



November 14, 2014

# VOR Weekly News Update

News and views for VOR Advocates

Speaking out for people with intellectual & developmental disabilities

[About VOR](#) \* [Refer a Friend](#) \* [Donate](#)

## VOR and YOU

- 1. How you can help VOR grow:** A message from VOR's Executive Director
- 2. VOR member publishes a children's book on coping with loss**
- 3. VOR's Tamie Hopp** presents on History and Future of Deinstitutionalization

## FEDERAL NEWS: CMS "COMMUNITY" RULE

- 4. Ohio:** Federal rule change could be costly, change mission of autism program

## STATE NEWS

- 5. Oregon: Adult abuse:** An ongoing worry in Oregon
- 6. Oklahoma:** 17 Deaths Raise Questions About Care Of Developmentally Disabled
- 7. Delaware** must be open to new ideas on housing
- 8. Pennsylvania:** For Trust in DPW be Restored, Admissions Must be Allowed: Member Response to Benjamin Settlement Victory

## HEALTH CARE NEWS

- 9. A Model for Nursing Interventions**

## **QUOTABLE**

**Coming Up:** Speakers to be announced for VOR's 2015 Annual Conference

Calendar Reminders

## VOR and YOU

- 1. How you can help VOR grow:** A message from VOR's Executive Director



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## About VOR

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**From Julie Huso, VOR Executive Director \* November 14, 2014**

Happy Friday! I wanted to give you a few ideas on how you can make a difference and help VOR grow!

- Tell someone new about all the benefits of VOR and why it is so important to you to be a member!
- Ask your parent group and family members to become a member of VOR if they are not already.
- Contact us at VOR and let us know what we can do for you!! We are here to support you and your loved ones.
- Review your own personal philanthropic plans and goals and consider increasing your giving to VOR. We have done great work throughout the US and this cannot be done without you!!!

Thank you and have a wonderful weekend!!

### **2. VOR member publishes a children's book on coping with loss**

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Long-time VOR member, Sally Kitt Chappell, faced a worry facing many parents of children with profound intellectual disabilities: "When I die, will Jennifer understand why I have stopped visiting?"

"As a writer, my solution to every problem is a book," says Chappell. "So I illustrated and wrote one for her entitled *Gloria Goldfish Loses a Loved One.*"

The story is simple. Gloria loves swimming and having lunch with her mother, (or grandmother depending on the edition). or playing hide-and-

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seek. One day her mother warns her that she might die soon, but tells her that the sadness she feels will stop one day and she will enjoy life again, and this comes true. The book's beautiful watercolor illustrations, by Chappell, also tell the story for non-readers.

"To my surprise, the staff at the Shapiro Developmental Center, where my daughter calls home, reacted with great enthusiasm for the book," says Chappell. "They said it would not only help thousands like my daughter, Jennifer, but also countless very young typically developing children face the loss of a loved one."

Chappell is an accomplished author. She is a member of PEN, a worldwide association of writers, and is the recipient of the Association of American Publishers award for the best book in architecture in 1992. *Gloria Goldfish Loses a Loved One* is her first children book.

"I have published many books and articles over the years, but this slim volume has brought me more satisfaction than the rest of them put together," says Chappell.

### **3. VOR's Tamie Hopp presents on History and Future of Deinstitutionalization**

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**For Immediate Release \* November 12, 2014**

ELDRIDGE – Tamie Hopp, a national advocate for people with intellectual and developmental disabilities, presented on the history and future of deinstitutionalization at the Sonoma Developmental Center in Eldridge on Saturday, November 8.

Hopp is the Director of Government Relations and Advocacy for VOR, a national nonprofit organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities. She has been involved in disability advocacy for 19 years.

The Parent Hospital Association for Sonoma Developmental Center, which represents families and advocates and is an affiliate of VOR. sponsored

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the presentation.

