



# BULLETIN

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

<http://www.disabilityinfo.gov>



## LaPlante Testifies At Senate Finance Committee

Mitch LaPlante, a researcher at the Center for Personal Assistance Services at UC San Francisco, appeared as a witness at the US Senate Finance Hearing titled "Home and Community Based Care: Expanding Options for Long Term Care". The hearing is on Tuesday Sept 25th at 10am in the Dirksen Office Building, Room G-50.

Senator Tom Harkin, Iowa, co-sponsor of the "Community Choice Act" began the hearing with a presentation that was followed by a panel of 4 presenters:

Bob Liston, Advocate from Montana  
Mitch LaPlante, University of California, San Francisco  
Patrick Flood, Director of Health and Human Services, Vermont  
Kevin Concannon, Director of Health and Human Services, Iowa

LaPlante presented testimony that included PAS Center research on the topics of unmet need, cost of HCBS vs. institutions, and the cost of the Community Choice Act.

The following is an excerpt of the report of the Hearing from the American Association of Persons with Disabilities (AAPD).

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***Panel Urges Broader Coverage of Home and Community Based Care***

*State health care officials and other witnesses told the Senate Finance Committee Sept. 25 that there is "an institutional bias" in the Medicaid program that places people with disabilities and the elderly in nursing homes, instead of allowing them to live in their own homes with home and community based care.*

*Speaking at a Sept. 25 committee hearing on "Home and Community Based Care: Expanding Options for Long Term Care," panelists urged support of the Community Care Act (S. 799) that would give Medicaid beneficiaries the choice of either going to a nursing home or getting personal care attendant services in their own homes.*

*Bill sponsor Sen. Tom Harkin (D-Iowa) told the committee that "there is a Medicaid bias where two-thirds of the money goes to nursing homes and a third goes to community care."*

*He added that home and community based services (HCBS) would provide personal attendance services that allow people to live independently and fully participate in their communities, goals he said were part of the Americans With Disabilities Act that became law 17 years ago.*

***'Mandatory' Option***

*Although Iowa and other states have Medicaid waivers to offer HCBS, Harkin said there are "bureaucratic entanglements" for*

*participating in the services, including a Medicaid spending cap and long waiting lists "It is time to move beyond the waivers and have broad-based community care," Harkin said.*

*The deputy secretary of the Vermont Agency of Human Services, director of the Iowa Department of Human Services, and the director of Montana Fair Housing echoed the request that Congress pass a law making HCBS a mandatory option offered under the Medicaid program.*

*"By making HCBS a mandatory benefit it would greatly reduce the institutional bias," said Mitchell La Plante, associate professor at the University of California, San Francisco, Department of Social and Behavioral Science.*

For more information on all witness statements, go to <http://www.finance.senate.gov/sitepages/hearing092507.htm>

A link to watch video of the hearing will be available on that page soon.

To read the AAPD report of the hearing, go to <http://www.aapd.com/News/longtermcare/070926bna.htm>

**On the Center for PAS website**

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

- *Meeting the Nation's Need for Personal Assistance Services State of the Science Conference*

A new page with links to the conference summary and conference proceedings is now available.

To go to the conference web page, go to [http://www.pascenter.org/sos\\_conference](http://www.pascenter.org/sos_conference)

To retrieve the conference summary as a pdf, go to [http://www.pascenter.org/documents/SOS\\_Conf\\_Summary.pdf](http://www.pascenter.org/documents/SOS_Conf_Summary.pdf)

To retrieve the conference proceedings as a pdf, go to [http://www.pascenter.org/documents/SOS\\_Conf\\_Proceedings.pdf](http://www.pascenter.org/documents/SOS_Conf_Proceedings.pdf)

- *State legislation regarding wages and benefits of home care workers: Thirteen promising practices*

This report focuses on promising examples of state legislation seeking to specifically increase the hourly wages or benefits of home, direct or personal care workers. The final list of promising practices consists of 11 bills and 2 legislative appropriations (LA and WY) from 2001-2007. Seven of the 13 bills or legislative appropriations considered 'promising practices' (AK, DC, LA, MI, NH, NY 2001-02, WY) for increased wages for workers and six (ME, MA, MT, NY 2007-08, WA 2006, WA 2004) are related to collective bargaining agreements/insurance coverage.

