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May 2, 2014



Speaking out for people with intellectual & developmental disabilities



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## VOR Weekly News Update

News and views for VOR Advocates

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## **1. VOR Annual Conference and Congressional Initiative. THERE IS STILL TIME TO REGISTER!**

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Register for [VOR's Annual Conference](#) by **May 5 (extended deadline)**, [online or by fax/mail](#), to secure your spot at VOR's Annual Conference and reserve your [Hotel Room \(also due May 5\) at the same time](#).

***Make your plans today. See you in June!***

## **2. VOR Submits Testimony for Record Asking Senate to Prohibit Federal Funding for Forced Deinstitutionalization; Hundreds of Choice Advocates Share Their Support**

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**VOR \* April 18, 2014**

VOR is a national organization that advocates for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD). On April 18, VOR submitted written testimony calling on the U.S. Senate to prohibit the use of U.S. Department of Justice appropriations in support of deinstitutionalization activities which evict eligible individuals from their homes.

Nearly 500 advocates for family members and friends also submitted a statement for the record in support for VOR's testimony. Thanks to all who took action!

[Read VOR's Testimony Here](#)

## **STATE NEWS**

### **3. Tennessee: Greenville Resists Closure of Green Valley Developmental Center**

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***The Tennessean \* April 27, 2014***

In small-town Greeneville, a 52-year-old facility for people with limited mental functioning continues to operate despite a nationwide movement.

More than 100 people, ranging in age from 29 to 91, still live inside Greene Valley Developmental Center. At its peak there were more than 1,000 residents, but no one new has been admitted in three years. The state has plans to move just a few people out, even though outside experts have said most residents would be better off living elsewhere.

In recent years, relatives and guardians of Greene Valley residents have resisted allowing their loved ones to move from the security and familiarity of a place where many have spent nearly their entire lives.

[Read more, comment and share](#)

[Watch a great video](#)

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#### **4. Pennsylvania: Who knows best? Dispute over disabled man's care magnifies guardianship's complexities**

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***TimesOnline (Pittsburgh) \* April 8, 2014***

The tug-of-war over Dominic's fate highlights the challenging dynamic of court-appointed guardianships, which often pit an unknown third party assigned to make decisions in the best interest of a ward against family members who inherently feel they know what's best for their relative.

Every month, Dominic intently waits at the door of his group home for his mother to arrive, and he immediately asks her, "When's the next hearing?"

A court hearing, in Dominic's eyes, means going home, or at least leaving a place that he calls prison, said his mother, Nancy Pantoni. She has been trying since 2010 to change legal guardianship of her 27-year-old son, who has intense special needs because of a genetic disorder.

But, it's that obsession with going home that his guardian, a caseworker with Jewish Family & Children's Service of Pittsburgh, asserts in court record may be holding the young man back from coping with the 24-hour care he needs and taking opportunities to work or to socialize.

As a result, Pantoni's interactions with Dominic have been restricted by the guardianship agency, which declined to comment on the specific case because of privacy concerns.

She can visit for one hour a month. No phone calls. And she said she's not informed when he's admitted to the hospital or his medications have changed.

Pantoni, a divorced mother of three, filed for bankruptcy connected to her efforts to regain some semblance of control in her son's life. She said she feels decisions made by the guardian have been detrimental.

"His health has significantly deteriorated so much that I'm concerned for his life," she said. "I'm on a mission to save my son's life, I really am. I'll do anything."

[Read more, comment and share](#)

#### **5. New Jersey autism services evolve to meet need**

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***Atlanticville \* April 27, 2014***

Jersey has steadily evolved since the mid-1900s, from a system keen on large-scale, segregated institutions to one that pushes for community-based living.

That is expected to continue to the point where any look into the inner workings of the present service structure is but a fleeting glance, said Liz Shea, who oversees the state Division of Developmental Disabilities.

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## 6. Washington State: Thousands of Families Left Out Of State Funding To Help With Developmental Disabilities

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**Seattle Times \* February 24, 2014**

"No funding available" may best summarize the system for residents with developmental disabilities in Washington state, where some 14,600 families determined eligible for services don't receive any.

