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March 13, 2015



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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COMING UP:

- More Speaker Features for VOR's Annual Conference

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VOR and YOU

1. Annual Conference Speaker Feature: VOR President Ann Knighton

Past Annual Conference Participants already know how Ann Knighton, VOR's President, will begin her Message to the Members and her State Report:

"Greetings from the great State of Georgia!"

That standard opening line will be followed by VOR news and milestones from the past year and expectations for the coming year. As with past Presidents, Ann's Message to the Membership will help set the tone for the Conference and the year ahead.

Ann brings a lifetime of experiences to the podium. She's been advocating for her daughter, Erika, for the more than half a century. Many of those years have been alongside VOR families from across the United States. She has a unique way of ensuring that our past journey is celebrated and not forgotten. While

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also using these past experiences to inform us as we face forward and continue on the long road ahead.

You can get to know Ann by reading her published "[Excerpts from a Diary](#)" about her experiences as a young mother with a daughter with profound disabilities; and by viewing a [short video of Ann expressing gratitude to VOR](#).

Please plan to join us in Washington, D.C. to hear Ann's presentation. As previously reported, she'll join a great line up of presentations, including **Terry Farmer** and **Lois Sheaffer**, who we featured in past weeks, and Scott **Osterfeld**, our dinner keynote speaker, will be featured in the near future.

[Complete details and registration information are available on VOR's website.](#)

See you in Washington, D.C.!

If you are not able to attend our D.C. events but would like to help, [click here to see our Sponsorship Opportunities](#).

STATE NEWS

2. Wisconsin cuts back on long-term institutional care for the disabled; Parents, guardians worry that state's move to community placements endangers vulnerable patients

*Wisconsin Center for Investigative Journalism * March 8, 2015*

VOR Editor's note: This story features VOR's State Coordinators Rebecca and Kevin Underwood.

Aaron Underwood's seizures finally came under control when, at age 3, he was admitted to a state care facility for the developmentally disabled. His mother soon realized the treatment he received there was better than what she and her husband could provide.

"I'm surprised he didn't die from what I did because I made some stupid mistakes," said Rebecca Underwood, who lives near the city of Hartford, about 30 miles northwest of Milwaukee.

Aaron, 35, still lives at Central Wisconsin Center in

Madison. He is unable to sit up without support. Lacking purposeful movement, he functions at the level of a four- to 12-week-old infant, unable to speak.

The care the facility provides its residents and their families, his mother said, “turns their lives around.”

But fewer Wisconsin residents are receiving institutional care. In 1970, the state’s three centers housed 3,700 people. At the end of last year, their total population was 389.

[Read more, COMMENT and share](#)

Sidebar Article: State’s move toward community care for disabled follows national trend:

“Nationally, the pushback against this trend has been led by VOR, an Illinois-based nonprofit group that advocates on behalf of people with developmental disabilities and their families. Tamie Hopp, the group’s director of government relations and advocacy, notes that Medicaid rules say guardians for those with developmental disabilities must be “given the choice of either institutional or home and community-based services.”

[Read more, COMMENT and share](#)

3. Illinois: Murray Center Funding Included in Rauner Budget Proposal

WSIL 3 (abc) (Centralia, IL) * March 11, 2015

Centralia’s Murray Developmental Center remains open three years after former Governor Pat Quinn called for its closure. Governor Bruce Rauner wants to continue funding the facility.

The center currently holds about 220 patients, all with severe disabilities. The Murray Center will now look to add about 40 new staff members.

[Read more, comment and share](#)

4. Virginia: Community placement doubles mortality rate

News and Advance (Lynchburg, VA) * March 11, 2015

In her March 1 letter to the editor, Commissioner Debra Ferguson, of the Department of Behavioral Health and Developmental Services stated “safetv

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and care of those with intellectual disabilities are our paramount concerns,” yet the schedule for training center closures and the actions of the department she leads indicate otherwise.

Data provided by the department last fall to the Virginia Senate work group and posted on its [website](#) at were sufficient for me to perform an analysis comparing the mortality rate of those who have left training centers with a similar population of those who remained. My analysis showed that the mortality rate of those who left was double that of those who stayed.

At that time, the department did not have an analyst on staff who could review this work or perform a much needed follow-on analysis to determine the underlying causes for this disparity in mortality. Although the department has since indicated it will hire such an analyst, meanwhile, discharges progress without hesitation.

Moreover, the June 30, 2014, deadline in the settlement agreement with the Department of Justice for collecting and analyzing safety and health data has long since slipped by.

While I do not question Commissioner Ferguson’s good intentions, the evidence cries out for a realignment of priorities for transitioning residents from training centers: Make sure the community is safe first.

ROBERT W. ANTHONY, PH.D.
Reston

News and Advance Editor’s note: With a doctorate in physics, the writer spent his career analyzing government program performance including extensive work involving mortality analysis.

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5. Ohio: House Panel Hears Opposition To Developmental Disabilities Budget Proposals

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Gongwer News * March 10, 2015

Developmentally disabled Ohioans, their families and those who care for them voiced opposition Tuesday to budget provisions aimed at transitioning residents from institutional settings to community and home-based programs.

Among the 64 witnesses that were scheduled to testify before the House Finance Health and Human Services Subcommittee, most spoke to the Department of Developmental Disabilities executive budget proposal and, in particular, to Intermediate Care Facility requirements that would limit the number of residents per room and restructure reimbursement and funding rates.

