

# *Disability Advocacy Collaborative Bulletin*

*Disability Rights is a Civil Rights Issue*

*January 2005*

If you want something to appear in the next edition or have an article you would like us to include please send it to me at [jayne@kleinmanconsulting.com](mailto:jayne@kleinmanconsulting.com) or Jayne Kleinman, 55 Corrigan Ave., Meriden, CT 06451, 203-238-9391.

**ADDRESS CORRECTIONS AND REMOVALS:** If you are not interested in receiving this information or you would like this information sent to a different e-mail address, please e-mail Jayne Kleinman at [jayne@kleinmanconsulting.com](mailto:jayne@kleinmanconsulting.com) with your request, or simply reply to this message.

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## Calendar of Events

<b><i>Date</i></b>	<b><i>Event</i></b>	<b><i>Location</i></b>	<b><i>Sponsor</i></b>	<b><i>Contact</i></b>
Jan. 7	Visitability Teleconference	Teleconference		(785) 233-4572 or 1-800-711-8914 or <a href="mailto:jeklund@tilrc.org">jeklund@tilrc.org</a>
Jan. 11 – 11 am - 1 pm	PPT Workshop (see article below)	MARC Offices – Portland	MARC Community Resources	Laura Hastillo – 860-342-0700 ext 14
Jan. 12 10 – 11 am	PJ case public comment period (see article below)	Seminar Hall – Rensselaer University		Marlene – 860-713-6926
Jan. 15-16	Wheelchair Basketball Tournament (see article below)	HSC Comm. Center – New Britain	CT Spokebenders	skosloski03@comcast.net
Jan. 14 & Feb. 5 9:30 am - 12:30 pm	Tax Information Workshops (see article below)	NEAT Marketplace, 120 Holcomb St., Hartford	NEAT Marketplace	Neatmarketplace.org
Jan. 19 10:00 am – 2:30 pm	Kids’ Mental Health Day (legislative initiatives to support children’s mental health)	State Capitol, Room 310	FAVOR, Inc.	860-563-3232 <a href="mailto:mcole@favorct.org">mcole@favorct.org</a>
Feb. 7 - 10 am	Disability Awareness Forum (see article below)	Legislative Office Building	DD Network	Mary Eberle 860-679-1500 or <a href="mailto:meberle@uchc.edu">meberle@uchc.edu</a>
Feb. 15 – 10 pm	On a Roll on PBS (see below)	10 pm on PBS (television)	PBS (check local listings)	
Feb. 26 – March 2	ADAPT National Action	Washington, DC	ADAPT	512/442-0252 or 303/733-9324
June 3-4	Moving through Life Changes, Self Determination	Farmington Marriott	DD Council, DMR, and FAVOR	Email: <a href="mailto:yvette.johnson@po.state.ct.us">yvette.johnson@po.state.ct.us</a> - (860) 418-8709
July 25-28	Youth Leadership Forum	UConn campus - Storrs	CT YLF	<a href="http://ctylf.org">ctylf.org</a>

## **Collaborative Initiative Begins**

The Disability Advocacy Collaborative is officially off and running, starting January 1, 2005 with a grant of \$27,970 from the DD Council. Stan Kosloski and Jayne Kleinman are leading the charge.

The ultimate goal is to create a strong, unified cross disability network that will give people with disabilities and families a more powerful voice in Connecticut and beyond. The two year plan includes offering cross disability self-advocacy workshops in 5-6 regions of the state in 2005, to lay the foundation for a disability “convention” in the fall of 2006 when Connecticut will elect (or re-elect) a Governor, Attorney General, and Secretary of State.

During January and February the Collaborative will be developing a comprehensive contact list, recruiting individuals to be on a Steering Committee, obtaining collaborative agreements from disability advocacy organizations, researching self advocacy training curricula, and lining up local leaders in the various regions of the state.

