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Speaking out for people with intellectual & developmental disabilities



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**Reminders:
Help VOR Grow!**

January 30, 2015

VOR Weekly News Update

News and views for VOR Advocates

[About VOR](#) * [Refer a Friend](#) * [Donate](#)

VOR and YOU

1. **VOR Conference:** Register now to attend our one-of-a-kind event
2. **Free Webinar:** Dental Coverage and Access for Adults in Medicaid: Opportunities for States

MENTAL HEALTH NEWS

3. **Bring Back Facilities:** Improving Long-term Psychiatric Care

STATE NEWS

4. **New Jersey** Assembly panel OKs bill concerning developmentally disabled adults living in out-of-state facilities
5. As **New York** Moves People With Developmental Disabilities to Group Homes, Some Families Struggle

AUTISM RESEARCH

6. **Autism** Genes Often Differ. Even Among Siblings

**2015
Conference:
Advocating for
Choice by
Expanding
Opportunities**

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About VOR

7. Autism Moms Suffering PTSD Says Study

QUOTABLE, by William B. Dawson, Esq.

COMING UP:

- No VOR *Weekly E-News Update* Next Friday, February 6, 2015
- Speaker Features for VOR's Annual Conference

Calendar Reminders

VOR and YOU

1. VOR Conference: A One-of-a-Kind Event

**VOR Annual Conference and Congressional Initiative
Advocating for Choice by Expanding Opportunities
June 6-10, 2015
Washington, D.C.**

REGISTRATION NOW OPEN!

[NEWLY DESIGNED CONFERENCE](#)

[FLYER](#) (featuring [Artwork by Carsten](#)). Flyer offers complete DETAILS, including agenda, conference registration form, links, and hotel reservations

[CONFERENCE and INITIATIVE Online Registration](#)

[HOTEL RESERVATIONS](#)

Coming Up: Speaker Features!

2. Free Webinar: Dental Coverage and Access for Adults in Medicaid: Opportunities for States

Sponsored by Centers for Health Care Strategies (CHCS)

[Free Registration Required \(Click Here on "REGISTER NOW" Button\)](#)

Date and time:

Tuesday, February 17, 2015 12:00 pm eastern

**2015
Conference:
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Opportunities**

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About VOR

standard time

Program:

CHCS Webinar

Duration:

1 hour 30 minutes

Description:

During this 90-minute webinar, the Center for Health Care Strategies (CHCS) will provide an overview of adult dental coverage in Medicaid, highlighting key opportunities and challenges in advancing oral health care access. Oral health leaders from Colorado and Kentucky -- both Medicaid expansion states -- will share their states' experiences expanding dental coverage and access for low-income adults. The webinar is the first in a series from CHCS' Advancing Dental Access, Innovation, and Quality for Adult Medicaid Beneficiaries initiative, supported by the DentaQuest Foundation and the Robert Wood Johnson Foundation.

[Click Here for More Information](#)

MENTAL HEALTH NEWS

3. Improving Long-term Psychiatric Care; Bring Back Facilities

**The Journal of the American Medical Association *
January 20, 2015**

Summary: *The article argues that the caring for people with mental illnesses require community and "institutional" options; both are necessary as part of a continuum of care that provides real choice.*

Excerpts

During the past half century, the supply of inpatient psychiatric beds in the United States has largely vanished. In 1955, 560 000 patients were cared for in state psychiatric facilities: today there

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are fewer than one-tenth that number: 45 000.¹ Given the doubling of the US population, this represents a 95% decline, bringing the per capita public psychiatric bed count to about the same as it was in 1850—14 per 100 000 people. A much smaller number of private psychiatric beds has fluctuated since the 1970s in response to policy and regulatory shifts that create varying financial incentives.

For the past 60 years or more, social, political, and economic forces coalesced to move severely mentally ill patients out of psychiatric hospitals.

Deinstitutionalization has really been transinstitutionalization. As state hospitals were closed, patients with chronic psychiatric diseases were moved to nursing homes or to general hospitals where they received episodic psychiatric treatment at significantly higher costs. Others became homeless, utilizing hospital emergency departments for both care and housing. Indeed, the current crisis in Nevada—where the lack of psychiatric beds has resulted in overcrowded emergency departments filled to capacity with psychiatric patients—may be a harbinger of the future. Most disturbingly, US jails and prisons have become the nation's largest mental health care facilities. Half of all inmates have a mental illness or substance abuse disorder; 15% of state inmates are diagnosed with a psychotic disorder.

These are not new problems.

For persons with severe and treatment-resistant psychotic disorders, who are too unstable or unsafe for community-based treatment, the choice is between the prison–homelessness–acute hospitalization–prison cycle or long-term psychiatric institutionalization. The financially sensible and morally appropriate way forward includes a return to psychiatric asylums that are safe, modern, and

humane.

