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Speaking out for people with intellectual & developmental disabilities



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**Reminders:
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March 20, 2015

VOR Weekly News Update

News and views for VOR Advocates

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Early Bird Registration Deadline: April 1, 2015

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QUOTABLE, by Neil deGrasse Tyson

COMING UP:

- Scott Osterfeld Speaker Feature: Dinner Keynote Speaker at VOR's Annual Conference

Calendar Reminders

VOR and YOU

1. Early Bird Registration Rates Expiring Soon: Have you registered yet for VOR's Annual Conference?

Conference registration fees, which include great presentations and dinner, will increase on April 1, 2015.

[Complete details about our Annual Conference \(June 7\) and Washington Initiative \(week of June 8, 2015\) in Washington, D.C. are available here.](#)

You can [register online](#) or [by mail](#).

Register now and save!

Thank you!

STATE NEWS

2. New Jersey Speaker Sweeney halts 'Return Home NJ' bill criticized by disabled people's families

***NJ.com* * March 16, 2015**

What just a week ago looked like an appealing alternative to the Christie administration's controversial Return Home NJ plan for hundreds of profoundly disabled people was derailed today — and is likely dead.

State Senate President Stephen Sweeney (D-Gloucester) today declined to let the Senate vote on a bill (S2600).

Sweeney said the idea of forcing some people to return to

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the state and letting others remain [due to a proposed grandfather clause that requires an individual have lived out-of-state for at least 25 years] "is a horrible choice, but hopefully we can negotiate with the administration."

Scrapping the Christie administration's Return Home NJ plan is "the fairest choice," he said. "I think the better solution is to shut it down leave everybody where they are at."

[Read more, comment and share](#)

3. Ohio: Lawmakers Question Thrust of Administration Budget Proposal; Disability Rights Ohio (P&A) Defends System Changes

Gongwer News * March 17, 2015

A finance subcommittee that's become accustomed to fielding backlash against developmental disabilities budget proposals heard support Tuesday for plans to shift more people from institutional settings to home- and community- based care.

Although a majority of the more than 100 witnesses to speak before the House Finance Health and Human Services Subcommittee were opposed to at least some portions of the Department of Developmental Disabilities proposed budget, a handful said the recommendations put the state in line with national trends by encouraging community integration for disabled Ohioans.

The slight turn in testimony provided the panel the opportunity to grill Disability Rights Ohio [Protection & Advocacy] Executive Director Michael Kirkman. Some have argued that the civil rights group is at the crux of the budget proposals drawing ire.

Mr. Kirkman told the panel that negotiations with the state in regard to its compliance with federal standards continue and DRO has not determined whether the budget proposals are sufficient to stave off a lawsuit.

Noting that there are [20,000] Ohioans on wait lists to receive disabilities services, Chairman Rep. Robert Sprague (R-Findlay) asked why the organization thinks it would be beneficial to reduce the number of ICF beds.

"There are a lot of individuals not just in the room here today, but also in the last week who are upset about the risk we're creating for our families because of the upheaval in the entire system," he said. "We're sitting here as representatives of the citizens of Ohio thinking why in the world would we make these wholesale changes to satisfy a federal agency.

"What gives you the right to come in and tell our citizens what's best for them when, in a lot of cases, the advocates who in almost all instances, at least in my district, the parents of those with developmental disabilities have built this system

in Ohio really from the ground up?" Rep. Sprague asked.

[Read more and share](#)

4. Ohio: Testimony Opposes Closure of Developmental Centers

Gongwer News * March 17, 2015

A large portion of the testimony on the developmental disabilities portions of the executive budget has been devoted to Intermediate Care Facility changes, but those with opinions on developmental center closures also spoke up on Tuesday.

The state announced last month that it would shutter the Montgomery and Youngstown developmental centers by June 30 because the number of individuals they serve has significantly declined in the last decade and will continue to do so under new budget provisions that favor community-based settings.

Staff and family members involved with the facilities set to close chartered busses to the Statehouse Tuesday to testify before the House Finance Health and Human Services Subcommittee and urge lawmakers to stop the closures as well as support a measure that would establish a closure commission (HB 73).

Sally Tyler, health and policy analyst for the American Federation of State, County & Municipal Employees, which is represented by the Ohio Civil Service Employees Association, asked the panel to consider why it would close down two developmental centers when there are thousands of people on waiting lists to receive services.

"Legislators and other policy-makers cannot afford to look at this demand for services as an either/or equation, but unfortunately it is frequently framed in this way," she said. "A budget which starves these vital services in general forces advocates for various residential and program settings to fight over the same narrow piece of the pie, when the best solution for those in need would be to enlarge the pie, so that all the waiting individuals can receive services, honoring the full spectrum of consumer choices."

Ms. Tyler said she is supportive of better integrating disabled Ohioans into the community and providing them with opportunities to live the lifestyle they chose, but suggested that the state keep developmental centers open while it works to transition from an institutional-heavy model to one that's more focused on community- and home-based care. She also offered support for Intermediate Care Facilities and sheltered workshops, which are also facing downsizing as a result of DODD proposals.

She further questioned the impetus behind the proposals to close the centers and move people out of other facilities, saving that Centers for Medicare and Medicaid rules that

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encourage community integration may eliminate funding for facility-based services, but don't prohibit them from being offered.

