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Speaking out for people with intellectual and developmental disabilities

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Challenge! Recruit 5 New VOR Members Today!

December 7, 2012

VOR Weekly News Update

News and views for VOR Advocates

Did you receive this as forwarded e-mail? If so, someone thought you would benefit from VOR's information. Please consider joining VOR and receive this E-News Update publication weekly!

VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities

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VOR and You

1. VOR Calls National Council on Disability's Deinstitutionalization Toolkit Reckless

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December 5, 2012 * For Immediate Release

PLEASE SHARE WITH YOUR LOCAL MEDIA

VOR, a national organization advocating for high quality care and human rights, strongly objects, in substance and in principle, to the National Council on Disability's (NCD) newly released "Deinstitutionalization: Unfinished Business" policy document (110 pages) and accompanying "toolkit" (a how-to manual) (201 pages).

VOR represents thousands of individuals, families and legal guardians, organizations and advocates around the country who value individual choice and recognize that true person-centered planning begins with the individual and his/her needs. One size does not fit all. An array of quality service and support options is needed to ensure that choice, based on individual need, is accommodated.

NCD used more than 300 pages to advocate for closing specialized homes – Medicaid-licensed Intermediate Care Facilities (ICFs/MR) – serving our nation's most profoundly disabled citizens. This insensitive, reckless attitude will cause these vulnerable individuals to suffer grievous harm and even death.

Read more

2. Do the Math: Abolishing the Charitable Deduction Will Cost Charities Billions

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***The Chronicle of Philanthropy* * December 2, 2012**

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Challenge! Recruit 5 New VOR Members Today!

Celebrating Home: Holiday Shop and Benefit VOR

Make a Lasting Impact with a Will Bequest

VOR.net: Your one-stop advocacy resource

Over its nearly 100-year history, the charitable deduction has become one of the most time-tested provisions in the Internal Revenue Code.

But it has also been a perennial target by people on both ends of the political spectrum who want to eliminate or restrict it.

While economists have long studied the impact of the deduction, they have not reached a clear consensus on how much it matters. A new study, however, along with recently released IRS data make it quite clear that America’s charitable organizations could be hurt greatly if donors lost all or part of the charitable income-tax deduction as lawmakers seek ways to avert the looming “financial cliff."

The new study of the wealthy and their philanthropy, released last month by Bank of America, asked affluent people (mostly with incomes of $200,000 or more and net assets of at least $1-million) how they might alter their giving if deductions were eliminated.

Just under 50 percent said their giving would remain the same. But nearly 49 percent said they would decrease their giving—and 20 percent of those people said they would “dramatically decrease” their giving. Less than 2 percent said their giving would increase.

[Read More](#)

State News

3. Missouri: Justice Department's aggressive actions force centers to close

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***St. Louis Dispatch* * December 3, 2012 * By Mary Vitale (VOR Board Member), Letter to the Editor**

The article “Northwest center for disabled is closed” (Nov. 27) brings to light a national issue about the care of people with severe mental and physical disabilities.

Part of the real story behind the nationwide closing of habilitation centers [ICFs/MR] is the aggressive action by the Department of Justice. The department is grossly misinterpreting the 1999 Supreme Court *Olmstead* decision, which states: “We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. ... Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.”

Contrary to this clear statement, the Justice Department is using this decision to threaten states with lawsuits claiming that the civil rights of the residents are being violated, just because they live in one of these centers. To avoid a Justice Department lawsuit, governors of states are settling out of court and agreeing to close habilitation centers. The fact that these residents are thriving in these centers is being ignored.

Across the nation, families rely on the comprehensive, life-saving services offered at habilitation centers. We are greatly alarmed by the misguided, aggressive actions of the Justice Department that are putting our family members in harm’s way. Families are to be the primary decision makers about services received.

Related story

4. Wyoming: Study would examine downsizing Lander health care facility

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Star-Tribune **(Casper Wyoming) * November 13, 2012**

Wyoming lawmakers want to study the possibility of downsizing a state residential facility that cares for people with intellectual disabilities and brain injuries.

