



BULLETIN

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

<http://www.disabilityinfo.gov>



Harkin introduces Senate bill to support community-based services

Senator Tom Harkin (D-IA) introduced the Medicaid Community-Based Attendant Services and Supports Act of 2005 (MICASSA) Wednesday, February 16, 2005. The legislation, co-sponsored by Senator Arlen Specter (R-PA), would increase access to community-based services and supports to Americans with disabilities and older Americans. Similar legislation was introduced in the House.

"I strongly believe that it is important to level the playing field and give eligible individuals equal access to community-based services and supports," Harkin said. "This vital legislation will open the door to full participation by people with disabilities in our neighborhoods, workplaces, our economy, and our American Dream."

Specifically, MICASSA gives individuals who are currently eligible for nursing home services and institutional facilities equal access to community-based attendant services and supports, and establishes a demonstration project to evaluate service coordination and cost sharing approaches for those eligible for both Medicaid and Medicare. The legislation also provides additional funding to states to help them reform their long term care systems and increase the provision of home and community based services.

"This legislation is needed to truly bring people with disabilities into the mainstream of society and provide equal opportunity for employment and community activities," Harkin said.

The following Senators co-sponsored the Harkin-Specter legislation: Edward Kennedy (D-MA), John Kerry (D-MA), Joseph Biden (D-DE), Mark Dayton (D-MN), Mary Landrieu (D-LA), Jon Corzine (D-NJ), Charles Schumer (D-NY), Frank Lautenberg (D-NJ), Joseph Lieberman (D-CT), and Christopher Dodd (D-CT).

For more information, see

<http://harkin.senate.gov/news.cfm?id=232219>

New and updated reports on home and community-based services available

An update of the report 'Federal Systems Change Grants to States and Territories: 2001-2004' is now published on the PAS Center website. The table provides state-by-state information on federal Systems Change Grants for the period 2001-2004 and includes all grants awarded in 2004. This report is one in a series of five reports available online that present information on national initiatives to develop home and community-based services (HCBS) including the extensions to the existing Medicaid HCBS program infrastructure and federal funding for new innovations. The reports are:

1. Federal Systems Change Grants to States and Territories: 2001-2004
2. Home and Community-Based Services: Federal Funding to States.

3. Home and Community-Based Services: Selected Robert Wood Johnson Foundation Grants to States.
4. Home and Community-Based Services: Medicaid Research and Demonstration Waivers.
5. Home and Community-Based Services: State-only funded programs.

Each of the reports provide summary information accessible to the public, consumers, advocates, researchers and professionals about federal funding sources and the programs that are developing as a consequence of this funding. For example, the 'Federal Funding to States' report includes information on HCBS funded by the Older Americans Act.

For more information on Federal Systems Change Grants to States and Territories: 2001-2004, go to:

<http://www.pascenter.org/systemschange/>

For more information on Home and Community-Based Services: Federal Funding to States, go to:

http://www.pascenter.org/federal_funding_to_states

For more information on Home and Community-Based Services: Selected Robert Wood Johnson Foundation Grants to States, go to:

http://www.pascenter.org/foundation_grants/

For more information on Home and Community-Based Services: Medicaid Research and Demonstration Waivers, go to:

http://www.pascenter.org/demo_waivers



For more information on Home and Community-Based Services: State-only funded programs, go to:

http://www.pascenter.org/state_funded/

Updated report on community integration lawsuits now online

The online report 'Home and Community Based Services: Olmstead and Olmstead-related Lawsuits' has been revised for 2005 to include recent lawsuits. The details of existing cases have also been revised to reflect progress in cases. The report includes 141 Olmstead and Olmstead-related lawsuits concerning community integration which have been brought in 42 states, Guam and Washington D.C.

For more information, go to:

<http://www.pascenter.org/olmstead/>

Medicaid HCBS program data viewable by state, and for the entire United States, 2001

From data collected by Center for PAS researchers, two sets of information concerning Medicaid home and community based services (HCBS) are now viewable by state, and for the entire United States, on the Center for PAS website. First, a series of tables report the most recent available (2001) participant and expenditure data for the three Medicaid HCBS programs: (1) the mandatory home health benefit, (2) the optional state plan personal care services benefit, and (3) optional 1915(c) waivers. Second, tables report program descriptions and contact

information for all Medicaid 1915(c) waiver programs operating in 2004.

