



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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**2. Introduction: Great work by VOR members across the country; advocacy tools on VOR's website**

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VOR leaders and members have been doing a really great job reaching the media and raising awareness for the importance of choice and family decision-making. VOR will continue to feature these examples.

One of VOR's greatest strengths is our collective, national voice. Across many states, the challenges faced by "choice advocates" for people with intellectual and developmental disabilities are similar, often relating to [faulty cost savings](#) assumptions, a misreading and application of [Olmstead](#), and a misguided belief that smaller settings will provide higher [quality services](#).

Resources relating to these challenges are available on [VOR's website](#) and are responded to, in whole or part, by the excellent editorials, news coverage and interviews below. Follow the examples set by these advocates and speak out in your state to the media, the legislature, and your state's officials.

**3. Illinois: Rita Burke, President of the Illinois League of Advocates and VOR State Coordinator Interviewed at State Capital**

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Rita Burke, President of the Illinois League of Advocates for the Developmentally Disabled (IL-ADD) and VOR Illinois State Coordinator, talks about her opposition to mental and developmentally disabled center closures announced by Gov. Pat Quinn. [Featured on YouTube](#); soon to be posted on VOR's website.

See also "[A Voice for the Most Vulnerable](#)," by Rita Burke (State Journal-Register, January 27, 2012).

#### **4. Related Illinois Coverage: Families and Legislators left in the dark**

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##### **Illinois Times \* February 9, 2012**

Illinois lawmakers left a meeting on Tuesday, Feb. 7, with few financial details on how the state plans to close the Jacksonville Developmental Center. The Commission on Government Forecasting and Accountability held the meeting at the Capitol to hear the Quinn administration's plan for potentially closing the center.

Rep. Jim Watson, R-Jacksonville, said that he was shocked by both the lack of financial details that were provided in the report, considering Illinois' current financial problems, and the lack of information that has been provided to the families or guardians of the residents at the JDC.

"The administration will say that they have a detailed plan, but it was obvious that nobody on COGFA agreed with that," Watson said. "If this is a person-centered process, then why are the families and guardians not being contacted about this information?"

On the day of Gov. Pat Quinn's State of the State address, Feb. 1, family members of residents at the Jacksonville Developmental Center were at the Capitol to protest closing the facility.

Rita Burke, president of the Illinois League of Advocates for the Developmentally Disabled, said that the purpose of the protest was to let Gov. Quinn and Illinois lawmakers know that there is a physical presence standing up for not closing the JDC.

"Too often, the people with the most significant disabilities, our family members, are invisible because they are so significantly impaired," Burke said. "This is an extremely dangerous plan, closing the JDC, that will harm numerous individuals, and it was not well considered."

For this story families were interviewed: Janet Anderson, Kathy Stucky, and Rita Burke.

## **5. Virginia: Another great news broadcast by Anchor Sam Brock (CBS); plus Washington Post coverage**

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Parents like Anne Sale, who's 49-year-old son Roger lives in the Northern Virginia Training Center, slated for closure in 2015, described her reaction to the deal as 'devastating,' adding that it felt like a knife through the back. Sale is not alone in her concern. An entire community of parents and family members with loved ones at NVTC spoke with CBS 6 in the aftermath of the deal, relaying their fears. [Watch the video here.](#)

**[Washington Post Coverage:](#)** Families frustrated by Virginia's decision to close most of its large institutions for the developmentally disabled took aim this week at the federal civil rights lawyers whose investigation set in motion the plan to wind down the facilities.

## **6. Louisiana: Choice is Needed**

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**[Terry Lafleur, President, Pinecrest Parents' Association](#) \* Feb. 8, 2012 \* Alexandria Town Talk**

I read an article in *The Alexandria Town Talk* on January 25 with admiration for the dedication of the mothers who met with the Governor to express support for school choice (*Jindal: Louisiana parents deserve school choice for children*). Admiration, but no surprise. As parents ourselves, we understand that parents will do almost anything in support of their children's well-being. We fight every day for our daughter's health, safety and happiness. She lives at Pinecrest Supports and Services Center where she receives compassionate care and training every day.

Unfortunately, the Governor does not support my decisions as a parent.