The study would examine the effect of gradually transitioning people who use Wyoming Life Resource Center in Lander to services in their communities. The center would then become a safety net for people without other options.

The Joint Labor, Health and Social Services Committee asked for a bill authorizing the study while meeting Monday in Casper to discuss ways to deal with escalating Medicaid costs.

To address costs and large waiting lists, the committee also voted to draft legislation that would transition the state to a new program where some waivers have capped spending limits. That bill, along with the bill authorizing the downsizing study, must be approved by the full legislature.

Read more

5. Illinois: State Representative pursues audit of grant issued by Dept. of Human Services to Community Resource Associates

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***Breese Journal* (Illinois) * December 6, 2012**

Learning more about the financial and contractual details which have enabled Community Resource Associates (CRA) to work for the Department of Human Services (DHS) may be significant in the continued fight to save Murray Developmental Center in Centralia, Illinois.

DHS contracted with CRA to handle the transition of the state's developmentally disabled citizens from state-operated facilities to community-based group homes.

In October, state Rep. John Cavaletto of Salem filed a House Resolution directing the Auditor General to conduct a formal audit of the grant issued by the DHS to CRA.

Last week, Cavaletto sent a formal request for House Speaker Michael Madigan to discharge House Resolution 1247 from the Rules Committee and allow it to be voted upon by the full House of Representatives.

"A lot of my constituents and I have some very serious issues relating to how DHS is handling the closure process at Murray Center and this resolution will go a long way toward addressing our questions and concerns. I filed this resolution back in early October and I'm requesting the Speaker to let it out now and allow for a vote," Rep. Cavaletto said.

6. Georgia: State nursing home in Milledgeville to close in 2013

Reminders:
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***The Telegraph* (Macon, GA) * November 25, 2012**

In a little more than a year, the James B. Craig Nursing Center at Central State Hospital in Milledgeville will close, sending 127 severely disabled patients to smaller community nursing facilities and forcing many of its 350 employees to search for new jobs.

"We're anticipating closing the Craig Center Dec. 31 of 2013,". Patients will gradually be evaluated and moved to other facilities with varying levels of care depending on patients' needs.

There are three reasons the Department of Behavioral Health and Developmental Disabilities has chosen to close the state-run nursing home, Regional Hospital Administrator Dan Howell said.

"Number one is the state of Georgia is choosing not to be in the nursing home business any longer," Howell said. "Two is the belief that the individuals who currently reside at the Craig Center can be supported within existing community care providers."

And third, he said, state officials aren't sure the Craig Center's continued operation would meet standards of a settlement with the U.S. Department of Justice.

"Under this agreement, the state of Georgia will provide services in the community to hundreds of people with developmental disabilities and thousands of people with mental illness," Thomas Perez, assistant U.S. attorney general for civil rights, said then.

The settlement gave Georgia five years to provide 9,000 mentally ill people with community-based care. That included creation of at least 1,000 Medicaid waivers to move all developmentally disabled people in state hospitals to community nursing care, including increased family and housing support.

Read more

Research News

7. Sibling Caregivers Find Responsibilities A Struggle

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Disability Scoop * December 6, 2012

About half of adult siblings of those with developmental disabilities either are or plan to be the primary caregiver for their brother or sister, but many are unprepared for the responsibility, a new survey finds.

The national poll released Wednesday indicates that among adult siblings of those with a disability, 23 percent are currently serving as primary caregivers while 1 in 3 expect to take on that role in the future. And many are finding the experience to be daunting, fraught with emotional and financial challenges and little support.

The survey conducted by the market research firm Ipsos on behalf of Easter Seals solicited feedback from 351 brothers and sisters of people with developmental disabilities from across the country. A control group of nearly 1,400 adults with typically developing siblings was also polled.

Read More

Related: VOR's Sibling's Voice website

8. Autistic Adults Report Significant Shortcomings in Their Health Care

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Science Daily *** December 6, 2012**

Researchers at Oregon Health & Science University (OHSU) have found that adults with autism, who represent about 1 percent of the adult population in the United States, report significantly worse health care experiences than their non-autistic counterparts.

