



December 13, 2013

VOR Weekly News Update

News and views for VOR Advocates

Speaking out for people with intellectual & developmental disabilities

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1. Coalition supporting housing options receives response from CMS

VOR * December 13, 2013

In September, VOR joined 15 state and national organizations that advocate in support of a full array of residential options, in sending a [letter](#) to Kathleen Sebelius, Secretary of the U.S. Department of Health and Human Services, and Marilyn Tavenner, Administrator for the Centers for Medicare & Medicaid Services (CMS). The groups called on HHS/CMS to reject a proposed CMS rule that would so narrowly define "community" that current and future [innovative housing options](#) for people with intellectual and developmental disabilities (I/DD) and autism, would no longer be eligible for Medicaid Home and Community Based Services (HCBS) funding. As a result, current homes would be defunded, evicting well-served residents, while also preventing innovative housing expansions in the future.

In November, [CMS' Tavenner responded with a letter](#), stating in part, "Thank you for sharing your perspective on the need for residential programs and housing options that meet the specific needs of individuals with autism and other intellectual/developmental disabilities . . . CMS received many comments similar to yours that we are carefully considering. In developing the final rule, CMS hopes to ensure that people with disabilities and those living with chronic illnesses receive Medicaid HCBS in settings that are similar to their home and are integrated into their community, while ensuring that they have ample access to a choice of settings."

State administrators, [members of Congress](#), healthcare professionals, service providers, and, most importantly, people with disabilities.

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their families and caregivers, have gone on the record by submitting formal written opposition to CMS. Hundreds of letters and comments have made clear the many flaws in this policy shift. VOR, in coalition with other organizations, will continue to speak out against this proposed rule.

[Read sign on letter](#)
[Read CMS' response](#)
[Read more about this issue](#)

Related to call to action follows . . .

2. Take Action: Sign Petition opposing CMS' narrow, "one-size-fits-all" definition of "Community"

What Matters Most Campaign * December 13, 2013

[What Matters Most \(WMM\)](#), a coalition of people with disabilities, parents, family members, and guardians in support of "respecting options and expanding opportunities for people with disabilities" has prepared a petition OPPOSING the CMS proposed definition of "community" (see related article, above).

[You are encouraged to sign this petition.](#)
[Check it out at the WMM website.](#)

Quality in the Community?

3. Ohio: Neglect and abuse of Ohio's disabled slips under the radar

NewsChannel5 (Cleveland, Ohio) * November 8, 2013

According
a [NewsChannel5 investigation](#), providers failed to conduct criminal background checks or

consult an existing abuser registry that resulted in individuals with criminal and abusive records being hired, resulting in great risk and injury to the people they were left alone with. A state legislator is now calling for reform.

The Investigative Series

PART I: Ohio Department of Developmental Disabilities often fails to act, leaving disabled at risk

The Ohio agency that oversees those with developmental disabilities often fails to act despite serious health and safety violations by service providers. More than 2,000 people with disabilities were victims of abuse last year - ranging from physical and sexual assaults to neglect. In addition - according to statistics provided by the agency - of 1,587 compliance reviews of service providers in 2012, 38 percent, or 603, were cited for failure to follow state health and safety regulations. In Cuyahoga County alone, we reviewed 165 inspection reports since 2009 and found 874 serious compliance violations. Even so, service providers are rarely put out of business. The investigation found 2,000 cases of physical and sexual abuse, neglect and misappropriation in 2012 across Ohio. Among the findings were 76 cases involving sexual abuse, 373 involving physical abuse and 1,072 cases of neglect. All were found to be substantiated by the Ohio Department of Developmental Disabilities. Since 2002, 470 individuals have been placed on a state abuser registry and the exclusive investigation has created a searchable database to more easily identify offenders.

PART II: Hundreds of Ohio service providers for disabled repeatedly ignore health, safety

regulations

Hundreds of Ohio service providers for disabled repeatedly ignore health, safety regulations. Of 1,587 compliance reviews of service providers performed by the Ohio Department of Developmental Disabilities, 600 failed to follow state regulations.

PART III: Sexual abuse, neglect triggers increased scrutiny of service providers for Ohio's disabled

As a result of the *NewsChannel5* investigation, Ohio State Senator Mike Skindell is proposing new legislation that would require the Ohio Department of Developmental Disabilities to post inspection and compliance reports online. Skindell said without a requirement to post reports, key information about service providers is largely kept secret, protecting service providers and allowing them to operate in secrecy. The National Down Syndrome Society is also calling for greater transparency in response to our investigation. Similar inspection reports can already be obtained online for child care centers and nursing homes. If passed, Ohio would join Arizona and Idaho who have already made inspection and compliance reports of service providers for the disabled available online.

[Read more, comment and share](#)

Read Related: [VOR's "Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities," \(revised November 2013\)](#)

Legal Update

4. Illinois: Judge tosses most State motions

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in federal Murray case

***WILY/WRXX News* * December 9, 2013**

A federal judge Friday tossed out the majority motions filed by the state in a court case that has the futures of Murray Center residents at its core.

