



Speaking out for people with intellectual and developmental disabilities



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## Reminders: Help VOR Grow!

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## VOR Weekly News Update

*News and views for VOR advocates*

**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. Twitter, VOR and You: Using Social Media - A Message from VOR's Marketing Committee

Dear VOR Members and Friends.

VOR.net:  
Your one-stop  
advocacy  
resource

Recently, VOR Members and others received “Twitter 101: A helpful overview of Twitter Basics,” by Jill Goldstein, VOR Board Member, Marketing Committee Member and President of JGoldsteinPR (New York, NY). In coming weeks, you’ll receive other helpful “101s” on two other popular social media tools, Facebook and LinkedIn.

VOR’s social media campaign, coordinated by the VOR Marketing Committee, is part of the organization’s broader effort to grow VOR through greater awareness and involvement by current members, new members and volunteers. Enhanced use of social media is an easy, inexpensive method to draw in more people. It only takes a few clicks from a number of our members to help increase our internet presence, resulting in a wider circulation of our message, greater awareness of our shared mission, more advocacy in support, and increased members and donations.

The “Social Media 101s” are aimed at encouraging the involvement of our members in this way. The “101s” are designed to help some of our members to learn how to use social media easily and safely, both for their own personal enjoyment and as a way to help VOR. There is no requirement to do this, but it's fun and it's an easy way to stay in touch with VOR's efforts and to support us with just a few clicks of the mouse.

A special thanks to VOR’s Marketing Committee members (all volunteers) for their time and expertise: Jill Goldstein, Larry Stopa ([E-Power Marketing](#)), and [Jill Barker](#). And, a special thank you to all VOR members and friends who work with us to use social media tools to VOR’s advantage.

Respectfully,

*Hugo and Cristy Dwyer*

Co-Chairs, VOR Marketing Committee

**FOCUS ON ILLINOIS: Quinn’s “bold plan” not without problems and critics**

**2. Illinois: Gov. Quinn's 'bold' plan for care of developmentally disabled**

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**Chicago Tribune \* October 9, 2102**

VOR Note: State officials describe broken bones, incarcerations, hospitalizations and psychiatric placements of former Jacksonville Center residents as

"a few bumps in the road." Excerpts of a Chicago Tribune article (which was also reprinted in [Governing Magazine](#)), follow.

Advanced by Governor Pat Quinn, Illinois plans to close four of its eight centers for the developmentally disabled during the next two years. In all, the plan calls for 600 of the roughly 2,000 residents to be placed in new homes.

Critics of the proposal, including families and workers, contend that some residents simply are better served in institutionalized settings. They say specialized care simply isn't available in certain parts of the state, particularly after social service providers have struggled under years of state budget cuts.

The employee union and a parents group also have raised questions about how the administration has handled moves that have already taken place, saying that in the rush to close facilities, some families are being pressured to make decisions they aren't ready to make.

The first facility scheduled to close is the one in Jacksonville, about a half-hour west of Springfield. Initially slated to shut down on Oct. 31, administration officials acknowledge they may miss the mark as the state works to match residents with new places to live. Opponents say it's not that easy: Some people simply can't live in such settings and need the structure that they've come to know at a state institution, whether that be because of severe mental disabilities, behavior problems or particularly fragile medical conditions.

"These people aren't all cut from one cloth — each has specific needs," said **Rita Burke**, [\[VOR State Coordinator\]](#) and president of the Illinois League of Advocates for the Developmentally Disabled, an umbrella organization for parents whose children live in state facilities.

"Now, the governor's office says it is doing person-centered planning, but their person-centered planning has a predetermined outcome, and that is that everyone is appropriate to live in the community. How is that objective when they know before they even look at your son, daughter, brother or sister, where they are supposed to go?"

Burke points to her 42-year-old son, Brian Burke, who lives at the Choate Developmental Center south of

Carbondale. She said he was expelled from four private care facilities before he found a stable home there. Rita Burke worries what would happen if Quinn decides to close Choate, saying parents are concerned that the state is placing people wherever a provider is willing to take them, regardless of staff training and qualifications.

"In state-operated development centers, we have people who have dedicated their lives, their professions, to serving these types of individuals," Burke said. "In the community, that is not what we have. We have direct-care staff who in many cases make minimum wage and have a high turnover rate. We expect that many people aren't going to do well in community settings because they are just not being offered the same level of care."

Indeed, the American Federation of State, County and Municipal Employees Council 31, which represents state workers, said one example of poor care came just days after a woman who uses a wheelchair was transferred from the Jacksonville center to a group home outside St. Louis.

