



# BULLETIN

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## IN THIS ISSUE:

- Center for PAS State of the Science Conference
- On the Center for PAS website
- Resources
- News
- Research articles and reports
- **SELECTED CONFERENCES DURING July, August, and September 2007**

Center for Personal Assistance Services  
Department of Social & Behavioral Sciences  
University of California San Francisco  
3333 California Street, Suite 455  
San Francisco, D.C. 94118  
Telephone: 866-PAS-9577 (866-727-9577) or  
415-502-7190 TDD/TTY: 415-502-5216  
E-mail: PAS@ucsf.edu  
<http://www.pascenter.org>

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

<http://www.disabilityinfo.gov>



## Center for Personal Assistance Services State of the Science Conference

A one-day state of the science conference on meeting the nation's needs for personal assistance services (PAS) was held by the national Center for Personal Assistance Services at the University of California San Francisco (UCSF) at the National Press Club on April 27, 2007. The conference was sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR) and the Agency for HealthCare Policy and Research (AHRQ).

PAS, also known as personal or attendant services, is defined as paid or unpaid help with activities of daily living or instrumental activities of daily living for individuals with disabilities who are living at home, in the community, and at the workplace. The conference had two purposes: (1) to summarize, synthesize, and disseminate current research findings on PAS to researchers, policy makers, advocates, and other stakeholder groups, and (2) to discuss research issues in the delivery of PAS in order to develop a future research agenda for the study of PAS.

The conference was attended by 120 individuals representing a broad array of organizations and individuals including: researchers, academics, federal and state policy makers, consultant, PAS users, policy analysts, health professionals, and

representatives of disabled and aged advocacy and consumer organizations. Registration was from 24 states and three international areas.

Opening statements were presented by David Keer, NIDRR; D.E.B. Potter, AHRQ; and Mike Oxford, Director of the Topeka Independent Living Resource Center and Charlene Harrington, Ph.D., Director of the Center for PAS.

Research presentations were made on Met and Unmet Need for PAS by Mitch LaPlante, Ph.D. and on Home and Community-Based Services: National Trends and Inter-State Variations by Martin Kitchener, Ph.D., with comments by Mike Collins, Executive Director of the California State Independent Living Council. Some of the key points made were:

- The 22 billion hours of paid and unpaid PAS provided annually are worth \$200 billion (85 percent are unpaid). Of individuals who use PAS, 20-30 percent have unmet needs and they often experience adverse consequences including: hunger, discomfort, involuntary weight loss, and injury. The cost of eliminating the unmet need for PAS would be \$1.4-\$3.7 billion per year, or one-tenth of previous cost estimates.
- The Medicaid program provided home and community based services to 2.6 million people and spent about \$29 billion in 2003. Even though expenditures have grown by 65 percent since 1999, there are wide variations across states in participants and expenditures, and an unmet need based on the large and long waiting lists for services in many states.

The session on PAS in the Workforce and the Workplace was introduced by Steve Tingus, Director of NIDRR and moderated by David Keer from NIDRR. Steve Kaye, Ph.D. at UCSF presented Trends in the PAS Workforce followed by comments from Vera Salter, Director of the National Clearinghouse on the Direct Care Workforce. Lewis Kraus, MPH, MCP, Vice Present of InfoUse, presented on the ADA and Beyond: Reducing Barriers to PAS at Work, followed by D.J. Hendricks from the Job Accommodation Network on the Use of PAS in the Workplace.

Some of the key points made were:

- The PAS workforce has grown rapidly from 1989 to 2005, parallel to the growth in Medicaid home and community based service expenditures. There are large variations in the ratio of PAS workers to people with disability across states and in wages for workers. Although wages for PAS workers have increased with inflation over time, they have not kept paced with similar wages in entry-level occupations and most do not have health insurance coverage. The future growth in the workforce is hampered by the low wages, poor working conditions, immigration policies, and threatened Medicaid cuts.
- Barriers to individuals with disabilities participating in the workforce were identified including limited access to PAS in the workplace. PAS users generally had to find their own funding sources for PAS at work, faced long waiting times for PAS, and reported negative attitudes by co-workers and supervisors about their need for or use of PAS. Promising practices included the use of shared

personal assistance and using outside contractors and public funds to provide PAS.

Bob Kafka, from ADAPT of Texas (American Disabled for Attendant Services Today) introduced the luncheon speaker, Andrew Imparato, J.D., President and CEO of the American Association of People with Disabilities who spoke on Justice Delayed: Modernizing PAS Policy in a Challenging Environment.

- While the percent of expenditures for institutional care has decreased as home and community based services have increased, the support for people to live at home and in the community is not adequate. Disability advocacy groups need for form coalitions with other advocacy groups to support legislative changes. The United Nation's Convention for the Human Rights for Persons with Disabilities needs to be promoted within the US and internationally.

