



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

August, 2005

**Need this newsletter in an alternative format?
Please let us know.**

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

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

This Bulletin is supported by a grant the Disability Advocacy Collaborative has received from the Connecticut Council on Developmental Disabilities. In addition, in-kind support is being provided by the UConn Center on Disability, and Communitas, Inc. serves as the project's fiscal agent. To all three we extend our appreciation.

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Calendar of Events

<u>Date</u>	<u>Event</u>	<u>Location</u>	<u>Sponsor</u>	<u>Contact</u>
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 pm	P.A.T.H.S. Transportation Forum	Bridgeport North Branch Library Comm. Center	UConn Center on Disabilities	jkleinman@uchc.edu
Aug. 24 2:00-4:00 pm	P.A.T.H.S. Transportation Forum	Mansfield Senior Center	UConn Center on Disabilities	jkleinman@uchc.edu
Aug. 25-27	"SPAM" and "Common Itch" (see article below)	Eugene O'Neill Theater – Waterford	Second Step Players	860-887-0014 sjwilliams@artreachheals.org
Sept. 8 7:30 pm	Disability Awareness - Kathy Buckley-4 time Amer.Comedy Nominee "America's First Hearing Impaired Comedienne"	Trinity College (CART and interpreters available)	Trinity College "Themed Housing" group and the Office of Campus Life	haley.kimmet@trincoll.edu
Sept. 16	"Creating Inclusive Communities for Everyone" (see article below)	Farmington Marriott Hotel	UConn Center on Disabilities	860-679-1500 (ask for Stan or Chris)
Sept. 27	Thought Approaches to Difficult Behavior – Dave Yieter	Institute of Technology and Business Development (New Britain)	Council on Developmental Disabilities	ed.preneta@po.state.ct.us
OCTOBER—Disability Employment Awareness Month.				
Oct. 15 8:30 am - 3:00 pm	People First Conference	Bristol Clarion Hotel	People First of CT	Advozealot@aol.com

Oct. 19-21	ABCD Leadership Forum (see article below)	Four Points Sheraton in Meriden	Northeast Assets Leadership Project	860-571-8463 ryan@ctassets.org
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. 17-20	“Reclaiming Freedom: A Call to Action”	Hartford	National Assn. for Rights Protection and Advocacy (NARPA)	narpa.org/narpa 334-491-6277
Nov. 12	Adult employment and advocacy	Hartford	Nonverbal Learning Disorders Assn.	NLDA@nlda.org
Sept. 16, 2006	Disability Advocacy Collaborative Convention	CT Expo Center Hartford	Disability Advocacy Collaborative	jjk1009@hotmail.com 203-238-9391

Disability Advocacy Collaborative Update and Meeting Dates

The six Introductory Meetings held by the Disability Advocacy Collaborative during June and July proved a rousing success. The purpose of the meetings was to introduce advocates to the Collaborative, explain its purpose and goals, the importance of the developing 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.

As a result of the Introductory Meetings, three regions have already set dates for follow up meetings (all meetings are at 5 pm):

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

Other regional follow up meetings are in the process of being arranged.

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

Two Inclusion Related Conferences Upcoming This Fall

On September 16, 2005 “Creating Inclusive Communities for Everyone,” a conference hosted by the UConn Center on Disabilities, will take place at the Marriott Hotel in Farmington. Funded under the Real Choice Systems Change Grant, the conference will help participants (e.g., community leaders, advocates, local elected officials and ADA Coordinators) develop inclusion strategies and initiatives to use in their own towns and communities.

The central question for conference participants is “How can I help build a welcoming, accessible, and inclusive community that supports all its residents to be full participants?”. Jim Diers, former director of the City of Seattle’s innovative Department of Neighborhoods, will be the keynote speaker. Jim has found many ways to get people, including people with disabilities, more involved with their community and more involved in decisions that affect their lives. David Hasbury and Jay Klein will facilitate the day, using an innovative participant-oriented format to elicit concrete suggestions for community change. Call Chris Gaynor or Stan Kosloski at 860-679-1500 for more information.

