

HAPPY NEW YEAR!!!

VOR is the only national organization advocating for a full range of residential and support options for people with mental retardation, including Medicaid-certified Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) and home and community-based care. VOR supports choice.

VOR Weekly E-Mail Update January 5, 2007

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- 1. National Council on Disability Congressional Outreach
- 2. The Combating Autism Act of 2006 passes Congress and is signed by President
- 3. President Signs Critical Respite Bill for Family Caregivers - The Lifespan Respite Care Act of 2006 (HR 3248) is now law
- 4. Congress Extends Mental Health Parity Provision for Additional Year
- 5. CMS Publishes Final Patients' Rights Rule on Use of Restraints and Seclusion - Better, More Extensive Training of Staff Required
- 6. Aging and Disability Resource Center Grants Announced
- 7. 2005 Census Data Regarding People With Disabilities

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- 1. National Council on Disability Congressional Outreach
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On December 11, NCD published the first of a number of upcoming monthly two-page briefings for Congress, highlighting major points in the NCD report The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities (www.ncd.gov/newsroom/publications/2005/longterm_services.htm).

NCD undertook research for this report because it has grown increasingly concerned about (a) the lack of a coherent national policy for long-term services and supports (LTSS) for all people with disabilities; (b) the fragmented nature of service and support delivery systems, with uneven access and service provision; and (c) LTSS costs of 22 percent or more of state budgets, which are fast becoming unsustainable. Additionally, NCD noted that no single federal program, federal agency, or congressional committee is charged with the responsibility for the management, funding, and oversight of LTSS; however, 23 federal agencies are actively involved in LTSS using the NCD definition.

The purpose of this research is to produce new knowledge and an understanding of current experience with LTSS and the future need for affordable LTSS for people with disabilities. On December 18, NCD notified members of the House Livable Communities Task Force and the Senate Special Committee on Aging about the release of the NCD report Creating Livable Communities, available at www.ncd.gov/newsroom/publications/2006/livable_communities.htm.

The report identifies a number of strategies that can be applied to the design and support of livable community principles. The strategies have been initiated by federal and state government agencies as well as the private sector. These entities have recognized the power of collaboration and the use of distinct tools to guide and stimulate systemic changes to make communities more livable for all. The letters to Congress can be found at www.ncd.gov/newsroom/correspondence/2006/blumenauer_12-18-06.htm and www.ncd.gov/newsroom/correspondence/2006/smith_12-18-06.htm.

2. The Combating Autism Act of 2006 passes Congress and is signed by President

THE WHITE HOUSE OFFICE OF THE PRESS SECRETARY December 19, 2006

STATEMENT BY THE PRESIDENT

For the millions of Americans whose lives are affected by autism, today is a day of hope. The Combating Autism Act of 2006 will increase public awareness about this disorder and provide enhanced federal support for autism research and treatment. By creating a national education program for doctors and the public about autism, this legislation will help more people recognize the symptoms of autism. This will lead to early identification and intervention, which is critical for children with autism. I am proud to sign this bill into law and confident that it will serve as an important foundation for our Nation's efforts to find a cure for autism.

FACT SHEET COMBATING AUTISM ACT December 19, 2006

Today, President Bush Signed The Combating Autism Act Of 2006. This Act authorizes expanded activities related to autism research, prevention, and treatment through FY 2011. There are more than 1.5 million cases of autism in the United States.

* Since the President Took office, National Institutes Of Health (NIH) Funding For Autism-Related Research Has Increased By Over 80 Percent - From \$56 Million In FY 2001 To An Estimated \$101 Million In The FY 2007 Budget, Including Support For Autism Centers of Excellence. In addition, the Budget includes approximately \$15 million at the Centers for Disease Control and Prevention (CDC) for autism surveillance and research, including five regional Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology. In October, CDC initiated a \$5.9 million study to help identify factors that may put children at risk for autism spectrum disorders and other developmental disabilities.

The Combating Autism Act Enhances Research, Surveillance, And Education Regarding Autism Spectrum Disorder.

