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August 16, 2013



Speaking out for people with
intellectual & developmental
disabilities



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VOR Weekly News Update

News and views for VOR Advocates

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VOR and You

1. [Have you taken action? Calling for DD Act Investigation, Reform and Reauthorization has never been easier.](#)
 2. **VOR Submits Comments to Long Term Care Commission: Seeks fiscal reason, individual choice, and national staffing standards**
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On July 31 and August 16, VOR submitted comments to the Commission on Long Term Care. The Commission was established under Section 643 of American Taxpayer Relief Act of 2012 (P.L. 112-240) (January 2, 2013) ([About the Commission](#))

In its [first submission \(July 31, 2013\)](#), VOR cautioned the Committee against a “less for more” approach to financing Medicaid long-term care services for people with intellectual and developmental disabilities (I/DD). With 80% of long-term care resources being spent in community-based settings on 80% of the I/DD population in a vast majority of the states, there is not, we submit, any “institutional bias.”

In its [second submission \(August 16, 2013\)](#), VOR urged the Commission to support uniform staffing standards, including national background checks and minimum staff licensing, certification and training requirements, to ensure the consistent delivery of quality of care in community-based settings serving people with intellectual and developmental disabilities (I/DD). The Commission’s

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authorizing statute charges the Commission, in part, to consider workforce development strategies.

As soon as possible, individuals and organizations are encouraged to [submit their own comments](#). The Commission's report must be finalized by September 12. Comments can be submitted to comments@ltccommission.senate.gov.

3. VOR's Jill Barker earns seat on Michigan Developmental Disabilities Council

Governor Rick Snyder * August 9, 2013

For Immediate Release

August 9, 2013

State of Michigan, the Office of the Governor

Snyder makes appointments, reappointments to Developmental Disabilities Council

LANSING, Mich. – Gov. Rick Snyder today announced eight appointments and three reappointments to the state Developmental Disabilities Council. Housed within the Michigan Department of Community Health, the 21-member council advocates for people with disabilities on a statewide level.

“The varied backgrounds and experiences of these individuals will be a tremendous asset to the council moving forward,” Snyder said.

Appointees will serve four-year terms expiring Sept. 30, 2016, and their appointments are not subject to the advice and consent of the state Senate.

Appointed are:

[Jill Barker](#), of Ann Arbor, is mother of two sons with cerebral palsy. She is president of Friends of the Developmentally Disabled, a member of the board of directors of the Just Us Club in Ann Arbor, a participant in the DDAdvocates of Michigan and is a member of the Washtenaw Community Health Organization

Recipient Rights Advisory Committee. She also sits on the Board of Directors of VOR, a national advocacy organization that supports a full range of services and residential options for people with intellectual disabilities. Barker holds a bachelor's degree from Antioch College. She will represent parents or guardians of a child with a developmental disability and fills a vacancy.

[Read more](#)

[Read Jill's DD News Blog](#)

4. On the web: Richard Male's Keynote Presentation at VOR's 2013 Annual Conference: "Very inspirational!"

"To see beyond today, we must first visit history: During my 4 decades in the nonprofit sector I have seen the government consistently close down institutions that your family and loved ones have depended upon for necessary quality care. VOR has been swimming against the proverbial political tide for years. You have fought diligently to keep these institutions open, all the while, watching as every state has tried to close down these same support systems due to rising costs and changing community and ideological values."

[Read more](#)

[Read other 2013 Annual Conference and Initiative Reports](#)

5. Reminder: California Petition - There is time for choice advocates to lend their voice for choice in support of individuals with intellectual disabilities and their families

Reminder. There is still time to sign this petition: Governor Brown - Save Sonoma Developmental Center!

[Read Petition, Sign and Share](#)

Legal Update

6. Illinois: Judge puts some Murrav Center

residents under court-appointed guardian

***News-Democrat* * August 8, 2013**

A judge in Clinton County issued an injunction that puts some residents of the Warren G. Murray Development Center under the custody of a court-appointed guardian, rather than the state, which is closing the center.

Circuit Judge William Becker issued the order, which could put a wrinkle in the state's plan to close the state-operated center in Centralia. Becker's order covers Murray Center residents who do not have private guardians and are wards of the state. The court-appointed guardian will be Stuart Freeman, a local attorney.

The order was granted at the request of Friends of Murray Center, which is a group of employees and others who oppose the closing.

Wylie Blair, an attorney for Friends of Murray Center, said the order does not prevent the center's closure.

"It just precludes the residents of Murray Center who are wards of the state from being transferred out of Murray Center, absent consent of the guardian," Blair said. "It's up to him to look into their situation and find out whether their best interests are being followed."

He added, "We're not seeking to prevent the place from closing, we're just seeking to make sure, whether Murray does or does not close, that the wards of the state have their best interests looked after."

The private guardians of some Murray Center residents have tried to block the state from moving their loved ones from the center. The state has hired a firm to assist in transferring patients to other facilities, but some guardians have refused to give the firm permission to see the medical files of their loved ones.

Opponents of closing the center say some of its residents have been tricked into moving to private care centers, with one resident being promised that he'd be taken to weekly Chicago Cubs games if he moved.

Becker's order extends a temporary order issued last week by Circuit Judge Dennis Middendorff. Middendorff issued a temporary order because the state had not yet been given time to present arguments.

Gov. Pat Quinn says closing the center and transferring its residents to private, "community care" centers will save the state money and give its residents a better quality of life. Opponents of the closure question the savings, and say some residents have disabilities that are too profound for the type of care offered at a private center.

State Rep. Charlie Meier, an Okawville Republican who is trying to keep the center open, said Becker's ruling represents "another good day" for Murray Center.

The state Department of Human Services issued a statement saying the agency will "continue to follow all court orders that have been entered regarding Murray Center while also continuing in our commitment to re-balance the system of care for persons with disabilities in the State of Illinois."

