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January 10, 2014



Speaking out for people with
intellectual & developmental
disabilities



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**Reminders:
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VOR Weekly News Update

News and views for VOR Advocates

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Coming soon: Next week registration for VOR's Annual Conference will open and we will announce our Conference speakers. Watch your email for more details.

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VOR and You

1. Reminder: [VOR's Nominating Committee seeks individuals interested in serving on the VOR Board](#)

2. Arkansas Legislators hear from families and VOR on importance of family decision-making and choice

On January 8, 2014, the Arkansas Legislative Council's Joint Hospital and Medicaid Study Subcommittee considered the value of Arkansas' Human Development Centers, publicly-operated Medicaid Intermediate Care Facilities for Individuals with Intellectual Disabilities.

Expressions of support for HDCs and concerns about their future were expressed by ten family/guardians, along with invited testimony from Darrell Pickney, President of the Families & Friends of Care Facility Residents (FF/CFR) (Jonesboro HDC), Jan Fortney, FF/CFR's Secretary (Conway HDC), and John Morris, an FF/CFR Member (Arkadelphia HDC). In support of this testimony, FF/CFR distributed a very helpful "[What Legislator's Really Need to Know](#)" about HDCs handout and a [compelling statistical presentation](#).

Darrell also serves as VOR's Arkansas State Coordinator and the Subcommittee welcomed [testimony from Tamie Hopp, VOR's Director of Government Relations & Advocacy](#). VOR's testimony covered legal, cost and quality arguments in support of residential choice and encouraged lawmakers to begin

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their analysis with the informed perspective of families/guardians:

"Central to VOR's advocacy is the highest respect and deference to the individual choice – true person-centered planning – and where necessary, the input of families and legal guardians. Here, where the Subcommittee is considering the value of Arkansas' five Human Development Centers, the proper place to start is with the view of the families.

"In the case of Human Development Center residents, the input of families and legal guardians is vital to ensuring good care decisions. Over 83% of the residents have severe (18%) or profound (65%) intellectual disabilities and require the informed help of their families and legal guardians who know them best."

The only testimony in opposition was from the Disability Rights Center, Arkansas' federally-funded Protection & Advocacy System.

[Watch related news video featuring Darrell Pickney](#)

3. Speak Out! Media Coverage Opportunity

New York Times Columnist Nicholas Kristof is seeking reader input for "Most Neglected Topics" for coverage in his Sunday blog.

Read his first 2014 blog on mental illness and call for [reader ideas here](#), and then call on Kristof to cover the impact of forced deinstitutionalization on people with intellectual and developmental disabilities here (character limit, including spaces, is 1,500) [here](#).

Here's what VOR wrote:

"People with intellectual disabilities (ID), a diagnosable mental disorder formerly called "mental retardation," and their care needs, are particularly neglected by the media. What coverage there is typically focuses on success stories, but neglects the underbelly of this story: The fate of thousands of individuals with profound ID, many of whom have additional physical, medical and/or behavioral disabilities, who are forcibly removed from specialized care ("deinstitutionalization"). The actions that cause this removal, often federal funded and instituted by groups like Protection & Advocacy and the U.S. Department of Justice, result in needless suffering from abuse, neglect, isolation and death because the necessary level of specialized care and trained staff are simply not available in most community settings. Tragedies due to forced deinstitutionalization in a dangerous

quest for "normalization," need far wider coverage. So does the collateral damage felt by individuals who seek community living but end up waiting years, even decades, living with aging parents who can no longer adequately care for them, while advocacy and funding focus on moving high needs individuals from congregate facilities. As you reported, failing to provide people with mental illness adequate care results in homelessness, incarceration, or worse. Some people with ID face not homelessness and prison, but instead are suffering and dying in what are supposed to be caring settings."

Legal News

4. Illinois: First day of Murray Center lawsuit draws fire from both sides

News-Democrat * January 7, 2014

CHICAGO — A federal judge began hearing arguments and testimony Tuesday in a lawsuit about whether the state can close its Warren G. Murray Developmental Center in Centralia.

Plaintiff attorney Judy Sherwin, in her opening statement, said the lawsuit isn't just about Murray Center, because the case will "determine for many years to come" how Illinois cares for people who have developmental disabilities.