* The Act Authorizes Research Under NIH To Address The Entire Scope Of Autism Spectrum Disorder (ASD). Autism, sometimes called "classical autism," is the most common condition in a group of developmental disorders known as the autism spectrum disorders (ASDs). Other ASDs include Asperger syndrome, Rett syndrome, childhood disintegrative

disorder, and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS).

* The Act Authorizes Regional Centers Of Excellence For Autism Spectrum Disorder Research And Epidemiology. These Centers collect and analyze information on the number, incidence, correlates, and causes of ASD and other developmental disabilities. The Act also authorizes grants to States for collection, analysis, and dissemination of data related to autism.

* The Act Authorizes Activities To Increase Public Awareness Of Autism, Improve The Ability Of Health Care Providers To Use Evidence-Based Interventions, And Increase Early Screening For Autism. The Act authorizes the Secretary of Health and Human Services to:

- Provide information and education on ASD and other developmental disabilities to increase public awareness of developmental milestones;

- Promote research into the development and validation of reliable screening tools for ASD and other developmental disabilities and disseminate information regarding those screening tools;

- Promote early screening of individuals at higher risk for ASD and other developmental disabilities as early as practicable;

- Increase the number of individuals who are able to confirm or rule out a diagnosis of ASD and other developmental disabilities;

- Increase the number of individuals able to provide evidence-based interventions for individuals diagnosed with ASD or other developmental disabilities; and

- Promote the use of evidence-based interventions for individuals at higher risk for ASD and other developmental disabilities as early as practicable.

* The Act Calls On The Interagency Autism Coordinating Committee (IACC) To Enhance Information Sharing. The IACC provides a forum to facilitate the efficient and effective exchange of information about autism activities, programs, policies, and research among the Federal government, several non-profit groups, and the public. The Combating Autism Act requires the IACC to provide information and recommendations on ASD-related programs, and to continue its work to develop - and update annually - a strategic plan for ASD research.

3. President Signs Critical Respite Bill for Family Caregivers - The Lifespan Respite Care Act of 2006 (HR 3248) is now law

National Respite Coalition Press Release December 21, 2007

Washington, DC (December 21, 2006) - The Lifespan Respite Task Force, a coalition of over 170 national, state, and local organizations, applauds the signing of The Lifespan Respite Care Act of 2006 (HR 3248) into law. The bill was introduced and championed in the US House of Representatives by Rep. Mike Ferguson (R-NJ) and James Langevin (D-RI). A companion bill in the Senate was cosponsored by Senator Hillary Clinton (D-NY) and Senator John Warner (R-VA). The Lifespan Respite Task Force includes a diverse group of national and state organizations: state respite and crisis care coalitions; health and community social services; disability, mental health, education, faith, family caregiving and support groups; groups from the child advocacy and the aging community; and abuse and neglect prevention groups.

Family caregivers are providing 80% of long-term care in the US, a level of care valued at \$306 billion a year, more than what is spent on nursing home and paid home care combined. Even though most families take great joy in providing care to their loved ones so that they can remain at home, the physical, emotional and financial consequences can be overwhelming without some support, such as respite. Respite provides the much needed temporary break from the often exhausting challenges imposed by constant caregiving.

The new law would authorize \$289 million over five years for state grants to develop Lifespan Respite Programs to help families access quality, affordable respite care. Lifespan respite programs are defined in the Act "as coordinated systems of accessible, community-based respite care services for family caregivers of children and adults with special needs." Specifically, the law authorizes funds for: * development of state and local lifespan respite programs; * planned or emergency respite care services; * training and recruitment of respite care workers and volunteers; and * caregiver training.

When the bill passed the House, Rep. Ferguson, whose own father was a caregiver for his ill mother for 6 years said, "Today's action by the House of Representatives represents not only an important victory for family caregivers nationwide, but it also sends America's caregivers a clear message: Your selfless sacrifice is appreciated, and help is on the way."

"On behalf of over nation's family caregivers who desire to keep their loved ones at home despite limited support, we commend Rep. Ferguson, Vice-chair of the Health Subcommittee of the House Energy and Commerce Committee, Rep. Langevin, and Senator Hillary Clinton (D-NY) and Senator Warner (R-VA) for their leadership, and especially want to thank them, their colleagues from both sides of the aisle, and the White House for taking action to help the burgeoning numbers of family caregivers," said Jill Kagan, Chair of the National Respite Coalition, and facilitator of the Lifespan Respite Task Force. "Relatively minimal investments in respite help family caregivers provide this care at home and in the community. At a time when federal and state fiscal resources are limited, this is the most compassionate and fiscally responsible thing we can do, and a most welcome gift in this holiday season."

