



Speaking out for people with intellectual & developmental disabilities



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**Reminders:  
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**About VOR**

# VOR Weekly News Update

News and views for VOR Advocates

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## THANK YOU SPONSORS and PARTICIPANTS

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## **VOR and YOU**

**1. Get Ready! #GivingTuesday will be here before you know it**

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**What is #GivingTuesday?**

This December 2, will mark the 3rd annual **#GivingTuesday** – a day of giving back to kick off the holiday giving season.

It is a day (on or near) defined by generosity, sandwiched right between Thanksgiving (a day of gratitude) and Black Friday and Cyber-Mondays (days of spending). The **#GivingTuesday** movement is promoted by nonprofits and participants across the country who urge doing good through volunteering and [financial giving](#).

As one organization put it, “In a very short time, **#GivingTuesday** has revolutionized year-end giving and transformed it into a mainstream movement for social good.”

**What does it have to do with VOR?**

**Leading up to #GivingTuesday (on or near December 2), VOR will encourage our members and social media followers to think about how to benefit VOR on this annual day of giving.**

We’ll remind you of our annual year-end giving campaign and ask that you consider a [contribution](#). We’ll also ask that you **PLEASE**

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**SHARE** VOR's information with all of your social media networks ([Twitter](#), [Facebook](#) and [YouTube](#)) and also share the old fashioned way through email and dialogue with friendships, advocacy organizations, families.

Use **#GivingTuesday** as your motivation to share information about VOR and the great advocacy we are doing with everyone you know.

**How you define #GivingTuesday for VOR's benefit is really up to you.**

More information and ideas on how you can participate is coming soon and often.

**Thank you!**

**2. Pennsylvania victory: Settlement agreement protects choice; VOR as *Amicus x 2***

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**VOR \* October 9, 2014**

On September 25, attorneys for family intervenors secured a favorable settlement in *Benjamin v. Pa. Department of Public Welfare (DPW)*.

The settlement requires the State to enable hundreds of Pennsylvania's intellectually disabled residents to remain in their current state facility ("ICF/IID") homes or transition into community-based care, according to individual choice.

"Finally after almost 5 1/2 frustrating years, efforts to construct an agreement culminated in a very good outcome," said Bert Springstead, lead intervenor and retired VOR Board Member and State Coordinator. "For example, it is expected that an unbiased implementation of the agreement's protocols will diminish the

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current mistrust of DPW by many family members and guardians."

**[Read more and share](#)**

**Read also: "[Carl Solano Assists More than 1,000 PA Institutionalized Mental Health Patients from Being Removed from Residential Programs](#)," Schnader Law Firm Press Release (September 24, 2014)**

**SPECIAL EDUCATION AND "INCLUSION"**

**3. Special Education Charters Renew Inclusion Debate**

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***Education Week \* September 16, 2014***

Parents go to great lengths to meet the special and often demanding needs of children with disabilities.

In Diana Diaz-Harrison's case, that meant opening a charter school in Phoenix for her son, who has autism—and for other students like him—when she felt his needs weren't being met in regular district-run schools.

"For my typical daughter, we chose a charter school that specializes in the arts ... that meets her needs," said Ms. Diaz-Harrison. "So for my little boy with autism, what can meet his needs? A school that can help him with his communication, ease his anxieties, help him move forward and make academic progress. We didn't have a school like that—now we do."

The school that Ms. Diaz-Harrison opened this year—the 90-student Arizona Autism Charter School—is among dozens of charters nationwide that focus on serving students with disabilities. Such schools help counter the long-running criticism that charters don't serve enough of those students.

But they also renew questions about the best educational environment for students with disabilities: Is it a specialized school or a more mainstream setting with general education students?

[Read more, comment and share](#)

#### **4. Supreme Court Seeks Input on Individuals with Disabilities Education Act (IDEA) Case**

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*Disability Scoop* \* October 7, 2014

The U.S. Supreme Court is asking the Obama administration to weigh in on a case involving who should pay for private school tuition while special education disputes are litigated.

The high court asked the U.S. solicitor general on Monday to provide an opinion on a case known as Ridley School District v. M.R. which centers on the “stay-put” provision of IDEA.

Under the law, school districts must pay for students to remain in their existing educational placements while special education disputes between parents and schools are sorted out.

However, the Ridley School District in suburban Philadelphia — joined by a handful of education groups — is arguing that a district’s obligation to pay for a private placement should end once a court rules in the schools’ favor, no matter if a child’s parents continue to pursue their claims.

[Read more, comment and share](#)

#### **STATE NEWS**

**5. New York: Family pleads to Gov. Cuomo “Give our daughter a chance”; State seeks to bring her “home” to New York despite**

## **repeated failures in New York programs**

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As she went through childhood, Sam was kicked out of numerous schools and treatment centers in New York, all of which willingly took on the challenge of handling her only to find that her violent behavior simply exceeded their capabilities. As her parents, we started Samantha off at each new school filled with cautious hope that this might be the right situation, only to be thrown back into a desperate quest for a new program as her treatment failed to take hold again and again — five times in all.