Ruth Brannon, NIDRR moderated the afternoon session on Future Research and Policy Directions. Future Research and Policy Directions from the PAS Center was presented by Robert Newcomer, Ph.D. from UCSF. Joshua Wiener, Ph.D., Senior Fellow at RTI International spoke on Consumer-Directed Home Care: Washington State and Beyond. Nancy Miller, Ph.D., Associate Professor at the University of Maryland Baltimore County spoke on Focusing on the Needs of Vulnerable Working Age Populations. Finally, Peter Kemper, Ph.D., Professor at Pennsylvania State University presented Three Types of Evidence Needed to Expand and Improve PAS.

- Research priorities should focus on provider training, provider/consumer communications, wage and benefit policies, housing and PAS linkages, support for informal caregivers, and the integration of services across the continuum of care.
- Medicaid beneficiaries in Washington State who used consumer-directed services were more satisfied than those using agency directed services. Future research should study quality through government regulation, identify the determinants of workforce retention and quality of services, and identify the impacts of consumer directed services on prices and cost effectiveness.
- Working age individuals are a growing proportion of the nursing home population, and they tend to be minority, male, never married, with low educations, on Medicaid or uninsured, and have chronic conditions. Future research should study vulnerable working age group to understand the risks to institutionalization, prevention of institutionalization, and how to maintain independence and employment.
- To expand and improve personal care services, the effects of public programs should be studied such as on unmet need and on families. Trend data on costs, on delivery, and outcomes of personal care are needed along with studies of how to improve the jobs and skills of personal care workers.

A summary of the conference can be found on the PAS Center's website at [http://www.pascenter.org/sos\\_conference](http://www.pascenter.org/sos_conference).



someone with a life-threatening illness or long-term disability. Host Dr. Geila Bar-David, a gerontologist and Caregiving specialist, guides viewers through this provocative and informative video series. Illustrated through the stories of 19 diverse caregivers, the caregiving journey is revealed to yield many rewards. Included are the emotional, physical, and psychological steps taken during a caregiver's experience.

To learn more, go to

[http://mavc.com/pages/item\\_detail.asp?ItemID=1117](http://mavc.com/pages/item_detail.asp?ItemID=1117)

## News

### **CMS Awards Grants to 13 States for Alternatives to Nursing Home Care**

The Centers for Medicare and Medicaid Services (CMS,) U.S. Department of Health and Human Services, has awarded grants to thirteen states and the District of Columbia for ALTERNATIVES to nursing home care. The thirteen states and the District of Columbia will receive \$547 million over 5 years to develop long term care programs that will allow individuals to receive services in their homes or in their communities. This is the second round of grants that will eventually provide \$1.7 billion to states to develop alternatives to the institutionalization of individuals with disabilities and the elderly.

For more information, go to

[CMS link](#)

### **New Project on Occupational Injury Among Personal Assistance Workers**

Robert Newcomer, Ph.D. has received funding for a new research project on Occupational Injury Among Personal Assistance Workers. The project is a state-wide survey of PAS providers and recipients in California's In Home Supportive Services program (IHSS). The funding agency is the National Institute for Occupational Safety and Health (NIOSH). The primary aim of this study is to document the occurrence of PAS work-related injuries over 12-months, the number of lost work days due to these injuries, and workers' perceptions of the occupational factors that contributed to these injuries. A secondary aim is to document consequences arising from any injuries.

For more information, contact the project director at

[Robert.Newcomer@ucsf.edu](mailto:Robert.Newcomer@ucsf.edu)

### **Texas Consumer Direction Legislation Signed into Law**

On June 16, 2007 Texas Governor Rick Perry signed a bill into law (S.B.1766) which would modernize language in Texas statute relating to consumer direction models of service delivery. Specifically, rather than referring to a voucher payment program for eligible adults with long-term care needs, the law will more clearly establish a "consumer direction model," defined as a service delivery model under which a consumer exercises control

over his or her individual service plan or over the persons delivering the services. The new law also charges the established Consumer Direction Work Group with developing recommendations to expand delivery of consumer direction services, to optimize the provider base for consumer direction, to expand access to support advisors, to monitor national research for best practices, and to provide assistance on outreach efforts.

For more information, go to

<http://www.capitol.state.tx.us/BillLookup/History.aspx?LegSess=80R&Bill=SB1766>

### **US Supreme Court Rules on Home Healthcare Workers Wage Rights**

A 9-0 decision by the US Supreme Court upheld a long-standing exception to the minimum wage law for workers providing "companionship services" at home to those who are sick or elderly.

