



# BULLETIN

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<http://www.ed.gov/nidrr>  
<http://www.disabilityinfo.gov>



## Disaster preparedness

As this past month's events show, when people move out of institutions and into the community, disaster preparedness is a critical piece of living independently. In the wake of the recent hurricanes, as well as fires, floods, and earthquakes, the Center would like to point out some resources for preparing for disasters for people with disabilities and personal assistants.

On the Center for PAS website are two resources on the PAS Users web page. The first is the disaster preparedness section of the "Working Together: Personal Assistance Training and You" information. It covers preparing for emergencies, preparing yourself, and evacuating. It also includes forms for Emergency Contacts and Emergency Medical Information that can be critical in an emergency.

To get this information, go to [http://www.pascenter.org/pas\\_users/index\\_old.php](http://www.pascenter.org/pas_users/index_old.php), under Health and Safety, Disaster Preparedness.

The second resource is a radio interview with June Kailes. June has assembled a tremendous amount of disaster information and resources for people with disabilities and emergency managers at her website (<http://www.jik.com/disaster.html>). On the radio show, she gives some insights to her experience in assembling this information.

To hear the radio show, go to [http://www.pascenter.org/pas\\_users/radio.php](http://www.pascenter.org/pas_users/radio.php) and select Junes Kailes interview.

## Hurricane resources

A series of resources has become available after Hurricane Katrina at Independent Living Research Utilization (ILRU) at TIRR, themselves evacuated for Hurricane Rita. ILRU is now operating a disaster management assistance line for centers for independent living and statewide independent living councils. Centers and SILCs in the areas affected by Hurricane Katrina and other centers serving evacuees can call for information about disaster related resources for people with disabilities and assistance in center reconstruction and restoration.

ILRU Disaster Management Information Line for CILs and SILCs  
866.203.5111  
9:00 a.m. - 4:00 p.m. Central Time

They have also posted the following resources:

Archive of Web cast on Disaster Relief Strategies for Individuals with Disabilities  
<http://www.ilru.org/html/training/webcasts/archive/2005/09-14-LF.html>

Hurricane Katrina Relief Assistance for People with Disabilities-Listings of Phone Numbers, Web Links, and Other Resources for Individuals and Organizations  
<http://www.ilru.org/html/whatsnew/announcements/katrina.html>

ILRU Equipment and Supplies Exchange Message Boards for CILs and Other Organizations-Post Your Needs and What You Have to OFFER  
[http://ilru.virtualhosts.com/cgi-bin/forum/board\\_show.pl?bid=31](http://ilru.virtualhosts.com/cgi-bin/forum/board_show.pl?bid=31)

ILRU News Journal with Latest Updates on Hurricane Relief for People with Disabilities  
[http://www.livejournal.com/users/ilru\\_il/](http://www.livejournal.com/users/ilru_il/)

## New PAS Users and Nursing home resources available on the Center for PAS website

The Center for Personal Assistance Services website has a newly revised home page designed for PAS users. Aimed to provide information and resources to assist in living independently, as well as provide a place for PAS users to learn from experts and each other, the page contains the following information:

- [Guide to Using PAS](#) - Using information from "Working Together: Personal Assistance and You", a web resource developed by InfoUse, this link contains questions and answers to basic issues in being an employer of a personal assistant or attendant.
- [Ask Mike](#) - Mike Oxford, Executive Director of the Topeka Independent Living Resource Center and Past President of the National Council on Independent Living (NCIL) will take questions from PAS users about anything related to PAS. The questions and answers will be posted on this page.
- [Web links](#) - This resource uses questions to group web resources under commonly asked-about issues.
- [In your own words](#) - We want to hear from you and others do too. This is an opportunity to share your story about using PAS.
- [Center for PAS Radio](#) - MP3 files of the Center for PAS sponsored radio shows on

"Disability and Senior News Report" hosted by Maggie Dee on KUSF in San Francisco. You can listen to them on your computer or download them to your iPod.

- [Help in my state](#) - This is a link to the state agency information located on the Center for PAS website.