And on October 19-21, the Northeast Assets Leadership Project will sponsor a leadership forum at the Four Points Sheraton Hotel in Meriden. The event promises to be an inspiring and educational colloquium for New England and New York community activists, project leaders, scholars, and citizens. Jody Kretzmann, Co-director of the Asset Based Community Development (ABCD) Institute at Northwestern University in Chicago, and Mike Green, faculty member at the ABCD Institute, are among the speakers. A track dedicated to those interested in the ABCD basics will be offered, as well as “advanced labs” for experienced practitioners.

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

Newly Planned P.A.T.H.S. Forums

(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. Five successful forums have been held in Groton, Manchester, Torrington, Newington and Hamden. There will be two more forums: August 16, 1:00 - 3:30 pm at the North Branch Library Community Center, Bridgeport, and August 24, 2:00 - 4:00 pm at the Mansfield Senior Center. The UCONN Center on Disabilities is interested in hearing from people with disabilities who use 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.

Transportation Security Administration Seeks Input

The federal Transportation Security Administration (TSA) is seeking to train airport screeners to ensure "effective, safe, comfortable, dignified and respectful screening" at all security checkpoints. Toward that objective, TSA has developed guidelines with input from various disability groups and organizations. If you have a disability and have recently taken an airplane trip, the TSA would like to know about your experience with airport security. Respondents are asked to take a few minutes to respond to the online survey before Aug. 23. If interested, go to www.tsa.gov/public/display?theme=156 .

The Americans with Disabilities Act Coalition of Connecticut, Inc. (ADACC) Recruiting New Board Members

The Americans with Disabilities Act Coalition of Connecticut, Inc. (ADACC) is recruiting new Board Members. They are looking for people with disabilities, family members, advocates, government, business and industry representatives, and human services professionals who desire to work together to foster a better understanding of and compliance with the ADA. ADACC provides information, training, and technical assistance regarding ADA issues to individuals and organizations around Connecticut. The ADACC board meets six times a year, and board members serve on various working committees to help direct the overall activities of the board. For more information, please contact: Evelyn Oliver Knight at 860-424-4871, evelyn.knight@po.state.ct.us, Tony LaCava at 203-378-6977, tlacava@drcfc.org, or Lisa Caron in the ADACC office at 860-297-4383, 860-566-2102 (TTY), adacoalition@sbcglobal.net.

On the Road with the Second Step Players

The Second Step Players are a 19 year old traveling troupe of writers, musicians, and comedians; educators, advocates, and political activists; and people who have been marginalized from society by labels like bipolar, borderline, alcoholic, addict and schizophrenic. Often referred to as *Saturday Night Live Meets One Flew Over the Cuckoo's Nest*, the goals of the troupe are to reduce stigma and promote recovery.

A new offering of the Second Step Players will be performed on August 25-27 at the Eugene O'Neill Theater in Waterford. Entitled "SPAM: Do You Know What You're Really Getting?", the performance will also include relevant comedy about mental health issues and an original musical, "The Common Itch". For ticket information, call 860-887-0014. Comments are also welcomed at sjwilliams@artreachheals.org.

Towards Civic Accessibility: Municipalities and the Americans with Disabilities Act

On Thursday October 27, 2005 the University of Connecticut School of Law in Hartford is presenting "Towards Civic Accessibility - Municipalities and the Americans with

Disabilities Act". The Keynote Address will be delivered by Attorney John Wodatch, Chief of the Disability Rights Section of the Civil Rights Division, US. Department of Justice. Informative sessions for municipal administrators, ADA coordinators and municipal attorneys include: General overview of municipal ADA obligations, employment issues, accessible recreation, planning accessible events, law enforcement & the ADA, new ADA accessibility guidelines, emergency planning & the ADA, and zoning accommodations under the ADA. For more information contact adaconference@sbcglobal.net

DD Council Announces Request for Proposal to Support KASA

The Connecticut Council on Developmental Disabilities intends to award a grant to an in-state entity to support the continued development of Connecticut KASA (Kids As Self Advocates). The grant is for up to \$80,000 from January 1, 2006-December 31, 2006, \$50,000 from January 1, 2007-December 31, 2007 and \$30,000 from January 1, 2008-December 31, 2008. To qualify an organization must be a Connecticut not-for-profit, 501c(3) tax-exempt organization.