For more information, go to:

<http://www.pascenter.org/medicaid/>

New state-by-state information available on Center for Personal Assistance Services website

State-by-state resources can be found on the Center for Personal Assistance Services website at

http://www.pascenter.org/state_based_stats/index.php

In the past quarter, several new and updated resources are now available by state, including

- An updated estimate of the number of PAS workers and workers per persons with self-care difficulty from the Census' 2003 American Community Survey

http://www.pascenter.org/state_based_stats/state_statistics_2003.php?title=State+and+National+Disability+Data

- The number of participants and expenditures for Medicaid 1915(c) Waivers for 2001.

http://www.pascenter.org/state_based_stats/medicaid_waiver.php?title=Medicaid+1915%28c%29+Waiver+Data+by+State

- An updated list of Olmstead cases in each state.

http://www.pascenter.org/state_based_stats/olmstead_home.php?title=Olmstead+Decision+and+Lawsuits+by+State

- An update of the searchable database of recently and currently funded research and demonstration projects to expand and improve the personal assistance services workforce in the United States.

http://www.pascenter.org/state_based_state/workforce_projects_inventory_home.php?title=Workforce+Development+Projects+in+PAS

- Contact information and descriptions for each waiver offered by state.

http://www.pascenter.org/state_based_state/medicaid_waivers_info.php?title=State+Medicaid+Waiver+Contact+Information+and+Descriptions

- A list of PAS Workforce resources related to each state. The list data is provided and maintained by Center partner National Clearinghouse for the Direct Care Workforce.

http://www.pascenter.org/state_based_state/xml.php?title=PAS+Workforce+Library

Center partner Job Accommodation Network (JAN) to host annual conference in San Francisco

The Job Accommodation Network's (JAN) Annual Conference, *Empowering Employers to Build an Inclusive Workforce* will be held in San Francisco on September 26-27, 2005. This event provides a unique learning opportunity for human resource managers, compliance officers, disability program managers, and other professionals to discover ways that enhance an organization's ability to accommodate and employ people with

disabilities. Instruction by JAN staff and national experts will include three training tracks addressing accommodation strategies, ADA/legal issues, and innovative employment practices. Invited keynote speakers include Dr. Roy Grizzard, the Assistant Secretary for Disability Employment Policy for the Office of Disability Employment Policy, U.S. Department of Labor; Michael J. Lotito, partner with Jackson Lewis; Dinah Cohen, Director for the Department of Defense Computer/ Electronic Accommodations Program (CAP); and Paul Steven Miller, Professor of Law, University of Washington School of Law.

Registration is limited to 300 participants. The conference will also have booths from exhibitors of goods and services.

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

Center advisor wins national award

Center for Personal Assistance Services advisor Paul Longmore recently became the first professor to win the Henry B. Betts Award from the American Association of People with Disabilities. Longmore, professor of history, was honored for his work as a disability rights activist and leader in the academic field of disability studies. The award comes with a \$50,000 prize.

For more information, see San Francisco Chronicle news story at:

<http://sfgate.com/cgi-bin/article.cgi?f=/c/a/2005/03/09/BAGG1BM5C1.DTL>

and San Francisco State University news story at <http://www.sfsu.edu/~news/2005/spring/26.htm>

Center news

- Center researcher Martin Kitchener has been awarded a new grant for a study of states' long-term care strategy and performance in expanding access to home and community-based services. The project will begin in May 2005.
- Center researchers Martin Kitchener and Terence Ng will present a symposium on national trends in 1915(c) HCBS Waivers at the National Association of State Units on Aging (NASUA) Annual HCBS Waiver Conference in Orlando, Florida in May. The symposium will be chaired by Martin Kitchener with three discussants: Mary Jean Duckett (CMS), Bridget Simone (New York Medicaid) and Beth Kidder (Florida Medicaid). More information on the symposium can be found on the Center website at <http://www.pascenter.org/presentations/index.php>
- The Shepherd Center in Atlanta, Georgia has developed a training for staff to help consumers understand consumer direction in personal assistance services. They have used printed versions of the consumer training section of the Center for PAS website, developed by InfoUse (http://www.pascenter.org/pas_users/index_old.php), as the textbook for their training.
- Center researchers Mike Oxford and Lewis Kraus along with Center advisor

Steven Gold will conduct a workshop entitled "Living Independently and Personal Assistance Services" at the 2005 National Council on Independent Living (NCIL) Independent Living (IL) Conference in Washington, DC in July.

Kaiser Family Foundation releases guides on Medicaid and Medicare

The Kaiser Family Foundation recently released new guides, prepared by Bob Williams and Henry Claypool of Advancing Independence and Jeff Crowley of the Georgetown University Health Policy Institute, that explain the role of Medicare and Medicaid for roughly 20 million children, adults and seniors with disabilities.