Judge Marvin Aspen scolded the Department of Human Services for their motion seeking to have hundreds of letters, and affidavits submitted in the case thrown out.

Aspen says in his ruling that the court need not discuss in detail the state's dismay at the number of affidavits or declarations, submitted by plaintiffs for their fact witnesses, as the court did not limit the parties to any particular number of witnesses, and he sees no reason to constrict plaintiffs' ability to present their case.

The judge also notes that while the letters are not sworn affidavits, hearsay can be considered in entering a preliminary injunction, despite the state's assertion that it is not.

He says some of the letters—particularly the letters from guardians describing in detail their wards' conditions and experiences in different types of housing—include facts relevant to the issues to be determined at the Jan. 6, preliminary injunction hearing.

DHS also asked the court strike testimony from witnesses who describe what it called "inconsequential" incidents, specifically, took issue with two declarations from Murray employees who state that they were instructed to transfer a resident's belongings to a home, only to discover upon arrival that the home was not yet habitable.

DHS claimed that the incident was entirely irrelevant because the legal standard does not require that the transfer of hundreds of residents must be "glitch-free in every respect."

The court, however, disagreed, saving the

employees testimony describes an incident where defendants planned and initiated a move to a home that was still under construction, without inspecting the physical condition of the building or confirming that staff or safeguards were in place.

Aspen said such evidence may support the plaintiffs' assertion that the state is rushing the assessments and transfers of residents and failing to ensure that the new housing arrangements are suitable for the disabled residents displaced from Murray.

As noted on prior occasions, Aspen commented that this case is of the utmost importance for plaintiffs and their wards, yet also carries significant ramifications for defendants, who seek to close Murray as soon as possible.

[Read more, comment and share](#)

[Read VOR's Letter to the Court in Support of Murray Residents and Their Families](#)

5. Illinois: Judge delays ruling on state wards

Belleville News-Democrat * December 12, 2013

A Clinton County judge on Wednesday gave the supporters the Murray Center "a huge Christmas present," according to their leader.

Judge William Becker decided to postpone ruling on whether the 23 residents of the Murray Center who are wards of the state will be included in the federal civil rights lawsuits and other legal actions pending on behalf of the other residents at Murray Center, as parents and guardians attempt to stop the state's closure of the Centralia facility for adults with developmental disabilities.

Rita Winkeler, chairman of the Murray Center Parents Association, said that the judge's ruling means the residents who are wards of the state will not be moved out of Murray Center for the time being.

"At this point, no one can be moved from Murray Center unless the parent or guardian wants them to," Winkeler said. "What Judge Becker is saying is that the issues of the (wards of the state) are similar to the issues of the plaintiffs in the federal lawsuit, so he is going to wait until the federal lawsuit is resolved before he would rule on the issue."

The federal lawsuit alleges that the residents' civil rights under the Americans with Disabilities Act and other rights are being violated by closing the institution and moving them to smaller homes. Winkeler said some of the residents need full-time nursing care and specialists that they would not be able to access living in community homes of two to four people.

The federal lawsuit will have a settlement hearing in Chicago on Thursday, Winkeler said. If no settlement is reached, it will go to court in January.

[Read more, comment and share](#)

6. Supreme Court To Consider What Defines Intellectual Disability

***Stateline* * December 10, 2013**

How should states decide if someone convicted of a crime has an intellectual disability, when the answer means life or death? This spring the Supreme Court will wade back into these murky waters, 12 years after it took the death penalty off the table for criminals with mental disabilities but left the details to the states.

In its 6-3 decision in *Atkins v. Virginia*.

authored by Justice John Paul Stevens, the court prohibited states from executing anyone with “mental retardation.” Mental health professionals define it as substantial limitations in intellectual functions such as reasoning or problem-solving, limitations in adaptive behavior or “street smarts,” and evidence of the condition before age 18. (Mental retardation is the term used in law, but most clinicians and The Associated Press refer to the condition as intellectual disability.)

After the decision, most states stuck with the three-pronged clinical definition, but Florida, Georgia, Mississippi and Texas set their own standards. Under Florida’s law, if you have an IQ over 70, you’re eligible for execution regardless of intellectual function or adaptive behavior.

[Read more, comment and share](#)

Quotable

"Thanks to VOR, Ginger is truly home for the holidays. Thank you for giving me access to such outstanding legal representation and all the support to carry this cause forward. You really are exceptional in the best possible way." ~ VOR Member from Maryland

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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. [Details coming soon](#)

Week of June 9, 2013

VOR 2014 Congressional Initiative: Families and advocates visit Capitol Hill. [Details coming soon](#)

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.**

VOR
836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007

Tel: (605) 399-1624
Toll Free: (877) 399-4867
Fax: (605) 399-1631
Email: info@vor.net

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