CT-KASA is a statewide, youth-directed, self-advocacy program formed to enhance the skills and opportunities of those students who have completed, or are currently completing, the transition process from school to work or college, and to provide socializing, leadership development and mentoring opportunities to youth with disabilities. The deadline for applications is August 22. To receive a copy of the RFP please contact: Yvette Johnson, Disability Policy Specialist, Connecticut Council on Developmental Disabilities, 460 Capitol Avenue, Hartford, Connecticut 06106.

More DD Council News

The DD Council has announced a series of workshops that may be of interest to parents, adults with disabilities and advocates:

Tuesday, September 27, 2005

"Thoughtful Approaches To Difficult Behavior." This workshop is a follow-up to the Council's May 2005 workshop on "Restraints." The goal of this presentation is to inspire participants to consider a thoughtful approach to difficult behavior.

Time: 10:00 a.m. to 4:00 p.m. - Tuition: FREE

Registration Deadline: September 20, 2005. Limited to 75 participants.

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

Tuesday, October 25, 2005

"Adaptive Strategies For Families Who Have Children With Impairments For Working With Schools." This workshop will focus on assisting families to build better relationships with their school systems. Strategies and information will be offered that

are designed to improve parents confidence and knowledge when attending their child's IEP meetings.

Time: 10:00 a.m. to 2:00 p.m. - Tuition: FREE

Registration Deadline: October 18, 2005. Limited to 50 participants.

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

Tuesday, November 1, 2005

"Carrying A Big Stick: Issues Of Power And Control That Lead To Violence In Human Services." This workshop is a follow up to the Council's May 2005 workshop on "Restraints." This workshop will further explore awareness of human service system power and control dynamics that can slip into violence against service system recipients, although often in a disguised fashion. The goal of the workshop is to help participants take a personally coherent stance in the face of human service system power, service and control.

Time: 10:00 a.m. to 4:30 p.m. - Tuition: FREE

Registration Deadline: October 26, 2005. Limited to 50 participants.

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

Special Ed Advocates Available

The Arc of Connecticut has trained advocates available to assist parents get what they and their children need from their PPT meetings. Advocates are located statewide and are advised by an experienced lawyer. Call Attorney Kim Pisinski for more information at 860-953-8335, ext. 12.

Did You Know?

The Center for Disability Rights in West Haven has created a for-profit organization called Butterfly Equipment that makes available to area residents new and pre-owned equipment. All proceeds from the sale of equipment go toward supporting the mission of the Center.

New items include portable ramps, modular ramps, grab bars and batteries. Used equipment includes manual and power wheelchairs, shower benches, walkers, hoier lifts, and reachers. For more information call 203-500-2155 or e-mail

butterflyequipment@mmode.com.

Adapted Rowing Program Christened

Bill Mancini, President of the Connecticut Chapter of the National Spinal Cord Injury Association (NSCIA), was featured in a series of local media reports in July about the newly established Connecticut Adaptive Rowing Program. The program was created as a partnership between the Rehabilitation Hospital of Connecticut, Riverfront Recapture, and the Connecticut NSCIA chapter.

The program first took to the water on June 1, after some dry-land training for both able-bodied participants and those with disabilities. On Monday and Wednesday evenings through September, pairs of rowers put in at Riverfront Recapture's Community Boathouse at Riverside Park in Hartford and row for an hour, first going up the river, north of the railroad bridge and back again at least once and often twice.

ADA Anniversary Celebrates Accessible Programs

On July 26, the Connecticut Developmental Disabilities Network, in collaboration with the ADA Coalition of Connecticut, celebrated the 15th anniversary of the signing of the Americans with Disabilities Act. "Out & About: Celebrating the Spirit of the ADA" honored four organizations from across Connecticut who have gone above and beyond in developing programs that are accessible and usable by people with disabilities. The Groton Parks & Recreation Department, the National Center for Boundless Playgrounds in Bloomfield, Northwest Park in Windsor & the Windsor Lions Club, and the Connecticut Children's Museum in New Haven were recognized by the event sponsors and by their legislators, who presented the organizations with official citations from the General Assembly. The event, which was held at the Legislative Office Building in Hartford, was televised by CTN. The event can be viewed at: www.ctn.state.ct.us/ondemand.asp.

