



Speaking out for people with intellectual & developmental disabilities



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VOR and YOU

1. VOR's Julie Huso to Attend American Health Care Association's National Conference and Expo

VOR * October 1, 2014

WASHINGTON, D.C. - Julie Huso, Executive Director of VOR, a national organization for people with intellectual and developmental disabilities, will attend the [American Health Care Association/National Center for Assisted Living's Convention & Expo](#) in Washington, D.C. on October 6, 2014.

VOR advocates for high quality care and human rights for all people with intellectual and developmental disabilities across the country. The annual AHCA/NCAL event includes educational sessions, inspiring general sessions, and an interactive Expo Hall for long-term and post-acute care professionals for seniors and people with developmental disabilities.

"VOR represents many individuals with profound intellectual and developmental disabilities who receive high quality care in the private long-term care facilities represented by AHCA/NCAL," said Huso. "As an exhibitor and participant, we get a chance to thank these providers for their compassionate and skilled care."

[Read more and share](#)

INTERNATIONAL NEWS

2. Canada: Alberta premier reverses plan to close centre for developmentally disabled

About VOR

Make a Lasting
Impact with a
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About VOR

The Daily Courier * September 19, 2014

RED DEER, Alta. - Alberta's new premier has decided a care home for the developmentally disabled that was slated for closure will remain open for those who want to stay.

Following more than a year of protests about the transfer of residents out of the Michener Centre in Red Deer, Jim Prentice announced Friday that no one else will have to leave.

"We will not close this facility on my watch," Prentice told a crowd at the care centre.

"I think it is inhumane to locate severely disabled Albertans from their homes in the autumn of their lives ... All of the residents will be permitted to live out their remaining years in this special place that has long been their home."

[Read more, comment and share](#)

Read related: "[Whiplash Jim rewrites policy so fast, the civil service can't keep pace](#)" (relating to an email which seems to contradict Premier Prentice's pledge to keep the center open; he claims the email is an error and stands by his word)

STATE NEWS

3. New Jersey: Bills would protect developmentally disabled from abuse and neglect

NJ Spotlight * September 29, 2014

Family members of New Jerseyans with developmental disabilities, alleging widespread instances of abuse – and subsequent cover-ups -- are pushing for a law that would bolster state oversight of caregivers.

Legislators have introduced two bills: A-

Make a Lasting Impact with a Will Bequest

1109/S-896, which aims to protect adults with developmental disabilities, and A-3619/S-3629, which is specifically aimed at protecting children with disabilities.

The first bill is named Stephen Komninos' Law, after a 22-year-old man with intellectual disabilities who died in 2007 from choking on food while unsupervised at a group home.

The second bill is named after Tyler Banuls, who legislators said was abused by his peers and neglected by those responsible for providing services to him.

The bills would require the state to make at least three unannounced site visits each year to facilities and programs serving people with developmental disabilities to check whether there is any danger of abuse or neglect by caregivers.

In addition, the legislation would require facilities to notify family members within two hours if a resident with disabilities has been injured. The state would be required to verify the severity of an injury within two days.

[Read more, comment and share](#)

4. Vermont: What Happens When Sheltered Workshops Close?

Disability Scoop * September 30, 2014

VOR Comment (as posted on *Disability Scoop* in response to this article): *This article does well to celebrate the successes of Vermont's employment initiative for people w disabilities. It is wonderful that 38% of eligible persons with disabilities have found employment (hopefully meaningful employment). The article, however, skims over the underbelly of Vermont's 'success,' but numbers don't lie. If 38% have jobs, that means 62% don't. That's 1,860 people who are unable to find employment and may be isolated and lonely each day, and who also now do not even have the choice of learning new skills at a workshop or supported employment setting. Like so many other disability movements, the cart has been put ahead of the horse, resulting in harm to individuals."* [You are encouraged to comment too.](#)

What Happens When Sheltered Workshops Close?

Vermont closed its last sheltered workshop in 2002, four years after the state told workshop providers that they were being carved out of the system.

But the shift actually began in the 1980s, when the University of Vermont received a grant to build programs for integrated employment in partnership with state disability agencies. The movement grew and policymakers eventually decided sheltered workshops no longer fit the state's values on the treatment of people with disabilities.

The Vermont Developmental Disabilities Services Division started by not allowing new people in sheltered workshops, where people with disabilities work only with other people like them.

"We closed the front door," said Jennie Masterson, the agency's supported employment services coordinator.

The next step was to cut funding to sheltered workshops over time.

[Read more, comment and share](#)

5. Ohio: (Opinion) Disabled workers need more options, not less

The Cincinnati Enquirer * September 27, 2014

Last week I attended the Medicaid Home and Community Based Care conference in Washington, D.C., to learn more about changes that will most certainly transform the lives of people with intellectual disabilities. My fear is that the change will be good for some, but devastating for many more.