To retrieve the report, go to [http://www.pascenter.org/pas\\_workforce/promising\\_practices.php](http://www.pascenter.org/pas_workforce/promising_practices.php)

- *Successful strategies for recruiting and retaining direct service workers (CMS)*

Updates on the progress of the 2006 Centers for Medicare and Medicaid Services' National Direct Service Worker (DSW) Resource Center grantees outline 10 successful strategies for recruiting and retaining direct service workers.

For more information, go to [Detailed updates on each of the DSW Demonstration Grants](#)

- *Contact Info and Descriptions for Medicaid Waivers*

This is an update of contacts for HCBS waivers.

For more information, go to [Contact Info and Descriptions for Medicaid Waivers](#)

- *New Ask Mike question and response*

Mike Oxford talks about Medicaid waivers and choosing community options in a response to a person seeking an agency that has PAS.

To read the letter and response, go to [http://www.pascenter.org/pas\\_users/ask\\_mike8.php](http://www.pascenter.org/pas_users/ask_mike8.php)

## **Harrington to speak at International Disability Forum**

Charlene Harrington, the director of the Center for Personal Assistance Services, will speak at the International Forum on

Disability and Development: Caring, Participation, and Action in Beijing China in December. The theme of the forum, jointly sponsored by the China Disabled Persons' Federation, Peking University, University of Southern California, and Griffith University, is "Caring, Participation, and Action", which includes the following sub-themes:

- \* Education and Development
- \* Employment and Development
- \* Rehabilitation and Development
- \* Social Security and Development
- \* Community Service for Disabled Persons
- \* Disability Prevention
- \* Disabled Children
- \* Disabled Elderly Persons
- \* Marriage and Family of Disabled Persons

The purposes of the forum are:

- \* To commemorate the first anniversary of the Convention on the Rights of Persons with Disabilities issued on December 13, 2007, and have an across-the-board discussion regarding the value of the disabled, the social determinates, and issues such as the disabled people's health, employment, welfare, and education, among the academic fields, policy-making circles, and business communities;
- \* To celebrate: the 16th International Day of Disabled Persons, annually observed on December 3rd; the publication of the White Paper of the Development of Enterprise of Chinese Disabled Persons; and to provide a platform promoting the adoption and implementation of policies for the disabled by senior policy-making institutions and officials;
- \* To commemorate the anniversary of the second nationwide survey on the disabled (completed on December 3rd, 2006) and together, with an academic discussion on "Disability and Development," to make China's and other countries' policies for the

disabled people to become more pertinent in the near future;

- \* To encourage communication and exchange on the prevention and rehabilitation of disabilities, and to discuss policies and measures to encourage and support non-profit organizations and private sectors' development in catering the disabled people; and

- \* To provide professional training by international experts and enhance the construction of a network and team-building for the progress of the disabled community.

## News

### **Ohio Taking Steps to Allow Older Adults More Independence**

During the last month, lawmakers in Ohio have taken steps to expand options that allow older adults with long-term care needs to remain independent and living in the community. First, in July, Ohio expanded Medicaid - which last year began to cover assisted living costs for recipients who decided to move into such facilities - to include residents already living in those facilities. Then, on August 5, 2007, the Dayton Daily News reported that Governor Ted Strickland eliminated the 1,100-person waiting list for the state's Passport program, which provides home care services to seniors 60 and older who are Medicaid eligible, by adding 5,000 slots to the program. Such moves allow low-income seniors and their families more access to the types of long-term care services they prefer.