The Connecticut 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 AJ Papanikou Center for Excellence in Developmental Disabilities Education, Research, & Service.

The Corporation for Supportive Housing

The Corporation for Supportive Housing is a non-profit organization that helps other non-profits develop and operate service-supported affordable housing for homeless individuals and families with mental health or substance abuse issues. The initiative is financed by the State in a project called the Next Step Initiative. Funds are targeted for support services and rental subsidies for persons who have been homeless or at risk of becoming homeless and also experiencing mental illness, addiction, or other chronic health problems such as HIV/AIDS. For more information contact Francesca Martin at fmmartin@snet.net

Kathy Buckley - Comedienne

On Thursday, September 8, 2005, the Disability Awareness Quad and the Office of Campus Life at Trinity College will host Kathy Buckley, America's first hearing impaired comedienne, and four time American Comedy Award nominee. Her performance is based upon her experiences growing up with a hearing loss and manages to incorporate a number of serious lessons in a light-hearted way. Kathy has appeared on a variety of shows including The Tonight Show and Regis and Kathy Lee, as well as Entertainment Tonight, Extra, and Inside Edition. Interpreting and CART (computer-aided real time transcription) services will be provided. The event will take place at 7:30 pm at the Vernon Social Center located on Vernon Street in Hartford. Parking will be available along Summit and Vernon Streets. Please call 610-653-4803 or email Haley.Kimmet@trincoll.edu if you have any questions or would like the event flyer.

Sit-in in Tennessee Continues

Did you know a group of activists are conducting a sit-in in the Tennessee Governor's Office? Other than disability related list servs, why are we not hearing about this in the rest of the country?

The why: Tennessee Governor Phil Bredesen has proposed substantial cuts in Medicaid services, including cutting all community services to people who rely on ventilators. When asked directly by Randy Alexander of Tennessee ADAPT what Bredesen's plans were in relation to cuts in Medicaid services to individuals who use ventilators, Governor Bredesen replied, "I'm not going to cut their services - I'm just going to put them in the nursing homes." Alexander then asked "so you are saying you will institutionalize people because they have a disability"? "Yes," replied Bredesen, "I care about them. I'm not cutting their services - I'm going to provide their services in a nursing home."

The what: Day 1 - June 20, 2005 - TennCare enrollees, people with disabilities, medical professionals, and other concerned Tennesseans occupy Governor Bredesen's Office after the Governor releases plans to ignore Olmstead and directly violate citizen's rights by making questionable cuts in Tennessee's Medicaid program.

Day 45 - August 3, 2005 – Sit-in continues, and advocates explore what community life is like in states with alternatives to nursing homes.

The original statement of demands:

"We are here in the Governor's Office, as afforded by the Constitution of Tennessee to assemble peaceably, to instruct the governor. We call on the Governor to:

1. Halt all of the termination letters immediately, halt the process for cutting enrollment, and halt the reduction of benefit limits.

2. Provide written agreement to resume talks with us before June 30th, and to review reforms and revenue generation that could allow TennCare to be maintained for those who are proposed to be cut and receive benefit limits.
 - a. That these talks happen in a manner fully accessible to the public, and
 - b. That they engage enrollees and medical professionals chosen from and with in this participating group”.

To read more about the background, the demands, and to follow the sit-in on a daily basis go to the Memphis Center for Independent Living website at www.mcil.org.

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

Comments Sought on NIDRR’s Draft Long-Range-Plan

Individuals are invited to review and comment on a draft long-range plan prepared by the National Institute on Disability and Rehabilitation Research (NIDRR). The plan emphasizes five "domains" as areas for expanded research efforts in the next five years in support of people with disabilities: employment; participation and community living; health and function; technology for access and function; and disability demographics.

