



BULLETIN

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



CENTER NEWS: PAS Center website

The Center for Personal Assistance Services website has recently released 2003 state-by-state data from the American Community Survey (ACS). For each state, there is the number of people with a disability, by type of disability, by self-care difficulty (a measure of personal assistance need), and by demographic variables. The state pages also list the number of home and personal care workers in each state (according to ACS data), state Olmstead plans and any finished or ongoing Olmstead-related legal cases, and agencies related to PAS and their contact information.

The website is located at <http://www.pascenter.org>
For more information on the state pages, go to:
http://www.pascenter.org/state_based_stats/index.php

California In-Home Supportive Services Update

California governor Arnold Schwarzenegger's preliminary 2004-05 Budget Bill proposed to eliminate a component of the state's In-Home Supportive Services (IHSS) program serving approximately 68,000 individuals. This component, known as the Residual Program, included Protective Supervision and Domestic Care services, and services provided by parents and spouses. Under the then existing regulations and the state's approved state plan for Medicaid, these services did not qualify for shared financing with the Medicaid program and were thus funded solely by state

and county sources. The objective of the administration's proposal was to obtain an estimated net savings from the IHSS program in Fiscal Year 2005 of \$366 million.

PAS Center researchers produced a report (funded by the California Healthcare Foundation) examining several assumptions underlying the state's original net savings estimate and considering potential increased costs (such as nursing home placement) not included in the administration's original net savings estimates. The analyses show that the original savings estimates were optimistic. As a result of the project's findings and input from others, the state modified its proposals and requested Medicaid approval to move much of its residual program under the regular IHSS program. This request was approved and the federal government now covers half the cost of these services. The parent and spouse provider component of the residual program could not be accommodated in this manner, but the state obtained an 1151 waiver to Medicaid that also allows federal contributions to pay parents and spouses to carry out PAS. Obtaining federal funding likely yields more true cost savings to the state, and with far fewer untested assumptions about transfers into community care facilities and nursing homes, than the original proposal for program elimination.

For more information, go to:
http://www.pascenter.org/publications/publication_home.php?id=73

New report on occupational injuries and illnesses for Nursing Aides, Orderlies, and Attendants

The latest data released by the U.S. Department of Labor reveals that in 2002, the occupational group "Nursing Aides, Orderlies, and Attendants" had the second-highest number of occupational injuries and illnesses that resulted in missed workdays, compared to all other occupational groups.

For more information, go to:
http://www.pascenter.org/publications/publication_home.php?id=67

An estimated 1 million workers in the U.S. provide personal care services to persons with disabilities in their homes

PAS Center researchers have estimated the number of Home and Personal Care Workers for the U.S. overall and for each state from the 2002 American Community Survey (ACS).

For more information, go to:
http://www.pascenter.org/state_based_stats/acs_workforce.php

Researchers from the home and community based PAS project have recently published the following four articles in leading research journals

Kitchener, M., T. Ng, and C. Harrington. 2004. "Medicaid 1915(c) Home and Community-Based Services Waivers: A National Survey of Eligibility Criteria, Caps, and Waiting Lists." *Home Health Care Services Quarterly* 23/2: 55-69. This paper reports that 57 percent of reporting waiver programs used some type of financial cap in addition to the cost neutrality requirement, 33 percent used more restrictive financial eligibility criteria than for institutional services and there were 157,640 persons nationwide on waiver waiting lists in 2002.

For more information, go to:
http://www.pascenter.org/publications/publication_home.php?id=26

Kitchener, M, H. Carrillo, and C. Harrington. 2003. "Medicaid Home and Community-Based Programs: A Longitudinal Analysis of State Variation in Expenditures and Utilization." *Inquiry* 40/4: 375-389. This reports that higher spending on Medicaid HCBS programs was found in states with greater percentages of aged people, smaller percentages of minority populations, higher personal income per capita, more generous Medicaid reimbursement rates and eligibility, and a larger supply of home health agencies.

For more information, go to:
http://www.pascenter.org/publications/publication_home.php?id=28

Kitchener, M, A. Bostrom, and C. Harrington. 2004. "Smoke Without Fire: Nursing Facility Closures, 1997-2001." *Inquiry* 41/2: 189-202. This study reports that despite much concern in the media and among policy makers, only 56 California nursing facilities closed between 1997 and 2001. Statistical analysis of these closures shows: (1) hospital-based facilities are 600 percent more likely to close than are free-standing homes; (2) reducing bed size by 52 beds increases the risk of closure by 460 percent; (3) facilities with losses of 5 percent or worse are more than twice as likely to close; and (4) a one standard deviation increase in county competition raises the risk of facility closure by 140 percent.

