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Speaking out for people with intellectual & developmental disabilities



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Help VOR Grow!**

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January 9, 2015

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Calendar Reminders

VOR and YOU

1. VOR's Nominating Committee seeks individuals interested in serving on the VOR Board

January 9, 2015

Dear VOR Members and Advocates,

The VOR Nominating Committee announces its search for Board of Director Nominees.

The Committee is seeking individuals interested in serving on the VOR Board of Directors for 3 year terms beginning July 1, 2015.

Please respond by January 23, 2015. The Committee is seeking applicants who:

- Have a passion for our cause on behalf of individuals with intellectual disabilities.
- Can commit time for board meetings, committee planning and meetings, assist in reaching out to current and prospective members, and attend the Annual Conference.
- Are team players who work well with others in a group.
- Listen well and are thoughtful in considering issues.
- Are willing and able to assist in development efforts.

If you are interested in receiving a VOR Board application form or learning more, please contact Sybil Finken, Chair of the VOR Nominating Committee at finkensrc@aol.com or 712-527-

3250; or Julie Huso, Executive Director at jhuso@vor.net or at 605-370-4652.

The Nominating Committee will be contacting all interested applicants in early February.

Thank you for your consideration.

Sincerely,
Sybil Finken, Chair

2. VOR to Pennsylvania Legislature: Pennsylvania already has an Olmstead Plan

VOR * January 6, 2015 * Submitted to Patricia A. Berger, Esquire, Senior Counsel/Project Manager, Pennsylvania House Legislative Budget and Finance Committee

Pennsylvania State House Resolution No. 903 (2014) directs the Legislative Budget and Finance Committee to –

*“conduct a comprehensive review and issue a report of the Department of Public Welfare, Office of Developmental Programs’ implementation of the 1999 ruling by the Supreme Court of the United States in *Olmstead v. L.C.*, relating to the closure of State centers for people with intellectual disabilities and the provision of home-based and community-based services.” (H.R. 2014-903).*

H.R. 2014-903 is motivated by an allegation that Pennsylvania does not have an “*Olmstead* Plan with measurable objectives demonstrating how *Olmstead* will be implemented.” Further, H.R. 2014-903 incorrectly indicates that the “closure of the five State centers for people with intellectual disabilities and the provision of home-based and community-based services” are the only ways to comply with *Olmstead*.

VOR respectfully submits that the Commonwealth of Pennsylvania already has an *Olmstead* Plan: The Settlement Agreement in *Benjamin v. Department of Public Welfare* approved by District Judge John Jones on September 25, 2014.

Benjamin, a federal class action lawsuit, was filed by Disability Rights Network (DRN) alleging violations of the Americans with Disabilities Act (ADA), as interoreted by *Olmstead v. L.C.*

In defense and leading to Settlement, Pennsylvania spent more than \$1 million dollars in attorney fees and costs associated with the *Benjamin* litigation. Pursuing a legislative review of what has already been resolved favorably in court over 5 years at significant taxpayer expense would be contrary to public trust and an absurd use of scarce State resources.

[Read full letter here](#)

[Read VOR's *Amicus* Briefs here](#)

January 9, 2015 Update: In response to VOR's letter, confirmation was received that "As part of our study we will be discussing the *Benjamin* Settlement Agreement [finalized several months after H.R. 2014-903 was adopted] and how it reflects the implementation of *Olmstead*. We do not expect that our report will have specific recommendations regarding the closure of the remaining state centers."

3. VOR and Colorado's Save our Regional Centers file joint comments in response to Colorado's *Olmstead* Plan

VOR * January 6, 2015 * Reggie Bicha, Executive Director, Colorado Department of Human Services

Colorado's Save Our Regional Centers (SORC) and VOR have submitted comments in response to Colorado's Community Living Plan (July 30, 2014).

SORC, a VOR affiliate, and VOR represent individuals with profound intellectual and developmental disabilities receiving Regional Center supports, their peers across Colorado, and their families and legal guardians.

Colorado's Community Living Plan - it's "response to the *Olmstead* decision" - "will be monitored and updated," and that "its contents will continually evolve" (Plan, pp. 4-5). SORC and VOR offer input at this time with the expectation that we will be included as key stakeholders in all aspects of Plan implementation going forward.

