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March 7, 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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Coming up: [Pitfalls Seen in a Turn to Privately Run Long-Term Care](#) (NYT, March 6, 2014)

VOR and YOU

1. Facebook 500 – We did it!

Thanks to all who visited [VOR's Facebook page](#) within the past few weeks. We've topped 500 Likes. Help us keep up the momentum. Visit our page and ask your friends to do the same.

2. Are you [registered](#) yet? We'd love to see you in Washington, D.C.

Be part of the only networking, national conference, speakers, presentations, and Congressional visits that promote individual and family decision-making based on person-centered needs and choices. Please register today. Your voice matters. Numbers count. Please join us.

National and Federal News

3. Coalition sends letter to Marilynn Tavenner, Administrator for the Centers for Medicare & Medicaid Services, regarding new "Community" rule

March 5, 2014

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A letter signed by 41 organizations, including VOR, was sent this week to Marilyn Tavenner, Administrator for the Centers for Medicare & Medicaid Services. Organizations, representing the Coalition for Community Choice, expressed “appreciation of the earnest effort to balance many perspectives in your consideration of Home and Community-Based Services (HCBS) Settings Final Rule (CMS 2249-F/2296-F),” while also requesting that CCC have “opportunity to review proposed State Guidance Letters and provide input before publication.”

[Read full letter here](#)

4. Worry over closing of workshop for developmentally disabled; some say other jobs aren't always possible

The Columbus Dispatch * February 24, 2014

“These workshops are hugely important,” said Cathy Ticknor, 49, a workshop participant who loves her job.

Public policy, however, is fast turning against them. Sheltered workshops are criticized as discriminatory for paying subminimum wages and depriving participants of the experience of a typical workplace. State and federal directives show a growing preference for helping people with developmental disabilities obtain community jobs.

Workshop supporters don't want the policy pendulum to swing too far. They say it's unfair and unrealistic to assume that most everyone with developmental disabilities will be able to find, enjoy and keep community jobs.

[Read more, comment and share](#)

5. Under New DSM, Autism Diagnoses May 'Significantly Decrease'

Disability Scoop * March 3, 2014

The number of people diagnosed with autism could be reduced by nearly a third under new diagnostic criteria for the developmental disorder, with some who previously qualified for a diagnosis on the autism spectrum left out, according to a [study](#) published in the Journal of Autism and Developmental Disorders.

Last May, a new edition of the Diagnostic and Statistical Manual of Mental Disorders, known as the DSM-5, introduced sweeping changes to the criteria for an autism diagnosis. The update did away with Asperger's syndrome, childhood disintegrative disorder and pervasive developmental disorder, not otherwise specified, instead establishing an umbrella classification of “autism spectrum disorder” with clinicians indicating a level of severity

[Read more, comment and share](#)

6. Congress Eyeing Tax-Free Disability Savings Accounts

***Disability Scoop* * February 21, 2014**

With significant public backing and support in Congress, advocates say federal lawmakers are poised to consider a major change to the money-saving abilities of those with disabilities. Congress is expected to take up the Achieving a Better Life Experience, or ABLE, Act as early as this spring, pending a Congressional Budget Office analysis.

The bill would establish special accounts to allow people with disabilities to save up to \$100,000 without risking their eligibility for benefits like Social Security and individuals could retain Medicaid no matter how much is deposited.

[Read more, comment and share](#)

Read Related: [How the ABLE Act will help parents of children with disabilities](#) (*Washington Post*, March 6, 2014)

7. Medicaid Expansion Spurs States to Fight Fraud, Overpayments

***Stateline* * National Conference on State Legislatures * March 5, 2014**

States are stepping up efforts to combat health care fraud and over-payments that cost them billions of dollars a year. In 2013, more than 100 bills designed to combat Medicaid fraud and abuse were introduced in state legislatures in at least 23 states, according to the National Conference of State Legislatures, and at least 35 of them became law. States also are fighting fraud in ways that don't require legislation, such as improving communication among state agencies, said NCSL's Megan Comlossy. Currently, 19 states are considering 45 bills related to controlling Medicaid fraud and errors, she said.

