



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

[Registration](#) and [Sponsorship Details](#) are now available for VOR's Annual Conference and Washington Initiative, June 8 - 12, 2013 in Washington, D.C. Please join us!

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!

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6, 2013

Coming up

[State, in dispute with parent over care of her disabled son, seeks to remove her as guardian](#)

VOR and YOU

1. Registration Information for “How Congress Works: The Basics,” VOR Webinar

VOR’s Legislative Committee Chairman, Peter Kinzler, and VOR’s Washington Representative, Larry Innis, will co-host “How Congress Works: The Basics,” a free VOR webinar.

How Congress Works will cover the basics, including the various hurdles a bill must clear before passage, the difference between appropriations, reauthorization, the budget and more.

This free Webinar will take place Tuesday, April 23, 2013 at 10:00 am pacific / 11:00 am mountain / 12:00 pm central / 1:00 pm eastern.

[Click here to register](#)

Once you are registered you receive a unique URL (web address) to use on the day of the webinar and a call in number for audio by phone.

2. Time is ticking! Register TODAY for VOR’s Annual Conference and Initiative: *Together We Will!*

VOR Annual Conference and Initiative: Facing the Future - Together We Will

June 8 - 12, 2013

Washington, D.C.

On Sunday, June 9, 2013, VOR will host its Annual Conference in Washington, D.C. Featured speakers will include AHCA's Renee Naylor who will be part of a panel to discuss how quality care for people intellectual and developmental disabilities (I/DD) can be provided consistently across all settings and

states. Other presentations include a Legislative Briefing with staff from Capitol Hill and VOR's Peter Kinzler and Larry Innis, who combined have more than 50 years of experience working with Congress; and a motivational presentation by Richard Male, an expert in nonprofit leadership and strategic vision. Participants will also hear from VOR leaders, who will provide updates on VOR accomplishments and activities, with awards being presented to past president, Polly Spare, who served for 9 years, and to the family of VOR's late-founder, Marty Pratt. Dinner will be provided.

On Saturday, June 8, 2013, the day before the Conference, VOR's Board will meet, participants will offer State Reports, and VOR will host a free evening hospitality networking event. During the week of following the Conference, beginning Monday, June 10, participants will canvas Congress with VOR's legislative priorities. Initiative participants are provided with presentation folders to leave with each office.

Event details, registration, and hotel information is available on [VOR's website](#). Sponsorships make VOR's Conference and events possible. Information about [sponsorship opportunities](#) is also available on VOR's website.

3. Use Your Voice: Public comment opportunity - let the National Council on Disability hear from you

The National Council on Disability (NCD) is an independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities.

NCD's quarterly meetings are open to the

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public. People and organizations that represent the interests of people with disabilities are encouraged to attend these meetings, in person or by phone. The next NCD meeting is April 22 – 23, 2013 in Washington, D.C. [The focus of this meeting will be NCD's future "Policy Roadmap."](#) Families living in the D.C. area are encouraged to attend in person or you can join the meeting by phone ([download the agenda, with location and phone details, here](#)).

Public Comment Opportunities

There are [three limited public comment portions](#) of the meeting, first come, first serve:

- Monday, April 22, 4:45 pm - 5:15 pm EASTERN (30 minutes) (in person or by phone)
- Tuesday, April 23, 11:45 am - 12:00 pm EASTERN (15 minutes) (in person or by phone)
- Tuesday, April 23, 9:30 - 10:00 am EASTERN (in-person comments only).

Families of individuals whose loved ones require life-sustaining specialized care are encouraged to share your stories. [NCD needs to hear from you.](#)

You may also provide **written public comment** at any time by sending your comments in writing to Lawrence Carter-Long, Public Affairs Specialist, at LCarterLong@ncd.gov, using the subject line of "Public Comment."