The proposed plan was published in the Federal Register in a supplementary section on July 27, 2005, and is accessible at <http://a257.g.akamaitech.net/7/257/2422/01jan20051800/edocket.access.gpo.gov/2005/05-14741.htm>. NIDRR will consider all comments received within 30 days of publication and make any necessary revisions to the plan. For more information on NIDRR, go to www.ed.gov/about/offices/list/osers/nidrr/index.html.

Roadmap for Mental Health Reform Released

The Campaign for Mental Health Reform, a partnership of 16 national mental health organizations including NAMI, released an important report recommending a series of actions that Congress and the Administration can take to improve services for people with mental illnesses. The report, entitled "Emergency Response: A Roadmap for Federal Action on America's Mental Health Crisis," describes the negative consequences, including criminalization, homelessness and suicides, that occur when people do not have access to the treatment and services they need.

In July 2002, President Bush’s New Freedom Commission on Mental Health proclaimed that America’s mental health system is fragmented beyond repair and emphasized the need for a wholesale transformation to a system far more responsive to the needs of

consumers and their families. The report released by the Campaign for Mental Health Reform contains a series of federal legislative and administrative recommendations for achieving this transformation. To see the entire "Roadmap" report, the executive summary, a list of the organizations comprising the Campaign for Mental Health Reform, and other information contact elise@nami.org, or contact NAMI, 2107 Wilson Blvd. Suite 300, Arlington, VA 22201.

. For more information on the New Freedom Commission report go to www.cms.hhs.gov/promisingpractices/mentalhealth .

Two-Day Monitoring Conference Open to the Public on the Restructuring of RSA

The federal Rehabilitation Services Administration (RSA) has announced plans to hold a public meeting to seek comments and suggestions about the Administration's monitoring process. The public meeting will be held from 9 a.m. to 5 p.m. Wednesday, August 24, 2005 and 9 a.m. to 4 p.m. Thursday, August 25, 2005 in Washington, DC. [Note: OSERS plans to close RSA's Regional Offices on September 30, 2005. For more information contact David Esquith, Rehabilitation Services Administration, Office of Special Education and Rehabilitative Services, U.S. Department of Education, 400 Maryland Avenue, SW, Room 5175, Potomac Center Plaza, Washington, DC 20202. Telephone: (202) 245- 7336. If you use a telecommunications device for the deaf (TDD), you may call the Federal Relay Service (FRS) at 1-800-877-8339.

Protect Food Stamps

The Food Research and Action Center is asking individuals to send a strong message to Congress to protect the Food Stamp Program "against budget cuts and damaging structural changes." There have already been major cuts and many individuals previously eligible have been denied eligibility. The Alert notes that "too many people are hungry; too many hungry people are not getting food stamps; too many people cannot afford to lose even one cent of food stamp benefits; the average benefit amounts to just one dollar per person per meal."

According to the recent Alert, the FY 2006 Congressional Budget Resolution instructs the House and Senate Agriculture Committees to design policies to cut \$3 billion over five years from programs under their jurisdiction by September 16, 2005. In addition, a House bill to reauthorize the Temporary Assistance for Needy Families (TANF) Program (H.R. 240) would give the executive branch of the federal government extraordinary authority to change Food Stamp Program rules. For updates on developments go to frac.org/Legislative/Budget_06/Alerts. [Food Research and Action Center Action Alert 7-7-05].

Gap in Dental Care

A recent article in the Pittsburgh *Post Gazette* refers to a Pennsylvania class action suit, filed in 2000, claiming a big gap in dental care for people with disabilities. Medicaid-funded dental payments are "grossly inadequate to ensure access to care for adults and children with disabilities", according to papers filed in the case. The article refers to the shortage of dentists to provide care due to low Medicaid payment, Medicaid red tape, discomfort on the part of some dentists to work with people with disabilities and the limited resources that can provide specialized service such as sedation and additional treatment time. According to the article, the American Academy of Developmental Medicine and Dentistry has reported that similar lawsuits have been filed in more than 20 states demanding improved access to medical and dental care for people with developmental disabilities. "Untreated oral health problems may lead not only to pain but to other health conditions, including diabetes, stroke and heart or lung disease."

