



Speaking out for people with intellectual and developmental disabilities



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VOR Weekly News Update

News and views for VOR Advocates

Notice: A *VOR Weekly Update* will not be published on Friday, November 23, 2012. Happy Thanksgiving!

Did you receive this as forwarded e-mail? If so, someone thought you would benefit from VOR's information. Please consider [joining VOR](#) and receive this E-News Update publication weekly!

VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities

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VOR and You

1. A Message from VOR's President - VOR! “A rose by any other name . . .”

As many of you are aware, in 2011 the VOR Board of Directors and membership approved an official name change, opting to keep our well-recognized acronym (VOR, pronounced “V-O-R”) in place of terminology that some families, advocates, and even policymakers. found offensive. At that time. VOR

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found itself defending our name and our use of terminology to the point it was difficult to present our message. Ultimately such dialogue over our name was counter-productive to our core message in support of residential choice for individuals with I/DD. Other organizations, such as The Arc-US (formerly, "Association for Retarded Citizens") and NAACP have also opted to preserve a well-recognized acronym in place of terminology that had, to some audiences, become offensive. For these reasons, the membership voted in support of changing VOR's name, recognizing, as Shakespeare wrote, that the names of things do not matter, only what things are ("A rose by any other name would smell as sweet", *Romeo and Juliet*).

“What does VOR’ stand for?”

While use of an acronym alone can also raise questions, the question is more easily answered and becomes less of a debate than one over terminology. Now, VOR advocates can simply say, “VOR is a national organization speaking out for people with intellectual and developmental disabilities” (our official by-line) or can recite our mission, “VOR is a national organization advocating for high quality care and human rights for people with intellectual and developmental disabilities.”

I am very grateful to our dedicated membership. Thank you all for your dedicated advocacy on behalf of VOR. Together we are stronger. Together we will prevail.

Sincerely,
Ann Knighton
President

2. “VOR exists to speak for the voiceless”: VOR Case Statement for Support

Earlier this month, the VOR Board of Directors approved a comprehensive VOR “Case Statement” to enhance VOR growth and to provide detailed information to all members and volunteers who have opportunities to discuss VOR and our advocacy.

Please share our [Case Statement now on our website](#), along with [our year end financial appeal](#) with individuals, businesses and organizations that may like to support VOR in advocacy or financially.

Thank you!

3. Olmstead Petition! Take Action

By Laurie Stengler, Murray Parents Association (Illinois)

Laurie Stengler, a representative of the Murray Parents Association in Illinois, has submitted a petition to the White House to request enforcement of Olmstead to include the right to choose facility-based care. Supporters of this petition have until December 20 to sign the petition, with the hope of reaching 25,000 signatures. If accomplished, the White House agrees to review the information and send a response to all signing the petition. "I am really hoping we can a strong show of support for this and any help you can provide is much appreciated," says Laurie.

Please forward this email and [the link to the petition](#) to as many of your contacts as soon as possible. We need to let the Obama administration know that enforcement of this decision has gone too far compelling states to close vital centers and putting the most severely disabled at risk for abuse and neglect.

Direct

Link: <https://petitions.whitehouse.gov/petition/enforce-olmstead-including-disabled-citizen's-or-guardian's-right-choose-institutional-over/FNhKx6Rc>

VOR Awareness: Reaching the Media

4. "Ann Landers" Column connects VOR with struggling families

In April, 2012, a letter was featured from the brother-in-law of two adults with disabilities in the advice column, "Annie's Mailbox" (formerly, "Ann Landers"). Signed as "Need Another Opinion," the writer expressed frustration and concern about his wife's need to care for her two disabled siblings in

their home. VOR offered a response which appeared in some newspapers across the country in late-November (see below). As a result, VOR has heard from families in California, Washington State, Kentucky, Idaho, Florida and Texas. We are working providing advocacy support to these families with the help in some cases from VOR State Coordinators and key members. We are grateful for the opportunity to offer these families the advocacy they lacked before finding VOR, and are grateful to our dedicated leaders for providing such expert volunteer assistance.