Any individual or group who has not yet expressed an interest in being a part of the initiative should contact Stan Kosloski (860-679-1513, [skosloski@uchc.edu](mailto:skosloski@uchc.edu)) or Jayne Kleinman (203-238-9391, [jayne@kleinmanconsulting.com](mailto:jayne@kleinmanconsulting.com)). Opportunities for involvement include being a part of the project’s Steering Committee, being a Resource Person for the project, or being involved in a leadership role in the community or region in which you live.

The UConn Center on Disability is providing substantial in-kind support for this important initiative.

## **General Assembly Convenes**

The 2005 session of the General Assembly convened on Wednesday, January 5<sup>th</sup>, beginning a new year that promises to be dramatically different than 2004 when the scandal surrounding former Governor John Rowland dominated the news. This is the year of the long session (January to June), and the Disability Advocacy Collaborative’s Bulletin will do its best to keep you informed of developments. Improved community based services for individuals with psychiatric disabilities will be one key issue on the table (see item below). To connect directly with the state General Assembly, go to [www.cga.ct.gov](http://www.cga.ct.gov)

Your support is needed to preserve and enhance supports for people with disabilities and their families. Call your legislators today!

Senate Democrats: 1-800-842-1420  
House Democrats: 1-800-842-1902  
Senate Republicans: 1-800-842-1421  
House Republicans: 1-800-842-1423

## **Hartford Courant Urges Governor and Legislature to “Keep the Promise”**

“Connecticut's failure to provide adequate prevention, diagnosis, treatment and support for the growing number of residents seeking help for mental illness has cost the state plenty. It has cost many who suffer from these illnesses even more.

Lt. Gov. Kevin Sullivan is dead right in asserting that Connecticut does not need more studies to determine that its mental health system is in crisis. It needs action. Very little has happened in the four years since a blue-ribbon task force made recommendations for fixing the system. With too few services available in their communities and too few treatment options, adults and children with mental illness continue to be warehoused in emergency rooms, hospitals, jails or nursing homes at public expense. Many go untreated and end up in homeless shelters and on the street. What's more, only a fifth of those who need treatment actually get it.

The situation has never been more urgent. The state Department of Correction reports a 40 percent increase in prisoners with mental illness in four years. They now make up 16 percent of the prison population and, at \$44,000 a year per head, are serving longer sentences due to lack of community alternatives.

Adults with serious mental illnesses end up in nursing homes for the same reason: there are few alternatives. This care is not only expensive, but inappropriate. Timely treatment can mean the difference between recovery and lifelong disability, yet young adults with mental health problems can wait up to two years for proper care.

At the request of Gov. M. Jodi Rell, Mr. Sullivan and a cabinet of experts have put together a comprehensive blueprint for repairing and rebuilding the system. It covers every facet, from education to treatment to supportive housing, complete with estimated costs and suggestions for how to pay for it. This intelligent strategy merits more than token attention from the legislature.

Some will balk at the estimated cost - \$34.5 million in the first year and up to \$64.6 million in the fourth and final year. And it may not be realistic to tackle it all at once. But as Mr. Sullivan points out, the net cost would be drastically lowered if the state takes advantage of a federal program that offers states money to provide services that rehabilitate.

It's hard to understand why, but Connecticut, according to Mr. Sullivan, is the only state in the nation that has failed to take full advantage of the millions available for this worthy purpose. In a budget discussion with The Courant's editorial board recently, Mrs. Rell implied that applying for federal matching funds would require the state to spend more, something she doesn't see happening because of a projected \$1.3 billion deficit.

The truth is that the state already pays out of pocket for rehabilitative services that it could be reimbursed for. It also spends far too much on extravagantly expensive, ineffective care of the mentally ill. If some of that money were re-invested in the priorities Mr. Sullivan has outlined, the state would benefit in the long run.”

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## **The Crisis of America’s Uninsured**

“The Crisis of America’s Uninsured”, a photo exhibit of personal accounts of being without health insurance, will be on display from January 4 – February 14 in the Legislative Office Building in Hartford. Consisting of twenty oversized black and white photographs by award-winning photojournalist Ed Kashi, the exhibit also includes accompanying text by writer Julie Winokur.

The photo exhibit is presented by the Health Care for All Coalition.

