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September 27, 2013



Speaking out for people with
intellectual & developmental
disabilities



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Help VOR Grow!**

VOR Weekly News Update

News and views for VOR Advocates

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Calendar Reminders

VOR and You

1. **Reminder! Take Action – Call on National Council on Disability to Support Choice**

**Make a Lasting
Impact with a
Will Bequest**

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Your one-stop
advocacy
resource**

**Take Action!
If not us,
who?**

VOR Action Alert * September 26, 2013

VOR needs your help urging the federally-funded National Council on Disability to develop a reasonable policy that fully embraces services based on individual choice and needs, consistent with the *Olmstead* Decision: “We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.”

[Take Action. Just one Click.](#)
[View all VOR's Current Action Alerts](#)

**2. Announcing the 2013 Recipients of the
Jordy Engels Award**

VOR joins with our Florida affiliate, DSI Supporters, Inc.; Ed and Virginia Carraway, VOR Florida State Coordinators; and David and Leni Engels, long-time VOR members, in proudly announcing the 2013 Jordy Engels Award.

This year's recipients of the Jordy Engels Award are Don and Ruth Stover. In presenting this award, we recognize the decades of service offered by the Stovers to our community of individuals with intellectual and developmental disabilities, and their families. They have contributed much to our shared advocacy in Florida and nationally.

Both Don and Ruth are long-time VOR members. Don is the current President of the family association at Tachachale DSI, a state-operated Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) and a member of the Family Care Council in Florida. Don and Ruth regularly attend meetings

Reminders: Help VOR Grow!

Make a Lasting
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for disability advocates, offering a reasoned voice for choice at every opportunity.

Congratulations Don and Ruth and thank you for all you do.

*VOR, Speaking out for individuals with intellectual and developmental disabilities
DSI Supporters, Inc.*

*Ed and Virginia Carraway, VOR State Coordinators
David and Leni Engels, Members*

3. VOR Releases Key Principles to Ensuring Rights and Opportunities for All People with Disabilities

VOR's Legislative Committee recently released "[Respecting Individual Choice: The Rights of All People with Disabilities](#)," including "Key Principles" to ensure that all disabilities with individuals are entitled to the same rights and opportunities.

Underpinning each "Key Principle" is respect for diversity of need and individual choice.

Most individuals with disabilities are capable of determining job opportunities, leisure activities, and housing options, and have the right to exercise individual choice, with any necessary supports.

Other individuals experience profound I/DD or other serious I/DD and medical and/or behavioral disabilities. These individuals have rights, too, and need the support of their families and legal guardians to ensure that their choices for housing, employment, and services are safe, comfortable and responsive to their needs.

[Read more](#)

4. VOR's Connie Howard tells disability advocates, "We must work together, not apart"

Casner Tribune * September 21, 2013 * Opinion

Editorial by Connie Howard, VOR's Wyoming State Coordinator

[Note: This editorial also appeared in the *Lander Journal* ("Working Together," 9/25/2013), the *Gillette News Record* ("Wyo. needs to do more for developmentally disabled," 9/25/2013) and the [Wyoming Tribune Eagle](#) ("Families of the disabled must carry their torch," September 20, 2013)]

About the author: *Connie Howard is VOR's Wyoming State Coordinator. Connie's son, Mark, has profound intellectual disabilities and has received high quality, specialized supports in both facility-based and community-based settings.*

We must work together, not apart

I have been advocating for people with developmental disabilities for 53 years. By no coincidence, that's also how old my son is.

Mark is developmentally disabled. While young, I never said "I want to be an advocate for people with disabilities when I grow up." Like so many other families of individuals with developmental disabilities who daily advocate for their loved ones, my son has brought out the advocate in me.

While my advocacy is certainly motivated by my son and his needs, I also recognize that he is part of something much bigger. Mark is part of a population of developmental disabled adults who are served by a complex web of state and federal programs all designed to ensure that he and his peers are adequately and safely served in settings of their choice.

Calling on the general public to support the least-abled among us is the greatest moral test of our government and its people, as noted so aptly by Hubert Humphrey.

The compassion of the general public in helping to provide my son and his peers the

supports they need is not lost on me I recognize that what Mark receives is a blessing, not an entitlement.

But, the system is not perfect and that motivates me too.

[Read more, comment and share](#)

State News

5. Illinois Murray Center's fate is in judge's hands

*The News-Democrat (Southwestern Illinois) **
September 21, 2013

BREAKING NEWS - September 27 - [Federal trial over Murray Center closure postponed to November](#)

RELATED NEWS - September 27 - [Court guardian presents troubling testimony on community conditions](#)

The year-plus battle over the state's plan to close its Warren G. Murray Developmental Center will play out soon in a federal courtroom in Chicago.

U.S. District Judge Marvin Aspen set aside three days beginning Oct. 1 to hear testimony and arguments from the state and supporters who want to keep open the Centralia center, which has been home to about 270 adults with developmental disabilities.

The plaintiffs in the suit are the Murray Parents Association and the Illinois League of Advocates for the Developmentally Disabled, as well as a handful of individually-named family members of residents.

