



Speaking out for people
with intellectual disabilities

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VOR Weekly News Update

News and views for VOR advocates

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VOR and You

1. **Hurry! "Early Bird" Rates expiring soon – register for VOR's Annual Conference and Initiative today!**

VOR's 2012 Annual Conference and Initiative is June 9 - 13, 2012 in Washington, D.C. Registration rates for the Sunday, June 10, 2012 conference will increase on April 1. See VOR's [Conference Flyer for complete information including an agenda, hotel and transportation information, and a registration form](#). You can also [register online](#).

Please join us!

2. **Announcement: New novel released by VOR member and author, Dr. Charles Banov**

"[Love is Two People Talking](#)," a novel by Charles H. Banov, MD, is "a heartwarming story about the importance of communication between family and friends. It examines

a myriad of emotional issues including old age, alienation, physical illness, suicide and one's relationship with his Creator."

Dr. Banov and his wife, Nancy, are longtime VOR members. Their daughter, who has intellectual disabilities, has been served in group home and state ICF/MR settings. Nancy has been a leading advocate in her state and is working on a federal response to abuse and neglect in community settings.

Dr. Banov's new novel, released in honor of National Developmental Disabilities Awareness Month, is loosely based on the story of his family.

For more information, visit [Dr. Banov's author website](#).

3. VOR submits Congressional testimony seeking restrictions on DOJ appropriations

In response to a request by the Department of Justice for an additional \$1.5 million and 50 positions (including 25 attorneys) for the Civil Rights Division, VOR submitted [written testimony](#) to "protect the interests of the residents of ICFs/DD and their families to be the primary decision-makers regarding where they reside" and pointed to abuses in several states where DOJ attorneys did not consult with families prior to taking action and sought closure of facilities contrary to the residents' choice and welfare.

Specifically, "in response to the blatant and repeated disregard of the ADA requirement for individual choice of residency by the DOJ's Civil Rights Division," VOR asked Senate and House appropriators to include the following language in the DOJ Civil Rights Division appropriations:

(1) In any action taken by the Department of Justice, including investigations, that involves the residents of an ICF/ID, DOJ shall consult with the residents (or, if a resident has a legal representative, the resident's legal representative) and families among all other interested parties before taking action.

(2) If, after taking action, families wish to intervene on behalf of their family member with ID/DD in the DOJ action, DOJ is encouraged to support such intervention. VOR's testimony will be part of the Senate and House Subcommittees' report on the hearings.

[Read VOR's complete testimony here.](#)

How you can help - Speak out!

As demonstrated in VOR's testimony to Congressional

appropriators, DOJ's "*Olmstead* enforcement" in several states has failed to consider individual choice and family decision-making, contrary to *Olmstead*. Some Courts have taken exception to these actions by DOJ. In Arkansas, where DOJ's action against a state operated ICF/MR was dismissed, the federal judge admonished DOJ for pursuing its litigation without a client:

"Most lawsuits are brought by persons who believe their rights have been violated. Not this one....All or nearly all of those residents have parents or guardians who have the power to assert the legal rights of their children or wards. Those parents and guardians, so far as the record shows, oppose the claims of the United States. Thus the United States [Department of Justice] is in the odd position of asserting that certain persons' rights have been and are being violated while those persons – through their parents and guardians disagree."

In **Virginia**, a federal judge in 2009 decision wrote that "the argument made by ARC and the United States [DOJ] regarding risk of institutionalization fails to account for a key principle in the *Olmstead* decision: personal choice." Still, DOJ persisted and earlier this year entered into a federal settlement agreement with the Commonwealth of **Virginia**, the terms of which, if approved by the court, will result in the closure of four state-operated ICFs/MR. Likewise, in **Georgia**, a DOJ settlement calls for the closure of all its state ICFs/MR. As a Georgia parent so aptly wrote, "[I]f everyone is forced to accept community living, then no one has choice [contrary to *Olmstead*]." VOR feels strongly that these actions are contrary to *Olmstead* and contrary to the rights and welfare of affected ICF/MR residents and their families.

If you agree, you are encouraged to submit a complaint with the U.S. Inspector General (OIG) for the Department of Justice. [Details can be found on the OIG/DOJ website](#). A complaint regarding waste, fraud, abuse or misconduct concerning Department of Justice employees, contractors, and grantees can be submitted in any form to the OIG by mail, fax or email:

Office of the Inspector General
U.S. Department of Justice
Investigations Division
950 Pennsylvania Avenue, N.W.
Room 4706
Washington, DC 20530

oig.hotline@usdoj.gov

(202) 616-9881 fax

There is also an [Online Reporting Form](#) that can be used. Additional information concerning the OIG's jurisdiction, the confidentiality of complaints, and how to report allegations of retaliation is available on the [OIG/DOJ website](#).

4. VOR submits testimony in California Senate Human Services Committee in support of choice

March 13, 2012

In response to the troubling report by *California Watch*, please listen to the families. They will implore a "fix it, don't close it" response.

As noted in the Senate Human Services Committee background paper, the 1,800 individuals with ID/DD who reside in California's Developmental Centers are among the most vulnerable California citizens. The vast majority have severe to profound ID/DD, in addition to complex medical conditions and physical disabilities, or dangerous behavioral challenges.

