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April 11, 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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## **Calendar Reminders**

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### **VOR and You**

**1. What are you waiting for? Register today for VOR's Annual Conference and Initiative**

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[All details, including information about our event, speakers, Congressional Initiative, registration and hotel information are available on our website. See you in June!](#)

### **FEDERAL NEWS**

**2. Sebelius Resigns as HHS Secretary; OMB Director to Be Named as Successor**

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*Nonprofit Quarterly* \* April 11, 2014

Kathleen Sebelius tendered her resignation as Secretary of the Department of Health and Human Services (HHS) late Thursday. Her almost five years of service in President Obama's cabinet was marked by her high profile and combative oversight of the implementation of the Affordable Care Act (ACA), or Obamacare. The widely-reported problems associated with the rollout of the insurance signup site healthcare.gov, including its exorbitant cost and shaky technology, are seen as the key events associated with her tenure as HHS Secretary.

Although Politico says that Sebelius is "leaving on her own terms," the timing and nature of her departure leaves no doubt that even her supporters were ready for a change at HHS. As recently as March 31st, she said that she would remain as HHS Secretary at least through November 2014. "I'm in," she said at the time. Many reports of the announcement of her resignation were based on HHS statements, not the White House, and there has been a notable weakness in the standard praise and regret quotes from the White House that typically accompany the resignation of a Cabinet officer.

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### **STATE NEWS**

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### **3. Rhode Island: Justice Department Urges Shift Away From Sheltered Workshops**

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*Disability Scoop* \* April 8, 2014

In a first-of-its-kind settlement, the U.S. Department of Justice says a state has committed to overhaul its system of sheltered workshops and day programs for people with developmental disabilities.

“Today’s agreement will make Rhode Island a national leader in the movement to bring people with disabilities out of segregated work settings and into typical jobs in the community at competitive pay,” said Jocelyn Samuels, acting assistant attorney general for the Civil Rights Division at the Justice Department. “We believe that Rhode Island will be a model for the nation with respect to integrated employment for people with disabilities.”

Despite the push toward community-based offerings, Samuels said individuals with developmental disabilities will be able to remain in segregated environments if they choose.

“To ensure informed choice, individuals with I/DD may also remain in sheltered programs if they request a variance after they have received a vocational assessment, a trial work experience, outreach information and benefits counseling,” Samuels said.

[Read more, comment and share](#)

Read related [DDNews Blog: Michigan Employment First Policy: One size fits all?](#), by VOR's Jill Barker.

### **4. U.S.: Why Must People with Disabilities Prove Their Choice is Valid?**

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*Autism Housing Network* \* March 19, 2014

In a recent New York story about abuse, [Billy Nacmias](#) shares how his life was drastically changed by the introduction of a nature-based program, the Center for Discovery [set on a 1,000-acre farm]. If the Center that gave Billy new hope and purpose in life created an option that offers him a home, job, and opportunity to change the lives of his peers everyday - shouldn't he have the option to be supported in a place that has given him a happier future? New regulations may restrict funding for that life changing option...

The Center for Medicare & Medicaid Services (CMS) just released a “Settings Requirements Compliance Toolkit” to states in reference to their

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application for future Home and Community-Based Services (HCBS) funding. The toolkit is to assist states in their application to comply with the new HCBS regulations. Every state must submit a Transition Plan to comply with new requirements by March 2015.

[Read more, comment and share](#)

## 5. New Mexico: Mental health care homes study: No new rules

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*Albuquerque Journal* \* April 11, 2014

Shela Silverman, director of the nonprofit Mental Health Association of New Mexico, points to a 2010 House Joint Memorial concerning board and care homes in Las Vegas, New Mexico.

The state Department of Health (DOH) was asked to convene a committee to study how licensure could work to ensure that people being released from the New Mexico Behavioral Health Institute “are admitted to the appropriate residential care facilities.”

After meeting with consumers, advocates, home operators and other state agencies, the first recommendation a DOH committee provided the Legislature was not to initiate any new regulations or processes. The reason given was “state budget and DOH resource constraints.”

However, the committee also recommended that the Las Vegas hospital and DOH’s Division of Health Improvement work with providers to develop minimum standards and draft regulations for homes. It also suggested that state oversight be established through contractual agreements with operators, which currently don’t exist.

“The issue is what are the minimal health and safety standards that should be used to contract?” said Silverman.

That issue has been highlighted anew by the deaths last fall of two former residents who died of carbon monoxide poisoning **in the storage shed (their “boarding home”)** they were paying to live in north of Las Vegas shortly after they left the hospital.

What would Silverman like to see done?

“First, they have to start discharging people only to licensed boarding homes. but those boarding homes

need to be reviewed by the people at the state hospital,” she said. **“You also have to have licensed people trained to administer meds and they have to be able to pass a background check. And if they’re licensed, you have to have standards. Right now, there are none.”**

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## **6. New Jersey: New Jersey: Couple loses fight to keep daughter at Woodbridge Developmental Center**

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**NJ.com \* April 9, 2014**

An Old Bridge couple, who fought to keep their daughter at the Woodbridge Developmental Center until a bed became available at a Clinton facility, had to say goodbye Tuesday morning when she was relocated to a South Jersey developmental center against their wishes.

Theresa Kauffman, 46, who has lived in the Woodbridge Developmental Center for 32 years, was moved at 9 a.m. Tuesday to the Vineland Developmental Center as part of the state’s plan to close the Woodbridge facility by the end of the year, according to a news release from Save Residents’ Homes at Developmental Centers, a coalition of families, friends and caregivers of the residents of New Jersey’s developmental centers.

Thomas and Frances Kauffman tried to stop the move in court, but their motion was denied, however “they intend to keep fighting for the rights of their daughter in the Office of Administrative Law, where the matter will now be heard. The Kauffmans and the other families remain hopeful that they will prevail on the merits and the DDD will be compelled to comply with its statutory obligations prior to arbitrarily shipping these disadvantaged individuals to other facilities,” said their attorney, Charles Kelly.

[Read more, COMMENT, and share](#)

## **April is Autism Awareness Month**

### **7. AUTISM News**

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**AADMD Info Blast \* April 3, 2014 (citing *Medical News Today*)**

[Los Angeles Biomedical Research Institute \(LA BioMed \) launches study of MDMA-assisted therapy for social anxiety in autistic adults \(MDMA = \(3,4-methylenedioxy-N-methylamphetamine\)](#)

['Autism rates soar 30% in 2 years,' CDC say](#)

[A look inside brain cells offers new clue to autism](#)

[Autism begins in the womb, according to a new study](#)

#### **8. Under New DSM, Autism Diagnoses May 'Significantly Decrease'**

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***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, researchers say.

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.

Now, a [study](#) published in the Journal of Autism and Developmental Disorders is adding to worries that some who previously would have qualified for a diagnosis on the autism spectrum will be left out.

Researchers found that 31 percent of those who met the diagnostic criteria for autism under the old DSM may no longer meet the new standards. Without a diagnosis, children may not qualify for needed services, researchers said.

Even before the updated DSM was finalized, many advocates voiced concerns. That led those behind the revision to insert language into the autism definition stipulating that anyone with a "well-established" diagnosis of autistic disorder, Asperger's or PDD-NOS under the old DSM should be considered to have autism spectrum disorder going forward.

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## Quotable

"As hope grows, so does the power of people." ~  
MSNBC

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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](mailto: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**

**\* 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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