We are necessary stakeholders with valuable input.

[Read complete comment here](#)

About VOR

DEFINING COMMUNITY

4. Finding Communities That Connect and Nurture the Like-Minded

The New York Times * December 26, 2014

Fountaingrove is one of a number of niche retirement homes catering to people with similar interests and passions. Although some special-interest communities have been around for a while — the Lillian Booth Actors Home, for example, an assisted-living and nursing care facility for entertainment professionals, in Englewood, N.J., was founded in 1902 — they have become more popular over the last decade.

One type of innovation is the university-based retirement community, in which residents live near a college campus, take classes and also have access to skilled nursing care. While exact statistics aren't available, Mr. Carle estimates that there are about two dozen such communities.

A handful of senior-oriented co-housing communities have formed in the last decade, said Raines Cohen, a certified senior adviser and co-housing coach in Berkeley, Calif. They are similar to communes in that they are often formed by groups of individuals rather than developers, but there are separate homes and amenities for individual owners and no communal business, just “the opportunity to share and connect when they want to,” Mr. Cohen said.

Communities have sprung up for, say, those of Indian heritage (ShantiNiketan, in Tavares, Fla.) or retired letter carriers (Nalcrest, in Polk County, Fla.) or those who share a passion for recreational vehicles (at the Escapees Care Center, in Livingston, Tex., you can live in your R.V. and get three meals a day, along with medical treatment).

[Read more, comment and share](#)

5. Kentucky: An Oasis of Care for People With Intellectual Disabilities

The New York Times * December 30, 2014

For years, parents like Ms. Kramer have struggled to find

About VOR

compassionate health care for their adult children with profound disability, among the most medically underserved populations in the country. They are told their children are not welcome: too disruptive in the waiting room, too long in the examining room — beyond the abilities of doctors who have no experience with intellectual disability.

“It’s been really hard to find anyone to even take him,” Ms. Kramer says. “Much less the experience when you go into a waiting room with someone as challenging as Trey.”

Now, though, Ms. Kramer has a place to go: the Lee Specialty Clinic, one of the very few free-standing facilities designed exclusively to provide medical and dental treatment — and a sense of welcome — to people with intellectual disability.

The 17,000-square-foot clinic, which opened in June, offers certain amenities. A reception area with natural light and easy-to-clean cushions. Extra-wide halls. Scales designed to weigh people in wheelchairs. An overhead tram to lift patients into dental chairs.

Just as important, say the clinic’s co-directors, Dr. Henry Hood and Dr. Matthew Holder, is its staff, trained to understand what their patients and families have been through. For example, Dr. Hood says, parents will often recall being told at the last medical clinic “to get your son or daughter out of here, and don’t ever bring them back.”

Experiences like these are what have motivated Dr. Hood and others to meet their needs, beginning with the opening of a dental clinic for people with intellectual disability in 2002. The clinic was named after its two strongest proponents: Louise Underwood, a family advocate, and a state legislator, Jimmie Lee, whose support began with visits he had made to state institutions as part of his legislative duties. [The Underwood and Lee Clinic continues to operate on the campus of Hazelwood, a state-operated Intermediate Care Facility for Individuals with Intellectual Disabilities (ICFs/IID) in Louisville, Kentucky. The late-Louise Underwood was a longtime VOR Board Member, member and advocate].

[Read more, comment and share](#)

[Related Video](#)

STATE NEWS

6. NEW YORK investigators cite hundreds of disabled abuse cases

AP (Albany) * December 23, 2014

The new agency responsible for protecting disabled New Yorkers in state care reports 571 cases of abuse or neglect confirmed in its first year of investigations.

The state Justice Center, which operates a 24-hour hotline, says it took about 84,000 reports concerning the nearly 3,000 facilities or programs operated, licensed or certified by six state agencies, though about 40 percent concerned incidents outside its jurisdiction or requested information.

Its first annual report shows 15,412 reports were classified as alleged abuse or neglect that required investigation, which included multiple reports of single cases.

The reports shows 571 completed cases found evidence to "substantiate" at least one allegation of abuse or neglect, about 20 percent of the cases.

Center staff investigate themselves and also review findings by the six agencies.