At least 10 states — Arizona, Arkansas, Florida, Illinois, Kansas, Michigan, New Jersey, New York, Texas and Utah — have passed laws creating Medicaid inspectors general, according to NCSL.

[Read more, comment and share](#)

State News

8. Georgia's Annual Quality Management Report for January 2013 – December 2013 raises alarm

Outcomes due to Settlement implementation, which requires the downsizing and closure of facilities for people with intellectual and developmental disabilities and mental illness, are troubling. According to the Georgia Department of Behavioral Health & Developmental Disabilities' "[Annual Quality Management Report](#)," January 2013 - December 2013, there have been 1,200 hospitalizations of individuals (mental health and developmental disabilities) residing in community residential programs; 344 individuals requiring treatment beyond first aid; 318 incidents requiring law enforcement services; 305 individuals who were expectantly absent from a community residential or day program; and 210 alleged physical abuse of an individual. A total of 82 unexpected deaths of individuals with mental illness and developmental disabilities were reviewed during 2013.

9. Georgia: Augusta center staff rallies during ice storm

Georgia Department of Behavioral Health and Developmental Disabilities * March 4, 2014

The ice storm which caused over 700,000 power outages across Georgia in February hit few areas harder than Augusta, but staff at East Central Regional Hospital (ECRH) were ready to shield their clients from the worst of the storm before the first snowflake fell. Said Nan Lewis, the hospital's regional administrator, "ECRH had its share of both triumphs and lessons learned. The team came together to make it through those cold, dark hours....Though the ice storm presented many challenges and inconveniences, the teamwork displayed by Governor Deal, Commissioner Berry..., and all staff at ECRH ensured that clients remained safe."

[Read more, comment and share](#)

10. Virginia: "Very Good News," says families: Revised training-center bill advances in House

Earlier this week, the Virginia House of Delegates passed SB627 with amendment by a vote of 99-0; and the Virginia Senate approved the same by a vote of 38-0. The bill now goes to Governor McAuliffe, who has 30 days to sign it.

Passage of the bill was strongly supported by families of training center (state ICFs/IID) residents. It requires Department of Behavioral Health and Developmental Services (DBHDS) to:

1. Certify, before any resident is transferred to either the community or another Training Center, that the receiving placement "provides a quality of care that is comparable to that provided in the resident's current training center regarding medical health, developmental, and behavioral care and safety".

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2. Disclose “all permissible placement options available under the Commonwealth’s August 23, 2012, settlement agreement with the U.S. Department of Justice, including the option to remain in a training center.”

3. “Convene a work group of interested stakeholders, which shall include members of the General Assembly, to consider options for expanding the number of training centers that remain open, in whole or in part, in the Commonwealth.”

11. Tennessee: When people with intellectual disabilities leave facilities, results can fall short

***The Tennessean* * February 10, 2014 (“Broken Trust” series)**

An audit by the state comptroller last fall, and a federal court monitor’s report tracking former residents of three of the state’s institutions, found that troubling problems trail many of the state’s formerly institutionalized residents. While the state saves millions of dollars each year by serving people outside institutions, officials at private agencies concede that a lack of adequate state funding has at times hampered their efforts to help people achieve the best quality of life. Identified problems include 257 reported allegations of abuse, neglect and exploitation; isolation; delays in doctor-recommended treatments in some cases and “numerous instances” of inadequate dental care; and a dramatic increase in deaths after people leave institutions (deaths among people with intellectual disabilities transferred from institutions nearly doubled between 2009 and 2013, from 19 to 34); incarceration; and missing former residents.

[Read more, comment and share](#)

Related: [VOR's Abuse and Neglect document](#) (updated since last week) (February 2014)

12. Tennessee: State Fights back against abuse of disabled adults

***The Tennessean* * February 27, 2014 (“Broken Trust” series)**

The beating of an intellectually disabled young man by his caretaker, captured in disturbing cellphone video footage obtained by The Tennessean, is a rare occurrence, “something so egregious and so horrendous it bothers every one of us to know it’s occurred,” the Department of Intellectual and Developmental Disabilities’ chief attorney said Wednesday.

