



Speaking out for people with  
intellectual & developmental  
disabilities



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**Reminders:  
Help VOR Grow!**

## VOR Weekly News Update

News and views for VOR Advocates

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

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**Did you receive this as forwarded e-mail? If so,  
someone thought you would benefit from VOR's  
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receive this E-News Update publication weekly!**  
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**\$5,000  
Challenge:  
Help VOR send  
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Washington,  
D.C!**

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## ***Quotable***, by Thoreau

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### **VOR and YOU**

#### **1. VOR's Facebook Challenge: We're halfway there!**

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In celebration of VOR's 30th Anniversary, VOR has received a challenge gift of \$1,000.

Our goal is \$5,000 and we are halfway there! Your gift will help grant the opportunity for other advocates to network with like-minded individuals, attend [VOR's Conference](#) and personally visit Members on Congress to voice our shared mission in support of choice for all individuals with I/DD.

To contribute in response to this challenge, [click here](#). Your gifts make a difference! Please share this challenge with others on Facebook!

[Read more](#)

#### **2. VOR's Mary O'Riordan honored by U.S. Rep. Mike Thompson in *Congressional Record***

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***Congressional Record* \* Volume 159, number 7, pages e418**

*Editor's Note: Ms. O'Riordan is a VOR Board Member-nominee, former VOR Board Member, and Member of VOR's Legislative Committee. VOR offers our congratulations to Ms. O'Riordan for this great honor and shares Rep. Thompson's admiration for your tremendous advocacy and compassion for people with intellectual and developmental disabilities.*

**Honoring Mary O'Riordan, Parent Hospital Association County Of Sonoma  
Rep. Mike Thompson (D-CA)  
*Congressional Record***

Mr. Speaker, I rise today to recognize Mary O'Riordan, who is retiring after nine years as President of the Parent Hospital Association (PHA) at Sonoma Developmental Center.

Ms. O'Riordan dedicated her life to serving persons with developmental disabilities. As President of PSA. she was in constant contact

with state legislators in Sacramento and federal representatives in Washington, DC, traveling multiple times to both capitals to advocate on behalf of association members. She also served six years on the board of directors of VOR, the national advocacy group for persons with developmental disabilities.

Ms. O'Riordon's advocacy is rooted in her personal experience. Michael, the second of her four sons, was severely disabled and lived at Sonoma Developmental Center (SDC) until his death in January 2011. It was his experiences at SDC, the place he called home, that led her to champion the institution, its staff and its residents.

[Read more](#)

### **3. VOR supports Senator Chris Murphy's call for an investigation of group homes; VOR's letter to Inspector General**

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**VOR \* April 18, 2013**

VOR strongly supports [Senator Murphy's request](#) for an immediate investigation into the preventable, predictable widespread tragedies impacting people with I/DD in small settings across the country.

[Read VOR's full letter](#)

### **4. [Celebrating 30 Years: VOR Milestones](#)**

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**New!** Updated information about [VOR's Milestones](#) over 30 years is now available online. Learn about VOR's many accomplishments in its Legislative, Legal, Media and Education advocacy.

### **5. VOR in the press: More residents for WLRC could mean more efficiency**

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[Billings Gazette](#) (April 18, 2013) and [Casper Star Tribune](#) (April 17, 2013)

The articles "[Study could decide future of Wyoming Life Resource Center](#)," (April 7) and "[Redesign of Wyoming disability program causes concern. frustration](#)" (April 7). point to a

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perplexing inconsistency in our collective commitment to assist the least among us.

How can the 90 residents of WLRC have so much, while parents like Helen Norcross must endure war zone-like alarms every time her teenage son tries to leave the home?

A natural reaction would be to take from WLRC residents and give to families suffering at home. A "robbing Peter to pay Paul" approach, however, has not worked well in other states and will leave many Wyoming citizens without adequate care. As Wyoming officials confront the question of WLRC's efficiency, why not think outside the box and ask whether the center would operate more efficiently with more residents. Years of downsizing has resulted in artificially inflating WLRC's cost without any windfall for community residents.

Wyomingites have a rare opportunity to do more with more. The WLRC is a jewel. Open its doors and serve more very disabled and deserving citizens.

*Tamie Hopp*

*VOR Director of Government Relations & Advocacy*

*Rapid City, S.D*

### **Calendar Reminders**

**6. Tuesday, April 23: [Register today](#) for VOR's free "How Congress Works: The Basics," webinar**

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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.](#)

**7. Tuesday, April 23: Comment Opportunity - National Council on Disability's Quarterly Meeting**

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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 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](mailto:LCarterLong@ncd.gov), using the subject line of "Public Comment."

#### **8. Deadlines approaching: VOR Annual Conference and Hotel Reservation deadlines coming up. Register today and reserve your room at the Hyatt!**

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VOR Annual Conference and Initiative: Facing the Future - Together We Will  
June 8 - 12, 2013  
Washington, D.C.

[Click here for complete details, including agenda, conference registration and hotel reservation information.](#)

Information about [sponsorship opportunities](#) is also available on VOR's website.

#### **Legal News**

#### **9. Illinois Families Seek Preliminary Injunction**

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### **WJBD News \* April 16, 2013**

The Murray Parents Association and others suing the Illinois Department of Human Services and two of its top officials say at the minimum material issues of fact exist to warrant a hearing on their motion for a preliminary injunction to keep Murray Developmental Center in Centralia open.