For more information, go to

<http://www.daytondailynews.com/search/content/oh/story/news/local/2007/08/05/ddn080507passport.html>

### **Consumer-Directed, Home and Community Services for Adults with Dementia**

The Alzheimer's Association released a public policy issue brief by Dr. Jane Tilly in July 2007 called "Consumer-Directed, Home and Community Services for Adults with Dementia." The brief describes the provisions of consumer-directed, home- and community- based programs that serve older adults with dementia in 11 states, including provisions related to determining whether a participant needs assistance with managing services, meeting family caregiver needs and quality assurance. It also provides policy recommendations for states considering expansion or implementation of consumer-directed programs that serve dementia families. One recommendation is that "states need to evaluate a family caregiver's needs when that caregiver is making it possible for the adult with dementia to remain in the community and then connect the caregiver with available supportive services."

For more information, go to

[http://www.alz.org/join\\_the\\_cause\\_issue\\_brief.asp](http://www.alz.org/join_the_cause_issue_brief.asp)

### **GAO releases Highlights of Forum on Modernizing Federal Disability Policy**

In August, the General Accounting Office (GAO) released a report called Highlights of a GAO Forum: Modernizing Federal Disability Policy, which concluded that to the

extent that federal disability programs match current realities, benefits can be achieved for individuals with disabilities, business, and government, but that the "solutions are likely to require fundamental changes" through regulation and legislation. Furthermore, they note that if there is no federal leadership at this time, "there could be fewer options in the future available to policymakers seeking to improve federal disability programs. "

To retrieve the report, go to

<http://www.gao.gov/new.items/d07934sp.pdf>

## **Research articles and reports**

### **Special Edition of Journal of Aging & Social Policy focusing on Personal Assistance**

The Journal of Aging & Social Policy has published a special edition on personal assistance. Guest edited by Martin Kitchener from the Center for Personal Assistance Services at the University of California, San Francisco, it is Volume 19, Number 3 2007. The journal included the following articles:

*Medicaid State Plan Personal Care Services: Trends in Programs and Policies*

This article presents the latest available data on the Medicaid Personal Care Services (PCS) optional benefit. This option allows states to fund non-medical assistance services for Medicaid recipients, including help with daily living activities provided by family caregivers or direct care workers. The article, "Medicaid State Plan Personal Care Services: Trends in Programs and Policies," by Dr.

Martin Kitchener, Terence Ng and Dr. Charlene Harrington, reveals that between 1999 and 2002 the number of states providing the benefit went from 26 to 30 and national program participation increased by 27%. At the same time, program expenditures per person declined, the range of services provided declined and almost half of the programs placed a cap on the hours of service provided.

*Paid Personal Assistance Services: An Exploratory Study of Working Age Consumers' Perspectives*

This study examined the experiences of individuals who use paid personal assistance services (PAS). Structured interview data were collected from a convenience sample of 24 working-age individuals from diverse backgrounds recruited from Centers for Independent Living in nine states. Respondents described their general satisfaction with current paid PAS, but many reported previous experiences with poor care related to the low wages, lack of training of PAS providers, and an inadequate supply of providers. Respondents reported many unmet needs because of a shortage of hours provided by state programs and the lack of help with daily living activities, transportation, childcare, and social activities. The respondents strongly preferred consumer-directed care.

*Estimating the Expense of a Mandatory Home- and Community-Based Personal Assistance Services Benefit Under Medicaid*

This study aims to provide an estimate of the expense of a mandatory personal assistance services (PAS) benefit under Medicaid for persons with low incomes, low assets, and significant disability. Design and methods: We use year 2003 data from the Survey of Income and Program Participation to estimate the number of people living in households who would be eligible, based on having an institutional level of need and meeting financial criteria for low income and low assets, combined with additional survey data on annual expenditures under Medicaid programs providing PAS. Results: New expenditures for PAS are estimated to be \$1.4-\$3.7 billion per year (in 2006 dollars), depending on the rate of participation, for up to half a million new recipients, more than a third of whom would be ages 65 and older. These estimated expenditures are a tenth of those estimated by the Congressional Budget Office for implementing the Medicaid Community-Based Attendant Services and Supports Act (MiCASSA). Implications: Creating a mandatory PAS benefit for those with an institutional level of need is a fiscally achievable policy strategy to redress the imbalance between institutional and community-based services under Medicaid.