Social Security Revamps Disability Benefits

People seeking disability benefits from Social Security can expect to spend less time waiting for a decision under changes rolled out on July 26, the anniversary of the Americans with Disabilities Act. Social Security Commissioner Jo Anne Barnhart said people who are clearly disabled could be approved for benefits in as little as 20 days under the new procedures, which the agency expects to start putting into action next spring. [The Associated Press, Mary Dalrymple, Tuesday, July 26, 2005]

Five Tips on How to Apply for the New Medicare Drug Benefit

The Medicare Rights Center, a national consumer group, has offered five tips to help older adults and people with disabilities complete the application for the new Medicare drug benefit, which will become available next January:

1. You do not have to submit documents proving your income and assets, but you will need to gather your financial records to complete the application,
2. If you are married and live with your spouse, you must provide your spouse's income and assets even if only one of you is applying for the extra help.
3. People receiving both Medicare and Medicaid benefits who are enrolled in a Medicare Savings Program (MSP) or receiving Supplemental Security Income (SSI), will automatically qualify for the extra help and do not have to apply for the assistance.
4. If you and your spouse are both applying, you can apply on the same form.
5. Use an original application form; using a photocopy or an application printed from the internet will delay the processing of your application.

For more information about these tips go to www.medicarerights.org/app_tips.pdf.

For more information about the Medicare prescription drug benefit, visit Medicare Interactive (www.medicareinteractive.org/aarp), a one-stop, interactive web site providing older adults and people with disabilities user-friendly consumer information about health care benefits, rights and options. You can also call 1-800-MEDICARE to get the toll-free number for counselors at your local State Health Insurance Information and Assistance Program (SHIP). [Global Action on Aging, Senior Journal, July 7, 2005].

Also Medicare Related

Former Sen. John Breaux of Louisiana has announced the creation of the Medicare Rx Education Network, composed of more than 40 groups that have an interest in the new program. The groups include the AARP, Blue Cross Blue Shield, Easter Seals and American Medical Association.

The network's top priority is to educate the public about Medicare's program to subsidize prescription drugs. It plans a public relations blitz to tout the program, including a TV commercial, a Web site and a 24-hour toll-free phone number for information. Several of the participating organizations plan to carry educational advertisements in their publications. Because Medicare recipients must apply for the drug program in addition to their regular coverage, the network intends to inform as many people as possible about it before applications begin to be accepted in November, Breaux said. According to Medicare and Medicaid Administrator Mark McClellan, "The new network and its efforts will be a big help towards our goal of reaching seniors and people with disabilities. [July 19, 2005, Global Action on Aging].

More on Medicare....

A new web-based service will help Medicare beneficiaries of limited income and resources gain access to the extra help available to them through the Medicare Modernization Act of 2003. The service, which will also help them enroll in other health care and prescription drug assistance programs, was developed by the Administration on Aging (AoA) with the assistance of the Centers for Medicare & Medicaid Services (CMS) and the National Council on the Aging (NCOA).

“The new service is a special version of BenefitsCheckUpRx updated for the extra help with Medicare drug coverage. It is available at <http://www.BenefitsCheckUp.org/rx>. BenefitsCheckUpRx will help older adults, people with disabilities, and the advocates who work with them take advantage of the Medicare low-income subsidy, the comprehensive extra help that covers 95 percent of drug costs on average for people with Medicare who have limited means.

The NCOA has also created a special organizational version that will provide training and ongoing customer support for Area Agencies on Aging, State Health Insurance Assistance Programs, State Units on Aging, and other local agencies that serve seniors

and persons with disabilities. Check out www.cms.hhs.gov/medicarerereform/states/whatsnew.asp

"But You Still Look so Well...."

"But You Look So Well: Living with MS," was first produced in 2001 and focused on the newly diagnosed individuals with invisible MS symptoms, such as numbness, pain, fatigue, visual or cognitive impairment. A follow-up film, "But You Still Look So Well: Living with MS," is available. This 84-minute film is a follow-up on three people and their families who were newly diagnosed prior to the filming of the first documentary. You can hear about where they are today and what they have learned. Both films offer hope and reassurance that life does indeed go on after a diagnosis of MS. The video is available for loan through the MSF Lending Library, 888-MSFOCUS (673-6287). Contact AudreyGeyer@aol.com to purchase a copy.