4. Congress Extends Mental Health Parity Provision for Additional Year

Source: Bureau of National Affairs (BNA)

Before adjourning for the year earlier this month, Congress passed a provision in the omnibus tax extenders legislation (H.R. 6111) to extend current mental health parity law until the end of 2007.

Under the provision, group health plans that provide medical and surgical care as well as mental health care would be barred from imposing coverage limits on mental health care that are not in place for other medical coverage. The provision would impose a \$100 fine per day for violations.

The provision would cost \$35 million over five years, according to a summary of the bill provided by the Senate Finance Committee. The House approved the measure, the Tax Relief and Health Care Act of 2006, Dec. 8; the Senate followed suit the following day.

Legislation approved in 1996 requires group health plans that offer mental health benefits to set the same annual and lifetime caps on mental health coverage as for other medical/surgical services.

Mental health advocacy groups said the 1996 law has loopholes that need to be closed by barring group health plans from requiring higher copayments, deductibles, and coinsurance payments for mental health services, compared to other health benefits. Groups such as the American Psychiatric Association have criticized Congress for merely passing extensions of the current law, rather than addressing the cost-sharing issues.

Employer groups have countered that passing more sweeping mental health parity legislation would increase health care costs for businesses.

Pamela Greenberg, chairwoman of the Coalition for Fairness in Mental Illness Coverage, which is comprised of provider and consumer associations, told BNA Dec. 19 that the coalition is pleased Congress extended the current law, but said broader changes are needed to put mental health care coverage on a par with other health care coverage.

With Democrats in control of both the House and Senate for the 110th Congress, Greenberg said she is "very positive" the incoming Congress will pass mental health parity legislation, and is hopeful Bush would sign such a bill.

5. CMS Publishes Final Patients' Rights Rule on Use of Restraints and Seclusion - Better, More Extensive Training of Staff Required

Source: CMS December 2006

Health care workers who employ physical restraints and seclusion when treating patients must undergo new, more rigorous training to assure the appropriateness of the treatment and to protect patient rights, according to a regulation published in the Federal Register today by the Centers for Medicare & Medicaid Services (CMS).

The patients' rights regulations set forth, as a condition of participation (CoP) in the Medicare and Medicaid programs, the expectation that health care facilities will protect the rights of patients. These protections are part of Medicare's revised CoP requirements that hospitals must meet. The requirements apply to all participating hospitals including short-term, psychiatric, rehabilitation, long-term, children's and alcohol/drug treatment facilities.

"Through this regulation, CMS will hold all hospitals accountable for the appropriate use of restraint and seclusion," said Leslie V. Norwalk, acting administrator of CMS. "Today's action reinforces this administration's commitment to patient safety and the delivery of high quality health care services."

"These new rules demonstrate our commitment to advancing patient safety and patient rights in health care facilities," said Eric B. Broderick, D.D.S., M.P.H., Acting Deputy Administration at HHS' Substance Abuse and Mental Health Services Administration. "Today we are taking needed steps to solidify training requirements and essential reporting to reduce and ultimately eliminate seclusion and restraints."

To address concerns about the improper use of restraints and seclusion and in response to the 4,000 public comments received on the interim final rule, the final regulation strengthens the staff training standard and specifies components of the training. The rule also expands the category of practitioners who may conduct patient evaluations when a restraint or seclusion tactic has been implemented.

CMS currently requires that a patient be evaluated "face-to-face" within an hour of a patient being restrained or secluded for the management of violent or self-destructive behavior. Prior to this rule, these actions had to be reviewed within that hour by a physician or "other licensed independent practitioner (LIP)." Today's action expands that list to include a trained registered nurse (RN) or physician assistant (PA). The rule requires, however, that when an RN or PA performs the 1-hour-rule evaluation, the physician or other LIP treating that patient be consulted as soon as possible.