For more information, go to:
http://www.pascenter.org/publications/publication_home.php?id=74

Kitchener M., M. Beynon, and C. Harrington. 2004. "Explaining the Diffusion of Medicaid Home Care Waiver Programs Using VPRS Decision Rules." *Healthcare Management Science* 7/3: 237-244. This paper presents the first Variable Precision Rough Sets (VPRS) analysis of national data to examine interstate variation in the Medicaid HCBS waiver program. The exposition provides a detailed discussion of the methodological options and processes, tests the generated rules using a leave-one-out cross-validation, and compares VPRS classification accuracy with regression analyses of the same dataset. The results demonstrate that VPRS offers a robust method with two distinctive features for health care research. First, for policy makers and their audiences, VPRS results are presented as "if, then" decision rules with likelihoods stated as percentages. Second, for

analysts generating evidence for health policy, VPRS provides a rigorous data mining tool and acknowledges inherent analytical uncertainty in the field.

For more information, go to:

http://www.pascenter.org/publications/publication_home.php?id=75

CMS encourages states to give Medicaid beneficiaries more control over the long-term care services they receive

More states than ever are re-directing Medicaid funds to keep more people out of institutions and living in their own communities and homes, and there are many approaches that states can use to accomplish this, the Centers for Medicare & Medicaid Services (CMS) said today in a letter to state Medicaid directors.

"There is growing evidence that states can enable more people to live in the community by giving the elderly and people with disabilities more control over how they get the Medicaid services they need," said CMS Administrator Mark B. McClellan, M.D., Ph.D. "Because the concept of money following the person's own preferences improves satisfaction and may reduce Medicaid costs too, we intend to keep taking steps to remove barriers, real or perceived."

For a pdf version of the letter, go to:

<http://www.cms.hhs.gov/states/letters/smd081704.pdf>

PAS Center partner JAN hosted 2004 Symposium in September

The Job Accommodation Network (JAN) held its annual worksite accommodation and Americans with Disabilities Act (ADA) symposium September 20-21, 2004 in Orlando, FL. This year's symposium was entitled Charting the Course: Accommodating and Employing People with Disabilities. In addition to general sessions and three concurrent training tracks emphasizing accommodation issues, innovative employment practices, and legal issues, the symposium offered luncheon keynote speakers, numerous exhibits, and a technology demonstration area hosted by the Florida Alliance for Assistive Services and Technology (FAAST).

The Accommodation Training Track addressed techniques for hiring, retaining, accommodating, and promoting people with disabilities. The Innovative Employment Practices Track covered effective techniques for managing employees with disabilities, responding to accommodation requests, working through the accommodation process, and implementing accommodations in business cultures. The ADA/Legal Track concentrated on current and pending ADA and Rehabilitation Act issues including the interaction of the ADA with other disability legislation such as the Family and Medical Leave Act (FMLA). The "Workplace Accommodation Challenges" concurrent session included a discussion of personal

assistance services and referred participants to an on-line reference document (<http://www.jan.wvu.edu/media/PAS.html>), which was developed by the Center for Personal Assistance Services and JAN.

Richard Pimentel of Milt Wright and Associates opened the symposium with his presentation "Putting a Face on Disability." Mr. Pimentel offered the audience of employers and One Stop personnel both laughter and tears with his life experiences as a person with a disability. Two luncheon guest speakers provided information on moving people with disabilities into the workforce. Dinah Cohen, Director of the Department of Defense Computer/Electronic Accommodations Program (CAP), explored programs to assist employers in saying "You're hired!" to people with disabilities in her talk, "The New Apprentice." Ronald W. Drach, Director of Strategic Planning and Legislative Affairs, U.S. Department of Labor, Veterans' Employment and Training Service, described improvements already made in services for veterans and improvements soon to come in "From Military to Civilian -- Then and Now." The closing session, "Americans with Disabilities and their Civil Rights: Past, Present, and Future," was introduced by JAN's Lou Orslene and featured Peter Blanck, Director, Health Policy & Disability Center at the Iowa College of Law. In the closing event, Dr. Blanck educated the audience by discussing the issues present in district and Supreme Court ADA cases in the past few years. He also used this opportunity to counter the misinformation by those who believe that the ADA is actually suppressing the employment of people with disabilities.