To see the free summary article from the Los Angeles Times, go to

[LA Times link](#) (The full text is available for cost at that link)

To see the summary article from the New York Times, go to

<http://www.nytimes.com/2007/06/12/nyregion/12home.html?ref=nyregion> (Registration is required)

### **Montana Leads the Way in Covering Caregivers: Other States Also Explore Ways to Insure the Uninsured**

The National Clearinghouse on the Direct Care Workforce notes that Montana has

approved a new way of providing health care coverage for health care workers. As of January 2009, the state will increase its Medicaid payments to agencies that deliver in-home care so they can purchase health insurance for a significant number of their direct-care employees.

For more information, go to

<http://archives.subscribermail.com/msg/c1ae064d804f4c33b9469e100c75da22.htm>

## **Research articles and reports**

### **Special journal issue focusing on PAS issues**

A special issue of the Journal of Aging and Social Policy was published recently focusing on personal assistance. Volume 19, Issue 3 of the journal included the following three articles from the PAS Center:

*Mitchell P. LaPlante, H. Stephen Kaye, and Charlene Harrington. (2007). "Estimating the Expense of a Home and Community Based Personal Assistance Services Benefit Under Medicaid." Journal of Aging and Social Policy. 19 (3): 47-64.*

Personal assistance services (PAS) are essential for many people of all ages with significant disabilities, but these services are not always available to individuals at home or in the community, in large part due to a significant bias toward institutions in the Medicaid program. 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. We used 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. New expenditures for personal assistance services 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). 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.

*Kitchener, M., T., Ng and C. Harrington. (2007). Medicaid State Plan Personal Care Services: Trends in Programs and Policies. Journal of Aging and Social Policy. 19 (3): 9-26.*

Policymakers face mounting pressures from consumer demand and the 1999 Olmstead Supreme Court decision to extend formal (paid) programs that deliver personal care to the elderly, chronically ill, and disabled. Despite this, very little is known about the

largest program that delivers personal care: the Medicaid State Plan personal care services (PCS) optional benefit. This paper presents the latest available national program (participant and expenditure) trend data (1999-2002) on the Medicaid PCS benefit and findings from a national survey of eligibility and cost control policies in use on the program. The program trends show that, over the study period, the number of states providing the Medicaid PCS benefit grew by four (from 26 to 30) and national program participation, adjusted for population growth, increased by 27 percent. However, inflation-adjusted program expenditures per participant declined by 3 percent between 1999 and 2002. Findings from the policy survey reveal that between 1999 and 2002, there was a marked decline in the range of services provided.

*Grossman, Brian R., Kitchener, M., Mullan, J.T., and Harrington, C. (2007) Paid Personal Assistance Services: An Exploratory Study of Working-Age Consumers' Perspectives. Journal of Aging and Social Policy. 19 (3):27-45.*

This study examined the experiences of individuals who use paid personal assistance services (PAS). Structure interview data were collected from a convenience sample of 24 working-age individuals from diverse backgrounds recruited from Centers for Independent Living in 9 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.

To retrieve the issue, go to  
[Journal of Aging and Social Policy Link](#)

### **New journal articles published by PAS Center staff related to PAS**

A new paper entitled "Developing Personal Care Programs: National Trends and Interstate Variation, 1992-2002" authored by Martin Kitchener, Terence Ng, Helen Carrillo, Nancy Miller, and Charlene Harrington has been published in the journal *Inquiry*.

For more information, go to  
[http://www.pascenter.org/publications/publication\\_home.php?id=622](http://www.pascenter.org/publications/publication_home.php?id=622)

"Personal Assistance Services (PAS) for Workers with Disabilities: Views and Experiences of Rehabilitation Service Providers," an article being published in the forthcoming June issue of *Disability Studies Quarterly (DSQ)*, presents the results of research conducted to determine the experiences and perceptions of rehabilitation service providers on the provision of PAS in the workplace. Authored by Sita Misra, Louis E. Orslene, and Richard T. Walls, the study focused on (a) the definitional problems surrounding workplace PAS, (b) accessibility to PAS at the workplace, and (c)

availability of resources (money and trained personal attendants).

For more information, go to  
[http://www.pascenter.org/publications/publication\\_home.php?id=623](http://www.pascenter.org/publications/publication_home.php?id=623)

"Barriers to Documenting Occupational Injuries Among Personal Assistance Services Workers" has been published in the *American Journal of Industrial Medicine*. Authored by Teresa Scherzer and Robert Newcomer, this paper notes that current limitations undercount the prevalence and consequences of PAS-related occupational injuries among agency workers and largely ignore independent providers.