The plaintiffs contend that some Murray residents have disabilities so profound they couldn't reside safely outside an institution. They say the state is planning to close all seven of its developmental centers, including Murray, which would leave the residents without a place to go in Illinois if they're not accepted at private centers or if things don't work out for them at a

private center.

The lawsuit alleges that closing Murray Center and other state-operated developmental centers would violate the residents' rights under the Americans with Disabilities Act and would run afoul of federal Medicaid regulations.

The suit asks that the state be prohibited from closing state-operated developmental centers, or reducing the services they provide, "unless or until equivalent, appropriate replacement services are provided to prevent inappropriate hospitalization, injury or death to residents in violation of the developmentally disabled residents' rights under federal and state laws."

[Read more, comment and share](#)

6. Virginia Families Call on State to Stop Efforts to Coerce the Families into Moving Their Loved Ones into Communities that are Not Prepared to Care for Them

Press Release * September 18, 2013 * by the Parents and Associates of Northern Virginia Training Center; the Central Virginia Training Center Families and Friends; the Parent Advocacy & Advisory council of Southwest Virginia Training Center; and the Parents Organization of Southern Virginia Training Center

For Immediate Release

When Lorraine Koury told the social worker for her sister Teresa, who has profound intellectual disabilities (ID), that she wanted Teresa to remain in a state-run Training Center for people with ID, the social worker told her, "you better choose a community group home now, before all the good ones are taken." In [a letter](#) sent today, the leaders of the family groups representing the residents at four of Virginia's Training Centers for people with ID, called on William A. Hazel, Secretary of Health and Human Resources. to stop putting undue

pressure on people to leave the Centers and take steps to protect the rights of the Commonwealth's most vulnerable citizens.

The plan to close four of the State's five Centers was developed by Virginia as a means of implementing an agreement with the U.S. Department of Justice to provide more community choices for people with ID, although the agreement does not require the closure of any Center and guarantees the Authorized Representatives (ARs) the right to elect for their residents to receive care in a state-run Training Center.

The Center family group leaders have consistently argued that the Commonwealth is acting in an unduly hasty fashion, setting arbitrary closure deadlines and coercing people into moving into a community that is not prepared to care for them properly, while ignoring other options that would retain smaller Training Centers as part of the system. The letter identifies key concerns about State actions that the leaders do not believe have received adequate responses.

[Read more, comment and share](#)

[Read the Families' Letter](#)

Visit and "Like" the "[Keep Virginia's Training Centers Open](#)" Facebook page

7. California: Advocates rally in Sonoma to support Eldridge developmental center

***The Press Democrat* * September 14, 2013**

With time ticking down on a task force created to determine the fate of four state-run institutions that house some of California's most profoundly disabled people, supporters of the Sonoma Developmental Center hit the town plaza Saturday in an attempt to rally support for keeping them open.

About 60 people attended. many of whom

have family members who they say could not receive the care they need anywhere else if the state moves to “evict” them from the place most have called home for decades.

[Read more, comment and share](#)

8. Inclusion in Michigan: Benjamin's Hope shows off campus at Firelight Festival of Hope

***Holland Sentinel* * September 12, 2013**

The Hundreds who gathered for the Firelight Festival of Hope, including people with autism or Down syndrome, their families and others, share founder Krista Mason's vision for a campus where the developmentally disabled would feel as comfortable as those without. This shared vision is how Benjamin's Hope has come this far, with seven young adults living on the 40-acre campus with homes, a small community building, walking trails and a barn (with cats, rabbits, dwarf goats and alpacas for whom the residents are responsible).

Another \$3 million will complete the campus with a large community center and a fourth house. The Reformed Church in America/Christian Reformed Church church plant and a final house already are paid for.

This Firelight Festival also was Benjamin's Hope's grand opening.

[Read more, comment and share](#)

Federal News

9. Congresswoman introduces “anti-dumping” bill for mental hospitals

***The Sacramento Bee* * September 24, 2013**

Spurred by concerns that a Nevada hospital bused hundreds of mental patients across the country, in some cases to cities where they had no support system or treatment arrangements, Rep. Doris Matsui has introduced federal

legislation that would impose hefty fines on facilities that engage in so-called “Greyhound therapy.”

Matsui, a Sacramento Democrat, introduced the House bill last week; it would be the first federal law to specifically address “dumping” of mentally ill people by psychiatric hospitals onto other facilities or jurisdictions without a discharge plan. If approved, the measure would impose fines of up to \$10,000 on facilities that fail to follow discharge requirements for psychiatric patients set out by the U.S. Centers for Medicare and Medicaid Services. Repeat offenders would have 45 days to correct issues or lose federal reimbursement for the care of Medicare patients.

[Read more, share and comment](#)

Quotable

“First they ignore you, then they laugh at you, then they fight you, then you win.” ~ Mahatma Gandhi

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Calendar Reminders:

***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.**

*** AHCA/NCAL to host Intellectual and Developmental Disabilities (ID/DD) Day – October 6, 2013. [Details online.](#)**

*** VOR's 2014 ANNUAL CONFERENCE AND INITIATIVE * June 8 - 11, 2014 * Washington, D.C.**

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