The difference between our choice and the mothers he had lunch with? Our daughter happens to have profound intellectual disabilities. After suffering in a small residential program, she was admitted to Pinecrest, a facility that provides compassionate support to our daughter and her peers, all of whom have profound intellectual disabilities

and other complex challenges. Pinecrest is uniquely-suited to provide specialized supports, yet the Governor has supported the displacement of hundreds of residents from our three facilities, Pinecrest in Pineville, North Lake in Hammond and North West in Bossier City. Many of these individuals have or will be displaced against their parents' wishes; against their choice.

We are just as dedicated to our adult children with profound disabilities as the mothers who so effectively won the Governor's support for charter schools. No one knows better than mothers and fathers what our children need to succeed. When will the Governor find it in his heart to thank the parents of disabled children for "standing up for our kids?"

We were told, in an effort to save money, some residents would have to leave the facilities. Some have lived there for as much as thirty to forty years. But instead of reducing the population we are seeing more and more residents being admitted and the number of residents has changed very little.

Pinecrest has been home for mentally retarded residents but, now the new residents being admitted are much higher functioning and some do present a threat to our loved ones who cannot defend themselves. Pinecrest has a wonderful administrative staff and a very caring staff on the homes, but families are growing more afraid for the safety of their loved ones. We feel our voices are not being heard and for the first time since our daughter was born, we are no longer given a choice. PLEASE GOVERNOR, all we are asking for is to have a choice.

**7. New Jersey: Developmental center residents cannot speak up for themselves**

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**Cindy Bartman, President, Association for the Hunterdon Developmental Center and VOR New Jersey State Coordinator \* February 9, 2012**

Now that the Task Force for New Jersey Developmental Center Closure has been formed, the five members — three of whom were hand-picked by the governor — have carte blanche to target one or more developmental centers

for closure. But we won't hear anything from the residents of the centers, and that's because they don't understand what's in store for them.

These severely and profoundly intellectually disabled individuals are among the most vulnerable. They are growing old with all the frailties that come with age but unable to become independent individuals and lead a "normal" life.

Most of us can rely on our capacity to make informed and reasonable decisions, but for some, cognitive and adaptive growth takes on a new meaning. Even with decades of active treatment by professional staff, families wonder if their 40-, 50- or 60-year-old loved one will ever be able to tie his shoe laces or fasten a button, and the idea that a change in housing will somehow "cure" our loved one so that he becomes a self-actualized, working, taxpaying New Jersey resident is preposterous.

If the families believed that by moving into the community, our fragile population would miraculously gain a few I.Q. points, I'm sure they'd all be standing in line. With his appointments to the task force, it looks like our governor doesn't understand this, or he is being misled by some of the folks in state government in Trenton. In either case, the remedy is simple: I beg the governor to please visit a developmental center. Please.

#### **8. Arkansas: Debate about facilities brings families to state capitol; speak out for choice**

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[Watch the news coverage video.](#)

#### **9. Missouri: Concerns raised by families regarding future of Missouri habilitation centers**

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##### **Missouri News Horizon \* January 30, 2012**

Legislation in the Missouri House of Representatives is once again stoking fears about the future of the state's residential facilities for the developmentally disabled. State Rep. Zachary Wyatt, R-Green Castle, has offered a bill that would authorize the state to develop plans for each of the state's remaining 500 or so residents of the six mental health centers. The stated goal is to determine the

best treatment options for the residents and the cost of the services.

Parents and family members of habilitation center residents are opposed to the proposal. They testified during a hearing of the Missouri House Special Committee on Disability Services. Mary Vitale president of the Bellefontaine Neighbors Habilitation Center Parents Association [and Missouri VOR State Coordinator] said she worries that long term residents of the habilitation centers will not be able to adjust to the community setting.

“In all my research, I have seen nothing or heard anything that’s convinced me that the care of habilitation center residents would be cheaper, safer or better in the community,” said Vitale.

“Habilitation centers are successful, they’re cost effective, they’re stable, and they are sustainable over a long period of time.”

Wyatt sponsored nearly identical legislation last year that was shot down on the House floor. The bill was debated for three hours before failing to come to a vote.

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