For over 20 years, Job Accommodation Network (JAN) consultants have provided focused, trusted, and informed answers to

questions regarding the employment of people with disabilities. JAN's annual symposium provides a unique opportunity for human resource managers, supervisors, and other management professionals to attend workshops presented by JAN consultants and invited speakers, share information with their peers, and gain valuable guidance and resources that can be shared with others in their company or organization.

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

Results of focus groups and interviews to be shared

The Workplace PAS project of the Center has completed and analyzed interviews of employers, employment system personnel, and PAS users about PAS in the workplace. Presentations are being given on the results by Workplace PAS Project Director Susan Stoddard, Ph.D. at EmploymentAccess 2004, a conference of employers, employment system representatives, and PAS users sponsored by the Sensory Access Foundation and TransAccess, at the end of September and at the American Public Health Association (APHA) meetings in Washington DC in November.

A report by Sita Misra, Ph.D. from Center partner JAN on employer focus group is being submitted for publication. Most employers who participated in the focus groups provided job accommodations under the ADA. However, there is confusion by employers as to whether or not they provided PAS to their employees. This confusion stemmed from differing perceptions of definition of PAS among

employers and an unclear distinction between PAS relating to personal care and PAS relating to work tasks.

For more information on APHA, go to http://www.pascenter.org/presentations/presentation_home.php?at_conference_id=135&id=36

Training program opportunity announced

The Center announced a training opportunity for employers interested in hiring people with disabilities and people in rehabilitation agencies working on vocational and/or transitional planning. Based on the experience and findings of Center partner InfoUse during development of its award-winning video *Open Futures: Employees with Disabilities*, the Center Training and Dissemination Director Lewis Kraus presented the training to the attendees of EmploymentAccess 2004. For more information on requesting a training, contact Lewis Kraus at lkraus@infofuse.com

For more information on Employment Access 2004, go to <http://www.employmentaccess.org/html/schedule.html>

Center looks at consumer experiences of paid personal assistance services among the Navajo

Observations from focus groups among the Navajo completed by Center researchers Joe Mullan, Ph.D. and Brian Grossman found that Navajo users of paid PAS expressed a strong preference for consumer-directed PAS because of its flexibility and their control over the process. The ability to use family members as

paid assistants addressed many of the problems of PAS that they discussed: finding and maintaining attendants in a geographically challenging rural setting, obtaining flexible and appropriate help in a warm interpersonal context, and using quality services that are not an additional economic burden. Part of the reason for their preference may reflect the culturally competent Navajo staff who serve them. A paper summarizing the findings has been submitted for publication.

PAS Center staff profiled in Success Stories 2004: Consumer perspectives

Two PAS users who work at the Center for Personal Assistance Services, Alice Wong and Maggie Dowling, have been profiled in the recent publication *Success Stories 2004: Consumer Perspectives*, from The National Center for the Dissemination of Disability Research (NCDDR). The publication was funded by the National Institute on Disability and Rehabilitation Research (NIDRR). *Success Stories 2004: Consumer Perspectives* highlights a variety of successes as told by people whose lives have been positively affected due to involvement with a NIDRR supported project. This publication is based on items reported to the NCDDR in 2004.

In her story, Wong describes her work as a student researcher at the Center. She says, "By including the voices of consumers in our advisory board and producing qualitative research about people with disabilities, the center involves the life experience of people with disabilities into every aspect of its research. This can only enrich the quality of data that is produced."

Alice recently received her Master's degree. Congratulations, Alice.

In her story, Dowling shares her feeling about connecting a life of advocacy to research. She says, "My employment benefits the disability community and especially those who have not worked as a team member of viable research. I think we can ultimately change employment concepts to encompass more people with disabilities and their specific work accommodation needs, maximizing their ability within the world of employment."