While the woman was being moved, she fell off a lift and broke her leg. An inspector general's report for the Department of Human Services determined that staff members at the group home were negligent, but the agency sent more residents to live there. State officials call the matter an isolated incident, adding that inspectors have since visited the facility to see what measures have been put in place to prevent a repeat of the situation.

The union said there have been other red flags. Officials cite a report from a committee monitoring the closing of the Jacksonville facility that found of the 47 residents moved from April to mid-September, four had run-ins with police, 14 were admitted to the hospital and four more received psychiatric hospitalizations. One resident returned to a state-run center.

"These are precisely the concerns families have been talking about," said Anne Irving, director of policy for AFSCME. Irving said it is "ironic" that the state is turning to community-care centers after years of funding cuts and delayed payments that have forced facilities to cut staff, consolidate space and carry out other cost-saving measures.

Quinn officials said the union is making a big deal out of a few bumps in the road in an effort to maintain jobs.

[Read More](#)

### **3. Illinois: Former Murray resident homeless**

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***The Sentinel* (Centralia, Illinois) \* October 9, 2012**

As the state moves forward with its closure of state-operated developmental centers, evidence is already been seen of individuals who are falling between the cracks, such as former Murray Center resident Alvin Warren, who is now considered homeless.

"I lived in Murray from 2006 until 2007 and I moved to Dalton, but they didn't like me" Warren said Monday from his hospital bed in Centralia.

Reportedly, Warren moved from through a series of group homes and private apartments after leaving Dalton and has been since been living on the streets of the Metro East area since June.

Finding no options for shelter, Alvin made his way Sunday to Elm Cottage at the Murray Center, which he once called "home."

Greg Shaver, director of Kaskaskia Workshop, says of the facility, "No one can come back, now."

Shaver confirmed that other former SODC residents who have been unable to successfully make the transition out-of-state facilities have also been turned away, as the state will not allow facilities like Murray to bring in new residents.

Unlike many residents of SODCs and group homes, Alvin is his own guardian, which allows him to check himself out of not only facilities, but also the hospital. Shortly after his interview Monday afternoon, he was discharged from St. Mary's Good Samaritan Hospital in Centralia, and is believed to now be wandering the streets of the city.

But at this time, a man with the mind of a child roams the streets of Centralia, and the one place he returned to for help was forced to turn him away.

"I went to Murray for help. I lived in Apple Cottage, but I went to Elm Cottage to see Sandy," said Alvin, explaining that Sandy is his 31-year-old sister who lives at Murray." I told the tech I want to live there, but she told me Murray will be closed and it's too late, I can't come back."

### **4. Illinois: State Representative John Cavaletto**

## **introduces legislation seeking audit of Community Resource Associates (CRA)**

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**[WJBD News](#) \* October 5, 2012**

State Representative John Cavaletto filed a House Resolution Friday that directs the Auditor General to conduct a formal audit of the grant issued by the Department of Human Services (DHS) to Community Resource Associates (CRA) in regards to transferring patients out of the Murray Center.

Cavaletto state in a press release that he has a number of questions and concerns about how the closure process at Murray Center is being handled. He states a full audit is needed to make sure that everything is being done in a safe and proper manner. The resolution, filed as House Resolution 1247, would address a number of issues, such as whether all requirements of the grant are being met, and whether any prior business relationships have existed between the principals of CRA and staff within the Governor's office and DHS.

The resolution also looks at if CRA has any business interest in the group homes where residents are being transferred to.

Cavaletto has heard concerns regarding CRA's performance conducting resident assessments, saying, "Typically, resident assessments are done by facility staff and it involves a lot of interaction with the client, his or her doctors and medical staff, and family members. I've been informed that client reviews currently being conducted by CRA have very little observation and interaction with the patients before they make their transition recommendations. These are very vulnerable lives we're dealing with here and it's most definitely not the time to be cutting corners," Cavaletto said.

Financial agreements made between DHS and CRA authorizes payments up to \$1.35 million to CRA to develop a clinical transition plan. Additionally, CRA is to perform resident assessments costing \$5,300 per resident.

### **MORE STATE NEWS**

**5. New Jersey: State Senator Loretta Weinberg wants study of how the disabled fare in the community**

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***The Record* \* Tuesday, October 9, 2012**

More than 500 disabled individuals will need new homes as the state closes its Totowa (North Jersey) and Woodbridge developmental centers over the next five years.

