

Speaking out for people with intellectual & developmental disabilities



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Reminders: Help VOR Grow!

VOR Weekly News Update

News and views for VOR Advocates

Registration and Sponsorship Details are now availability for VOR's Annual Conference and Washington Initiative, June 8 - 12, 2013 in Washington, D.C. Please join us!

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!

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Quotable by Eleanor Roosevelt

Calendar Reminders

* Rescheduled! The State Coordinator and Member Webinar is now scheduled for Wednesday, March 13 at 12:00 pm central / 1:00 pm mountain

<u>Click here to register</u>. Registration details are also provided at the end of this Update.

- *Through May 1, 2013: <u>Be a Sponsor. Get a Sponsor:</u>
 Support VOR's Conference and Initiative. Sponsorship opportunities, in partnership with *EP Magazine*, are now available.
- * Sunday, June 9, 2013

VOR Annual Conference * Washington, D.C. <u>Registration now</u> available. Details online.

* Begins Monday, June 10, 2013

VOR Washington Initiative (Begins Monday, June 10, 2013) * Washington, D.C. <u>Details online.</u>

1. <u>Be A Sponsor. Get a Sponsor</u>: Help Support VOR's Conference and Initiative

Dear VOR Members.

Do have 10 minutes to spare?

I would like to ask each of you to take 10 minutes and think about who you know that might like to support VOR with an Annual Conference and Initiative Sponsorship or Exhibit.

Perhaps you know of a business, organization or friend who would appreciate the opportunity to showcase their business to a national audience, while also benefiting a VOR. Recognition opportunities for sponsors and exhibitors are abundant. In addition to recognition on VOR's website (www.vor.net), Weekly News Update e-publication, print newsletter, social media, email and conference signage and programs, this year for the

first time, some Sponsors will have free advertising opportunities in *EP Magazine*, which reaches 300,000 readers!

We must expand the number of sponsors and exhibitors for 2013 and in coming years. Please take 10 minutes to consider these and other ideas:

- * Does your parent/family group make a sponsorship donation?
 - * Who does your facility bank with?
- * Do you know the vendors at your loved ones facility?
- *Does your loved one use adaptive equipment, if so what is the company's name?
- * What personal relationships do you have who you could visit with and ask to become a sponsor?

Please share any names of potential new Annual Conference Sponsors and Exhibitors with Julie Huso at; ihuso@vor.net or 605-370-4652.

Thank you for your consideration! Sincerely.

Julie Huso

Executive Director

2. VOR State Coordinator and Member Free Webinar: All Members are welcome

Save the Date! March 13, 2013

Dear VOR Members:

As a friendly reminder, on March 13, 2013 at 12:00 pm central / 1:00 pm eastern, VOR will sponsor a State Coordinator and Member Webinar, hosted by Richard Male, for the purpose of providing an overview of VOR's State Coordinator, Member advocacy, and national programs. We will showcase the importance of the Coordinator program, while also featuring the VOR advocacy tools that are available to all members for their state advocacy. The Webinar is an opportunity for

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any committed VOR member to gain new advocacy and VOR awareness tools.

All VOR members are encouraged to attend. Please register today. Instructions for registration are below.

Respectfully, Ann Knighton President

State Coordinator and Member Webinar: Free and open to ALL VOR Members

Date: Wed, March 13, 2013

Time: 10:00 AM Pacific; 11:00 AM Mountain; 12:00

PM Central; 1:00 PM Eastern

Dial-In Number for Audio: 866.740.1260

Registration Link
Access Code: 4562930

Sequestration News

3. What Will Sequestration Mean for People with Disabilities?

National Council on Disability * February 28, 2013

A series of automatic, across-the-board cuts to federal government spending totaling \$1.2 trillion over the course of 10 years are set to take effect this Friday, March 1. Dubbed "sequestration" these cuts, if implemented, will be split between defense and domestic discretionary spending.