## **State Building Code up for Review**

The drafts of the 2005 State Building Code and the 2005 State Fire Safety Code have been approved by the Office of Policy and Management and by the Governor's Office. A public hearing has been scheduled for Friday, February 18, 2005 at 9:00 AM at the Police Academy in Meriden at which time written and oral public comment will be accepted. Drafts of the documents should be available on the DPS website shortly: [www.state.ct.us/dps/dfebs](http://www.state.ct.us/dps/dfebs) - follow the links to OSFM and OSBI.

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## **DD Network’s 2<sup>nd</sup> Disability Awareness Forum**

Allen Bergman, President and CEO of the Anixter Center in Chicago, will be the featured speaker at the DD Network’s 2<sup>nd</sup> Disability Awareness Forum on February 7, 2005. The event will begin at 10 am at the Legislative Office Building in Hartford. The main issue to be discussed is the use of Medicaid waivers to support community living for individuals and families with disabilities. The DD network, which includes the University of Connecticut Center on Disabilities, the DD Council, and the Office of Protection and

Advocacy, is joined by co-sponsors state Senator Mary Ann Handley and state Representatives Peter Villano, Lile Gibbons and Mary Ann Carson.

### **PPT Workshop in Portland**

MARC Community Resources is offering a workshop for parents and caregivers of children who receive special education services on Tuesday, January 11, 2005. The workshop will take place at the MARC offices at 12 Fairview Street in Portland from 11:00 am – 1 pm. Lunch will be provided. There is a registration fee of \$10. For more information call Laura Hastillo at 860-342-0700 ext. 14.

### **EAP Interested in Hearing from Parents**

An Expert Advisory Panel, created pursuant to the settlement of the P.J. v. State of Connecticut lawsuit, is interested in hearing from parents, professionals, and other interested parties who have experience with special education programs and services in Connecticut. The public comment opportunity will take place at the Rensselaer University Seminar Hall on Wednesday, January 12, 2005 from 10:00 – 11:00 am. Rensselaer University is located on Windsor Street in Hartford. For more information call Marlene at 860-713-6926.

The lawsuit was filed a number of years ago in order to address the unlawful segregation of students with intellectual disabilities in “special” programs. It was settled last year.

### **Bill Dombroski Invitational Wheelchair Basketball Tournament**

The first Bill Dombroski Wheelchair Basketball Tournament will be held the week-end of January 15-16 at the Hospital for Special Care Community Center (the former Mary Immaculate Academy) at the corner of Corbin Avenue and Osgood Avenue in New Britain. Four out-of-state teams will join the Connecticut Spokebenders in competing for the 1<sup>st</sup> place trophy. The Spokbenders kick off the tournament at 9 am Saturday against Temple University, and also have games at 2:15 pm and 5:45 pm Saturday and 12:30 pm Sunday. There is no admission charge.

### **New Federal Budget Weakens Housing Support**

The new federal budget, adopted in November, severely cuts just about every federal housing program, signaling a further worsening of opportunities for those seeking affordable housing. Although Section 8 funding was increased by 3%, and the administration’s plans to block grant Section 8 were beaten down (for now), there were a number changes that will be harmful for people with disabilities and other low income individuals:

- operating subsidies for public housing cut by 9%
- HOME funding reduced by 7%

- most other housing programs cut by 4%
- harmful policy changes adopted that affect residents with Section 8 vouchers
- “dollar based” budgeting adopted, wherein housing authorities get a fixed amount of money rather than a fixed amount of vouchers, creating strong incentives to concentrate tenants in poor neighborhoods with low rents
- housing authorities limited in financial flexibility to address local needs, while HUD is given greater flexibility to change Section 8 rules

The action by Congress does not block grant Section 8 at this time, but that is clearly the direction the current administration plans to move the program.