For more information, go to [http://pascenter.org/pas\\_users/index.php](http://pascenter.org/pas_users/index.php)

The Center for PAS website has a new Institutional Services page that provide links and a library on nursing home information. The Center feels that in order to better understand home and community services, it is useful to compare these services to institutional care. The PAS Center has therefore developed this section to provide detailed information on nursing homes and other institutional services. The information includes statistics on the supply, residents, and quality of services by state and across the nation. For other specific questions about institutional care, please contact the Center.

For more information, go to [http://www.pascenter.org/nursing\\_homes/index.php](http://www.pascenter.org/nursing_homes/index.php)

### **Promising practices on the Center for PAS website**

The Center for PAS has begun posting promising practice information via its website.

A database of PAS workforce best practices is available on the website of Center partner National Clearinghouse on the Direct Care Workforce.

For more information, go to <http://www.directcareclearinghouse.org/practices/index.jsp>

The Center for PAS is conducting a study of Medicaid Optional State Plan Personal Care Services (PCS) programs. The study involves two main activities. First, better practices (e.g., consumer direction) are identified from the literature to use as criteria for selecting promising programs. Second, detailed case studies are conducted on the promising programs. Presently, the selection criteria are available on the website.

For more information, go to [http://www.pascenter.org/home\\_and\\_community/index.php](http://www.pascenter.org/home_and_community/index.php)

### **New Long Term Care legislation proposed**

Senate Finance Committee Chair Chuck Grassley (R-Iowa) has introduced a bill (S 1602) that is intended to help reduce the cost and increase the accessibility of long-term care for elderly U.S. residents and individuals with disabilities, CQ HealthBeat reports. The legislation, which is co-sponsored by Sens. Evan Bayh (D-Ind.) and Hillary Rodham Clinton (D-N.Y.), would:

- Prohibit states from considering benefits paid under a long-term care insurance policy when determining eligibility for Medicaid;
- Expand a long-term care partnership that currently operates as a demonstration program in four states;

- Allow states to offer home- and community-based services as part of their state Medicaid plan; and
- Add a set of consumer protections recommended by the National Association of Insurance Commissioners to the definition of qualified long-term care services.

### **Updated Information on Medicaid Home and Community-Based Long-Term Care Programs**

Researchers at the PAS Center, with supported from the Kaiser Commission, have been monitoring the national development of the three Medicaid home and community-based programs (HCBS) for long-term care that states can operate (waivers, home health and state plan personal care optional benefit). In addition, states were also surveyed on policies such as eligibility criteria and waiting lists that are used to control Medicaid HCBS expenditure growth. A report, available online, presents the latest information on the development of Medicaid HCBS programs.

For more information, go to <http://www.kff.org/medicaid/7345.cfm>

### **Medicaid Benefits Online Database**

The Kaiser Commission on Medicaid and the Uninsured has updated and improved its Medicaid Benefits Online Database, an interactive tool providing easy access to

information on services provided by each state's Medicaid program.

The database contains Medicaid benefits survey data from 2003 and 2004 collected by Health Management Associates for the Commission. It includes information about 46 services, including whether the benefit is covered, co-payment requirements, limitations on the benefit (certain populations covered or prior authorization required and reimbursement methodologies for each of the 50 states, the District of Columbia and the US territories.

The redesigned site allows users to search by state or service as well as to customize a search, and permits comparisons between 2003 and 2004 information, or between benefits in a certain state and its regional neighbors. Additionally, you can easily print, e-mail or save your search results.

For more information, go to <http://www.kff.org/medicaid/benefits/index.jsp?CFID=1382220&CFTOKEN=3dfbad455df55e7-75DA9A66-96B0-97BD-8F4D5DB7E7CDD826>

### **Comparison of institutional and community expenditures for Long Term Care**

Steve Gold, a disability rights attorney, and advisor to the Center for Personal Assistance Services, published an informational bulletin earlier this month showing the comparison of institutional and community expenditures by state for long-term care. He notes that mental retardation/ developmental disabilities (MR/DD) expenditures in the community are

much higher than for physically disabled/aged disabled (PD/AD). He also notes that "only seven states spend more than 50% of their TOTAL LTC (i.e., both MR/DD and PD/AD) on community-based services as opposed to institutional services."