"Like other adults, adults on the autism spectrum need to use health care services to prevent and treat illness. As a primary care provider, I know that our health care system is not always set up to offer high-quality care to adults on the spectrum; however, I was saddened to see how large the disparities were. We really need to find better ways to serve them," said Christina Nicolaidis, M.D., M.P.H., principal investigator and associate professor of medicine (general internal medicine and geriatrics) at OHSU.

The study, published in the Journal of General Internal Medicine, was conducted by the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE), an academic-community partnership where academic investigators, autistic adults and other community members work together throughout the project.

Nicolaidis and colleagues surveyed 209 autistic adults and 228 non-autistic adults through a secure registration system for online studies. Autistic adults reported greater unmet health care needs, higher use of the emergency department, and lower rates of preventive services such as Pap smears. They also reported poorer satisfaction with provider communication and lower comfort in navigating the health care system or managing their health.

Read more

Federal News

9. Congress Votes To Strike 'Lunatic' From Federal Law

Disability Scoop * December 6, 2012

With near-unanimous approval from Congress, a bill is headed to President Barack Obama's desk to strip yet another term deemed offensive to people with disabilities from federal law.

The U.S. House of Representatives voted 398 to 1 Wednesday to pass a bill that would remove the word "lunatic" from the nation's laws. The measure was easily approved in the Senate in May and now advances to the White House for Obama's signature. Backers of the bill known as the 21st Century Language Act say it's an effort to update U.S. law for the times. The word "lunatic" originates from Latin and the outdated belief that mental issues were triggered by changes in the moon. The term is now considered derogatory by many with mental illness and other disabilities.

"Federal law should reflect the 21st century understanding of mental illness and disease," the bill's chief sponsor, Sen. Kent Conrad, D-N.D., said in introducing the measure earlier this year. "The continued use of this pejorative term has no place in the U.S. Code."

The effort to strip "lunatic" from the nation's books comes two years after Congress voted to replace the term "mental retardation" with "intellectual disability" in many areas of federal law.

The sole House vote against the bill came from Rep. Louie Gohmert, R-Texas, who told the Capitol Hill newspaper The Hill that he has no problem with the word “lunatic” being used in federal law.

10. Social Security Announces New Compassionate Allowances Conditions: Fast Track Disability Process Will Now Include 200 Conditions

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Social Security Administration Press Release *
December 6, 2012

Michael J. Astrue, Commissioner of Social Security, today announced 35 additional Compassionate Allowances conditions are in effect, bringing the total number of conditions in the expedited disability process to 200. Compassionate Allowances are a way to quickly identify diseases and other medical conditions that, by definition, meet Social Security’s standards for disability benefits. The program fast-tracks disability decisions to ensure that Americans with the most serious disabilities receive their benefit decisions within days instead of months or years. These conditions primarily include certain cancers, adult brain disorders, and a number of rare disorders that affect children.

“We have achieved another milestone for the Compassionate Allowances program, reaching 200 conditions,” Commissioner Astrue said. “Nearly 200,000 people with severe disabilities nationwide have been quickly approved, usually in less than two weeks, through the program since it began in October 2008.”

By definition, these conditions are so severe that Social Security does not need to fully develop the applicant’s work history to make a decision. As a result, Social Security eliminated this part of the application process for people who have a condition on the list.

Social Security has held seven public hearings and worked with experts to develop the list of Compassionate Allowances conditions. The hearings also have helped the agency identify ways to improve the disability process for applicants with

Compassionate Allowances conditions.

For more information on the Compassionate Allowances initiative, please visitwww.socialsecurity.gov/compassionateallowances.

Quotable

"*It had long since come to my attention that people of accomplishment rarely sat back and let things happen to them. They went out and happened to things.*" ~ Leonardo da Vinci

Tel: (605) 399-1624
Toll Free: (877) 399-4867
Fax: (605) 399-1631
Email: info@vor.net

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VOR
836 S. Arlington Heights Rd.
#351
Elk Grove Village, Illinois 60007
US