



Speaking out for people with intellectual & developmental disabilities



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VOR Weekly News Update

News and views for VOR Advocates

[Registration](#) and [Sponsorship Details](#) are now available for VOR's Annual Conference and Washington Initiative, June 8 - 12, 2013 in Washington, D.C. Please join us!

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VOR and YOU

1. VOR's Mary Reese Testifies Before House Appropriation's Subcommittee on Labor, HHS, Education and Related Agencies: Calls on Subcommittee to Stop Support HHS v. HHS actions

VOR * March 2013

On March 13, 2013, Mary Reese, a member of VOR's Board of Directors, testified before the House Appropriation's Labor, Health and Human Services (HHS), Education and Related Agencies Subcommittee. Calling lawsuits and advocacy by HHS-funded agencies against HHS-licensed and funded homes for people with intellectual and developmental disabilities (e.g. ICFs/MR) as an "absurd use of federal funding and cruel," [Reese](#) delivered hard-hitting testimony on VOR's behalf.

Specifically, VOR sought the Subcommittee's support for appropriations language to prohibit the use of HHS funding in support of deinstitutionalization activities which evict eligible individuals with I/DD from HHS-licensed Medicaid facilities, in violation of federal law.

"Deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics, by some HHS-funded agencies (discussed below) resulting in the downsizing and closure of HHS-licensed are a cruel and absurd use of federal funding," Reese testified.

VOR's [written testimony](#) for the record is available on our website, along with Mary's similar [verbal statement/testimony](#) and a picture of Mary testifying.

Mary's personal story and recent journey on behalf of her step-daughter, Ginger, was featured in the most recent issue of *The Voice*.

and was also the subject of a [Maryland television broadcast](#).

2. VOR hosts State Coordinator and Member Webinar: Materials and archive available

On March 13, 2013, VOR hosted its first Webinar for State Coordinators and members. Facilitated by Richard Male, of RMA Associates, Inc., and hosted by Julie Huso and Tamie Hopp, both of VOR, the webinar was well-attended and featured an overview of VOR's organization and mission, the State Coordinator program, and advocacy tools for all members.

[Listen to the Webinar](#)

[Access \(and share!\) VOR's expanded and revised VOR Advocacy Manual and Toolkit for State Coordinators, Members and Choice Advocates](#)

3. Joe Valenzano, Founder and CEO of *EP Magazine* and VOR Annual Conference Partner Receives the 2013 UNICO Americanism Award

American Association of Developmental Medicine and Dentistry * March 13, 2013

VOR congratulates Joe Valenzano on being named the recipient of the 2013 UNICO Americanism Award. UNICO is a national Italian American service organization. "Unico" is the Italian word for unique, one of a kind. And Joe is certainly one of a kind in his leadership and generosity toward people with developmental disabilities and special needs, and their families.

Joe is the Publisher/CEO of *Exceptional Parent Magazine* and a known advocate, educator and supporter of the disability community. The UNICO award was in recognition of his work on behalf of military families impacted by disabilities - either a child with intellectual and developmental disabilities or a warrior with an acquired service related disability. *Exceptional Parent Magazine* has provided military specific editorial content for the Department of Defense's Exceptional Family Member Program for

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many years. Joe has served with distinction on a number of advisory boards in the support of our military families.

Congratulations, Joe!

VOR is proud to be partnering with EP Magazine for [30th Anniversary Annual Conference](#). **Thanks to EP Magazine's generosity, Annual Conference Sponsors who donate \$6,500 or more are entitled to special advertising opportunities in EP Magazine, which reaches 300,000 readers.** For details on [EP's offer and all sponsorship categories](#), please visit VOR's website.

State News

4. Iowa: State needs more consistency in inspections: It's an obligation to vulnerable residents of facilities

[Des Moines Register Editorial](#) * March 11, 2013

A few decades ago, thousands of Iowans with mental and physical disabilities lived in large, government-run institutions. A national movement away from this model of care didn't eliminate the need to help these people. Instead, it gave rise to smaller, "community-based" facilities.