These guides offer a basic introduction to the Medicare and Medicaid programs, including answers to questions such as:

- How do people with disabilities apply for coverage under Medicare or Medicaid?
- What is Medicare's policy for covering durable medical equipment?
- Where can people with disabilities turn if they need help in applying for Medicaid?
- How do people with disabilities appeal Medicare coverage decisions?
- Can a person with a disability who has Medicare and/or Medicaid be employed and still keep their coverage?

To retrieve these guides in PDF or HTML format, go to <http://www.kff.org/medicare/med020705pkg.cfm>

Report released on informal caregivers

The Center on an Aging Society at Georgetown University has released the first in a series of Data Profiles on informal caregivers of older persons titled, "A Decade of Informal Caregiving: Are today's caregivers different than informal caregivers a decade ago?"

Family and friends are the primary source of long-term care provided to people who need assistance performing basic everyday activities. This Profile reports that spouses and adult children continue to be the primary caregiver - the one who takes the responsibility for coordinating the care and often provides most of the care needed.

The majority of primary caregivers are women, but the proportion of men as primary caregivers has increased over the past decade. Compared to a decade ago, a slightly smaller proportion of primary caregivers have child-care responsibilities and similar proportions of informal caregivers are employed today as were a decade ago. However, fewer caregivers report making adjustments to their current employment situation in order to provide care to an older family member. As the population continues to age, the composition of informal caregivers will inevitably change as well.

The series of Data Profiles, Family Caregivers of Older Persons is supported by a grant from the AARP Andrus Foundation and a grant from the Mathers LifeWays. This Data Profile was prepared by Katherine Mack.

For more information, go to

<http://ihcrp.georgetown.edu/agingsociety/public/caregiver1/caregiver1.html>

To retrieve a PDF of the report go to:

<http://ihcrp.georgetown.edu/agingsociety/pdfs/caregivers1-E.pdf>

Report released on consumer-directed programs for older adults

The National Association of State Units on Aging (NASUA) and The National Council on the Aging (NCOA) have released a report documenting the scope and characteristics of the growing number of consumer-directed programs for older adults across the United States. The report, "State of the States in Consumer-Directed Home and Community Based Services Results of a 2004 Survey of State Administrators, an Opinion Survey & Telephone Interviews", contains information about some 30 states operating 58 consumer-directed programs.

Report findings document the scope and characteristics of consumer-directed services; state aging administrators' views about consumer direction for older people; the motivating factors and barriers to the development of these programs; and effective practices in providing consumer direction to older people.

The research and the report were developed through a collaborative effort of NASUA and NCOA; with support from The Robert Wood Johnson Foundation. Matthew Greenwald and Associates conducted the surveys and initial data analysis. Donna Lind Infeld,



Ph.D. of The George Washington University, completed the data analysis and wrote the report.

The report and the executive summary as well as numerous resources and articles on consumer-directed services may be downloaded from the project Web site.

For more information or to retrieve the report, go to:
<http://www.consumerdirection.org/news.php>

Government Accountability Office (GAO) releases report on employers and One-Stop services

The Government Accountability Office (GAO) recently released a letter report titled "Workforce Investment Act: Employers Are Aware of, Using, and Satisfied with One-Stop Services, but More Data Could Help Labor Better Address Employers' Needs." The report (GAO-05-259) found that while about half of all employers are aware of their local one-stops, awareness increases with employer size, with about half of small, two-thirds of medium, and three-quarters of large employers knowing about their local one-stops. The report also found that, of all employers aware of the one-stops, about three-quarters of large employers are likely to use one-stop services, while approximately one-half of medium and one-quarter of small employers are likely to do so. Employers of all sizes primarily use one-stop services to help fill job vacancies.

To get a copy of the report, go to:
<http://www.gao.gov/cgi-bin/getrpt?GAO-05-259>

For highlights of the report, go to:
<http://www.gao.gov/highlights/d05259high.pdf>

The World Institute on Disability announces a new training video and curriculum for medical providers

"Access to Medical Care: Adults with Physical Disabilities", a 22 minute video about mobility, vision, hearing and communication impairment in outpatient settings has been released by the World Institute on Disability. The video offers physicians, dentists, nurses, social service and support staff, an introduction to crucial issues that affect the quality of care for patients with disabilities.

Through interviews with expert medical providers and a diverse group of people with mobility, vision, hearing and communication impairments, this video introduces and clarifies key concepts in treating adults with physical disabilities. Appropriate for outpatient clinical settings, the video:

- Explores the views and experiences of people with disabilities and providers in establishing rapport and effective communication,
- Addresses cultural competence, access and communication issues which often arise in the clinic,

- Identifies common myths and stereotypes which interfere with accurate assessment of patients,
- Explains barriers which result in disparities in health care delivery, including physical/ architectural, communication, attitudinal and social/economic policy,
- Identifies the most common access and accommodation needs of adults with physical, sensory and communication disabilities, as required by the Americans with Disabilities Act, and explains feasible, cost-effective solutions,
- Clarifies essential principles of quality care in treating people with disabilities,
- Reinforces key learning points in bulleted graphics (available in printed handouts in the curriculum).