For more information , go to  
<http://www.stevegoldada.com/stevegoldada/archive.php?mode=A&id=129;&sort=D>

### **Report on nursing facilities, staffing, residents, and facility deficiencies released**

A new report has been completed by the University of California, San Francisco, showing trends in U.S. nursing homes by state for the 1998 through 2004. The data are from the federal On-Line Survey and Certification System (OSCAR) reports that are completed at the time of the annual nursing home surveys by state Licensing and Certification programs for the U.S. Centers for Medicare and Medicaid Services.

For more information, go to  
[http://www.pascenter.org/publications/publication\\_home.php?id=250](http://www.pascenter.org/publications/publication_home.php?id=250)

### **Long Term Care testimony given**

Center for Personal Assistance Services Director Charlene Harrington provided testimony at a July 22nd hearing held by the National Commission for Quality Long-term Care. The Commission heard testimony that

included a number of recommendations about how to strengthen and support the direct-care workforce. Several of the more than 25 invited speakers discussed the importance of the workforce, including Dr. Harrington, who testified that "the most important measure of quality of care is the amount of nursing staff available to provide care."

Also speaking was another associate of the Center for PAS, Robyn Stone who is the executive director of the Institute for the Future of Aging Services (IFAS).

For more information, go to  
[http://www.pascenter.org/news/news\\_home.php?id=38](http://www.pascenter.org/news/news_home.php?id=38)

For Harrington testimony in html, go to  
[http://www.pascenter.org/news/Harrington\\_LTC\\_Testimony.html](http://www.pascenter.org/news/Harrington_LTC_Testimony.html)

### **CRIPA Report from NCD**

August 8, the National Council on Disability (NCD) released the report "The Civil Rights of Institutionalized Persons Act: Has It Fulfilled Its Promise?" This report examines the implementation of CRIPA, the Civil Rights of Institutionalized Persons Act which was enacted in 1980 to protect the rights of people living in state institutions, including public nursing homes, mental health facilities and institutions for people with intellectual disabilities.

To retrieve the report, go to  
<http://www.ncd.gov/newsroom/publications/2005/pdf/personsact.pdf>

## **Report on Nursing Home Transition**

The Kaiser Commission on Medicaid and the Uninsured published a report in August which aims to provide more information about nursing home transition programs and the people which they serve. The report analyses data from the 1999 National Nursing Home Survey to describe the characteristics of people who are 65 and older who are discharged back to the community after one year and the characteristics of people of the same age who remain in nursing homes for 90 days or longer.

To retrieve the report, go to  
<http://www.kff.org/medicaid/7386.cfm>

## **Center on Budget Priorities releases report on South Carolina Medicaid Waiver Proposal**

In August, the Center on Budget Priorities released a report reviewing the Medicaid waiver proposal for the state of South Carolina. South Carolina proposes to replace Medicaid with a system of state-funded "personal health accounts," which beneficiaries would use either to purchase health care services directly from providers or to enroll in private insurance plans or private health care networks. The key findings of the report were:

- South Carolina's proposal to replace its Medicaid program with a system of private accounts would reduce health coverage for vulnerable state residents

and raise their out-of-pocket health care costs significantly.

- The funds provided by the state for health care would be particularly inadequate for people with above-average health care needs, such as those with disabilities, chronic diseases, or other serious illnesses.
- The proposal rests on key untested assumptions, such as the belief that a system of managed care plans and provider networks will rapidly emerge in the state to serve Medicaid beneficiaries.

For more information, go to  
<http://www.cbpp.org/8-10-05health.htm>

## **Workplace PAS at 3 conferences in September**

Three conferences in September covered issues of employment of people with disabilities with a focus on workplace PAS.

The Workplace Accommodations: State of the Science Conference hosted by the Rehabilitation Engineering and Research Center on Workplace Accommodations (Work RERC) at the Center for Assistive Technology and Environmental Access (CATEA) at Georgia Tech brought together participants to discuss issues surrounding workplace accommodations such as Evidence-Based Practice, AT to Universal Design, Universal Design and Information Technology, Safety in the Workplace, Aging Workers, Telework, and Service Delivery. The conference features 33 presentations from experts representing research and training projects from the National Institute on Disability and Rehabilitation Research

(NIDRR), vocational rehabilitation, national and state organizations and industry. Selected papers from this conference will be presented in a special issue of the journal "Work." Susan Stoddard, Director of the Workplace PAS project at the Center for PAS, presented a talk entitled "Workplace Personal Assistance Services."