The basic rights specified in the regulation include a patient's right to notification of his or her rights in regard to their care, privacy and safety, confidentiality of their records, and freedom from the inappropriate use of all restraints and seclusion, in all hospital settings.

In the development of this final rule, CMS has been sensitive and responsive to the comments of the provider communities, protection and advocacy associations, private citizens, and the health care community in general. The intent of this regulation is to ensure the protection of each patient's physical and emotional health and safety. In this final rule, CMS has addressed public comments without compromising these protections.

Under the new regulations, hospitals must provide the patient or family member with a formal notice of their rights at the time of admission. These rights include freedom from restraints and seclusion in any form when used as a means of coercion, discipline, convenience for the staff, or retaliation.

Stricter standards for when a healthcare facility must report the death of a patient associated with the use of restraints and seclusion have also been adopted with this rule.

The regulation is in today's Federal Register and will become effective on February 06, 2007.

6. Aging and Disability Resource Center Grants Announced

Date: September 27, 2006 Contact: Administration on Aging Press Office
HHS Announces Efforts to Expand and Streamline Access To Long-Term Care in Communities through Grants to States HHS Secretary Mike Leavitt today announced nearly \$6 million in additional funding to 22 states to expand their efforts to establish single entry points to long-term care for families who are trying to learn about and access services in their communities.

These Aging and Disability Resource Center (ADRC) grants are part of the President's New Freedom Initiative and the Administration's commitment to bring transparency to health and long-term care so consumers can make informed decisions about their care options. "The President has directed us to tear down the barriers that make it difficult for people who need long-term care to remain in the community," Secretary Leavitt said. "By bolstering the resource centers through these grants, states can better serve families making effective long-term care decisions for a loved one, often with little time to prepare."

To date, 43 states have received over \$40 million in support under the ADRC initiative, which is jointly administered by the Administration on Aging (AoA) and the Centers for Medicare & Medicaid Services (CMS).

States are using ADRC funds to better coordinate and redesign their existing methods for providing seniors, younger people with disabilities, and family caregivers with information and personalized assistance in accessing services such as meals-on-wheels, personal care, housekeeping, specialized transportation, assisted living and nursing home care.

"We are very pleased with the advancements states have made over the past three years to simplify access to long-term care for the elderly and adults with disabilities through the ADRC initiative," said HHS Assistant Secretary for Aging Josefina G. Carbonell. "These resource centers have become visible and trusted places for information on long-term care options, and we are pleased to be able to assist states in furthering their efforts to make the ADRC the foundation for community-based care."

ADRC accomplishments to date include: creating public Web sites that give consumers easy access to information on the specific services available in their communities; co-locating staff from different agencies in a single location; and using computerized information systems to assess the needs of clients, activate the delivery of services, and monitor quality. ADRCs are also working with hospitals and nursing homes to help consumers avoid unnecessary placement in institutional settings. All ADRC grantees plan for eventual statewide coverage, and eight states are already positioned to achieve statewide coverage within three years.

"Providing people who have chronic care needs with personalized information and assistance so they can fully understand their options is essential to the transformation of our nation's health and long-term care system," said [former] CMS Administration Mark B. McClellan, M.D., Ph.D. "Aging and Disability Resources Centers are putting consumers in the driver's seat when it comes to making decisions about long-term care. These centers are also helping Medicare beneficiaries learn about and access their new prescription drug coverage and other preventive health benefits under Medicare."

For more information on the ADRC grant program, go to the AoA Web site at <http://www.aoa.gov>, the CMS website at <http://www.cms.hhs.gov/newfreedom/default.asp>, or the Aging and Disability Resource Center Technical Assistance Exchange at <http://www.adrc-tae.org>.