"Although some of the short-term decisions within this budget focus on the question of providing services to those with intellectual and developmental disabilities, they will have lasting impact on the way Ohio structures its overall system of long-term services and supports, which will affect the provision of services to seniors and those with physical disabilities, as well, and which will be in even greater demand in coming years," she said.

"This necessitates a deliberate and thoughtful approach to planning new services and modifying existing ones, rather than taking the drastic step of closing facilities while capacity within the community is still so lacking."

[Read more and share](#)

5. New Jersey: Christie files for extension to file State's Transition Plan; Speaks to Return Home Initiative

***NorthJersey.com* * March 17, 2015**

Responding to an Ocean County man whose severely disabled 21-year-old son faces the possibility of being forced back to New Jersey from a Pennsylvania facility under Christie's Return Home New Jersey policy, the governor said he thought that there was a compromise with the Legislature on a bill that would protect certain people from the Return Home requirements.

Parents and guardians have launched a campaign against the policy to bring back 387 people living at facilities outside of New Jersey. Christie's administration and the Legislature have been working to reach a deal on a bill that would cut the number of people who would have to come back to New Jersey. But the bill was pulled before Monday's voting session.

"Until yesterday I thought that was going to get done. And then as of yesterday the Senate President (Stephen Sweeney) decided not to post the bill that there had been bipartisan agreement on. I don't understand, really, why," Christie said. "I've got to get back with him and find out why we're not doing that."

Sen. Bob Gordon, D-Fair Lawn, said Monday that legislators had reached out to the state Department of Human Services with several questions on the legislation and hadn't received answers.

Christie's first question came from a man whose 24-year-old son with cerebral palsy could be affected by a new transition plan by the state to comply with federal mandates for

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community-based service programs to offer more access to "the benefits of community living."

Christie said that on Friday he authorized the plan's submission to the federal government be delayed by 30 days because of the outpouring of concern from parents and, he said, because the state hadn't gotten enough recommendations for the plan. The deadline was Tuesday.

"The bigger issue is that we have this transition plan that we have to get finished," he said. "I have 30 days to come up with a transition plan that will affect the entire, or a good part, of the (developmentally disabled) community."

[Read more, comment and share](#)

6. Vermont: Sign of the Times: Deaf Vermonters Seek Better Options for Services and Schooling

***Seven Days Vermont* * February 25, 2015**

But for some deaf students like Neila, services within mainstream schooling do not meet their needs. And if a student wants to attend a specialized school for the deaf, they must look outside Vermont. In 2014, 11 deaf children attended out-of-state schools, Moran said.

The only school for the deaf in Vermont, the Austine School, which Neila probably would have attended, closed last June. Founded in 1904, Austine was a private school in Brattleboro for students with hearing loss, but because enrollment had declined from 145 in the 1970s to just 25 during the 2013-2014 school year, the school had to close its doors.

Austine's closure impacted not just its students. Since 1998, the Vermont Center for the Deaf and Hard of Hearing had run the school and also provided an array of services to deaf individuals and families throughout the state. The school's funding crisis also affected the center, which closed in the fall. These losses have advocates and families saying it's time to reexamine services for the deaf in Vermont.

Since the beginning of September, every Sunday at dinnertime Neila has boarded a bus and traveled four hours south, along with six other Vermont children, to the American School for the Deaf in West Hartford, Conn. She returns home on Friday evenings to spend the weekend with her family.

[Read more, comment and share](#)

FEDERAL NEWS

7. IRS Green Lights Section 529A ABLE Disability Programs

***National Law Review* * March 16, 2015**

The IRS released Notice 2015-18 on March 10, 2015, giving

the green light to states to proceed with the establishment of tax-free investment programs for the disabled under new Section 529A of the Internal Revenue Code.

Section 529A, which became effective January 1, 2015, grants tax-free treatment to the earnings in so-called ABLE accounts established for eligible disabled beneficiaries and used for qualified disability expenses.

[Read more, comment and share](#)

8. Medicaid – Home and Community Based Settings Rule

Last week, the Centers for Medicare & Medicaid Services (CMS) provided updated portions of the CMCS Home and Community-Based Services (HCBS) Toolkit: [the HCBS Basic Element Review Tool for Statewide Transition Plans and the HCBS Content Review Tool for Statewide Transition Plans](#). The full HCBS toolkit, including the updated portions, is [available online](#).

RESEARCH NEWS

9. Autism Largely Rooted In Genetics, Study Finds

Disability Scoop * March 17, 2015

Genes may be more responsible for autism than previously thought, researchers say, with the developmental disorder traced to heritability in the vast majority of cases.

In a study of all twins born in England and Wales between 1994 and 1996, researchers found that autism is rooted in genetics 74 to 98 percent of the time.

"Our main finding was that the heritability of ASD was high. These results further demonstrate the importance of genetic effects on ASD, despite the dramatic increase in prevalence of the disorder over the last 20 years," said Beata Tick of King's College London, the lead author of the study published this month in the journal JAMA Psychiatry.

[Read more, comment and share](#)

QUOTABLE

"I am driven by two main philosophies: Know more today about the world than I knew yesterday, and lessen the suffering of others. You'd be surprised how far that gets you." ~ Neil deGrasse Tyson

Calendar Reminders:

Tuesday, March 24, 2015:

[American Health Care Association ID/DD](#)

[Washington Fly-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.

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