



# BULLETIN

August 2008

Vol. 5, Issue 3

## IN THIS ISSUE:

- News
- On the Center for PAS website
- Policy and Legislation
- Research articles and reports
- **SELECTED CONFERENCES DURING August, September, and October 2008**

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*This document was developed by the Center for Personal Assistance Services, funded by the National Institute on Disability and Rehabilitation Research (NIDRR) of the US Department of Education, grant #H133BO31102. The opinions contained in this publication are those of the grantee/contractor and do not necessarily reflect those of the US Department of Education. Please credit the source and support of federal funds.*

<http://www.ed.gov/about/offices/list/osers/nidrr/>

<http://www.disabilityinfo.gov>



## News

### **The Center for Personal Assistance Services Receives Five-Year Grant For Research On Personal Assistance Services For People With Disabilities**

The Center for Personal Assistance Services has received its second \$4.25 million, five-year grant from the National Institute on Disability and Rehabilitation Research.

The funding, for which the Center competed with other institutions nationwide, will enable the Center to continue its research and training activities related to personal care services provided to people with disabilities.

“Being awarded this grant for the second time in a row is a testament to the important work that the Center for Personal Assistance Services has accomplished in the past five years,” said Kathleen Dracup, RN, DNSc, dean of the UCSF School of Nursing. “We are excited about the progress we can make for people with disabilities in the next five years.”

The Center will continue to study issues regarding the availability and quality of services provided by formal and informal caregivers to some 15 million people

nationwide who need help performing activities of daily living, according to Charlene Harrington, PhD, RN, UCSF professor emerita of sociology and nursing, and the Center's director and principal investigator.

“The emphasis of our work is on providing support so that people with disabilities can live and work independently in their community, as opposed to being institutionalized in a nursing home,” Harrington said.

In the last five years, research through the Center has determined a more fiscally feasible cost for such care than was previously estimated by the Congressional Budget Office for the Community Choice Act (CCA). The CCA would allow Medicaid to pay for home and community-based services, rather than solely placement in a nursing home, for those who qualify for nursing home level of care. Center research also found that wage levels for PAS workers fell behind those of comparable occupations and that health benefits are scarce and job turnover rates are high among workers.

Common services provided by a personal care attendant include help with bathing, eating, dressing, walking, taking medication and shopping for groceries, Harrington said.

The Center will continue to conduct research in workforce issues related to home-based and community care. Other research and training topics will include:

- Improving access to PAS for people with disabilities
- Strengthening the PAS workforce to support individuals who are employed or seeking employment
- Understanding the economics behind PAS, including the relationship among PAS, employment, employment supports, and assistive technology (assistive technologies are those products that improve or enhance the functional capabilities of those with disabilities).

The Center also will continue to seek guidance and feedback from the community by working with its advisory committee, which is composed of local and national PAS users, disability advocates, business leaders, independent living center directors and academics. In addition, the Center will collaborate with faculty members at the Burton Blatt Institute, InfoUse, PHI (formerly the Paraprofessional Healthcare Institute), Research Triangle Institute, and the Topeka Independent Living Resource Center, and will work with consultants at the University of Maryland, University of Michigan and the Cardiff Business School.

Since 1994, work conducted in the UCSF School of Nursing, and specifically in the Department of Social and Behavioral Sciences and the Institute for Health and Aging, has focused on research and advocacy issues facing people with disabilities. Harrington said the Center's faculty members are among

the nation's leading researchers in their field, with decades of research and policy experience, hundreds of academic publications, and teaching experience in disability, health, long-term care, and policy studies.

Co-principal investigators for the Center include Steve Kaye, PhD, research director, and Mitch LaPlante, PhD, director, both of the UCSF Disability Statistics Center; Bob Newcomer, PhD, UCSF professor of sociology; and Lewis Kraus, MPH, MCP of InfoUse, a Berkeley-based firm specializing in research and dissemination that aids people with disabilities. Other UCSF faculty members include Susan Chapman, PhD, RN; Amy Houtrow, MD, MPH; Joe Mullan, PhD; and Taewoon Kang, PhD.

The National Institute on Disability and Rehabilitation Research is part of the U.S. Department of Education's Office of Special Education and Services.