Finally, when Sam was 12 years old, the sixth program we tried in her short life took hold. Where the very best medical professionals and specialized therapeutic schools in New York had come up short, our precious daughter thrived at the Judge Rotenberg Educational Center in Canton, Mass. The Rotenberg Center's behavioral treatment and education program is a resource of last resort, at one of the only schools in the country that will accept people with the most severe behavior disorders. People like Sam.

Then a funny thing happened. The New York Office for People With Developmental Disabilities decided that adults from New York with behavioral disorders like Sam's who are treated in other states should be returned to New York.

New York intends its effort to save money. It will do no such thing, because the ability of state schools to treat Samantha and others in her situation has proven to be inadequate. Ultimately, they will be forced into expensive pschiatric hospitals.

[Read more, comment and share](#)

**6. New Jersey: No End In Sight For Autistic Man Jailed; State's Return Home New Jersey Initiative and Developmental Center closures leave no other option - two PETITION opportunities**

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[Read update, published today](#)

Tyler Loftus, 23, has been sitting in New Jersey's Hunterdon County Jail since September 18. "Every day he calls and says, 'Mom, come get me, I don't want to stay here,'" his mother, Rita O'Grady, told me.

Diagnosed with autism and intellectual disability, Tyler has the cognitive capacity of a 5-year-old. He can't understand why he's not allowed to leave.

"I never consented to this placement," O'Grady said. "I specifically withdrew consent, because I knew what would happen. But the Arc [the agency that operated the group home] moved him anyway."

And there are facilities that specialize in the treatment of individuals with developmental delay and dangerous behaviors: the Woods School in Pennsylvania, for instance, where Tyler lived from the ages of 15 to 21. Closer to home there are state-run developmental centers, such as the one in Hunterdon, where Tyler has previously been admitted.

But these are no longer options. Governor Chris Christie's Return Home New Jersey program has put a moratorium on all out-of-state placements and "Christie is closing [developmental centers]." O'Grady told me.

“And he’s put a stop order on all new admissions. Ideally, Tyler would be at Hunterdon while a permanent placement is found, but they can’t take him.”

The problem, O’Grady explained, is that the community-based supports that Christie promised have not yet materialized.

[Read more, comment and share](#)

**Related: Two Private Citizen Petition Opportunities for New Jersey Citizens:**

- [Oppose Gov. Christie’s Return Home New Jersey Initiative](#)
- [Oppose Gov. Christie’s Return Home New Jersey Initiative and Developmental Center Closures](#)

## **HEALTH CARE AND PEOPLE WITH DEVELOPMENTAL DISABILITIES**

### **7. Caregiver training may help mentally disabled adults with dental care**

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*Reuters Health \* October 2, 2014*

Helping adults with developmental disabilities brush and floss their teeth is often hard for paid and unpaid caregivers, but family members could be in extra need of training, a new study suggests.

Researchers found poor brushing and flossing habits and high rates of dental disease in a survey of disabled adults, and many caretakers lacked confidence in their ability to help their charges with daily dental care.

People with disabilities have more cavities and periodontal disease than the general population. which can lead to loss of teeth and

infection. They also have cognitive, behavioral and physical challenges that can make brushing and flossing difficult.

[Read more, comment and share](#)

## 8. Where Are the Nurses?

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*New York Times* \* August 13, 2014

They're called "nursing homes," so most of us assume that they have nurses — registered nurses — on the premises.

But not all the time. In some facilities, not even most of the time.

The 1987 federal law intended to reform the country's nursing homes required a registered nurse on-site only eight hours a day, regardless of the size of the facility. Supporters at the time understood that in a building full of sick and disabled elders, health crises could occur at any hour. But getting the legislation passed required substantial compromises, including in regulations allowing reduced nurse staffing.

"It's something advocates have wanted to return to ever since," said Robyn Grant, director of public policy and advocacy for the National Consumer Voice for Quality Long-Term Care. "I think most people will be both shocked and appalled that there's not an R.N. on duty around the clock."

One person who was indeed "completely shocked" to learn this was Representative Jan Schakowsky, Democrat of Illinois. "This applied to nursing homes whatever the number of beds," she told me in an interview. "One hundred. Four hundred."

She responded by introducing on July 31 the bluntly titled [Put A Registered Nurse in the Nursina Home Act](#). or House Vote 5373. It

would require that a direct-care registered nurse (not an administrator) be present 24 hours a day, seven days a week, in all the nearly 16,000 nursing homes that receive Medicare or Medicaid reimbursement.

"It's been close to 30 years," she said. "It's high time to provide better care."

[Read more, comment and share](#)

Read related blog: [When more costs less: more RN's in nursing facilities equals better and less costly outcomes for patients](#) (DD News Blog by Jill Barker, October 8, 2014)

## **RESEARCH NEWS**

### **9. The 2014 State of the States in Aging and Disabilities Report Released**

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[The 2014 State of the States in Aging and Disabilities Report](#) is the result of a NASUAD survey of state aging and disability agencies. It covers policy, fiscal, and operational issues within each state including information about the structure of agencies, the supports provides, and the populations served by aging and disability agencies.

#### **QUOTABLE**

*"We may affirm absolutely that nothing great in the world has been accomplished without passion."* ~ by Georg Wilhelm Friedrich Hegel

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#### **Calendar Reminders:**

**Sunday, June 8, 2015**

VOR Annual Conference

#### **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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