For more information, go to  
[http://www.pascenter.org/publications/publication\\_home.php?id=617](http://www.pascenter.org/publications/publication_home.php?id=617)

### **2007 Case For Inclusion Report: An Analysis of Medicaid for Americans with Intellectual and Developmental Disabilities**

The Case for Inclusion 2007, ranks all 50 States and the District of Columbia on how well they are providing community-based supports to Americans with intellectual and developmental disabilities being served by Medicaid. Some of the reports key findings include:

- Forty one states have 176 large state institutions (more than 16 beds) housing 39,000 Americans;
- Only 16 states direct more than 80% of funding to people living in the community;

- Sixteen states report very large and long waiting lists for services; and
- Only one in four people with disabilities participates in competitive employment.

To retrieve the report, go to

[http://www.ucp.org/uploads/Case For Inclusion Report 2007.pdf](http://www.ucp.org/uploads/Case_For_Inclusion_Report_2007.pdf)

## **SELECTED CONFERENCES DURING July, August, and September 2007**

For more detail about these conferences, go to:

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

### **July**

*July 09 - July 12, 2007*

Annual Conference on Independent Living: 25 Years of Celebrating Accomplishments & Forging New Leaders.

Hosted By: National Council on Independent Living

Location: Grand Hyatt Washington DC, 1000 H Street NW.

<http://www.ncil.org/conference2007.html>

*July 16 - July 18, 2007*

The 18th Annual APSE National Conference - Employment for all.

Hosted By: APSE

Location: Hyatt Regency Crown Center, Kansas City, MO

<http://www.apse.org/documents/apse2007confbro.pdf>

*July 17 - July 19, 2007*

Workforce Innovations Annual Conference

Hosted By: Work Force Innovations

Location: Kansas City, MO

<http://workforceinnovations.org>

*July 17, 2007*

ADA Update: 17 Years Later

Hosted By: ADA

Location: Teleconference, 1:00-2:30 PM CT

<http://www.ada-audio.org/Schedule/>

*July 24 - July 27, 2007*

14th Biennial International Conference, The Intergenerational Current: Across the Life Span and Around the Globe

Hosted By: Generations United

Location: Washington, DC

[http://www.gu.org/GU\\_Co12281388.asp](http://www.gu.org/GU_Co12281388.asp)

*July 30 - August 04, 2007*

National Federation of the Blind Youth Slam

Hosted By: National Federation of the Blind Jernigan Institute

Location: Baltimore, Maryland

[http://www.blindscience.org/ncbys/Youth\\_Slam.asp?SnID=1479761418](http://www.blindscience.org/ncbys/Youth_Slam.asp?SnID=1479761418)

### **August**

*August 06 - August 07, 2007*

Empowering Employers to Build an Inclusive Workforce - JAN's Sixth Annual Conference

Hosted By: JAN

Location: Arlington, VA  
<http://conference.jan.wvu.edu>

*August 10, 2007*

Carework Conference  
Hosted By: The Carework Network  
Location: New York City, NY  
(see details in text above)

*August 11 - August 14, 2007*

American Sociological Association 102nd  
Annual Meeting  
Hosted By: American Sociological  
Association  
Location: New York City.  
[http://www.asanet.org/cs/root/leftnav/meetings/2007\\_annual\\_meeting\\_convention\\_home](http://www.asanet.org/cs/root/leftnav/meetings/2007_annual_meeting_convention_home)

*August 26 - August 29, 2007*

15th Annual Alzheimer's Association  
Dementia Care Conference  
Hosted By: Alzheimer's Association  
Location: Chicagoo, IL  
<http://www.alz.org/careconference/07/overview.asp>

## **September**

*September 17 - September 20, 2007*

Autumn Series on Aging: East Coast  
Hosted By: American Society on Aging  
Location: Philadelphia, PA

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

*September 19, 2007*

Facilitating Self-Employment for Veterans  
with Disabilities  
Hosted By: Start-Up-USA  
Location: Webcast, 2:00-3:00 PM ET  
<http://www.start-up-usa.biz>

*September 19 - September 21, 2007*

US Business Leadership Network Conference  
Hosted By: US Business Leadership  
Network  
Location: Orlando, FL  
<http://www.usbln.com>

*September 19 - September 22, 2007*

20th Annual National Independent Living  
Conference  
Hosted By: Daniel Memorial Institute  
Location: Denver, CO  
<http://www.danielkids.org/sites/web/content.cfm?id=276>

*September 30 - October 03, 2007*

The 23rd National Home and Community  
Based Services Conference  
Hosted By: National Association of State  
Units on Aging and New Mexico Aging and  
Long Term Services Department  
Location: Albuquerque, New Mexico  
<http://www.nasua.org/waiverconference/>



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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/>

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