### **ICDR Seeks Input on Disability Research Agenda**

The Interagency Committee on Disability Research (ICDR) encourages individuals with disabilities or organizations representing individuals with disabilities such as: 1) service providers, 2) disability and rehabilitation research and policy groups, and 3) advocacy organizations with specialized disability knowledge and experience, to suggest specific ways to improve future disability and rehabilitation research to benefit individuals with disabilities. They are also interested in hearing from individuals concerning how well the existing federal

research programs are responding to the changing needs of individuals with disabilities. These comments can cover a wide range of research areas, including, but not limited to, the following:

- Employment of people with disabilities
- Community integration and continuum of care
- Health disparities
- Access to assistive technology and universal design
- Transition of youth to employment and independent living
- Availability of accessible housing, transportation and recreation

Opportunities for public testimony on the federal disability research agenda are available in person or by telephone on August 5th and 13th for one session each day. The ICDR Stakeholder meetings are open to the public from 9 a.m.–12 p.m. Eastern time on August 5th and 1–4 p.m. Eastern time on August 13th at the Doubletree Hotel in Arlington, VA. The meetings may also be accessed by telephone or webcast. Registration is required to testify and each speaker will be given five minutes to present remarks on a first-come, first-served basis. ICDR panel members may ask the person testifying a specific question about the testimony, but will not respond directly to the issue presented.

If you cannot physically attend the Public Meeting, or do not wish to give comments orally by phone, you may still submit your written testimony. All testimony will be

treated the same regardless of the way it is transmitted.

For more information, go to  
<http://www.icdr.us/stakeholders/index.html>

### **Harrington Attends International Workshop**

Charlene Harrington attended a workshop on the International Analysis of Long-Term Care in Toronto on July 23-24, sponsored by the Social Sciences and Humanities Research Council of Canada. The workshop brought eight faculty together from Canada, the US, Sweden, Norway, the U.K. and Germany to discuss international collaborative research efforts. PAS Center faculty hope to expand their international research collaborations.

### **Massachusetts Settlement Will Bring Over 600 Individuals With Developmental Disabilities Out Of Nursing Homes.**

A settlement between the administration of Governor Deval Patrick and disability advocates in Massachusetts will allow over 600 nursing home residents with developmental disabilities to move to more independent community residences. The movement out is projected to take four years. Most of the residents are significantly younger than those the nursing facilities were designed for, and the 10-year old lawsuit focused on federal requirements for placement in the most integrated setting.

For more information, go to  
[http://www.pascenter.org/news/news\\_home.php?id=142](http://www.pascenter.org/news/news_home.php?id=142)

### **On the Center for PAS website**

The following are new resources available on the Center for PAS website (<http://www.pascenter.org>):

#### **Evaluation of California's Long Term Care Reimbursement Act**

Researchers at the University of California released an evaluation of impact of California's Long Term Care Reimbursement Act of 2004 (AB 1629) that showed that Medi-Cal costs for nursing homes increased by \$590 million between 2004 and 2006 without improvements in quality or access to care. Total costs for California's free-standing nursing homes were \$6.6 billion in 2006. The Long Term Care Reimbursement Act was designed to improve the quality of nursing home care by increasing Medi-Cal reimbursement rates, using a payment system based on actual costs of care for each facility with certain costs ceilings. Implemented in 2004-05, the system raised Medi-Cal rates from \$124 per day in 2004 to \$152 per day in 2006. The report showed that access for Medi-Cal residents, quality of care in nursing homes did not improve between 2004 and 2006. Expenditures for administrative costs increased and net income margins improved over the period.

For more information, go to

[http://www.pascenter.org/nursing\\_homes/index.php#lrcra](http://www.pascenter.org/nursing_homes/index.php#lrcra)

### **New Ask Mike questions and responses**

Recently, Mike Oxford answered a question about auxiliary grants and assisted living facilities.