The National Council on Disability (NCD) urges the Executive Branch and Congress to find a responsible alternative to sequestration to prevent potential harm to Americans with disabilities and their families.

State News

4. Virginia: Va.'s plan to close institutions remains unresolved (letter to the editor)

The Washington Post * February 22, 2013 * Letter to the Editor by Jane Powell, president of Central Virginia Training Center Families and Friends

The Feb. 18 Metro article "A troubling future for the disabled," about Virginia's plan to close its training centers for the intellectually disabled, stated that four of the five "are to be shuttered by 2020." But this is a decision that has yet to

be made.

On Aug. 23, District Judge John Gibney issued a ruling in which he stated, "Nothing in the decree compels Virginia to close any facility. . . . The Court recognizes that the Virginia Department of Behavioral Health and Developmental Services is trying to move away from a care model with Training Centers, but the ultimate decision whether to close any Training Center lies not with the Department but with the legislature." The Virginia General Assembly is considering its options.

The department has requested everincreasing funding to implement its own plan, which it has doggedly pursued in defiance of the terms of the state's agreement with the Justice Department over the centers.

Most training center families are unalterably opposed to discharge. Virginia's community capacity and protections are insufficient, as is the department's respect for the Supreme Court's Olmstead ruling regarding the proper placement of people with developmental disabilities.

5. Kansas: State Senate committee concurs on KNI consolidation

The Capital-Journal * February 25, 2013

The Legislature moved one step closer to shrinking the Kansas Neurological Institute ICF/ID this week, with a Senate budget committee agreeing with a recommendation to close one of the campus' 21 residential cottages.

The Topeka-based state institution for Kansans with severe developmental and physical disabilities currently has 163 beds and, as of last year, had 153 residents. Each cottage holds about eight residents. The Senate Ways and Means Committee members concurred with their House budget counterparts on a plan to

close the least full one and redistribute its residents.

KNI was targeted for closure in 2009 by a commission formed by Gov. Mark Parkinson that recommended transferring its residents to community-based care.

That recommendation has never been implemented, in large part due to outcry from legislators who say many communities wouldn't be able to provide the services needed for KNI residents to thrive.

Read more

6. New Jersey: Call Today & Save the Developmental Center: Make a phone call and help reverse the slated closing of the Woodbridge Developmental Center

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The Woodbridge (NJ) Patch * March 1, 2013

The Woodbridge Developmental Center may be the last thing that comes to mind when you think of home. For many severely disabled people and their families, though, it is as close to heaven as it gets.

Read more

7. New Jersey: Legislators want to keep Woodbridge facility open

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The Sentinel (Edison/Metuchen, NJ) * February 27, 2013

One by one, relatives of those living in the Woodbridge Developmental Center and the North Jersey Developmental Center came to the microphone to share their loved ones' stories.

Their goal: To convince state officials that closing the facilities would be detrimental to the lives of the state's most vulnerable residents. They spoke during a joint hearing of the the Senate Health, Human Services and Senior Citizens Committee and Assembly Human Services Committee in Montclair on Feb. 13.

Emotions ran high and many in the packed room shed tears during the five-hour hearing. The legislators heard the stories of people like

Jackie, Rosemary and Richard, as told by their family members.

The legislators heard the story of Rosemary, who is 57 and has lived at the Woodbridge Developmental Center (WDC), Rahway Avenue, for the past 38 years. She is classified as profoundly intellectually disabled and has a mental age of a 3-monthold. Her sister, Joanne St. Amand, a resident of Cranford and president of the WDC Parents Association, has been a vocal advocate for keeping the WDC open. She and others have gone from town to town in Middlesex County, asking governing bodies to pass resolutions against the facility closures.

Read more

Related news: NJ settles suit with P&A over developmentally disabled; 600 people to be transferred

8. Vermont: Important Medicare Case Settlement is Approved

DD News Blog (Editor, Jill Barker) * January 18, 2013

[Most low-income adults who are developmentally disabled are eligible for Medicaid when they turn 18. They may also become eligible for Medicare if a parent who has been paying into the Social Security System either dies, retires, or becomes disabled.]