State News

4. Illinois: VOR Member testifies in support of choice; and related Illinois news

Laurie Stengler, a VOR member from Illinois, represented VOR earlier this week at Illinois House and Senate Appropriations Committee hearings. Her testimony targeted (and opposed) proposed funding cuts to public developmental centers (ICFs/MR) and specifically called for continued funding for Murray Developmental Center which the Governor has said he will

close. Laurie's brother-in-law is a resident of Murray and she is a plaintiff in a [lawsuit](#) filed by families of affected residents at developmental centers across the state, and the Illinois League of Advocates for the Developmentally Disabled, a VOR affiliate and the statewide organization for developmental center residents and their families.

[Read Laurie's testimony on VOR's website](#)

Related Illinois News

***Attorney continues fight to save Murray Center**

Judith Sherwin, the Chicago attorney hired to file a federal suit against the State of Illinois on behalf of guardians and residents of the Warren G. Murray Developmental Center in Centralia toured the facility. According to Sherwin, despite the state's insistence that there are no plans to close all developmental centers in Illinois, multiple guardians say they have been told by top human services administration that is indeed the ultimate plan. Sherwin is seeking a temporary injunction against the closure of the Murray Center.

***Quinn's claim that Murray closure "right thing to do" blasted by opponents; State Rep. alleges self-advocates coached to support closure**

Families and advocates opposing closure offered brisk and unanimous objections to Governor Quinn's claims that the closure of Murray Center is the right thing to do and will save money statements. Those opposing the Governor's decision to shutter the Murray Center say his decision flawed and is not in the best interests of all Murray residents.

***Irony Alert: Governor Quinn listens to crowd outside the facility, but not to residents who live in the facility**

5. Wvovina: Studv could decide future of

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Wyoming Life Resource Center

Billings Gazette * April 7, 2013

[Part of a series](#) and a [photo gallery](#) including VOR's State Coordinator Connie Howard.

An oversized yoga ball held Tracy Carr's frail, bent body. Scoliosis has contracted her spine so much it nearly collapsed a lung, making her more susceptible to pneumonia. At 40 years old and only 70 pounds, pneumonia can mean death.

She requires constant one-on-one care. Doctors say she functions as a 6-month-old. She can't feed herself and scratches her eyes if her arm is left unattended.

Her story is typical of Life Resource Center clients, if there is a typical story. Tracy lived with her parents in Casper until they died. Then she moved in with her sister, Sharon Humberson. Soon after, Sharon's husband was diagnosed with cancer and her daughter with multiple sclerosis. Sharon has had back surgery twice to help the damage done by lifting her sister. Tracy nearly died of pneumonia while with Sharon, one of three cases she fought in a single year.

[Read more](#)

6. South Carolina: Study shows S.C. residential care facilities 'unsafe and deplorable'

The Post and Courier * April 10, 2013

Four years after an initial study found many South Carolina community residential care facilities were dirty, infested with insects and filled with residents who were mistreated by staff, a follow-up report by a nonprofit group shows little has changed.

The first report, titled "No Place to Call Home," was published in 2009. The follow-up report, "[Still ... No Place to Call Home](#)," was released Tuesday. Together, the reports

demonstrate a “depressing lack of progress,” the study said.

Some of the findings in the new study include:

- *Dead bugs and roach feces.
- *Stained mattresses and furniture.
- *Inadequate food supplies.
- *Not enough medicine or medical equipment.
- *Lack of toiletries, including shampoo and toothpaste.
- *Staff who yelled at residents.

According to the state Department of Health and Environmental Control, there are 477 licensed community residential care facilities in South Carolina with 16,999 beds. Protection and Advocacy for People with Disabilities refused to disclose which residential care facilities were included in the study. All 14 were inspected after unannounced visits.

Read Related: [Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities \(VOR, revised April 2013\)](#)

7. New Jersey: Our loved ones feel secure at developmental centers

***The Times* (Trenton, NJ) * April 6, 2013 * Letter to Editor by Patricia and Mark Russillo, Trustees of the Association for the Hunterdon Developmental Center**

It is a sad day when our severely developmentally disabled are placed out of the developmental centers they call home and into a community setting. The advocates for developmental center residents from six of the seven centers administered a survey to guardians and family members of our developmentally disabled loved ones who reside there and found an overwhelming 96 percent of respondents preferred continued developmental center services over community services.