Assistant Attorney General Thomas Ioppolo, in his opening, said it is the state's prerogative on whether to operate 15, 10 or five institutions.

U.S. District Judge Marvin Aspen set aside three days for hearing the case in the Dirksen federal building in Chicago.

Using a format set by the judge, the attorneys are cross-examining witnesses who already have submitted written affidavits.

[Read more, comment and share](#)

Related News:

News from Day 2 of the Trial: [Center director delivers surprising testimony in Murray hearing](#) (WILY/WRXX News * January 8, 2014): and

[“Murray Center trial: Is state 'dead wrong' to close it or catching up with the times?”](#) (*News-Democrat* * January 8, 2014)

News from Day 3 of the Trial: "[Quinn deputy testifies opposition in Centralia prevented new homes for Murray residents](#)" (*News-Democrat* * January 9, 2014)

Join the Conversation: [Murray families and the Arc respond at end of the hearing; opportunity for comments](#)

State News

5. New Jersey: Petition seeks to keep open two North Jersey developmental centers set to close

PolitickerNJ.Com * January 7, 2014

[Watch Interview with VOR's Joanne St. Amand](#)

TRENTON – Advocates delivered what they said were 10,000 signatures and a petition to the governor's office Tuesday in an attempt to keep two northern New Jersey developmental centers open.

The family members of center residents are hoping they can convince the state not to close Woodbridge and North Jersey developmental centers.

The emotions behind the crusade were summarized by Deborah Smith of Paterson, whose 43-year-old daughter Kesha is a profoundly disabled resident of North Jersey Developmental Center in Totowa in Passaic County.

Smith said they were given two choices: Move Kesha to a group home or to a developmental center in far Southern New Jersey.

“It's very stressful and I get upset thinking

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about it,” Smith said, “the thought of her that far from us.”

“One size doesn’t fit all,” Smith said of the prospect of her daughter moving to a group home.

[Read more, comment and share](#)

6. Massachusetts: The politically incorrect idea of bringing congregate and community care together

Massachusetts Coalition of Families and Advocates (COFAR Blog * January 7, 2014)

Two initiatives in two separate states call for something that would seem to make perfect sense — expand the missions of congregate care facilities for the developmentally disabled, and merge them with their surrounding communities.

In one case, the State of Delaware is proposing to expand services available at the Stockley Developmental Center by offering medical and dental care now available there to developmentally disabled and under-served persons living in the community. A Delaware state task force has also called for considering an indoor community sports center or outdoor playing fields at the Stockley facility; and opening up a therapeutic horseback riding program and a therapeutic pool at Stockley to the surrounding community as well.

Like most of the developmental centers in Massachusetts, the Stockley Center sits on hundreds of acres of largely unused land, and currently serves only a small fraction of the hundreds of people who lived there four decades ago.

In the second initiative, the Arc of Jacksonville in Florida has been awarded state funding and tax credits to help construct a

“planned neighborhood” in that state for adults with intellectual and developmental disabilities, according to The Florida Times Union. The newspaper reported that the “Arc Village” will house about 120 adults – ages 18 and older – in 97 one- and two-bedroom apartments. The \$17.7 million project will allow residents to “live, work, shop, recreate, and socialize,” in one place.

[Read more, comment and share](#)

Quotable

"The most difficult think is the decision to act, the rest is merely tenacity" ~ Emelia Earhart

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Calendar Reminders:

Tuesday, March 25, 2014

AHCA/NCAL's fifth annual "ID/DD Residential Services Providers Hill Fly-In." Questions? Dana Halvorson, dhalvorson@ahca.org.

June 8, 2014

VOR 2014 Annual Conference and Initiative: *"Making it Happen: Reforming Policy and Law in Support of Person-Centered Quality and Choice"; Hyatt Regency, Washington, D.C.* [Details coming soon](#)

Week of June 9, 2013

VOR 2014 Congressional Initiative: Families and advocates visit Capitol Hill. [Details coming soon](#)

Sunday, October 5, 2014

American Health Care Association's 2014 ID/DD Residential Services Day during AHCA/NCAL's 65th Annual Convention & Expo at the Gaylord National Harbor just outside of Washington, DC. Registration will open in Spring 2014.

Archives

***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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