*Personal Assistance in Sweden*

"Personal Assistance in Sweden" by Ulla Clevnert and Dr. Lennarth Johansson, provides an overview of the Swedish personal assistance program for people with disabilities. Established in 1994, the program "is intended to make it financially possible

for a person with severe disabilities to appoint a personal assistant, on their own or through a provider," to help with daily care. The personal assistant, who can be a family member, is supposed to help create a care plan that is suited to the person's needs and provide assistance with daily living. The program is available for children and adults, however adults over 65 are only allowed this benefit if they were enrolled in the program before they turned 65 years old. The article concludes that "the personal assistance has enhanced the quality of life for people with severe disabilities and their families."

*Provider and Care Workforce Influences on Quality of Home-Care Services in England*

A key trend in home care in recent years in England has been movement away from "in-house" service provision by local government authorities (e.g., counties) towards models of service commissioning from independent providers. A national survey in 2003 identified that there were lower levels of satisfaction and perceptions of quality of care among older users of independent providers compared with in-house providers. This paper reports the results of a study that related service users' views of 121 providers with the characteristics of these providers. For the most part, characteristics associated with positive perceptions of quality were more prevalent among in-house providers. Multivariate analyses of independent providers suggested that aspects of the workforce itself, in terms of age and experience, provider perceptions of staff turnover, and allowance of travel time, were

the most critical influences on service user experiences of service quality.

To retrieve the articles or the publication, go to

[Journal of Aging & Social Policy](#)

**New papers on Developmental Disability and Living in the Community released**

Charlene Harrington, Ph.D. and Taewoon Kang, Ph.D. completed three papers that examined individuals with developmental disabilities (DD) in California. The first paper entitled Factors Associated with Living in Developmental Centers in California reports on regression analyses of secondary data on clients, provider supply, population characteristics, and regions in 2004-05. The study found that while client needs were the most important factor predicting living in developmental centers (compared to home or the community), more individuals with similar needs were living at home and in the community. Men, other races, and older individuals had higher odds of living in developmental centers while the supply of residential care beds for the elderly reduced the odds. Wide variations in the odds of living in developmental centers across regions were found, controlling for client needs. Barriers to living at home and in the community need to be addressed.

The second paper entitled Disparities in Service Utilization and Expenditures for Individuals With Developmental Disabilities examined individuals living at home and in

residential settings in California in 2004-05. Regression analyses were conducted on the 175,595 individuals with developmental disabilities evaluated by regional centers. Of those with DD, 21 percent did not receive any purchases services from the regional centers, although they may have received services from other organizations and programs. Controlling for need, individuals age 3-21 and all racial and ethnic minority groups were less likely to received services and had lower expenditures. Provider supply and area population characteristics, and regional centers also explained the wide variations in service use and expenditures. The disparities by age, gender, and race/ethnicity need to be addressed.

The third paper entitled Variation in Types of Service Use and Expenditures for Individuals With Developmental Disabilities examined the patterns of use and expenditures for individuals living at home and in residential settings in California in 2004-05. Regression analyses were conducted on the 138,336 individuals with developmental disabilities who received services from regional centers. Controlling for client needs and other factors, the patterns of service use and expenditures varied widely by gender, age, and race/ethnicity. The provider supply, area population characteristics, and regional centers predicted wide variations. The underlying reasons for the variations need to be understood and new approaches are needed to ensure equity in access to services and expenditures.

Charlene Harrington will be presenting two of these papers in the California State Capital

on Wednesday October 3, 2007, sponsored by Assembly Member Jim Beall, Jr., Chair of the Assembly Human Services Committee. This is the second Roundtable Discussion on "Taking the Lanterman Act into the Future: Improving Outcomes, Accountability, Equity, and Fairness in the Developmental Service Delivery System."