Sonoma is a state-operated home for 430 of some of California's most profound disabled citizens. According to the state's website, approximately one thousand acres of land, lakes, and various structures encompass the Sonoma Developmental Center campus, including a residential campground, store/cafeteria, post office, petting farm, sports fields, swimming pool, plant nursery, and picnic areas.

Homes like Sonoma are threatened across the country, says Hopp.

[Read more and share](#)

Read Related News: [Close to Home: Time to end war over the Sonoma Developmental Center](#) (*The Press Democrat*, November 8, 2014 by Kathleen Miller, President, Parent Hospital Association for Sonoma Developmental Center)

### **FEDERAL RULE: CMS "COMMUNITY" RULE**

#### **4. Ohio: Federal rule change could be costly, change mission of autism program**

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*The Blade* \* November 11, 2014

**Editor's Note:** This is an excellent overview of the new CMS rule defining "community" for the purpose of continued Medicaid Home and Community-Based Services funding. Its focus is on Bittersweet, a farmstead in Ohio serving people with autism, but provided is also a good overview of a State's obligation to CMS with regard to the new rule and the role for stakeholders.

[Excerpts \(read full article here\)](#)

In January, the Centers for Medicare and Medicaid Services, or CMS, issued changes to its Home and Community-Based Services program, which provides waivers to Medicaid-eligible people with disabilities to live at home or in the community rather than in facilities the government deems institutional. The goal is to keep people out of settings with isolating qualities that keep them away from the broader

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community.

The rule states that waiver money cannot be given for programs in settings that aren't considered "home and community based" or are institutional or isolating. It has the potential to affect the nearly 6,000 facilities in Ohio that offer waiver services. Settings in the same building or "adjacent to" institutional-like settings [e.g., Intermediate Care Facilities] are also not eligible for HCBS waivers.

Bittersweet Farms provides a variety of day and residential services for people with autism.

In addition to 55 people who come for day services, many funded by Medicaid waivers, there are two residential programs on the 80-acre Whitehouse campus. One is a 20-bed intermediate care facility with individual rooms and a common kitchen and living space.

"My concern is they'll say, 'You can't live where you work,'" she said. "If in their zealousness they're losing choice, that's not better either."

Another potential problem for Bittersweet is the nature of its mission, as farmsteads are mentioned specifically in the federal rule. They aren't explicitly deemed not HCBS-eligible but will be looked at with "heightened scrutiny."

"We're quite clearly a campus-based, intentional community," she said. "There are assumptions that we isolate." But, Ms. Obee contends, Bittersweet is anything but isolating.

In response to the federal rule, the state of Ohio must create a transition plan, mapping out how it will make necessary changes so all facilities are in CMS compliance.

Lori Horvath is the deputy director of Medicaid development and administration for the Ohio Department of Developmental Disabilities. She said the current timetable is to publish the transition plan online by Dec. 1, where it will be open for public comment for at least 30 days.

The department also sent out a survey to providers, looking to figure out how many of them

would need to make changes in light of the rule. It received about 2,000 responses.

The plan must be submitted to CMS by March, including documentation of how the state's department of disabilities, in conjunction with the Ohio departments of Medicaid and Aging, responded to the comments. Then CMS can approve it or ask for clarification or changes.

[Read more, comment and share](#)

## **STATE NEWS**

### **5. Oregon: Adult abuse: An ongoing worry in Oregon**

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***Bellingham Herald* \* Nov. 4, 2014**

PENDLETON, Ore. — Abuse of vulnerable adults continues to be a concern in Oregon, according to a report from the Oregon Office of Adult Abuse Investigation and Prevention.

The office processed more than 35,000 reports of possible abuse or neglect in 2013 and determined 3,273 people were being abused. Adult Protective Services manager Therese Hutchinson said those numbers don't include abuse situations that are never reported to the state.

"We know that more abuse happens than we know about," she said. "I would encourage folks to call and report suspicious behavior, if they think someone is being harmed, and let us figure out if they are being abused."