## **Connecticut Native Bob Williams Issues Plea for “Simple Decency”:**

### **SAVING MEDICAID NEEDS TO BE ABOUT MORE THAN SETTling FOR THE STATUS QUO!**

Progressives and Americans of good will from across the spectrum should heed Bill Vaughan's clarion call to resist [President] Bush's attempt to destroy Medicaid program. Not only is it the largest publicly financed health coverage program in the U.S., Medicaid also can offer the most comprehensive prenatal, well child, acute care and long term services benefits package benefits package of any public or private plan in our nation. As such, it's an example of the kind of coverage that as progressives we should be working to make available all our people, including the poor, the rich and everyone in between.

Medicaid is not without its flaws, however. One of these is what is called its "institutional bias." Simply put, Medicaid spends **far more** money institutionalizing children, adults and older persons with disabilities than it does to provide the needed services and supports to enable them to live in their own homes and communities. Some progress has been made in remedying such gross inequities. But, nationally about 70% of Medicaid long term care funds are spent on nursing homes and other institutions. This is despite the fact the vast majority of people with severe disabilities on Medicaid, including many older people with Alzheimer's disease, live in the community.

A recent study found that of the roughly 3 million people with disabilities living in the community who need assistance with eating, bathing and dressing each day as many as one million do not get all the help they need. 80 percent said they could not get dressed everyday. 30 percent soiled themselves because they had no other choice. And, more than one in 10 said they had gone to bed hungry at least once in the last month for lack of help ( **LaPlante, M.P., Kang, T., Kaye, H.S., & Harrington, C. (2002). Unmet need for personal assistance services among adults living at home. San Francisco, CA: Disability Statistics Center.**

[http://www.pascenter.org/publications/publication\\_home.php?id=23](http://www.pascenter.org/publications/publication_home.php?id=23)

Those in nursing facilities fare little better and often far worse than this. In fact, one federal investigation found that over 90% of the nursing homes provide their residents with less than 3 hours of assistance with essential tasks like eating, bathing, dressing,

going to the bathroom, etc., each day (**U.S. the Department of Health and Human Services, Report to Congress: Appropriateness of Minimum Nurse Staffing Ratios In Nursing Homes. 2000**

<http://www.cms.hhs.gov/medicaid/reports/rp700hmp.asp?>).

Talk about throwing good money after bad.

As someone with a severe disability who has always gotten the assistance I need to live in the community all my life, and the son of a mother with dementia that died in a nursing home not because she "needed to be there" but because there was simply no other alternative, I am here to say that we must do better. This is why it's so disheartening to hear Vaughan and others cite the financing of nursing home care as the prime reason why we must preserve Medicaid "as we know it." There is much about the program that is vital and should be preserved and strengthened. But, there is likewise much about it that simple justice demands be changed. Ridding the program of its institutional bias once and for all tops this list.

Senators Tom Harkin and the late Paul Wellstone have led the good fight to do this by introducing legislation known as the Medicaid Community Attendant Services and Supports Act (MiCASSA) in every Congress in the last decade. Yet, most in the progressive community have given the bill tepid support at best, preferring instead to endorse the status quo and thus, the needless institutionalization, segregation and marginalization of millions Americans with disabilities of every age, race and region of our country. We can and must strive to do better.

Bob Williams  
Director, Advancing Independence  
Washington, DC  
[bobrw@bellatlantic.net](mailto:bobrw@bellatlantic.net)

### **“Join the Medicaid Debate, Challenge Governors”**

[A discussion by Steve Gold follows the Bob Kafka statement.]

**Bob Kafka of ADAPT, [bkafka@juno.com](mailto:bkafka@juno.com), writes:**

### **“If Not Now - When? Medicaid Reform in the 109th Congress!”**

The Community First! Resolution the Governors will be considering at the National Governors Assn (NGA) Winter Conference in DC in February will have major implications for the future of Medicaid in our country. What the NGA supports/opposes will influence Congress and the Bush Administration.

Governor Rendell of Pennsylvania has introduced the resolution that has the support of ADAPT and other national advocacy groups in the country. ADAPT asks for all national organizations to support the Community First! Resolution. It is also important that all the

Governors support the Community First! Resolution and the principle of the ADA's "most integrated setting." Please contact your Governor's office and ask for his/her support.