Becker's ruling follows a similar ruling, issued recently by a federal judge that temporarily prohibits the state from transferring Murray Center residents who have private guardians. The federal judge's order is in effect while a lawsuit challenging the center's closure plays out in court.

The center at one time had about 270 residents, but transfers to other centers have already begun, and there now are about 230 residents at Murray. The center, which has had a staff of about 530, is scheduled to close this fall.

[Read more, comment and share](#)

7. Massachusetts: Seven Hills families win a reprieve from eviction

***COFAR News Blog* * August 14, 2013 by David Kassel**

This post is about one of the few cases in Massachusetts in which families and guardians of the residents of a congregate care facility for the disabled appear to have won out over ideological efforts to move their loved ones into community-based group homes.

Some 43 residents of the Seven Hills Pediatric Center in Groton, who had been targeted for eviction under a federal lawsuit, will now apparently be allowed to stay in their long-time home at the nursing facility some five years after their parents began a campaign against the moves.

In May of this year, a federal district court judge formally ended the Rolland v. Patrick suit after the plaintiffs agreed the Patrick administration's efforts to move hundreds of developmentally disabled nursing home residents to group homes had satisfied the conditions of the suit.

Given that the suit is now over, the impetus to move the 43 residents out of the Seven Hills center is apparently over as well.

[Read more, comment and share](#)

8. Wisconsin: Mother sues group home after daughter's death

***The Journal Times* * August 3, 2013**

Tears flow freely from Linda Berger as she remembers the toughest decision she's ever made: to take her first-born daughter off life support and let her slip away.

Almost two years have passed since Berger, of Waterford, looked into her daughter's vacant, staring eyes. Gone was her little girl, who at 49

years old, still had the mentality of a 5-year-old because of brain damage she experienced at birth. Gone, she said, was the bubbly woman affectionately known by her nephews and niece as “silly Auntie Kelly.”

Her daughter, former Special Olympics silver and bronze medal winner Kelly Jorgenson, allegedly had eaten a bagel with peanut butter in her group home on July 24, 2011, and began choking. She was taken to the hospital, her mother said, unable to breathe.

Berger has sued her daughter’s assisted living center, Wanda Frogg Villa/Meadowhaven, at 524 Summit Ave., City of Burlington; its owner, Homes for Independent Living LLC; Oconomowoc Residential Programs Inc.; Philadelphia Indemnity Insurance Co.; as-yet unnamed insurance companies; the Wisconsin Department of Health Services; and Kathleen Sebelius, who is secretary of the U.S. Department of Health and Human Services.

Berger’s wrongful death lawsuit, alleging negligence, was filed in April in Racine County Circuit Court. It contends that staff knew Jorgenson was on a special diet but would steal food from the kitchen; knew that she wasn’t allowed to eat without staff supervision; knew she ate her food quickly and required directions from staff to slow down and chew her food; and knew she was a known choking risk.

The lawsuit allege, Jorgenson was left unsupervised for an unspecified amount of time, she found bagels and peanut butter, ate them rapidly and began to choke, and then ran choking to her bedroom — where she collapsed on the floor.

[Read more, share and comment](#)

9. Virginia: Woman With Down Syndrome Prevails In Guardianship Dispute

***Disability Scoop* * August 5, 2013**

In a closely-watched case centering on the rights of adults with disabilities, a Virginia woman has won the right to live with her friends rather than in a group home as her parents preferred.

Margaret “Jenny” Hatch, 29, who has Down syndrome, has been fighting for a year to live with her friends, Jim Talbert and Kelly Morris. Hatch previously lived with the couple, but more recently she has been living in a series of group homes against her wishes while under the temporary guardianship of her mother and stepfather.

On Friday, Newport News, Va. Circuit Court Judge David F. Pugh determined that Hatch needed the protection of a guardian, but said he had to take the young woman’s wishes into account. Accordingly, Pugh granted temporary guardianship for one year to Talbert and Morris, reports the Newport News Daily Press. During that time, the couple is to help Hatch become more independent.

[Read more, comment and share](#)

State News

10. New York: Hotline Nets Thousands Of Abuse Claims

***Disability Scoop* * August 6, 2013**

One month after launching a hotline to report neglect and abuse of people with disabilities, one state has logged more than 7,200 tips.

New York opened The Justice Center for the Protection of People with Special Needs on June 30 as part of a broader effort within the state to address concerns about abuse. The center is a law enforcement agency charged with protecting the state’s roughly one million residents with disabilities.

In its first month of operation, the Justice Center reported that it received over 7,200 reports to its 24-hour hotline. Of them, more

than 1,300 allegations of neglect or abuse merited further investigation, officials said in a report documenting the center's activity.

What's more, some 30 cases are now being reviewed by a prosecutor because of suspected criminal activity, they said.

Of the reports submitted to the Justice Center, 3,000 have been deemed "significant incidents." Another 2,900 related to financial misconduct, were legally-required administrative reports or were outside the scope of the center's work.

Cases of abuse and neglect are addressed by trained investigators within hours, officials said.

[Read more, share and comment](#)

Quotable

"I want you [VOR and its members] to realize that you are here not by accident, not because you were following the "political tide and climate", not because you were loved or even liked. You are here today because you have had the chutzpah, the courage, the will to stand by your values and say 'we are not giving up.' We will not be beaten down by the politicians and other naysayers. We have the courage to realize that VOR has lasted 30 years because we are doing things right and we have a belief in who we are and where we are going. I want you to look around the room and realize that a small group of people can help change the world one person at a time. We are here today NOT by accident." ~ **Richard Male's Keynote**

presentation at VOR's 2013 Annual Conference (June 9, 2013)

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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.](#)**

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