Adults with physical or intellectual disabilities, adults with mental illnesses and elderly adults all fall under the office's jurisdiction.

In situations where the abuse claims were substantiated, financial abuse accounted for the biggest number of cases at 32 percent. Neglect was a close second, with 28 percent of victims falling in that category. Other types of abuse include physical abuse, verbal abuse and sexual abuse.

[Read more, comment and share](#)

## 6. Oklahoma: 17 Deaths Raise Questions About Care Of Developmentally Disabled

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*Oklahoma Watch* \* November 1, 2014

The deaths of 17 developmentally disabled people transferring or already transferred out of two large state-run institutions are raising questions about whether the closing of the centers put residents' health at risk.

The deaths occurred after the state decided in November 2012 to shutter the facilities in Enid and Pauls Valley over the objections of some of the residents' guardians and parents. Almost all of the nearly 230 adult residents were to move to small, privately owned "community homes," where services are offered by various providers.

State Sen. Patrick Anderson, R-Enid, said he wants to know whether the impending closure of the facilities and the residents' transition into community homes contributed to the deaths.

Anderson wrote a letter to Attorney General Scott Pruitt on Oct. 24, one day after the most recent death. He called for a review of the deaths, which occurred in 2013 and 2014. The residents began moving out of the Northern Oklahoma Resource Center of Enid, or NORCE, and the Southern Oklahoma Resource Center in Pauls Valley, or SORC, in March 2013.

Among those who died, seven were living at NORCE, two were living at SORC, and eight had transitioned into community homes.

[Read more, comment and share](#)

## 7. Delaware must be open to new ideas on housing

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*The News Journal* \* Delaware Voice: Lanny Edelson \*  
November 4, 2014

Beth Miller's recent article, "[Families: Housing a matter of civil rights](#)," shines a most welcome light on an urgent issue in Delaware: the affordable

housing crisis for adults with intellectual and developmental disabilities. In the state of Delaware, there are 2,900 persons living at home with parents who are 60 or older. These parents all ask the same question: “What will happen to our loved ones when we are gone?”

[Read more, comment and share](#)

[Read related article: Those with disabilities: Where should they live?](#)

## **8. Pennsylvania: For Trust in DPW be Restored, Admissions Must be Allowed: Member Response to Benjamin Settlement Victory**

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**Submitted by Dan Torisky, President and Co-Founder of the Autism Society of Pittsburgh**

Magnificent news concerning the “right of choice” for residents of group home or state facility placements: to choose to remain where they are, or to transition into community based services.

Bert Springstead is to be congratulated for his steadfastness and especially attorneys Sidley Austin and Carl Solano, and VOR and others for their Amici.

Would that we had been successful in securing “right of choice” for residents of Western Center 15 years ago – then 38 residents of that facility, gleefully destroyed by ARC and PA-DPW – would still be alive. And God knows how many others’ lives statewide could have been saved or improved rather than forced by DPW into inappropriate placements, homelessness, substandard services – swelling the huge waiting lists of such individuals for out of home placements and supports.

[Read more and share](#)

## **HEALTH CARE NEWS**

### **9. A Model for Nursing Interventions**

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**Keene State College (New Hampshire) \* November 6, 2014**

Health education. That was the most common service provided in home visits by nurse practitioners to aging developmentally disabled adults – followed by nutrition and weight management counseling – in a study conducted by Keene State's Director of Nursing Joan Earle Hahn. The idea of the study was to give nurse practitioners a tool for helping adults with developmental disabilities stay healthy and manage their own health needs to avoid being placed in long-term care facilities. The results have implications for nurse practitioner training and the development of nursing curricula as well.

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#### **QUOTABLE**

*"Life often fails to be perfect, but never fails to be beautiful."* ~ Unknown (quoted by Madison House Autism Foundation)

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#### **Calendar Reminders:**

**Tuesday, December 2, 2014:**

**#GivingTuesday**

<http://vor.net/donate-now>

**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. Details coming soon.**

#### **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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