With the Ohio economy in a fragile rebound, it looks increasingly likely that Medicaid rules changes and an activist Department of Justice

effort will eliminate paid work training that allows more than 18,000 Ohioans – most with intellectual and developmental disabilities – to experience the benefits of work.

Pre-vocational training centers like the ones at Easter Seals TriState are the result of family advocacy efforts to ensure that adults with disabilities weren't isolated at home, but instead had opportunities to work with their peers at a wage commensurate with their productivity. Today, some claim that work centers perpetuate the isolation of people with disabilities, and stand in the way of their finding work in the community. With the Medicaid rules changes announced this year, it appears that over the next five years, states will be required to phase out support for facilities that exist primarily to provide work opportunities for people with disabilities.

[Read more, comment and share](#)

6. Floridians with developmental disabilities need more help (opinion)

***The Miami Herald* * September 25, 2014 * by Ven Sequenzia, Jr., President, Autism Society of America, Orlando**

Gov. Rick Scott stood up in June, in front of 7,000-plus people, and said how he is helping so many more people with developmental disabilities and he put an additional \$20 million in the budget to do away with the “critical needs” wait list.

Would you like the truth?

The Medicaid Waiver budget for 2013-14 was \$915 million, or \$46 million below the 2008 budget. It was actually the third lowest budget in the last six years.

This while the waiting list grew from 15,648 in Sept. 2007 to 21,140 in June 2014.

Now the final straw. The Agency for Persons with Disabilities (APD) returned approximately \$80 million “unspent” from this fiscal year to the state treasury. Yes, you read that correctly. Gov. Scott not only reduced spending, the agency returned unspent money, while 21,000 people are languishing on a waiting list.

[Read more, comment and share](#)

7. Florida: Bound to bed: a girl’s agonizing death

***The Miami Herald* * September 13, 2014**

An autopsy determined that the 14-year-old succumbed to dehydration, the result of a severe but treatable infection.

Her death spawned the 140th DCF neglect or abuse probe involving the Lake County home since 2001 — there have been eight more reports since then — and yet, the facility has never paid a fine and never been disciplined.

On Friday night as the *Herald* was preparing to publish Paige’s story, the Agency for Persons with Disabilities, or APD, which oversees programs for disabled people, filed an administrative complaint against Carlton Palms, this time involving a separate neglect allegation.

Paige was among about 500 children who died of abuse or neglect in Florida over the past six years after the state had received complaints about a caregiver — in this case, the center itself. Their stories are detailed in a *Miami Herald* series, [Innocents Lost](#).

In the most recent budget year, the state paid Carlton Palms about \$25 million to care for disabled individuals, an APD spokeswoman said. Despite the scores of abuse allegations, the home was given the highest ranking among “intensive behavior” providers licensed by the state.

[Read more, comment and share](#)

FEDERAL NEWS

8. Federal Guidance offers New Details On Autism Treatment Mandate

Disability Scoop * September 26, 2014

Federal officials are taking steps to clarify new requirements surrounding Medicaid coverage of autism treatments.

Over the summer, the Centers for Medicare and Medicaid Services issued a [bulletin](#) to states indicating that Medicaid programs across the country must provide “medically necessary diagnostic and treatment services” to beneficiaries with autism under age 21.

Now, the agency is [providing new details](#) about the mandate.

[Read more, comment and share](#)

SPECIAL EDUCATION NEWS

9. Parents as Special Education Project Managers

Special Ed Advocate by WrightsLaw * September 23, 2014

Your child's special education is a long-term project that needs a master planner and project manager. That's you!

Learn how to organize, plan, monitor progress, anticipate problems and keep the team focused.

In this issue of the *Special Ed Advocate* you will learn how the effective parent advocate stays focused, resolves problems, and avoids mistakes.

[Read more and share](#)

RESEARCH NEWS

10. Increasingly, Adults With Down Syndrome Face Alzheimer's

Disability Scoop * September 26, 2014

Jeff Malanoski, 57, lives with a neurological double-whammy: In addition to Down syndrome, he has Alzheimer's disease.

The two conditions are genetically linked. Even so, the combination was rarely seen years ago because people with Down syndrome usually didn't live long enough to develop Alzheimer's and other illnesses of aging.

But now medical advances have extended the life expectancy of people with Down syndrome, and families are encountering the reality spelled out in figures from the National Task Group on Intellectual Disabilities and Dementia Practices: Adults with Down syndrome are at high risk for developing Alzheimer's disease, and at an earlier age than the population as a whole. At least 25 percent of those older than 40 have Alzheimer's, and more than 50 percent of those over 60 do, compared with 6 percent of those over 60 in the overall population.

[Read more, comment and share](#)

QUOTABLE

"The moment my legs begin to move, my thoughts begin to flow." ~ Henry David Thoreau

Calendar Reminders:

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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