DODD Director John Martin has said that while it's important for the agency to provide more waivers for those who would prefer to live and work in a community or home-based setting instead of an ICF, the budget proposals are the result of Centers for Medicare and Medicaid rule changes.

The recommendations have also been made to appease Disability Rights Ohio [Protection & Advocacy], which threatened to sue the agency if it didn't move more quickly with plans to transition individuals out of institutionalized or segregated settings, he said during recent budget testimony.

While the budget proposals are geared toward improving community and workplace settings for disabled individuals, witnesses wearing badges saying "Intermediate Care Facilities and Workshops are Community" largely said residents prefer the ICF setting and would be devastated if they were required to move as a result of the required downsizing.

"I must start by sharing that I believe if someone wants the opportunity to move to a different home or to find a different job, they absolutely should be given that opportunity," Boyd's Kinsman Home Assistant Administrator Sherry Rinck said. "However, others who want to stay where they currently live or continue working where they currently work, should absolutely be given the same consideration, opportunity, and

choice."

Ms. Rinck told the panel that it's "insulting" that anyone would think that Boyd's residents were forced to choose living there because there weren't any other options available to them.

Rep. Barbara Sears (R-Sylvania) acknowledged that she has reservations about reducing funding for ICFs and workshops while restricting the number of people that can be admitted to the facilities because it takes away the choice of someone who would thrive there as opposed to in a community-based setting.

Michelle Pierce-Mobley, Director of Stillwater Center, which is a 98-bed ICF funded by Montgomery County, said the DODD requirements not only will push out some residents who don't want to or can't live in a facility defined as more integrated in the community, but also fails to address the health needs of certain residents.

[Read more and share](#)

6. Ohio: Reynoldsburg mom seeks care for severely autistic son

Columbus Dispatch * March 11, 2015

White spackling dots the walls of Chris Hess' town house. She tries to keep up with repairs, but by the time she gets ready to paint, her son has punched or kicked or gouged another hole.

Patches of her hair won't grow back anymore, and she carries scars from the 16-year-old's rages. Hess started working out so she would have the strength to restrain him.

"He is 6-4, and he weighs 242 pounds," she said. "I hate to say this, but I am petrified sometimes."

Her son Kristopher Conley has severe autism. He speaks just a few words, can barely use the bathroom on his own and is prone to aggressive and compulsive behavior, Hess said. Ask him to wash his hands, and he will scrub until the soap bottle is empty. Drive past a Dairy Queen without stopping, and he might try to break the car window.

The teen's presence is overwhelming — and dangerous — for him as well as his sister and his twin brother, who also has autism, Hess said.

Although Hess voluntarily relinquished custody of Kristopher to Franklin County Children Services two years ago in an effort to get him the expensive residential care he needed, he returned to his family's Reynoldsburg home in late January.

Hess and her sister Kenna Robinett met with two state representatives last week to talk about the struggle to find suitable residential care for teens with autism and other difficult mental-health problems.

"We don't know what else to do, and this situation is going to get worse," Robinett said. "This is my sister's family. There must be others."

[Read more, comment and share](#)

FEDERAL UPDATE

7. Common Issues, Model Comments & State Samples for Home and Community Based Services (HCBS) Transition Plans: A Tool for Continued Advocacy

National Health Law Program * March 6, 2015

Executive Summary

Advocacy on State Transition Plans for compliance with the recent HCBS regulations on community settings is ongoing from comments on draft and final plans to implementation issues and plan revisions.

This document identifies common issues in transition plans, model comments for those issues, and a compilation of comments from other advocates on those topics. This information should make it easier for advocates to identify problems in a state transition plan, make comments, and advocate for meaningful implementation of the HCBS regulations in their state.

[Read more and share](#)

DEFINING "COMMUNITY"

8. Florida: Former Prison May Become Home For Adults With Special Needs

Disability Scoop * March 10, 2015

VERO BEACH, Fla. — A 200-resident community for adults with autism and special needs could take over the former Indian River Correctional Institution.

Organizers of Bigger Dreams Inc. plan to modify the former state prison buildings, creating a community where adults with special needs can live independently and receive training for local jobs.

Family members of the adults with special needs and unrelated retirees also eventually could live in their own homes on the property, said Oliver Edwards, one of the nonprofit's organizers.

"It's big enough for a village," Edwards said of the property.

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HEALTH CARE NEWS

9. UMass Medical School working to improve oral health for people with intellectual disabilities

UMass Medical School Communications * March 9, 2015

People with intellectual disabilities are more likely to have untreated tooth decay, but finding dentists who are willing to provide them with dental care can be difficult. UMass Medical School's Eunice Kennedy Shriver Center is meeting this challenge through research and training to educate dental professionals and students about making dental visits easier for individuals with intellectual disabilities.

The online courses will undergo a trial in March with 120 dentists, dental hygienists and dentistry and dental hygiene students taking each course, allowing the research team to evaluate changes in participants' knowledge, self-efficacy and intention to treat patients with disabilities. The courses, similar to video documentaries, include advice from dental and behavioral experts and interviews with parents, caregivers and patients with autism and intellectual

disabilities.

[Read more, comment and share](#)

QUOTABLE

*"Honest disagreement is often a good sign of progress." ~
Mahatma Gandhi*

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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