Sen. Loretta Weinberg wants to make sure that in planning for those relocations, the state Division of Developmental Disabilities takes into account lessons learned from earlier developmental center closures. Toward that end, Weinberg has introduced legislation to require a study of how several hundred former residents of the North Princeton Developmental Center fared after it was closed in 1998.

"We now have enough of a lengthy history to determine how those former residents are doing," the Teaneck Democrat said. "We should have a good hard study of what happened to those people."

The Christie administration had originally planned to close the Vineland Developmental Center in South Jersey and had even begun transferring its residents last year. But in August a joint task force on developmental center closures set up by the administration and the Legislature decided the two North Jersey institutions should be shut down instead. It concluded that closing Vineland would cause severe economic hardship in that region.

Weinberg says her proposal would not alter that decision. But it would require the state to study everything from the types of residences and programs in which the former North Princeton clients are participating to mortality rates and the extent to which they've had to interact with the police.

Weinberg said the study called for in her bill would be far more extensive than a 2005 report. She also noted that because more time has passed, researchers would be able to get a more definitive picture of how the former North Princeton residents have fared.

**Cynthia Bartman, New Jersey coordinator of [VOR](#)** — a grass-roots organization of relatives of the developmentally disabled — supported Weinberg's call for a new study.

"The original study which Dawn Apgar had a hand in was all too brief to determine actual outcomes," Bartman said. "We, the family members with loved ones residing at one of the seven developmental centers, hope for transparency in reporting and a non-

prejudicial approach to this investigation." Weinberg's bill was approved by the Senate Health, Human Services and Senior Citizens Committee last week and is now awaiting action by the Budget and Appropriations Committee.

The senator said she has not yet gotten an Assembly sponsor for the legislation. But Assemblywoman Valerie Vainieri Huttle, D-Englewood, said she plans to introduce it. Vainieri Huttle added that she's also working on bills requiring the state to conduct follow-up studies on residents who leave the Totowa and Woodbridge centers as well as residents of other state centers who transition into community programs.

[Read more](#)

[Related Commentary](#)

## **6. California: Lanterman Developmental Center families call for quality staffing for their loved ones**

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[Save Lanterman Coalition](#) \* **October 10, 2012**

Californians with relatives living at Lanterman Developmental Center in Pomona, Calif., are searching for answers to their questions of who will care for their family members when Lanterman closes: poorly paid and inadequately trained direct-care staff, or licensed and certified professionals with decades of developmental-services experience. They will bring their concerns to an open meeting this Saturday with representatives of the California Department of Developmental Disabilities this weekend.

For more than 80 years, Lanterman Developmental Center has provided wrap-around, state-of-the-art care for people with a range of developmental disabilities and related medical issues. However, in 2010, the State of California announced its intention to close this center, which provides federally certified developmental and medical services found nowhere else in its Southern California region.

Since the closure was announced and approved, residents' families and conservators have worked to be a part of the California Department of Developmental Disabilities' process to find smaller local residences with the same level of dedicated, professional care provided at Lanterman. One of the programs approved by the California Legislature as

part of the closure would install licensed and certified Lanterman employees – many of whom have cared for this unique population for decades -- at smaller group homes. However, nearly three years into the closure process, family members report that there is no indication that DDS intends to implement the promised professional staffing program.

“During the DDS budget hearings earlier this year, an Assembly member accused the department of playing a ‘bait and switch’ on this most important component of the closure process,” said Art Lopez, whose brother has called Lanterman Developmental Center his home for approximately 37 years.

“Experienced, regulated staffing is a real matter of life and death to our loved ones, and we family members need real answers from the Department of Developmental Services.”

### **7. California: New Innovative Housing for People with Autism**

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**CBSfs.com \* October 3, 2012**

[Watch Newscast Video](#)

Sweetwater Spectrum, a new residential community in Sonoma, California, is a critical first step in a concept that can be reproduced around California and the U.S. The design specifically addresses the needs of adults challenged with autism. The first residents are expected to be settled in by January 2013.

Sweetwater Spectrum will serve 16 residents in four four-bedroom homes on its 3-acre campus.

VOR note: Although the story indicates that Sweetwater Spectrum is intended to be an alternative to “[isolated] institutions for people with developmental disabilities,” the hallmarks of today’s ICF/MR communities are being replicated in this new housing complex for people with Autism. Sweetwater’s founders describe the residential program as a calm, quiet and predictable setting that offers residents adequate care and security.

[Watch Newscast Video](#)

[Related: New Autism Study: Children With Autism Tend to Stray](#)

#### **Quotable**

*“From now on it is only through a conscious choice and through a deliberate policy that humanity can survive.” ~ Pope John Paul II*

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