The central themes of the Community First! Resolution are: 1. support for Federal legislation to end the institutional bias in the long term care system; 2. implementation of the Olmstead decision so no individual is forced to live in a nursing home or other institution because of the lack of home and community services; and 3. Medicaid reform should not result in block granting or losing any of the current Medicaid protections

**Steve Gold, [stevegoldada@cs.com](mailto:stevegoldada@cs.com), writes:**

**YOUR GOVERNOR AND "REFORMING" MEDICAID - THE BATTLE  
CONTINUES - Information Bulletin #75 12/04**

The NY Times front page story on 12/26/04 was entitled "Governors Unite in Medicaid Fight." In all likelihood, this will be the disability fight for 2005! While the Administration keeps hinting about "block grants" and super waivers, the Governors are singing a very different tune. They are telling the federal administration that "reform should not be part of a federal budget reduction process, especially if it does nothing more than shift additional costs to states." While we could agree with that, there's more.

The Governor of your State is an important player, and therefore your disability community **MUST** know the facts and be ready to hold your Governor accountable. Here are the Governors' arguments: 1. During the past four years, Medicaid's increases are due to increases in the number of eligible persons. 2. Medicaid pays for 70 % of all persons in nursing homes. 3. Persons who receive Medicare and Medicaid, known as the "dual eligibles," account for 42% of all Medicaid's expenditures.

These three issues **DIRECTLY** impact on persons with disabilities. Our responses?

1. I do not know if the number of persons with disabilities has increased that much over the past four years. Given the SSI numbers, I do not see it. Also, since the economy has gone down and as businesses continue to cut off health benefits for their workers and retirees, those probably are the reasons for the increased number of eligibles.
2. You can sure tell your Governor how to save substantial Medicaid money that they are paying to nursing homes. Let the consumer decide whether they want Medicaid to pay **LESS** and receive the same services in the community or pay **MORE** in the nursing homes. Your Governors know this, but the nursing home lobby has historically been big financial contributors to the election campaigns! If your Governor truly wanted to save substantial Medicaid funds, move the money from the nursing homes to the community.

**FACT:** In FY 2003, nationally Medicaid spent nearly \$ 45 billion on nursing home care versus \$ 4 billion on home and community based waivers for both the elderly and persons with disabilities (this excludes individuals with intellectual disabilities who normally are

not NH eligible.) [If you want this data for your state, email me at [stevegoldada@cs.com](mailto:stevegoldada@cs.com) and tell me your state.]

3. Because Medicare is 100% federally funded, and Medicaid is paid by both the federal and state governments, it's obvious why the Governors want the benefits for dual eligibles to be completely funded by only the federal government.

However, the real dual eligible issue is that they cost the States because Medicare does not pay for long-term care! The disability community must be careful that we do NOT want the only change to be WHO pays for nursing homes. We want persons to live in their own homes and communities and receive whatever they need there - whether payment is 100% federal or shared federal and state.

#### **What Advocates Should Do:**

1. Join ADAPT in Washington, DC. 2/25 -3/1 when the National Governors' Association will meet to discuss your future! Medicaid reform is their number one issue. For more information about the ADAPT action, call 512-442-0252 or 303-733-9324.

2. Get to your Governor NOW. Demand a meeting directly with the Governor - not bureaucratic intermediaries. Tell your Governor about specific folks who want to live in their community and tell your Governor to stop wasting Medicaid funds on expensive and unwanted nursing homes. Tell them to [support] a Money Follow the Person initiative and develop true community based services.

3. Know the facts about your State and its Medicaid funding. Don't let your Governor's office talk around you. We have the facts on our side!!

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. To contact Steve Gold directly, write to [stevegoldada@cs.com](mailto:stevegoldada@cs.com)

### **Do You File a Tax Return?**

Do you file taxes? Do you or a dependent have a disability? Do you have questions on what is deductible? Attend this workshop and get the advice of a tax expert! You'll file the smartest tax return ever!