[Read more, comment and share](#)

## NATIONAL

## 7. Blog/Opinion: Autism Research Isn't Helping People Live with Daily Reality

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**Posted on National Autism Network posted by Brian \* April 23, 2014**

"[Autism Research Isn't Helping People Live with Daily Reality](#)" - This article discusses autism research in the UK, particularly a project known as "A Future Made Together," and the article brings up a lot of good points that mirror outcry from the autism community in the United States. A Future Made Together project was designed to get the opinions of 1,700 individuals with autism, their families, practitioners, and researchers concerning the current state of autism research and where the funds towards autism should be prioritized. They found that the majority of autism research in the UK, as is the case here, was conducted on neural and cognitive systems, genetics, and environmental risk factors, as oppose to targeting the needs of individuals currently on the spectrum. Another similarity to the U.S. research is the fact that researchers fail to take into account individuals on the spectrum and their families before applying for grants and conducting autism research.

[Read, comment and share](#)

## 8. Delaware: Rule would change options for people with disabilities

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**The News Journal \* April 21, 2014**

More than a hundred people gathered at the Embassy Suites in Newark Monday morning to discuss a new federal rule that could dramatically change options in housing, employment and other basics for people with disabilities.

The new rule is meant to signal the government's intention to support the rights of people with disabilities to live and work in the least-restrictive environment and discourage congregate care settings. It comes with real teeth, because it will regulate the kinds of services the government will pay for

At first glance, the rule seems straightforward enough. It defines the kind of settings that the government will recognize as “home and community-based” and, therefore, eligible for certain services under Medicaid insurance.

Several clear examples of places that are neither home nor community-based were offered: Nursing homes, psychiatric hospitals, medical hospitals, intermediate care facilities for those with intellectual disabilities.

In addition to those institutional settings, several are presumed not to be home or community-based, including those that are within an inpatient treatment center, on the grounds of or next to a public institution, and those that effectively isolate people from those who aren't getting Medicaid assistance.

[Read more, comment and share](#)

## 9. New Rules For Disability Caregivers Prompt Changes

### ***Disability Scoop* \* April 28, 2014 (original source: Stateline)**

A new rule from the Obama administration designed to provide better pay and working conditions to 2 million home care workers is forcing many states to rethink how they look at Medicaid payments and may result in higher Medicaid costs.

Starting Jan. 1, home care workers in 29 states will, for the first time, be eligible for the federal minimum wage of \$7.25 an hour and overtime pay, under a new regulation from the U.S. Department of Labor. These workers go to homes of the elderly and people with disabilities to help with cooking, bathing and other daily tasks, and are paid by the clients or through Medicaid.

Fifteen states already had applied state minimum wage and overtime protections to home care workers, also called “direct care” workers, while six others and the District of Columbia offer just state minimum wages.

Many states have never considered Medicaid payments to be wages, said Sarah Leberstein, a staff attorney with the National Employment Law Project, which advocates for higher pay for the poor. “It’s a new mindset. The states will have to shift their thinking and take another look at their reimbursement practices and guidelines with the new wage rules in mind.”

[Read more, comment and share](#)

### ***Quotable***

*"If not us, who?"* ~ The late-Robin Sims, VOR's Past President

Please join us in Washington, D.C. this June. Your voice matters. [Conference](#) and [Hotel](#) reservations

due Monday, May 5, 2014.

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### **Calendar Reminders:**

**VOR Annual Conference Deadlines Approaching:**

**May 5:** Annual Conference Registration Deadline (prices increases after May 1). Register [online](#) or by [mail/fax/email](#).

**May 5:** [Hyatt Hotel Reservation](#) Deadline to guarantee group rate and availability. All VOR events take place at the hotel.

**June 8, 2014**

**VOR 2014 Annual Conference and Initiative:**

*"Making it Happen: Reforming Policy and Law in Support of Person-Centered Quality and Choice"; Hyatt Regency, Washington, D.C.*

[Register today!](#)

**Week of June 9, 2013**

**VOR 2014 Congressional Initiative:** Families and advocates visit Capitol Hill.

**Sunday, October 5, 2014**

American Health Care Association's 2014 ID/DD Residential Services Day during AHCA/NCAL's 65th Annual Convention & Expo at the Gaylord National Harbor just outside of Washington, DC. Registration information and the schedule can be found [here](#).

**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.

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