candy Harrington is the editor of *Emerging Horizons* and the author of *Barrier Free Travel: A Nuts and Bolts Guide for Wheelers and Slow Walkers*.

Religious Participation

The National Organization on Disability's Religion and Disability Program announced its updated seventh edition of *That All May Worship: An Interfaith Welcome to People with Disabilities*. This interfaith guide offers common sense advice to congregations, seminaries and national faith groups on becoming more accessible and welcoming to people with disabilities. "Where There Is No Vision, the People Perish: Interfaith Disability" will be held as a pre-summit on September 20 in Washington, DC. It will precede the national disability summit of the Alliance for Full Participation, a collaboration of ten national organizations and networks that work in the area of developmental disabilities, which will take place on September 21-23. The pre-summit will allow faith-based groups to discuss issues that will be presented in the main summit, as well as the role that religious groups play in providing support for people with disabilities and their families. Go nod.org/religion for more information.

From Australia – A Learning Device for People who are Deaf

When the Victorian College for the Deaf created Australia's first storybook CD ROM for sign language speakers, they had no way of telling that the interactive device would start a technology boom in able-hearing schools. The books, devised to overcome literacy problems in deaf students, have been adopted across Victoria. Produced as videos, CDs and DVDs, they use a three-way split screen with animated pictures appearing alongside the sign-language storyteller with English text, voice-over, music and sound effects.

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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.