The New England Assistive Technology Marketplace will be presenting "A Tax Information Workshop" for individuals with disabilities and their families. Armand Legault, a retired tax audit supervisor for the Connecticut Department of Revenue Services, will offer a workshop on Friday, January 14, 2005 from 9:30 am to 12:30pm and Saturday, February 5, 2005 from 9:30 am to 12:30pm. Registration is required. Please call: 860-243-2869 or 866-526-4492 or go to [www.neatmarketplace.org](http://www.neatmarketplace.org)

Workshop Topics will include: How to claim impairment-related work expenses for a person with disabilities, How to get tax breaks associated with age or disability, How to

claim deductions for medical expenses, What are your tax obligations as a Personal Care Assistant (PCA) employer, How to claim \$1000 property tax exemption, and What deductions are possible for adapted vehicles The workshop will be held at: The NEAT Marketplace, 120 Holcomb Street, Hartford, CT 06112 (corner of Holcomb & Coventry Streets.

### **Nationwide Study of Caregiver Support Services and Web-Based Database Released**

The Family Caregiver Alliance, in collaboration with the National Conference of State Legislatures, has released *The State of the States in Family Caregiver Support: A 50-State Study*. The study - a two year project - is said to be the first to examine publicly funded caregiver support programs in all 50 states and the District of Columbia since the passage of the landmark National Family Caregiver Support Program (NFCSP) in 2000. Findings show that every state now offers at least some caregiver support services funded by the NFCSP, but that support varies from state to state and is affected by limited funding levels. As a companion piece, a new, interactive, state-by-state online database has also been developed to help families and health and service providers find services in their area. Web site: [www.caregiver.org/caregiver/jsp/home.jsp](http://www.caregiver.org/caregiver/jsp/home.jsp)

### **On a Roll on PBS**

Two million Americans use wheelchairs. 54 million Americans have a disability. From his home state-of-the-art studio, Greg Smith – “the wheelchair dude with attitude” -- uses his popular nationally syndicated radio program to offer advice, encouragement and inspiration to not only the huge number of disabled Americans, but all Americans. His upbeat, positive, often humor-filled message closes the gap between the abled and disabled by stressing that we all need help from each other, every day. Directed by Joanne Caputo, ON A ROLL will air nationally on the acclaimed PBS series “Independent Lens” on Tuesday, February 15, 2005 at 10:00 P.M. (check local listings) in conjunction with African-American History Month.

### **Your Help is Needed!**

The Centers for Medicare and Medicaid Services (CMS) has announced a new National Coverage Policy process for wheeled mobility devices (manual wheelchairs, power wheelchairs and power operated vehicles/scooters). There is a 30 day public comment period that ends January 14th.

Your input is needed. Whatever policy CMS writes other insurers follow. Now is a unique opportunity for CMS to correct the antiquated outdated policy to ensure that individuals who have a functional mobility need receive appropriate and necessary wheeled mobility technology.

The CMS pages are as follows:

CMS Press Release -

<https://www.cms.hhs.gov/media/press/release.asp?Counter=1286>

Tracking Sheet -

<https://www.cms.hhs.gov/mcd/viewtrackingsheet.asp?id=143>

View Public Comment -

[https://www.cms.hhs.gov/mcd/viewpubliccomments.asp?nca\\_id=143&expand=Y](https://www.cms.hhs.gov/mcd/viewpubliccomments.asp?nca_id=143&expand=Y)

For more information you may also check out these websites:

<http://www.cliniciantaskforce.org>

<http://www.itemcoalition.org>

<http://www.unitedspinal.org>

**Please relay this Bulletin to your membership including those who do not have e-mail access. Make this available in large print, tape and for others who have difficulty accessing information. View and print this Bulletin in [RTF format](#) (compatible with most word processing software). Suggest your membership go to the library and go onto [www.kleinmanconsulting.com](http://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](http://www.KleinmanConsulting.com).**

**How can you find your federal Representatives and Senators? Go to [www.congress.org](http://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. To find your CT representatives call the Capitol Switchboard at 1-888-818-6641, visit [cga.ct.gov/](http://cga.ct.gov/) (note—this is a new website address) or enter your Zip code at [www.congress.org](http://www.congress.org).**