It astonishes me to hear the governor indicate

that the centers do not work. If he was to visit, he would realize that the centers provide professional, 24-hour, supervised, medical and custodial care for those most — with dedication and predictability. This predictability is beneficial for our loved ones' physical and emotional needs. Parents/guardians trust these professionals and consider them family. Furthermore, medical services, provided at the developmental centers, would cease if our loved ones were to reside in the community.

Our developmentally disabled reside at developmental centers all their lives. I could not imagine their level of anxiety if they had to leave their home. Gov. Chris Christie did not want to move into the governor's mansion because he did not want to take his children out of their environment, and that is his right as a parent. Parents/guardians should be granted the same consideration to make choices for where their loved ones reside. If the developmental centers were not appropriate to their best interests, they would not be there.

Please have compassion for our loved ones and respect where parents/guardians prefer their sons and daughters reside.

National / Federal News

8. Making the case for national caregiver background checks: A parallel example

Boston Herald * March 27, 2013

[State auditor finds 119 matches between sex offender, child care provider addresses](#)

VOR note: People with intellectual disabilities are often as vulnerable as infants and small children. Yet, caregivers who commit a crime against the person can cross state borders and find employment working with vulnerable populations. VOR supports national caregiver background checks.

9. Congressman Mike Thompson calls on

Feds to reject proposal which defines "community"

In an April 4, 2013 letter to Marilyn Tavenner, the Acting Administrator for the Centers for Medicare & Medicaid Services (CMS), Congressman Mike Thompson calls on the agency to rethink its pending proposal to narrowly define "community" for the purpose of licensing certain Medicaid programs. "I share my constituents' concerns that the CMS proposal relies on arbitrary criteria to determine whether a setting is 'community enough,'" Congressman Thompson writes. "Of particular concern is the proposed requirement that the Secretary of the Department of Health and Human Services 'apply a rebuttal presumption that a setting is not a home and community-based setting, and engage in heightened scrutiny' with regard to homes 'on the grounds of, or immediately adjacent to, a public institution,' or homes that are part of a 'housing complex designed expressly around an individual's diagnosis or disability,'" he writes.

The Congressman expresses concern that the proposed definition is so narrowly written that it is "antithetical to individual choice," threatens the viability of existing housing communities, and discourages future innovation and expansion of services.

[Read Congressman Thompson's letter.](#)

Calendar Reminders

10. AHCA/NCAL to host Intellectual and Developmental Disabilities (ID/DD) Day – October 6, 2013

AHCA/NCAL is pleased to announce that Intellectual and Developmental Disabilities (ID/DD) Day will be on Sunday, October 6. Session attendees will get to take part in a motivational and educational day, with speakers ranging from the Centers for Medicare and Medicaid Services (CMS) to a Coordinator of Community Outreach and Engagement to the President of the Grant Professionals

Association. Breakfast and lunch will be served.

If you have any questions about this exciting day, please feel free to contact AHCA's ID/DD Committee Chair, Renee Naylor (renee@westcaremgt.com), and AHCA's Director of NFP and Constituent Services, Dana Halvorson (dhalvorson@ahca.org). [ID/DD Day registration information/details can be found here.](#)

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Other Calendar Reminders:

*** Tuesday, April 23, 2013 - 12:00 pm central / 1:00 pm central**

FREE WEBINAR: How Congress Works: The Basics. Hosted by Peter Kinzler and Larry Innis. [Register here.](#)

*** Through May 1, 2013: Be a Sponsor. Get a Sponsor: Support VOR's Conference and Initiative. Sponsorship opportunities, in partnership with EP Magazine, are now available.**

*** Sunday, June 9, 2013**

VOR Annual Conference * Washington, D.C. [Registration now available. Details online.](#)

*** Begins Monday, June 10, 2013**

VOR Washington Initiative (Begins Monday, June 10, 2013) * Washington, D.C. [Details online.](#)

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

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