For more information, go to  
<http://www.workrerc.org>

Empowering Employers to Build an Inclusive Workforce is the title of the Job Accommodation Network's 2005 Annual Conference. The conference aimed to have participants "acquire knowledge and skills to accommodate employees with disabilities, comply with the ADA, and develop innovative employment practices. National experts answered issues of recruiting, hiring, retaining, promoting, and accommodating employees with disabilities; reviewed strategies employers have used to facilitate successful and cost-effective accommodations; and reviewed what the ADA says about employing people with disabilities. Susan Stoddard and Lewis Kraus of the Center for PAS presented a workshop on "Workplace Personal Assistance Services."

For more information, go to  
<http://conference.jan.wvu.edu>

EmploymentAccess 2005: Increasing Workplace Opportunities Through Innovation is a national conference uniting people with disabilities, employers, educators, rehabilitation specialists, technical developers, and manufacturers in more than 20 sessions on topics of access technology

for the workplace, ergonomics, and integrating persons with disabilities into the workforce. Susan Stoddard and Lewis Kraus of the Center for PAS gave a presentation on "Workplace Personal Assistance Services."

For more information, go to  
<http://www.employmentaccess.org>

## **State Medicaid Eligibility Cutbacks**

The Title II Community AIDS National Network has published an updated report on state activity to limit Medicaid eligibility. The report, called "2005 State Medicaid Eligibility Cutbacks & Exclusions: Proposed & Recently-Enacted" can be accessed via the National Health Law Project website.

To retrieve the report, go to  
[http://www.healthlaw.org/library.cfm?fa=detailItem&fromFa=detail&id=70858&folderID=43248&appView=folder&r=id~43248.appview~folder\\_fa~detail.rootfolder~23177](http://www.healthlaw.org/library.cfm?fa=detailItem&fromFa=detail&id=70858&folderID=43248&appView=folder&r=id~43248.appview~folder_fa~detail.rootfolder~23177)

## **Medicaid Commission Report**

A Medicaid Commission has been set up to advise the Secretary of State for Health and Human Services on how to 'modernize' the Medicaid Program. The Commission has two objectives. Firstly, to report on how to achieve \$10 billion of cost savings to the Medicaid program over the next 5 years. Secondly, the Commission is charged with making longer term recommendations for the future of Medicaid. The Commission published its first report regarding potential changes to Medicaid in the shorter term on September 1st. The report contains 6

recommendations for how to achieve cost savings. These cover reform of the prescription drug reimbursement formula, extension of the Medicaid drug rebate program, changes to the rules regarding transfer of assets for Medicaid eligibility, increase of the 'look-back' period, tiered co-payments for prescriptions drugs and reform of the Medicaid Managed Care Organization provider tax requirement.

For more information about the Commission, go to  
<http://www.cms.hhs.gov/faca/mc/details.asp>

The report is available at  
<http://www.cms.hhs.gov/faca/mc/090105rpt.pdf>

## **Public Opinion about Medicaid**

The Kaiser Family Foundation published the findings of a national survey of the Public's views about Medicaid in June. The majority of those surveyed were supportive of the Medicaid program, with only 12% stating that they would prefer federal funding of the program to be cut.

For further details about the survey, go to  
<http://www.kff.org/medicaid/pomr062905pk.g.cfm>

## **Scheduled presentations for Center researchers**

The Center for PAS will provide an RTC Update to the 11th Annual National Conference on Rural Independent Living in Honolulu, Hawaii in October.

An entire session will be devoted to Personal Assistance Services (PAS) at this year's American Public Health Association (APHA) Annual Meeting which has been moved to Philadelphia, PA in December 2005. Researchers from the Center for Personal Assistance Services will make three presentations in that session as well as three others. At the PAS session, Center staff will discuss findings of formal personal care programs and polices, experiences of PAS from people of color, and trends in supply and demand for PAS. Other presentations discuss the latest findings from studies of community integration litigation, PAS programs and policies, assistive technology, and disability statistics in local planning.