[Read more, comment and share](#)

7. TEXAS: Evicted and Helpless - Disabled residents to be forced out of state supported living center

The Austin Chronicle * September 19, 2014

"There has been a failure by those in control of the Capitol to do right by some of our most vulnerable citizens," State Sen. Kirk Watson, D-Austin, told the *Chronicle*.

The Sunset Advisory Commission, the state agency tasked with identifying governmental inefficiencies, voted on Aug. 13 to close the Austin SSLC and assign a committee to determine which five of 12 other state

supported living centers to shut down. The closures – largely for cost-saving reasons – would mark the first since 1995, and would affect nearly 300 intellectually and developmentally challenged Austin residents and potentially up to 1,000 residents statewide.

But while the Sunset recommendation will require legislative approval in the 2015 session – and an expected public fight from concerned guardians – DADS is "downsizing" the Austin center in the meantime, citing high overtime expenditures amid struggling employee recruitment and retention.

While some supporters of the plan have claimed the DADS decision was not influenced by the Sunset report, the department made clear in its letter that the personnel problems at hand are expected to be "even more challenging" in light of the state commission's recommendation. DADS called for the permanent closures of seven of the SSLC homes on the expansive Austin campus to ameliorate their staffing problems – or as they put it, develop, "a more intensive, census management plan."

[Read more, comment and share](#)

Read related news: [Texas Is Willing to Close State Schools, Sending Profoundly Mentally Disabled Persons Into the Community](#) (*Houston Chronicle*, December 23, 2014)

8. NEW JERSEY: Woodbridge Developmental Center closing means no happy new year for some families

MyCentralNJ.com * December 29, 2014

Story Highlights

* The Woodbridge Developmental Center will officially close Jan. 1.

* The last remaining residents were moved out of the Rahway Avenue facility on Dec. 11.

* Since plans to close the facility were first announced, 83 residents have been moved into community or group homes while 236 have been moved to other developmental centers, mostly in South Jersey

WOODBIDGE – For some families of residents who lived at the Woodbridge Developmental Center emotions are running

high this holiday season as the Rahway Avenue facility closes on New Year's Day.

"There is a lot of heartache at this time of year," said Joanne St. Amand, president of the Woodbridge Developmental Center Parent Association, a group representing relatives of people with developmental disabilities living at the state-run facility.

"People had traditions that had to be changed. Some people didn't get to celebrate with friends and staff," she said. "Others had celebrations but they were different."

And some families were unable to travel to see developmental center relatives who have been moved to facilities farther away.

[Read more, comment and share](#)

LEGAL NEWS

9. WISCONSIN: Appeals court rules against disability rights group in health care case

*AP (Milwaukee) * December 11, 2014*

The government has no constitutional obligation to provide health care to patients in state doctors' care, a state appeals court ruled Thursday.

Disability Rights Wisconsin [Protection & Advocacy (P&A)] filed a lawsuit in May 2009 against five University of Wisconsin Hospital and Clinics doctors, claiming they violated the rights of two developmentally disabled patients by withholding medical treatment. One, a minor who had pneumonia and required artificial nutrition and hydration, died.

The doctors were acting on guidance by parents or legal guardians who directed them to discontinue care.

The 4th District Court of Appeals agreed Thursday with a ruling by Dane County Circuit Court Judge Daniel Moeser, who said the government doesn't have a constitutional obligation "to provide health care, offer services or act to save a person's life."

The appeals court judges also cautioned that the ruling wasn't an opinion on doctors' potential obligations or whether the actions violate tort law or professional codes, but solely on the fact that Disability Rights Wisconsin hadn't presented sufficient legal argument that the doctors violated the constitution.

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MENTAL HEALTH IN THE NEWS

10. In transition to independent living, the 'dignity of risk' for the mentally ill

Washington Post * December 27, 2014

CONCORD, N.C. — On his 26th morning of independence, Kelvin Cook made a huge pot of coffee and ate oatmeal off a plate. His Social Security check had not arrived and he was down to \$5. He had a cellphone plugged into a wall, but it was out of minutes. Rent was overdue. He was out of his five prescriptions, including the anti-psychotic that had suppressed the symptoms of his schizophrenia for the past year, and now he felt sluggish.