To read that question and answer, go to

[http://pascenter.org/pas\\_users/ask\\_mike12.php](http://pascenter.org/pas_users/ask_mike12.php)

To read the all of the Ask Mike letters and responses, go to

[http://www.pascenter.org/pas\\_users/ask\\_mike.php](http://www.pascenter.org/pas_users/ask_mike.php)

### **Updates to Center for PAS website implemented**

Several improvements have been implemented on the PAS Center web site. These include:

- A more effective Google Search mechanism
- Updated links to SSA's Ticket to Work data ([http://pascenter.org/workplace\\_pas/index.php](http://pascenter.org/workplace_pas/index.php))
- New Medicaid Waiver data for Pennsylvania ([http://pascenter.org/state\\_based\\_stats/medicaid\\_waivers\\_info.php?state=pennsylvania#277](http://pascenter.org/state_based_stats/medicaid_waivers_info.php?state=pennsylvania#277) )

## **Policy and Legislation**

### **Tennessee Governor Signs Long-Term Care Legislation**

Governor Phil Bredesen joined legislators and long-term care advocates for a series of ceremonial bill signing events across the state to mark the passage of the Long-Term Care Community Choices Act of 2008. Bredesen proposed the legislation in his State of the State address in January to add new choices in home- and community-based services.

"The effect of this legislation is truly significant, and I appreciate the bi-partisan support of the General Assembly in making these changes," Bredesen said. "This is a wholesale approach to improving the way we handle long-term care in our Medicaid system. This legislation fundamentally restructures the way care is delivered in our state and will create positive changes for families in every county in Tennessee."

In January, Governor Bredesen marked this as the year to deliver on his promise to expand alternatives to nursing homes for elderly and physically disabled residents. These changes to the TennCare program, the state's largest single payer of long-term care services, allows \$1.2 billion in TennCare funds to be more evenly divided between traditional nursing homes and home- and community-based service providers. Prior to the new law, nursing homes received 98 percent of long-term care funds in Tennessee.

For the full text of the Long-Term Care Community Choices Act of 2008, go to <http://www.legislature.state.tn.us/bills/currentga/Chapter/PC1190.pdf>

## Research articles and reports

### **PHI Reports on Rapid Growth in Demand for Direct-Care Workers**

A new report from PHI, entitled Facts 1: Occupational Projections for Direct-Care Workers 2006-2016, confirms what consumer and long-term care providers already know - the rapid demand for services is outpacing the growth of the labor force.

By 2016, the direct-care workforce is expected to grow to 4 million, eclipsing registered nurses, teachers, cooks and food prep workers, fast food and counter workers, waiters and waitresses, and cashiers. Overall demand for direct-care workers is projected to increase by 34 percent over the next decade while the number of women aged 25-54—the main labor pool from which these workers are drawn—is projected to increase by less than 1 percent. Personal and Home Care Aides and Home Health Aides are projected to be the second- and third fastest-growing occupations in the country between 2006 and 2016.

These new projections speak to the historical proportions that the direct-care workforce has now assumed,” said Dr. Dorie Seavey,

PHI Director of Research and the report’s author. “This workforce can no longer be an afterthought in policy discussions.”

The report also shows that the majority of direct-care workers are now employed in home and community-based settings, and this trend will continue. PHI contends that this is a positive development but America is not prepared to care for its growing population of elders and people with disabilities.

It’s essential that state and federal policymakers develop workforce policy that supports growing demand for person-centered services delivered at home. “In order to meet demand during the next decade, the quality of direct-care jobs, particularly those in home and community-based settings, must be improved,” said Dr. Seavey. “Policymakers and employers must work together to make these jobs competitively attractive as compared to other occupations.”

To retrieve the full report in pdf, go to <http://www.directcareclearinghouse.org/download/BLSfactSheet4-10-08.pdf>

### **Paper on Consumer Direction and Elderly People with Mental Illness Released**

A new paper entitled, "Does Mental Illness Affect Consumer Direction of Community-Based Care? Lessons From the Arkansas Cash and Counseling Program", was published recently in the Gerontologist. The

authors examined whether consumer direction is effective for elderly people with mental illness. The treatment group, those that participated in Cash and Counseling (C&C), fared better than elderly people that have a mental illness but did not participate in C&C. They also fared as well as elderly people without mental illness that were in the program. Variables studied included measures of consumer satisfaction as well as objective measures such as health, among others. The reference is Ce Shen, Michael A. Smyer, Kevin J. Mahoney, Dawn M. Loughlin, Lori Simon-Rusinowitz, and Ellen K. Mahoney Gerontologist 2008 48: 93-104.