An agreement has been reached and a settlement approved in a class action lawsuit that is especially important to people covered by Medicare who have chronic or debilitating medical conditions from which they may not recover or improve.

In <u>Jimmo v. Sebelius</u>, No. 11-cv-17 (D.Vt.), the plaintiffs contended that Medicare has for years illegally restricted coverage of skilled nursing and therapy services only to beneficiaries who showed improvement.

Beneficiaries who needed services to maintain

their status or to slow deterioration were denied services on the basis that they would not improve. A settlement overturns the "improvement standard" and requires that skilled nursing and therapy services necessary to maintain a person's condition is covered by Medicare.

[Visit the Web site for Center for Medicare Advocacy, Inc. for the most complete information on the case that includes Frequently Asked Questions, personal stories, and links to important documents.]

The federal Centers for Medicare and Medicaid Services (CMS) has agreed to revise the Medicare Benefit Policy Manual to include new policy provisions. Skilled Nursing Facilities, Home Health Services, and Outpatient Therapy Services, including outpatient physical and occupational therapy and speech pathology services, will be covered "to perform a maintenance program [that] does not turn on the presence or absence of a beneficiary's potential for improvement from the therapy, but rather on the beneficiary's need for skilled care."

See The DD News Blog

Research News

9. National: Risk Of Victimization Greater For People With Disabilities

Disability Scoop * February 26, 2013

People with disabilities are significantly more likely than others to be victims of violence and are often more emotionally impacted when they are taken advantage of, new research indicates.

Odds of experiencing violence are two to three times higher for people with disabilities as compared to those without, researchers <u>report</u> in the journal PLOS ONE this month.

The risk extends to physical and sexual violence in domestic and non-domestic

situations.

Moreover, those with disabilities who are victims are twice as likely as others to have emotional difficulties in the aftermath of their experience, according to the study.

The findings come from an analysis of the 2009-2010 British Crime Survey, which includes data from over 44,000 adults living in England and Wales. The researchers indicate that their results are consistent with reports from the United States and other countries.

Clinicians need to be more aware of the risk for violence and the toll it takes on those with disabilities, researchers from the University College London and King's College London indicate in the study.

"Future research should evaluate the effectiveness of violence prevention programs in people with disability that address risk factors specific to this group, such as caregiver stress or communication barriers to disclosure," the study authors wrote.

10. Cerebral palsy breakthrough: "Possible path to a cure" for chronic condition

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news.com.au * January 31, 2013

A PROMISING study into cerebral palsy may pave the way to a cure for the chronic condition, experts have said. The study, published in the journal Stem Cells, found that patients who underwent a special treatment involving transfused umbilical cord blood cells experienced big improvements in brain and movement function.

Read more

11. Autism, Psychiatric Disorders Close Genetic Cousins

Disability Scoop * March 1, 2013

In the largest study of its kind, researchers are reporting that autism may be more closely tied to a

handful of other psychiatric disorders than previously thought.

Scientists analyzed the genomes of more than 60,000 people finding that those with autism, attention deficit hyperactivity disorder, bipolar disorder, major depressive disorder and schizophrenia may all share genetic risk factors. For the <u>study</u> published online this week in the journal The Lancet, researchers looked at the genomes of 33,332 people, each of whom had one of the five psychiatric disorders targeted, and 27,888 people with no mental health issues. They found four areas of genetic code with variations seen in people with all five psychiatric conditions.

The discovery could help improve understanding of the psychiatric disorders, researchers said, and may lead to more accurate ways to diagnose the conditions.

"Our results provide new evidence that may inform a move beyond descriptive syndromes in psychiatry and towards classification based on underlying causes," said Jordan Smoller of Massachusetts General Hospital who worked on the study.

Quotable

- "You must do the things you think you cannot do."
- ~ Eleanor Roosevelt

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