## **SELECTED CONFERENCES DURING October, November, and December 2007**

For more detail about these conferences, go to:

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

### **October**

*October 06 - October 08, 2007*

Annual National Conference on Rural Independent Living

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

Location: Missoula, MT

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

*October 06 - October 10, 2007*

26th Annual Meeting

Hosted By: National Association for Home Care & Hospice

Location: Denver, Colorado

<http://www.nahc.org/Meetings/am/07/home.htm>

*October 08 - October 11, 2007*

Autumn Series on Aging: West Coast

Hosted By: American Society on Aging

Location: San Francisco, CA

<http://www.asaging.org/asav2/autumnconference/as07/>

*October 11 - October 13, 2007*

7th Annual National Aging and Law Conference

Hosted By: The National Association of State Units on Aging

Location: Arlington, Virginia.

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

*October 14 - October 16, 2007*

Achieving Balancing by Offering Choice: Money Follows the Person. NASHP's 20th Annual State Health Policy Conference

Hosted By: National Academy for State Health Policy

Location: Denver Marriot City Center, Denver, Colorado

[http://www.nashp.org/docdisp\\_page.cfm?LID=AAA59523-5D5A-4CE2-8935A38A333D606E](http://www.nashp.org/docdisp_page.cfm?LID=AAA59523-5D5A-4CE2-8935A38A333D606E)

*October 14 - October 16, 2007*

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 18 - October 20, 2007*

25th Annual Conference

Hosted By: Closing the Gap Inc. Assistive Technology Resources for Children and Adults with Special Needs

Location: Minneapolis, Minnesota.

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

*October 26 - October 27, 2007*

Ensuring Equal Opportunities: A Whole Student Approach.

Hosted By: Association on Higher Education and Disability (AHEAD)

Location: Chicago, IL

[http://www.ahead.org/training/reg\\_training/index.php](http://www.ahead.org/training/reg_training/index.php)

*October 28 - October 29, 2007*

2nd National Concepts in Care Conference

Hosted By: Alzheimer's Foundation of America

Location: Philadelphia, PA

<http://www.alzfdn.org/events.shtml>

*October 29 - October 31, 2007*

Transcultural Mental Health in a Changing World: Building a Global Response

Hosted By: World Federation for Mental Health (WFMH).

Location: Minneapolis, MN.

<http://www.wfmh.com/documents/TransculturalPrelimFINAL.pdf>

November

*November 03 - November 07, 2007*

2007 Annual Meeting & Exposition

Hosted By: American Public Health Association (APHA)

Location: Washington, DC.

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

*November 12 - November 14, 2007*

2007 Fall National Association of State Medicaid Directors (NASMD) Meeting

Hosted By: NASMD

Location: Washington, DC.

[http://www.nasmd.org/Home/home\\_news.as](http://www.nasmd.org/Home/home_news.asp)

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*November 13 - November 16, 2007*

2007 C4A Annual Meeting and Allied Conference

Hosted By: California Association of Area Agencies on Aging (C4A)

Location: Los Angeles, CA

<http://www.c4a.info/CLC07HP.html>

*November 16 - November 20, 2007*

60th Annual Scientific Meeting of The Gerontological Society of America

Hosted By: The Gerontological Society of America

Location: San Francisco, CA.

<http://www.agingconference.com/>

*November 29 - November 30, 2007*

2007 Assistive Technology Expo - Empowerment in Progress: AT in Action

Hosted By: Partnerships in Assistive Technology (PAT)

Location: Raleigh, North Carolina.

<http://www.pat.org/expo.html>

December

*December 03 - December 05, 2007*

Consumer Directed Healthcare Conference

Hosted By: CDHCC

Location: Washington, DC.

<http://www.consumerhealthworld.com/cdhccf07/>

*December 05 - December 08, 2007*

Equity, Opportunity and Inclusion. 2007 Annual TASH Conference.

Hosted By: TASH

Location: Seattle, Washington.

<http://www.tash.org/2007tash/index.htm>

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/>