The change was not accompanied by changes in laws to require adequate government oversight of these facilities, however.

Now, more than 4,000 Iowans live in 178 residential care facilities. These individuals may be unable to prepare meals, balance a checkbook or get to a bus on their own. Though they don't need skilled nursing care, they do need daily assistance from staff. Iowa law requires these homes to undergo a full state inspection at least once every 30 months, a painfully lax standard considering the vulnerability of people who live in these facilities.

In spite of the 30-month minimum frequency, 39 percent of these homes for the disabled have

not undergone an inspection in at least 2 1/2 years. Some have gone almost four years without an inspection, according to state records.

The Iowa Department of Inspections and Appeals oversees the facilities, but it has no plans to add more inspectors, spokesman David Werning said. The agency is “making significant progress” getting caught up, he said.

Getting caught up isn’t enough. The state needs more than four people to inspect these homes and respond to the scores of complaints received each year. It isn’t as if this state doesn’t have the money.

Iowa has a budget surplus of \$800 million. The Legislature should require more frequent inspections of the residential care facilities and ensure there are adequate inspectors to conduct oversight. While our lawmakers talk about how to use the surplus for one-time tax refunds or paying teachers more, they ignore thousands of vulnerable people living in homes that are supposed to be regulated by the state.

Inspections check everything from staffing levels to employee training. They help ensure these facilities are safe and have the policies in place to prevent vulnerable residents from being harmed. What Iowa is doing now — scrambling to respond to complaints about these facilities — amounts to swooping in after the damage is done.

And this damage can be heartbreaking.

Four different residents at the Prairie View Residential Care Facility in Fayette were arrested last year on charges ranging from assault to sexual abuse and murder. The home had not undergone a full state inspection for 41 months.

The Pride Group care facility in Le Mars was last inspected in March 2010. That summer a

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registered sex offender was placed in a dormitory-style room with five residents. Within weeks, he sexually assaulted three residents.

Since Dallas Inc. in Adel was inspected more than three years ago, state inspectors have visited the home 19 times in response to complaints. In January 2011, a resident almost choked to death while left unattended and eating. Seven months later, that resident died after choking on crackers from the nurses' station.

Last summer a female resident who was committed to the facility because of mental issues was having sex with at least three male residents. The staff did nothing when the male residents didn't comply with instructions to stay in their rooms, state reports said.

There is not enough space to detail the problems in some of these homes. If the residents being victimized were the relatives of state lawmakers, would our leaders pay more attention to what is going on? These Iowans need someone regularly looking out for them. Lawmakers should finally require more oversight of care facilities and spend a tiny fraction of that budget surplus for inspectors to do so.

From the Des Moines Register

KEY FACTS ON INSPECTIONS

BACKGROUND: Iowa requires inspections of residential care facilities once every 30 months. In 2010, budget problems led Gov. Chet Culver and lawmakers to impose a one-year moratorium on any inspections of these facilities. In 2011, lawmakers extended that moratorium. The state only checked on these facilities after a complaint was filed.

CHANGE: However, by the fall of 2011, the Iowa Department of Inspections and Appeals recognized there were obvious problems. The agency ignored the moratorium and began inspecting the facilities. In 2012, lawmakers and Gov. Terry Branstad eliminated the ban. therebv

legalizing the inspections that had been done during the moratorium. The agency is still trying to catch up.

5. New Jersey: Governor's Plan for Housing Disabled New Jerseyans Continues to Lack Logic

***NewJerseyNewsRoom.com* * March 11, 2013 *
Special Commentary by Salvatore Pizzuro**

Housing for adult New Jerseyans with developmental disabilities continues to be a problem with no solution. Thousands of individuals with disabilities, who currently live with their families, are on a waiting list for long-term housing. The estimated time in which they will remain on the waiting list is in excess of seven years. In the meantime, their already elderly parents continue to get older, become more infirm, and eventually pass away.