For more information, see  
<http://www.apha.org/meetings>

## **Center Director awarded LTC study grant**

The National Institute on Disability and Rehabilitation Research announced that Professor Charlene Harrington, PhD, RN, has been awarded a field initiated grant for a two-year study of Developmental Disability Service Utilization and Expenditures in California. This study will analyze statistical data on the formal service utilization and expenditures for the 200,000 individuals with Developmental Disabilities (DD) living at home and in the community who are actively served by the California regional center program. The study focuses on issues access to long term care services including personal care services for individuals with DD. Multivariate analyses will be used to test hypotheses that factors other than needs are

major predictors of service use and costs of formal services for individuals with DD. The findings should inform the budgetary and policy debates around the allocation of resources and proposed cutbacks in DD services.

## **SELECTED CONFERENCES DURING October, November, and December 2005**

For more detail about these conferences, go to:

<http://pascenter.org/conferences/index.php>

### **October**

October 06 - October 10, 2005

11th Annual National Conference on Rural Independent Living

Hosted By: Association of Programs for Rural Independent Living (APRIL)

Location: Honolulu, HI

<http://www.april-rural.org/>

October 20 - October 22, 2005

23rd Annual Closing the Gap Conference

Hosted By: Closing the Gap: Computer Technology in Special Education and Rehabilitation

Location: Minneapolis, MN

<http://www.closingthegap.com/conf>

October 23 - October 26, 2005

24th Annual Meeting and Home Care & Hospice Expo

Hosted By: National Association for Home Care and Hospice

Location: Seattle, WA

<http://www.nahc.org/NAHC/Meetings/AM/05/>

### **November**

November 04 - November 05, 2005

World of Possibilities Expo-Bigger and Better in 2005

Hosted By: Caring Communities

Location: Dulles Expo Center, Chantilly, Virginia

<http://expo.caringcommunities.org/main.php>

November 04 - November 05, 2005

World of Possibilities Disabilities Expo

Hosted By: Caring Communities Inc.

Location: Alexandria, VA

<http://v1.dpi.org/lang-en/events/details?page=184>

November 09 - November 12, 2005

The Heart of Tash: 30 years and Still Beating Strong, 2005 Annual TASH Conference

Hosted By: TASH

Location: Milwaukee, Wisconsin

<http://www.tash.org/>

November 18 - November 22, 2005

58th Annual Scientific Meeting of The Gerontological Society of America

Hosted By: The Gerontological Society of America

Location: Orlando, FL

[http://eshow2000.com/geron/about\\_the\\_meeting.cfm](http://eshow2000.com/geron/about_the_meeting.cfm)

### **December**

December 07 - December 09, 2005

Fall 2005 Consumer Directed Health Care Conference & Expo



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Hosted By: Consumer Directed Healthcare Conference and Expo

Location: Omni Shoreham Hotel, Washington, DC

<http://www.cdhcc.com/default.asp?View=170&ShowID=119>

December 07 - December 09, 2005

Perspectives of Employment of Persons with Disabilities Conference

Hosted By: Department of Agriculture, Department of Defense, Department of Labor, Environmental Protection Agency, Equal Employment Opportunity Commission

and the National Institutes of Health/National Institute on Drug Abuse

Location: Hyatt Regency, Bethesda, MD

<http://register.grad.usda.gov/Conferences/Perspectives/DisabilitiesInfo.cfm>

December 10 - December 14, 2005

American Public Health Association 133th Annual Meeting

Hosted By: American Public Health Association

Location: Philadelphia, PA

<http://apha.org/meetings/>

The Center for Personal Assistance Services provides research, training, dissemination and technical assistance on issues of personal assistance services (PAS) in the United States. Personal assistance services (PAS) refer to help provided to people with disabilities to assist them with tasks essential for daily living. These tasks include bathing, dressing, getting around, toileting, eating, shopping, remembering things, and other activities. PAS, along with assistive technology such as wheelchairs, text readers, and hearing aides, help people with disabilities to participate in activities at home, at work, and in the community.

The purpose of this newsletter is to provide the latest news on issues relating to formal and informal PAS, home & community-based services, the PAS workforce, and workplace PAS within and outside of the Center.

Detail about the Center staff and advisors can be found at <http://www.pascenter.org/about/>