[Read more, comment and share](#)

STATE NEWS

4. New Jersey Assembly panel OKs bill concerning developmentally disabled adults living in out-of-state facilities

*The Record (North Jersey) * January 15, 2015*

Some adults with developmental disabilities that face a state-mandated move back to New Jersey from out-of-state facilities would get a reprieve under a bill that was moved out of a state Assembly committee Thursday.

The bill, approved by the Human Services panel, would require the state to continue paying for out-of-state services for people who meet a series of conditions, including long-term residence in the facility and family members who live within 15 miles.

“We need to make sure our most vulnerable are not sacrificed for savings, especially when it’s minor savings that carry major consequences,” said Valerie Vainieri Huttel, D-Englewood, a sponsor of the bill.

[Read more, comment and share](#)

[Read VOR's position in support of A3975/S2600](#)

[Read Attorney Paul Prior's excellent testimony in support of A3975/S2600](#)

5. As New York Moves People With Developmental Disabilities to Group Homes, Some Families Struggle

*New York Times * January 29, 2015*

Once, New York State had 22 institutions serving more than 27,000 people. By 2017, when the

Bernard Fineson Developmental Center in Queens closes, only two institutions — both far from New York City — will remain open, serving a total of 150 people. The Brooklyn center, which housed 614 residents in 1984, is down to 58 spread across five buildings on a 35-acre campus.

For some families of the highest-need residents left there, the policy has caused anger and anxiety. “Why is the governor closing the place of last resort for Brooklyn residents?” Mr. Cosentino, 73, said, his voice rising in panic.

[Read more, share AND COMMENT \(This article contains some common misrepresentations of *Olmstead* and cost – comments are needed\)](#)

AUTISM RESEARCH

6. Autism Genes Often Differ, Even Among Siblings

Disability Scoop * January 27, 2015

Adding to confusion about the roots of autism, new research suggests that varying genes are often responsible for the disorder even among siblings who share a diagnosis.

Kids who have an older brother or sister with autism are known to be at higher risk for the developmental disorder and scientists have thought this heightened occurrence was due to shared genes.

But a study released Monday throws a kink in that theory. After sequencing the whole genomes of individuals from dozens of families — each with at least two children on the spectrum — researchers found that less than a third of affected siblings shared the same autism-associated gene variations.

[Read more, comment and share](#)

7. Autism Moms Suffering PTSD Says Study

MyFox Houston * January 27, 2015

For thousands of moms of autistic children, research from the University of Wisconsin- Madison generated little surprise - findings that mothers of autistic children frequently suffer from Post Traumatic Stress Disorder at levels similar to those of soldiers who've engaged in extended combat.

"I thought yes, this is what I see, this is definitely what I see," said Katherine Loveland, Ph.D. who studies Autism and its impact on families at UTHealth Medical School.

She says the uninterrupted stress of contending with autism has a cumulative and punishing effect often made worse by unempathetic outsiders, making PTSD inevitable.

"The supports that a family needs to bear up under the stresses often aren't there. Instead, they receive blame, criticism and a lack of support," said Loveland.

With a patriot's heart and second son serving the nation, Michele Guppy draws a distinct line between what she endures and the unseen wounds America's sons and daughters suffered on the field of battle.

"I would never want to be in their shoes and I would never want them to be in mine. It's the same yet different," said Guppy, mother to 21 year old Brandon.

[Read more, comment and share](#)

QUOTABLE

"A goal must be specific. If you can't name it, you can't claim it." ~ by William B. Dawson, Esq.

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Calendar Reminders:

Tuesday, March 24, 2015:

[American Health Care Association ID/DD](#)
[Washington Flv-In](#)

Congressional speakers are being invited, a legislative update will be provided, and Hill visits will follow in the afternoon. Breakfast and a boxed lunch will be provided to you. [Registration is free but required](#). VOR members are encouraged to attend.

Sunday, June 7, 2015:

[VOR Annual Conference: ADVOCATING FOR CHOICE BY EXPANDING OPPORTUNITIES. Registration Open.](#)

Archives:

* Thursday, March 20, 2014

[VOR's "Regional Meetings: The Need for Advocates to Act Global and Local" Webinar.](#)

***Social Media Strengths: Using Facebook and Twitter to Advance Your Cause (VOR, July 2013).** [Visit VOR's website for a copy of the powerpoint presentation and an audio of the event.](#)

* **How Congress Works Webinar: Recorded - Listen Here.** Tuesday, April 23, 2013 - 12:00 pm central / 1:00 pm eastern. How Congress Works: The Basics. Hosted by Peter Kinzler and Larry Innis.

VOR
836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007
Email: info@vor.net

Tel: (605) 399-1624
Toll Free: (877) 399-4867
Fax: (605) 399-1631

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