While the state says any preliminary injunction would be premature, the Illinois League of Advocates for the Developmentally Disabled say as a practical matter it is the last recourse for the profoundly disabled to preserve a means of redress for the significant legal wrongs in progress. They note once the State's transition plan is completed, there will be legal arguments raised of mootness, despite belated recognition of injuries. [The advocates' attorney Judith Sherwin asks the court to probe beyond the written pleadings to rule on the requested preliminary injunction, particularly given the serious health, safety and welfare concerns at issue.](#)

Sherwin says despite blanket denials from the state, affidavits and anticipated testimony from concerned guardians and family members reveal statements made directly to them by State officials indicate the ongoing 'transition plan' includes closing all of the Development Centers and moving all residents into 2-4 bed community homes. The response notes 84% of the Murray Center residents have profound developmental disabilities resulting in cognitive and skill levels of an infant or young child.

Sherwin says the development center placements continue to be necessitated and guided by required medical and care services. The motion adds 2-4 bedroom group homes simply are not designed, structured or staffed to provide the services the severely developmentally disabled require and are entitled under federal law. In addition, many have a history of rejection from community placements due to the care requirements and behaviors that result from their profound deficits.

Sherwin says the residents injuries from the closure of Murray Center are ripe for adjudication and are neither speculative nor hypothetical. She notes while the state makes much over Department of Human Services Secretary Michelle Saddler and Director of Developmental Disabilities Kevin Casev having

immunity for violations of state law, the Eleventh Amendment does not provide immunity for state officials who violate federal law. Sherwin notes all the violations spelled out in the civil lawsuit are for federal laws.

It will now be up Northern District of Illinois Federal Court Judge Marvin Aspen to make a decision on granting the injunction or calling for an evidentiary hearing to gather more information.

[Read Complaint](#)

[Read Plaintiffs' Reply in Support of Injunction](#)

[Related News](#)

**10. Massachusetts: State, in dispute with parent over care of her disabled son, seeks to remove her as guardian**

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***Massachusetts Coalition of Families and Advocates (COFAR) Blog (David Kassel) \* April 10, 2013***

Apparently unable or unwilling to resolve a dispute over the proper residential placement for a developmentally disabled man, the state is seeking to remove the man's mother as his guardian.

The Department of Developmental Services has filed in Middlesex Probate Court to remove Patricia Feeley, a COFAR Board member, as guardian of her 27-year-old son, Michael, and to appoint James Feld, a Woburn attorney, in her place.

Feld is described in the petition only as an "advocate" for Michael Feeley, but DDS acknowledged in a court document that Feld had never previously met Michael.

DDS is not alleging any abuse or neglect of Michael, and in fact, has described Feeley in court documents as "devoted to him" and "concerned for his well-being." However, the Department contends that Feeley has rejected several suggested residential placements for Michael and is not acting in his best interest. And DDS is further alleging that Feeley's home, where Michael has lived his entire life, is not safe because it has excessive "clutter" in it.

Feeley has actively sought for several years to place her son, who has type 1 diabetes, in a suitable DDS facility. She maintains that the real reason DDS is seeking to remove her as her son's guardian is that the Department doesn't want to provide a residential

facility for him with 24-hour nursing care.

“The Probate Court is the wrong forum for this case,” Feeley maintains, adding she would be “devastated” if DDS succeeds in removing her as Michael’s guardian. A pre-trial conference in the case was scheduled in Probate Court on Thursday.

Michael, who has profound intellectual disability, is non-verbal and is unable to dress or bathe himself. Feeley said she was told his IQ was too low to measure. DDS’s petition to appoint Feld as guardian suggests that Michael be moved to a group residence in Chelmsford that Feeley noted does not have continuous, on-site nursing.

A friend and advocate of Feeley’s, who visited the North Chelmsford residence with Feeley last summer, maintained that the nurses there travel among several residences, one of which is in Lynnfield, about an hour away. The friend contended there are no nurses on site in the Chelmsford residence during the evening shift.

Feeley contends her son, who requires as many as seven injections of insulin per day, needs a residence with 24-hour, on-site nursing care. Feeley, 65, who works as a part-time clinical lab technician and is a certified nurse assistant, currently administers the injections herself, monitors Michael’s blood glucose, and personally provides all other care at home for him. Michael’s extensive care needs prevent her from working full time.

Feeley’s assessment of her son’s medical needs is backed up by a May 28, 2010 letter from a physician at Children’s Hospital in Boston, who wrote that Michael’s blood glucose spikes at times “for no apparent reason,” and that “it is not possible to predict when that might occur.” The doctor’s assessment continues: “A nurse needs to be present and able to attend to Michael’s needs at any time to avoid a delay in Mike receiving appropriate medical intervention.”

DDS, however, contends that Michael does not need 24-hour, continuous nursing.

[Read more](#)

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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.](#)

**\* Friday, April 26, 2013, 6:30 pm, Mila in Concert:** Benefit concert by renowned concert pianist, Mila Belakova. Click here for [concert poster](#), [press release](#), and [details](#).

**\*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.**

**Quotable**

*"The moment my legs begin to move, my thoughts begin to flow." ~ Henry David Thoreau*

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