Families of developmental center residents follow a moral charge to do what is best for their loved ones. Their family members are like small children, and absent evidence to the contrary, the law presumes that parents and family members of minor children and intellectual disabled adults, will act in the best interest of their loved ones:

"Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families." DD Act, 42 U.S.C. 15001(c)(3)(1993) (Findings, Purposes and Policies) (emphasis added).

We would no more tell parents of minor children where they should seek professional health care and educational supports than we should dictate or judge the care and support decisions of parents of adult children of individuals whose cognitive abilities equate to that of infants and small children.

[Read more](#)

State News: Louisiana, New York and Illinois

5. Louisiana: P&A identifies 6 local group homes among worse in Louisiana

***The Times-Picayune* * March 22, 2012**

The Louisiana Protection and Advocacy system, the Advocacy Center, has issued a [report](#) highlighting poor living conditions and inadequate programs in what it calls the 16 worse group homes in the state. "These are not the only deficient group homes in each region; they are simply the worst, in the opinion of the ombudsmen who visit them," said the report, "

Throughout the state, about 4,100 developmentally disabled people live in 509 group homes. The six local homes in the Advocacy Center report house a total of 46 people who live in dirty conditions where holes in walls aren't uncommon and upkeep and maintenance are spotty at best, said Nell Hahn, litigation director for the federally-funded Advocacy Center.

[Read Full Article](#)

From the report, "[When a House is not a Home: An investigation into conditions, care, and treatment in select group homes for people with intellectual disabilities in Louisiana](#)":

"The result of this investigation: These homes are often located in neighborhoods that are not safe. Homes systematically fail to provide proper medical, dental and mental health care to their residents; to insure that staff are properly trained and supervised; to insure that residents of the homes are treated with respect and that their privacy is maintained; to make sure that families are given the opportunity to participate in the lives of the residents; to insure that transportation is available to allow for full integration into the community; to provide clean homelike and well-maintained physical surroundings; and to provide a healthy, adequate diet."

6. New York: State Faults Care for Disabled

***New York Times* * March 22, 2012**

Nearly 300,000 disabled and mentally ill New Yorkers residing in large and small settings face a "needless risk of harm" because of conflicting regulations, a lack of oversight and even disagreements over what constitutes abuse, according to a draft state report obtained by *The New York Times*.

The Times last year identified numerous problems with the state's care for the developmentally disabled: only 5 percent of abuse accusations were forwarded to law enforcement, and employees who physically or sexually

abused the disabled were often transferred among group homes instead of being fired.

Ten percent of deaths of the developmentally disabled in state care were listed in a state database as having occurring from unknown causes, suggesting widespread failures in efforts to determine why people die in state care.

At the same time, executives at some nonprofit organizations hired by the state to care for the disabled have been earning seven-figure annual compensation packages and taking a wide range of Medicaid-financed perks for themselves and their friends and families.

"It's gross negligence that that report has not come out, and it's beyond frustrating," said Michael Carey, a leading advocate in the state, adding, "The reforms to date are baby steps towards monster problems." And Senator Roy J. McDonald, the chairman of the State Senate's mental health committee, sent a letter this month to the governor urging him to turn over the report "so that we can begin working towards enacting long overdue protections and safeguards."

[Read More.](#)

Read "[VOR Calls For Immediate Reform of Broken New York System of Care](#)"

7. Illinois: Disabled residents' families unite to protect Waukegan center; Relatives meet with lawmakers, seek to prevent any plan to close site

WGN Radio * March 19, 2012

Fearing the Kiley Developmental Center could be the next state-run facility closed by Gov. Pat Quinn, families of center residents met with Lake County officials Monday to stress its importance.

At the Waukegan center, politicians listened to families' stories about the facility, which has served the developmentally disabled with severe medical and behavioral needs since 1974. Though it is not on the state budget's chopping block this year, the Friends of the Ann Kiley Center — made up of residents' families — wants to keep it that way.

[Read more.](#)

8. Illinois: New Bill Aims to Keep JDC Open

WCIA – 3 * March 19, 2012

The closing of the Jacksonville Developmental Center

could be delayed if some lawmakers have their way. They're working on a new bill to challenge Governor Quinn's plans by targeting the Commission on Government Forecasting and Accountability. Right now, COGFA is in charge of offering recommendations to Governor Quinn concerning facility closures, but this new bill would change that. If passed, it would give the General Assembly the power to vote down or uphold COGFA's decision.

Sponsors say lawmakers should play more of a role in the process. Right now, Quinn has the final say.

[Read more.](#)

9. Illinois: Rally to Save Centralia's Murray Center

WSIL-TV * March 17, 2012

More than 1,500 people rallied outside the Murray Developmental Center Saturday urging Governor Pat Quinn not to close the facility. Last month, Quinn announced plans to close Murray as a way to deal with the state's budget crisis.

Murray is home to 276 mentally disabled residents. "We need the governor to know that we need our home and they need their jobs," says center resident Manuel Ford.

[Read More.](#)

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