[Read more, comment and share](#)

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13. Wisconsin: Man accused of abusing developmentally disabled adults

WISN 12 (ABC News) * March 3, 2014

A man who cared for developmentally disabled adults is now charged with abusing them. Milwaukee police believe the man took advantage of at least two women living in a residential facility. The living facility is supposed to be a refuge, a safety net for cognitively disabled adults near 52nd and Burleigh streets, but prosecutors said 32-year-old James Williams violated that trust by repeatedly sexually abusing two women, one of whom is described as functioning at a first-grade level.

[Read more, comment and share](#)

14. Florida: Testing for profoundly disabled children gets increased attention

Tampa Bay Times * February 26, 2014

Florida state education officials are working to overhaul the education accountability system and the plight of severely disabled students and their teachers is gathering increasing attention in the halls of the Florida Capitol. In one case, the school district insisted attempting to test Ethan, a boy in hospice care in what his parents described a "morphine coma. Teacher performance ratings are based on the assessment of severely disabled students. Although State education officials say the new formula for calculating teacher performance accounts for external factors, including whether a student has special needs, some teachers that premise. "How can their brain damage and multiple challenges be ignored as barriers to achievement?" teacher Sabrina Berger wrote. "My students do make achievements, but not on things being evaluated by tests."

[Read more, comment and share](#)

15. New Jersey: An Examination of Quality-of-Care Among Developmentally Disabled Individuals in the N.J. Community

New Jersey Newsroom * February 27, 2014*
Commentary by Salvatore Pizzuro

Governor Christie is rapidly relocating the Totowa residents to community settings and other developmental centers - in many cases at locations that elderly and infirm parents cannot travel to. Concerns are shared by hundreds of parents and family members throughout the State: Will they be able to travel to their loved one's new home? Will their son or daughter receive the appropriate medical and custodial care? What will the long-term

impact of the transition be?

[Read more, comment and share](#)

16. New Jersey: Woodbridge Developmental Center to close by year's end

***MyCentralJersey.com* * March 1, 2014**

“This decision to close the centers immediately is devastating for the residents as it rips them away from all care-givers who know them: both from family members who will not be able to visit them as regularly and from staff care-givers who know their individual needs and are like family to the residents,” said Joanne St. Amand, president of the Woodbridge Developmental Center Parents Association, whose sister is a long time resident of the facility.

“We know that there have already been serious consequences with previous transfers and feel strongly a timetable at this speed will cause even more individuals to die, be injured or end up in psychiatric hospitals than have already taken place in the first two years since announcing closure,” she said.

Assemblywoman Valerie Vainieri Huttle, D-37th, chair of the Assembly Human Services Committee, who has advocated for a moratorium on the closures until the issue can be further studied, said Christie is eliminating the choice for people to remain in what has been their home for decades.

[Read more, comment and share](#)

17. Kansas: KNI staff workers commended

***Kansas Health Institute (KHI)* * February 25, 2014 * Letter to Editor from Joan Kelley, Vice-President, KNI Parent Guardian Group Member, Governor's Council on Developmental Disabilities, VOR State Coordinator (Gardner, KS) and Shawn Sullivan, Secretary, Kansas Department for Aging and Disability Services (Topeka, KS)**

On Feb 4, 2014, the Topeka Capitol Journal estimated 13 inches of snow fell on Topeka, closing state and legislative offices. Many businesses were closed due to treacherous conditions.

Not all Kansas employees, however, stayed home.

At the Kansas Neurological Institute (KNI), most workers came to work anyway, braving difficult conditions, covering shifts for other staff who could not make it in, and happily assisting fellow employees with jump-starting vehicles or whatever needed to be done.

When we consider the direct-support staff wage at KNI - \$12.00 an hour - the daily care and support required of individuals with profound, complex medical and behavioral challenges, it is inspiring to reflect on the dedication of those who serve some of our most vulnerable citizens in this great State of Kansas

[Read more, comment and share](#)

Quotable

"You have brains in your head, you have feet in your shoes. You can steer yourself any direction you choose." ~ Theodor Seuss Geisel

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Calendar Reminders:

Tuesday, March 25, 2014

AHCA/NCAL's fifth annual "ID/DD Residential Services Providers Hill Fly-In." Questions? Dana Halvorson, dhalvorson@ahca.org.

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 will open in Spring 2014.

Archives

***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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