For Alice and Maggie's stories, go to http://www.pascenter.org/pas_users/index.php

For *Success Stories 2004: Consumer Perspectives* (162 pages) in html, go to:

<http://www.ncddr.org/du/success2004/>

For PDF, go to:

<http://www.ncddr.org/du/success2004/ss2004.pdf>

For more information on *Success Stories*, please call the NCDDR toll-free at 1-800-266-1832

**RTC on IL Management
publishes special issue of
Journal of Rehabilitation on the
web**

An article entitled "Expanding employment opportunities: Independent living center employment services and collaboration with vocational rehabilitation" by Workplace PAS Project Director Susan Stoddard, Ph.D. and Brenda Premo has been published along with five other articles about independent living management research and center programs in a special dedicated issue of the Journal of Vocational Rehabilitation (JVR). Stoddard provided the paper for the Rehabilitation Research & Training Center on Independent Living Management.

For more information, go to <http://www.wnyilp.org/RRTCILM/dissemination/publications.html>

**SELECTED
CONFERENCES DURING
October, November, and
December 2004**

For more detail about these conferences, go to:

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

October

October 07, 2004

Crossing Network Lines: Facilitating Partnerships and Building Coalitions Across Aging & Disability Service Networks to Improve Service Delivery

Hosted By: George Warren Brown School of Social Work, Washington University in St. Louis

Location: St. Louis, MO

http://pascenter.org/documents/crossing_network_lines.pdf

October 07 - October 09, 2004

Ten Miles Behind Me, 10,000 More To Go - Seventh Interdisciplinary Conference on Law and Aging

Hosted By: The Elder Law and Advocacy Section of the State Bar of Michigan

Location: Treetops Resort - Gaylord, Michigan

<http://www.michbar.org/elderlaw/home.html>

October 13 - October 15, 2004

26th Annual Conference

Hosted By: National Business & Disability Council

Location: Las Vegas, NV
<http://www.business-disability.com/Events/conferences.asp>

October 14 - October 16, 2004
Life at 50+: AARP
Hosted By: American Association of Retired Persons (AARP)
Location: Las Vegas, NV
<http://aarp.org/events/>

October 21, 2004
22nd Annual Closing The Gap Conference
Hosted By: Closing the GAP: Computer Technology in Special Education and Rehabilitation
Location: Bloomington, Minnesota
<http://www.closingthegap.com/conf/index2.html>

October 24 - October 27, 2004
23rd Annual Meeting & HOMECARExpo: The Transcendence of Home Care and Hospice
Hosted By: The National Association for Home Care & Hospice
Location: Phoenix Civic Plaza Convention Center, Phoenix, Arizona
<http://www.nahc.org/NAHC/Meetings/AM/04/home.html>

October 31 - November 02, 2004
2004 USBLN Conference
Hosted By: US Business Leadership Network (BLN)
Location: New York, NY
http://www.usbln.com/news/2004_USBLN_conf.pdf

November

November 06 - November 10, 2004
American Public Health Association 132nd Annual Meeting and Exposition
Hosted By: American Public Health Association
Location: Washington, DC

<http://www.apha.org/meetings/>
Center for PAS Presenting

November 11 - November 12, 2004
Social Policy as if People Matter: A Cross-National Dialogue
Hosted By: Adelphi University
Location: Adelphi University, Garden City, NY
<http://www.adelphi.edu/peoplematter/>
Center for PAS Presenting

November 17 - November 20, 2004
Blazing the Trail!: 2004 TASH Conference
Hosted By: TASH
Location: Reno, NV
<http://www.tash.org/2004reno/about.html>

November 19 - November 23, 2004
57th Annual Scientific Meeting of the Gerontological Society of America
Hosted By: The Gerontological Society of America
Location: Marriott Wardman Park Hotel, Washington, DC
http://eshow2000.com/geron/about_the_meeting.cfm
Center for PAS Presenting

November 29 - December 01, 2004
Consumer Directed Health Care Conference & Expo
Hosted By: Consumer Directed Health Care Conference
Location: Washington, DC
<http://www.cdhcc.com/default.asp?View=78#Learn%20about%20CDHCC>

December

December 07 - December 10, 2004
Immersion Learning about Change for Prosperity - a forum for young people with disabilities/special health care needs, their



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families, mentors and advocacy organizations.

Hosted By: Center For Self-Determination

Location: Chicago, Illinois

<http://www.self-determination.com/events/index.html>

December 08 - December 10, 2004

23rd Annual 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: Bethesda, MD

<http://www.grad.usda.gov/perspectives>

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/>