November 2012 (printed)

Dear Annie,

"Need Another Opinion" touched on a growing, silent crisis: Elderly parents caring for middle aged, developmentally disabled children. Often, care is not sought until the elderly parent becomes infirm or dies, leading to preventable emergencies and far more stressful situations. "Need" and his wife can arrange for appropriate care for her siblings who need living situations that provide for their independence and health. Eligibility for services can be determined by contacting the state's department of human services. Her siblings will likely qualify for Medicaid programs which may include housing, health care and other supports. Please suggest they contact VOR (vor.net) at 877-399-4VOR for information -- Julie Huso, Executive Director, VOR

Dear Julie Huso:

Thank you for the resource (Membership in VOR, an advocacy group for adults with intellectual and disabilities, is \$40 per year.).

5. Family advocates express concern; State shuts Northwest Hab Center as part of effort to move residents to group homes

***St. Louis Post Dispatch* * November 27, 2012**

The state of Missouri recently shuttered Northwest Habilitation Center. a state-run. 80-bed residential

care center for developmentally disabled people, the latest step in the state's effort to move residents into smaller, community-based homes.

Residents were moved to other state-run institutions or private homes under contract with the state to care for developmentally disabled people. The administration of St. Louis-area institutions for developmentally disabled people was consolidated as "part of a continued effort to more efficiently use state resources and facilities," Debra Walker, a spokeswoman for the state Department of Mental Health, said in an email.

The closure of Northwest follows that earlier this year of a center in Nevada, Mo., leaving nine centers in operation, three of them in the St. Louis area — in Bellefontaine Neighbors, St. Charles and south St. Louis County.

Missouri is one of many states trying to move clients into "community settings," such as private homes. Ten states and the District of Columbia have shut down all of their institutions. Two years ago, an effort failed in the Missouri Legislature to close all Missouri institutions.

"The community settings are more homelike and can be tailored to meet the needs of the individual," Walker said. "Individuals living in the community have more choices — for example, where they want to live, what food they eat, how they spend their day."

Some families, though, say life for profoundly disabled clients is better at state-run facilities where they can get 24-hour care, instead of in homes that are barely regulated.

In 2006, a Post-Dispatch investigation exposed widespread mistreatment of developmentally disabled residents of state institutions and privately run "community based" group homes, resulting in 21 deaths, hundreds of injuries and thousands of cases of mistreatment.

"When you remove fragile people from specialized care, tragedies are predictable, widespread and well-documented," **said Tamie Hopp, director of government affairs with VOR**, a national advocacy group. She said Missouri's motivation is not to

provide better care but to cut costs.

“There is a need for hab centers,” said **Mary A. Vitale**, who runs a parents group at Bellefontaine Habilitation Center, in Bellefontaine Neighbors, and has been a vocal advocate for maintaining institutionalized residential care. [Mary is also a VOR Board Member]

Vitale wrote a letter to the department earlier this year reporting that an investigation by parents in her group found unsafe conditions at several private homes where Missouri has moved mentally retarded clients.

“Three of the six addresses were four-family apartment buildings that had no exterior devices to assist any developmentally disabled resident,” she wrote. “One facility did appear to be appropriate from the exterior. These four locations are in neighborhoods that are located in and around high-crime areas, (with) collapsing buildings and abandoned properties. These are not safe neighborhoods for severely disabled persons.”

[Read More](#)

Quotable, by Saskia Davis

First, apologies to readers and to Saskia are in order. In the November 16, 2012 *VOR Weekly News Update*, Saskia’s “Quotable” was referenced in the Table of Contents, but not included in the *Update*. To make up for that oversight, I’ve included a couple more quotes by Saskia, a dedicated VOR member from Washington State. These come from her “[Symptoms of Inner Peace](#)” publication and website.

These “Inner Peace” quotes are appropriate for both the sometimes hectic Holiday season that is upon us and for the many challenges facing families of people with I/DD. As Saskia says, “Inner Peace. I hope you catch it.”

"Symptoms of Inner Peace," (excerpts) by Saskia Davis (VOR member)

- * “An unmistakable ability to enjoy each moment”
- * “A loss of interest in interpreting the actions of others.”

* “Frequent, overwhelming episodes of appreciation.”

* “Frequent attacks of smiling”

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