The grants are listed below:

Aging and Disability Resource Center Grant Program Fiscal Year 2006 Continuation Awards

Louisiana - Governor's Office of Elderly Affairs \$400,000

Maine - DHHS Office of Elder Services \$399,940

Maryland - Department of Aging \$400,000 Massachusetts - Executive Office of Elder Affairs \$399,976

Minnesota - Board on Aging \$400,000

Montana - DPHHS Senior and LTC Services \$400,000

New Hampshire - University of New Hampshire \$399,261

New Jersey - Department of Health & Senior Services \$400,000

Pennsylvania - Office of Healthcare Reform \$396,400

Rhode Island - Department of Elderly Affairs \$400,000

South Carolina - Lieutenant Governor's Office on Aging \$400,000

West Virginia - Bureau of Senior Services \$400,000

Aging and Disability Resource Center Grant Program Fiscal Year 2006 Supplemental Awards

Arkansas - Arkansas DHS Div. of Aging & Adult Services \$85,000

California - California Department of Aging \$85,000

Florida - Florida Department of Elder Affairs \$85,000

Georgia - Georgia Division of Aging Services \$85,000

Illinois - Illinois Department on Aging \$85,000

Indiana - Indiana Division of Disability, Aging and Rehabilitative Services \$84,744

Iowa - Iowa Department of Elder Affairs \$83,724

New Mexico - New Mexico Aging and Long-Term Care Dept. \$85,000

North Carolina - North Carolina DHHS Office of Long Term Care \$85,000

Wisconsin - Wisconsin Dept. of Health & Family Services \$85,000

7. 2005 Census Data Regarding People With Disabilities

Information Bulletin #186 (12/06) Steve Gold

Many disability advocates need up to date statistics by State or county for people with disabilities. The 2005 American Community Survey which can be found at

<http://factfinder.census.gov> and provides a lot of useful current data. Here is a national summary of the data:

* Nearly 15% of the population 5 years and over (i.e., 40 million people) have one or more disabilities.

* For the population 16-64 years, 12% of that population (i.e., nearly 23 million people) have one or more disabilities. Of all people 16-64 years, nearly 3% have a sensory disability, more than 7% have a physical disability, and 4.5% have a mental disability. [Remember people can have more than one type of disability and show up in two categories.]

* For the population 16-64 years, only 37.5% of the people with a disability are employed. That is, more than 14 million people with disabilities who are unemployed.

* For the population 65 years and over, 40.5% of that population (i.e., more than 14 million people) have one or more disabilities. Of all people over 65 years, 16% have a sensory disability, 31% have physical disability, 11.5% have a mental disability, nearly 10% have a self-care disability, and 16.6% have a "go-outside-home disability." * For the population 5 years and over who have one or more disabilities, 21.1% are below the poverty level (which is about \$9,200 for a single person). That is, more than 8 million persons have a disability and are below the poverty level. Of all people 5 years and over who are below the poverty level, 18.7% have a sensory disability, 21% have a physical disability, and 26.4% have a mental disability.

* As a comparison, for the population 5 years and over with no disability, 11.3% are below the poverty level, while for the same age group with one or more disabilities, 21.1% are below the poverty level.

This data is available by State and county at the above Census Bureau's web site.

Tamie Hopp

REFERRAL/MEMBERSHIP/CONTRIBUTION FORM

THREE EASY WAYS TO SUPPORT VOR > REFER, CONTRIBUTE OR JOIN

THANK YOU FOR YOUR SUPPORT!

TO JOIN OR CONTRIBUTE: \$25 per individual, \$150 per family organization, or \$200 per provider/professional organization. Extra donations are welcome! You may pay by credit card or check.

TO REFER SOMEONE TO VOR: Use the form below, including the additional sections for referrals.

Mail the completed form (if joining or contributing) with payment to: Voice of the Retarded
5005 Newport Drive, Suite 108 Rolling Meadows, IL 60008 847-253-6054 fax (for referrals or
credit card payments) vor@compuserve.com (for referrals or credit card payments)

FOR REFERRALS: The contact information provided is for someone I think would
consider membership with VOR.

FOR REFERRALS: You may use my name in any correspondence with this individual.

My name is _____.

Name

Address (if paying by credit card, use billing address). All forms must include complete address
including zip code)

City St Zip

Phone Fax

E-Mail

Family/Professional Organization Affiliation (if applicable)

VOR now accepts Master Card and Visa. If paying by credit card, please provide the following
information:

Amount to charge to card: \$1,000 \$500 \$250 \$150 \$50 \$25
\$_____ Other amount

Master Card Visa

Card Number: _____

Expiration Date: _____