Treating Adults with Physical Disabilities, an accompanying training curriculum offers a case-based learning exercise and extensive in-depth reference materials. It provides essential knowledge for appropriate provision of care and compliance with the Americans with Disabilities Act. The curriculum emphasizes access and communication as the fundamental components in addressing health care disparities for people with disabilities. Developed by the World Institute on Disability, Oakland, CA, www.wid.org, in collaboration with Center for Health Care Strategies, Kaiser Foundation Multi-Media, and the California HealthCare Foundation.

For more information, contact: Dr. Marsha Saxton, 510-251-4349.

New book released on care for elderly parents

Doing the Right Thing: Taking Care of Your Elderly Parents Even If They Didn't Take Care of You

By Roberta Satow, PhD

As we enter middle-age, more and more of us must confront the prospect of caring for our elderly parents. It's difficult enough when our relationships with them were close and loving. But it's especially difficult, even destructive, when our relationships with our parents were troubled or toxic. When faced with caring for a father or mother who didn't take care of us, old wounds reopen. We plunge back into crazy-making feelings from our childhoods as though we'd never grown up.

Fortunately, a brand-new book offers a compassionate and healing approach to navigating these challenges. Sociologist and psychotherapist Dr. Roberta Satow offers the wealth of her clinical knowledge, interviews with fifty caregivers, and her own candid accounts of caring for her ailing, elderly mother. The result is an emotional as well as practical guide for taking care of your parent – and, perhaps even more importantly, for using the experience as a way to resolve old issues and grow as a human being.

Available March 17, 2005

A Tarcher/Penguin hardcover, ISBN 1-58542-392-0

**SELECTED CONFERENCES
DURING April, May, and June
2005**

For more detail about these conferences, go to:

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

April

April 13 - April 16, 2005

Western Social Sciences Association 47th Annual Conference

Hosted By: Western Social Sciences Association

Location: Albuquerque, New Mexico

http://wssa.asu.edu/wssa_conference.htm

April 26 - April 28, 2005

8th Annual Coordinated Leadership Conference

Hosted By: California Association of Area Agencies on Aging

Location: Ontario, CA

<http://www.c4a.info/events>

May

May 02 - May 03, 2005

National Forum of the Thirty-First Institute on Rehabilitation Issues

Hosted By: Rehabilitation Services Administration (RSA)

Location: Doubletree Crystal City Hotel, Arlington, Virginia

<http://www.gwu.edu/%7Eiri/forum.htm>

May 15 - May 18, 2005

21st National HCBS Waiver Conference

Hosted By: The National Association of State Units on Aging

Location: Orlando, Florida

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

Center for PAS Presenting

May 17 - May 19, 2005

National ADA Symposium and Expo - The Annual Conference on Disability Issues

Hosted By: The Network of ADA & Information Technology Centers, a NIDRR project

Location: Kansas City, Kansas

<http://www.adaupdate.org/Symposium.html>

May 19 - May 21, 2005

Annual conference on the ADA and disability-related laws

Hosted By: Great Plains ADA & IT Center

Location: Kansas City-Overland Park Convention Center, in Kansas City, MO

<http://www.adaproject.org>

May 20 - May 21, 2005

World of Possibilities Expo-Bigger and Better in 2005

Hosted By: Caring Communities

Location: Maryland State Fairgrounds, Timonium, Maryland

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

June

June 01 - June 03, 2005

Health Professions: The Lifeline to America

Hosted By: U.S. Department of Health and Human Services, Health Resources and Services Administration, Bureau of Health Professions

Location: Marriott Wardman Park Hotel, Washington, DC

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



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Fourth Annual Bridges to Employment Conference: Exploring Career Opportunities for Latinos with Disabilities

Hosted By: Proyecto Visión, North Carolina Division of Vocational Rehabilitation and Agrability Program; El Centro Hispano; El Pueblo, Inc.; Cooperativa Latina and Partnerships in Assistive Technology.

Location: Raleigh, NC

<http://www.proyectovision.net/english/bridges/index.html>

June 18 - June 21, 2005

International Conference on Prevention of Dementia: Early Diagnosis and Intervention

Hosted By: Alzheimer's Association

Location: Marriott Wardman Park Hotel Washington, D.C.

<http://www.alz.org>

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/>