It has not been unusual for an adult, disabled person to become homeless under such circumstances. Yet, our governor initiated a plan two years ago to keep the disabled individuals in their family homes. His method has been to simply make the homes more accessible. Unfortunately, the plan ignores the problem of the parents being too old and infirm to care for their disabled off-spring; nor does it consider the issue of the parents passing away, leaving the disabled individual with nowhere to go.

The waiting list for housing becomes longer and longer as more individuals apply for housing assistance. The governor's office has attempted to ease some of the financial burden by attempting to close as many of the large residential institutions for the developmentally disabled as possible, and sending the residents to community settings.

The next obvious problem, however, is that there are not nearly enough appropriate community settings available to serve these

individuals.

In attempting to transfer residents of the large institutions to community settings, the governor's office has cited the "*Olmstead*" Supreme Court decision. The famous [Olmstead](#) case may be the most misinterpreted and misrepresented case by governmental officials in the history of civil jurisprudence.

Nowhere in the *Olmstead* decision does it say that all people with disabilities must be transferred to the community. The "least restrictive alternative" setting that is mandated by the United States Supreme Court is based on the unique needs and degree of disability of the client.

People with disabilities are unique and no two individuals are alike. Not all can have their needs met in the community. Furthermore, making the homes of parents of adults with disabilities more accessible will not address the lifelong needs of such individuals after the parents become older, more infirm and pass away.

It is obvious that the Christie administration is overwhelmed by the financial expenditures required to solve this problem. However, simplistic solutions that do not address the problem will eliminate all reasonable problem-solving.

[Read more](#)

Read Related: [Heartless decision should be reviewed](#)

Read Related: [Huttle and Wagner Sponsor Two Bills Regarding the Proposed Developmental Center Closures](#)

6. Deinstitutionalization: Mentally ill deserve better options

*Times Free Press (Tennessee) * Tuesday, March 5, 2013*

When 45 percent of the Hamilton County Jail's 500 inmates are on prescribed psychotropic drugs and are deemed mentally ill, we should know we have a problem.

And it's a statewide concern.

Tennessee has failed to help take care of the mentally ill and their families -- and sometimes their victims.

There simply is not a place or a program -- and certainly not a comprehensive policy -- for helping mentally ill people who fall between being in control enough to take medication and being so out of control that they have either committed a crime or threatened to harm themselves or someone else.

The crisis has been brewing since the 1990s, but it has only become a visibly acute problem in the past decade.

"Deinstitutionalization," the emptying of state psychiatric hospitals, became a national movement in the last half of the 20th century.

In 1955, there were 558,922 state hospital beds in the United States for patients with serious mental illnesses such as schizophrenia, bipolar disorder (known then as "manic depressive illness") or severe depression, developmental disabilities, dementia or other chronic brain diseases.

With the advent of medications that made it possible to stabilize many patients, the idea behind deinstitutionalization was fundamentally sound: Most patients could live safely outside a hospital while being treated in community facilities.

The trouble was -- and is -- that not enough alternative community facilities sprang up to take the place of those institutional programs. Nationally, 95 percent of the nation's public psychiatric hospital beds disappeared, but community psychiatric care exists for fewer than half the patients who need it.

[Read More](#)

Quotable

"All truths are easy to understand once they are discovered; the point is to discover them." ~ Galileo Galilei

Calendar Reminders

***Through May 1, 2013: Be a Sponsor. Get a Sponsor: Support VOR's Conference and Initiative. Sponsorship opportunities, in partnership with EP Magazine, are now available.**

*** Sunday, June 9, 2013**

VOR Annual Conference * Washington, D.C. [Registration now available. Details online.](#)

*** Begins Monday, June 10, 2013**

VOR Washington Initiative (Begins Monday, June 10, 2013) * Washington, D.C. [Details online.](#)

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