For the paper, go to  
<http://gerontologist.gerontologyjournals.org/cgi/content/abstract/48/1/93>

### **Kaiser Foundation Releases Reports On Consumer Directed Personal Assistance Services.**

The Kaiser Foundation recently released two reports on Consumer Directed Personal Assistance Services (CD-PAS). CD-PAS are methods of allowing individuals more control over their services, including options for hiring, firing and setting schedules for service providers. In 2006, forty-two states offered this option, but the utilization of the services remained limited. The Kaiser reports look at quality of training, motivational factors of the workers, and ways that states monitor quality. One report examines issues from the state policymaker perspective, and the other examines issues from the perspective of enrolled individuals.

For the paper, go to  
<http://www.kff.org/medicaid/kcmu032408pkg.cfm>

## **SELECTED CONFERENCES DURING August, September, and October 2008**

For more detail about these conferences, go to:  
<http://pascenter.org/conferences/index.php>

### **August**

*August 01 - August 02, 2008*

#### **2008 NBDA Regional Conferences: Southwestern Region**

Hosted By: National Black Deaf Advocates

Location: Little Rock, AR

[http://www.nbda.org/regional/Regional\\_Conference.html](http://www.nbda.org/regional/Regional_Conference.html)

*August 01 - August 04, 2008*

#### **American Sociological Association 103rd Annual Meeting**

Hosted By: American Sociological Association

Location: Boston, MA

[http://www.asanet.org/cs/2008\\_meeting](http://www.asanet.org/cs/2008_meeting)

*August 10 - August 12, 2008*

#### **Reinventing Quality Conference 2008**

Hosted By: Research and Training Center on Community Living

Location: Baltimore, MD

<http://www.reinventingquality.org>

*August 12, 2008*

**Accommodation Process**

Hosted By: Job Accommodation Network (JAN)

Location: Webcast, 2:00 - 3:00 P.M. ET

<http://www.jan.wvu.edu/webcast/>

*August 13 - August 17, 2008*

**Jewish Deaf Congress Conference**

Hosted By: Jewish Deaf Congress

Location: Princeton, NJ

<http://www.jewishdeaf2008.com>

*August 21 - August 24, 2008*

**The Kennedy Center's Leadership Exchange In Arts And Disability Conference And Training**

Hosted By: Kennedy Center

Location: Fort Lauderdale, FL

<http://www.kennedy-center.org/accessibility/education/lead/conference.html>

*August 24 - August 27, 2008*

**16th Annual Alzheimer's Association Dementia Care Conference**

Hosted By: Alzheimer's Association

Location: Garden Grove, CA

<http://www.alz.org/careconference/08/overview.asp>

**September**

*September 02 - September 05, 2008*

**West Coast Conference on Aging**

Hosted By: American Society on Aging

Location: San Francisco, CA

<http://www.asaging.org/asav2/COA08/indexwest.cfm>

*September 03 - September 06, 2008*

**21st Annual National Independent Living Conference**

Hosted By: Daniel Memorial Institute

Location: Orlando, FL

<http://www.danielkids.org/sites/web/content.cfm?id=276>

*September 04 - September 07, 2008*

**National Self Advocacy Conference**

Hosted By: SABE

Location: Indianapolis, IN

<http://www.sabe2008.org/register/presenter.aspx>

*September 04 - September 06, 2008*

**Life@50+ National Event & Expo**

Hosted By: American Association of Retired Persons (AARP)

Location: Washington, DC

[http://www.aarp.org/aarp\\_benefits/natl\\_events/aarp\\_benefits/natl\\_events/dc/](http://www.aarp.org/aarp_benefits/natl_events/aarp_benefits/natl_events/dc/)