Recently, the Obama administration has been trying to aggressively enforce the ruling in 24 states where efforts were thought to be lagging, potentially affecting tens of thousands of people. One of those states was North Carolina, which agreed in a 2012 settlement with the Justice Department to move at least 3,000 people with serious mental illnesses into independent living by 2020, as long as they wanted to move. No one could be disqualified from trying, including people who might be actively delusional, or who even might deny having a mental illness, provided that their safety and that of the community would not be compromised. "The dignity of risk" is how one Justice Department official described what the settlement aimed to give people who had been institutionalized, and this was why, earlier this year, Kelvin found himself talking to a woman who handed him a pamphlet explaining his civil rights.

[Read more, COMMENT, and share](#)

11. Three of the Last Five States Coming Around On Assisted Outpatient Treatment (AOT)

Treatment Advocacy Center * December 16, 2014

Even the most recalcitrant states are coming around on assisted outpatient treatment. Historically apathetic toward the plight of the most severely ill and their families, Maryland, New Mexico and Massachusetts have all taken great strides toward making court-ordered outpatient treatment available.

Massachusetts, New Mexico and Maryland are three of the five remaining states without court-ordered outpatient treatment laws. The steps forward in these states are a testament to the tireless advocacy of supporters and evidences that the country truly is at a tipping point for making treatment accessible for the most severely ill. The remaining two states are Connecticut and Tennessee.

[Read more and share](#)

What is Assisted Outpatient Treatment (AOT)?

According to the Treatment Advocacy Center, AOT is court-ordered treatment (including medication) for individuals who have a history of medication noncompliance, as a condition of their remaining in the community. Studies and data from states using AOT prove that it is effective in reducing the incidence and duration of hospitalization, homelessness, arrests and incarcerations, victimization, and violent episodes. AOT also increases treatment compliance and promotes long-term voluntary compliance, while reducing caregiver stress. (Source: Treatment Advocacy Center)

PRIVATIZATION NEWS

12. Dying and profits: The evolution of hospice

The Washington Post * December 26, 2014

The influx of for-profit companies into the hospice field has benefited patients, advocates say, because the commercial companies made big investments in technology, focused on efficiency and made care more accessible.

But a *Washington Post* analysis of hundreds of thousands of U.S. hospice records indicates that, as those companies transformed a movement once dominated by community and religious organizations into a \$17 billion industry, patient care suffered along the way.

On several key measures, for-profit hospices as a group fall short of those run by nonprofit organizations. The typical for-profit hospice:

- Spends less on nursing per patient.
- Is less likely to have sent a nurse to a patient's home in the last days of life.
- Is less likely to provide more intense levels of care for patients undergoing a crisis in their symptoms.
- Has a higher percentage of patients who drop out of hospice care before dying. High rates of dropout are often viewed as a sign that patients were pushed out of hospice when their care grew expensive, left dissatisfied or were enrolled for hospice even though they were not close to death.

The quality of individual hospices varies widely.

[Read more, comment and share](#)

QUOTABLE

"We are all distinctly and even delightfully diverse, different in our gifts, talents, and approaches to life. But equal in rights and human dignity, for which we have a rightful claim to receive from each other." ~ William Looney, VOR member from Washington State

Calendar Reminders:

Tuesday, March 24, 2015:

[American Health Care Association ID/DD
Washington Fly-In](#)

Congressional speakers are being invited, a legislative update will be provided, and Hill visits will follow in the afternoon. Breakfast and a boxed lunch will be provided to you. [Registration is free but required.](#) VOR members are encouraged to attend.

Sunday, June 7, 2015:

VOR Annual Conference: ADVOCATING FOR CHOICE BY EXPANDING OPPORTUNITIES. [Speakers Announced. Registration details coming soon. Check VOR's website often for updates.](#)

Archives:

* Thursday, March 20, 2014

[VOR's "Regional Meetings: The Need for Advocates to Act Global and Local" Webinar.](#)

***Social Media Strengths: Using Facebook and Twitter to Advance Your Cause (VOR, July 2013).** [Visit VOR's website for a copy of the powerpoint presentation and an audio of the event.](#)

* **How Congress Works Webinar: [Recorded - Listen Here.](#)** Tuesday, April 23, 2013 - 12:00 pm central / 1:00 pm eastern. How Congress Works: The Basics. Hosted by Peter Kinzler and Larry Innis.

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