Harry Potter Meets a Wheeler

Did the latest book from J.K. Rowling only whet your appetite for more? Check out La Guera's fanfic novel *Summon the Lambs to Slaughter*. A young woman with cerebral palsy, La Guera was discouraged that Hogwarts welcomed students from every corner of society except for the people with disabilities. So she created her own online novel-in-progress that features a main character with a physical disability. Read "[Harry Potter and the Wheeler](#)" in 360 Magazine for an excerpt from La Guerra's work as well as a link to subsequent chapters. [360 Magazine, July 20, 2005].

Harry Potter Site Opens Up

The official website for J.K. Rowling (www.jkrowling.com) has been changed so it can be used by people who are physically disabled, deaf and visually impaired. It can be used from a keyboard without a mouse, can be enlarged, paused or have noise switched off. It has interactive elements, pop-ups and sounds which are important to hidden messages and information. [CBBC NEWSROUND: 2005/07/20, Global Action on Aging]

"From 'Murderball' to Reluctant Movie Star"

From USA Today: Mark Zupan swigs beer. Spews out four-letter words. Sweats up a storm in the gym. Wrestles with his dog. Has crowd-surfed at a Pearl Jam show. And enjoys an active sex life with his live-in girlfriend, Jessica Wampler. Oh yeah, and he happens to be a quadriplegic who has been in a wheelchair since he was 18. That was when he was thrown from the bed of the pickup of his best friend, Christopher Igoe, and broke his neck. Spend two minutes with Zupan and you forget he's sitting in a beat-up chair that's both an extension of himself and at the same time completely overshadowed by his piercing intelligence, sharp-edged humor and outspoken, trash-talking personality. Yet his accident, Zupan says, is "the best thing that's ever happened to me." He means it.

Zupan, 30, is the captain of the U.S. quadriplegic rugby team, which competes in the Paralympics and took home a bronze medal at the Athens games. Also known as "murderball," it's a brutal, sometimes bloody sport that has wheelchair athletes pounding and slamming the living daylights out of each other. It's the subject of *Murderball*, a film that won the Documentary Audience Award at the 2005 Sundance Film Festival and opened in New York and L.A.

How do feel about Jerry Lewis and the Telethon?

“How do feel about Jerry Lewis and the telethon?” The Kids Are All Right Organization is asking Independent Living Centers and activists throughout the country to organize free public screenings sometime around Labor Day of the documentary “The Kids are All Right”, a half-hour video about a renegade Jerry’s Kid named Mike Ervin. A Muscular Dystrophy Association (MDA) poster child in the 1960s, today Mike is a disability rights activist who challenges the use of pity to raise money in the MDA’s annual Jerry Lewis Labor Day telethon. The documentary follows Mike and his group Jerry’s Orphans as they organize protests against the telethon in Chicago. The video includes intense footage of protests from three consecutive years paired with an interview in which Mike explains the history of Jerry’s Orphans and the reasons he co-founded the group.

For more information or if you would like to participate, call Barb Wesolekuor, 773-929-6362, email address: wes754@sbc.com, or go to their web site at www.thekidsareallright.org .

On the Television, Stage, Movies, Books, and in the Press Disabled Actors are Underrepresented

Actors with disabilities are underrepresented in movies and TV shows and are reluctant to ask producers for even minor accommodations, according to a study commissioned by the Screen Actors Guild (SAG). While 20 percent of all Americans have a physical or mental disability, fewer than 2 percent of TV show characters display a disability and only half of them have speaking roles, according to an executive summary of the report released in July. The study showed that a majority of the accommodations sought by actors were fairly minor, including needing a sign language interpreter, the opportunity to sit down periodically and proximity to a bathroom. SAG and the Alliance of Motion Picture and Television Producers said they will ask the Labor Department to expand a yearly casting data report to include disabilities. The report currently tallies opportunities in film and television by race, ethnicity, gender and age.

The SAG study was compiled using focus groups and a survey mailed to 1,237 SAG members who have identified themselves as having a disability. For more information go to www.sag.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.

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