*September 09, 2008*

**Substance Abuse And Employment**

Hosted By: VCU

Location: Webcast, 2:00-2.45 P.M. ET

<http://www.crprcep.org/training/webcastSeries.cfm/7>

*September 12 - September 15, 2008*

**"Liberation Through The Spoken, Written, And Sung Word" Power Of Words Conference**

Hosted By: Goddard College

Location: Plainfield, VT

<http://www.goddard.edu/powerofwords>

*September 22 - September 25, 2008*

**East Coast Conference on Aging**

Hosted By: American Society on Aging

Location: Philadelphia, PA

<http://www.asaging.org/asav2/COA08/indexeast.cfm>

*September 23, 2008*

**Learning Disabilities In The Workplace**

Hosted By: Ernst & Young

Contact LanaSmart@abilitiesonline.org (516-465-1510) or BrettEisenberg@abilitiesonline.org or 646-338-4680

Location: New York, NY

*September 24 - September 25, 2008*

**5th National Organizational Change Forum**

Hosted By: Co-sponsored by ICI

Location: Kansas City, MO

<http://www.crprcep7.org/latest.html>

*September 28 - October 01, 2008*

**24th National Home and Community Based Services Conference**

Hosted By: National Association of State Units on Aging

Location: Boston, MA

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

**October**

*October 01 - October 03, 2008*

**2008 Southwest Conference On Disability**

Hosted By: Center for Development and Disability

Location: Albuquerque, NM

<http://cdd.unm.edu/swconf/index.asp>

*October 05 - October 08, 2008*

**"Expanding Inclusion: The Business Strategy" UBLN Annual Conference And Career Fair**

Hosted By: USBLN

Location: Portland, OR

<http://www.usbln.org>

*October 05 - October 07, 2008*

**Charting the Course for State Health Policy. NASHP's 21st Annual State Health Policy Conference**

Hosted By: National Academy for State Health Policy

Location: Tampa, FL

[http://www.nashp.org/\\_conferences.cfm?LID=CON](http://www.nashp.org/_conferences.cfm?LID=CON)

*October 06, 2008*

**Public Meeting**

Hosted By: National Council on Disability

Location: Kansas City, MO

<http://www.ncd.gov>

*October 07 - October 11, 2008*

**2008 California Association For Postsecondary Education And Disability (CAPED) Convention**

Hosted By: CAPED

Location: San Francisco, CA

<http://www.caped.net/convention/program.html>

*October 11 - October 13, 2008*

**2008 Association of Programs for Rural Independent Living (APRIL) Conference**

Hosted By: APRIL

Location: Las Vegas, NV

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

*October 11 - October 15, 2008*

**NAHC's 27th Annual Meeting**

Hosted By: National Association for Home Care & Hospice

Location: Fort Lauderdale, FL

<http://www.nahc.org/Meetings/AM/08/>

*October 14 - October 16, 2008*

**Mile High Expectations for State Health Policy**

Hosted By: National Academy for State Health Policy (NASHP)

Location: Denver, Colorado

<http://www.nashp.org/conferences.cfm?LID=CON>

*October 15 - October 19, 2008*

**2008 American Congress of Rehabilitation Medicine-American Society of Neurorehabilitation Joint Educational Conference**

Hosted By: American Congress of Rehabilitation Medicine and American Society of Neurorehabilitation

Location: Toronto, Ontario, Canada

[http://www.acrm.org/annual\\_conference/](http://www.acrm.org/annual_conference/)

*October 16 - October 17, 2008*

**"Brewing Best Practices In Transition"**

Hosted By: Division on Career Development and Transition

Location: Milwaukee, WI

<http://www.dcdt.org/pdf/MilwaukeeConfBrochure.pdf>

*October 16 - October 18, 2008*

**26th Annual Conference**

Hosted By: Closing the Gap

Location: Minneapolis, MN

<http://www.closingthegap.com/conf/index.las>  
[so](#)

*October 23 - October 24, 2008*

**Raising the Bar: Implementing Evidence-Based Programs for Caregivers**

Hosted By: Rosalynn Carter Institute and The National Implementation Research Network

Location: Americus, GA

<http://www.rciconference08.org/conferencehome.html>



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### **2008 Annual Meeting & Exposition**

Hosted By: American Public Health Association (APHA)

Location: San Diego, CA

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

*October 29 - October 31, 2008*

### **Inclusion And Diversity In The Workplace Conference And Job Fair**

For more information contact [tsida@embarqmail.com](mailto:tsida@embarqmail.com)

Location: Jefferson City, MO

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/>