Speaking out for people with intellectual disabilities

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January 13, 2012

VOR Weekly News Update

News and views for VOR advocates

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Coming Up:

Stephanie Vance's E-Advocacy Course #4 (members only)

VOR and You

1. Call for VOR Board of Director Applicants

VOR’s Nominating Committee seeks individuals interested in serving on the VOR Board of Directors.

VOR is seeking applicants who:

- Have a passion for our cause on behalf of individuals with intellectual disabilities
- Can commit time for board meetings, committee planning and meetings, and can attend the annual meeting
- Are team players who work well with others in a group
- Listen well and are thoughtful in considering issues
- Are willing and able to assist in development efforts

If you are interested in receiving a VOR Board application form please contact Co-President Sybil Finken at finkensrc@aol.com or 712-527-3250 or Executive Director Julie Huso at jhuso@vor.net or at 605-370-4652.

If you would like to receive additional information from anyone on the nominating committee, please contact:

Ann Knighton, Co-President 706-993-6329

Bill Ryerson, First Vice President WTRyerson@aol.com or 336-765-6763

Mary O'Riordan, moriordan@aol.com or 415-927-05422

2. REMINDER: Save the Date: VOR 2012 Annual Conference, Legislative Briefing and Washington Initiative

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Conference Details Coming Soon

June 9 - June 13, 2012

Washington, D.C.

Action Center

3. Press Release / VOR Renews Calls for Moratorium on Deinstitutionalization Lawsuits

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Please feel share the following press release with your local media, especially if DOJ and/or P&A are active in your state. It is a follow-up to the press release we circulated on December 12, 2011 and shared with membership last week.This is another opportunity to connect with your local media and build relationships

VOR - Speaking out for people with intellectual disabilities

January 12, 2012

For Immediate Release

FMI: Tamie Hopp

Concerned About Deaths of Intellectually Disabled Individuals, National Organization Renews its Call for Moratorium on Deinstitutionalization Lawsuits

VOR, a national advocacy organization representing people with intellectual disabilities and their families, today renewed its urgent request of Members of Congress in several states to call for a moratorium of federally-funded deinstitutionalization lawsuits.

VOR renewed its call for Congressional action in light of ongoing reports by the New York Times which detail the 'unnatural or unknown" deaths, abuse, neglect, and financial fraud perpetrated on New York's most vulnerable citizens with intellectual and developmental disabilities (see, New York Times "Abused and Used" series, from March 2011 – current).

"Reports of people with profound disabilities experiencing harm and death after being displaced from specialized settings are frighteningly predictable," said Tamie Hopp, VOR's Director of Government Relations and Advocacy, citing a bibliography of similar reports from around the country.

A recent *New York Times* article reported that the Administration on Developmental Disabilities (ADD) released a report criticizing New York's federal protection and advocacy system, the NYS Commission on Quality of Care & Advocacy for Persons with Disabilities ("U.S. Report Criticizes New York on Monitoring Care of Developmentally Disabled," January 11, 2012).

VOR finds ADD's reaction to the horrors exposed by The New York Times a woefully inadequate and incomplete response to 1,200 deaths over the past decade ("In State Care, 1,200 Deaths and Few Answers," Nov. 6, 2011).

ADD's findings are predominately focused on process and budgeting and fail to even consider that ADD's support and funding of deinstitutionalization efforts – removing vulnerable people from specialized care – may be one of the major causes of problems in New York and other states. Despite the extraordinary level of deaths in the community, ADD persists in its blind devotion to community placement by pointing to the NYS Commission's "support for segregated educational . . . and residential programs" as problematic.

"It's not surprising that a self-audit of one its own programs would avoid the difficult question of whether small settings are prepared to safely care for all individuals with profound ID/DD," said Hopp. "If ADD won't ask those difficult questions, Congress must."

Citing the "enormity of the human tragedies taking place in New York and other states and the inadequacy of ADD's response," VOR has urged Members of Congress to respond by calling on these federal agencies to halt deinstitutionalization lawsuits until Congress has had time to investigate how these problems occurred, determine what changes in federal policies are necessary to protect the lives of people with ID/DD who reside in the community, and decide if changes are needed in federal policy to guarantee residential choice to the residents of facilities for people with ID/DD.

The Face of VOR

4. Thomas' Story

By Cheryl Felak, RN, BSN * Seattle, Washington * Dec. 31, 2011

Related Video: Fircrest - A Vital Public Asset

Related Audio: From Crisis to Stabilization - Thomas' Story

Thomas is my son. He'll be 18 years old in February 2012. He has an extremely rare genetic disorder which is neurodegenerative and has early onset dementia. Throughout his youth, he has had many prolonged hospitalizations in the inpatient psychiatric unit at a children's hospital. Due to his developmental disabilities, they really didn't know what to do with him. They didn't know about personal care. When he was 14 years old, he came home from one hospitalization with such extreme skin breakdown that it took about 5 months to clear up. Even with a 1:1 aide in the hospital setting, they were not able to provide for his personal care adequately. I would often arrive to see him with food on his face, food down the front of his shirt, teeth not brushed or a diaper that needed to be changed. In the hospitals the staff are not trained to care for DD patients and particularly on the psychiatric floors where children who are dually diagnosed (mental illness/developmetal disablity) tend to be hospitalized.

Thomas now lives at Fircrest, the Residential Habilitation Center (RHC) (a state ICF/MR and specialized DD Nursing Facility) near our home. It has been a Godsend, although he was denied admission for about a year. The State's Department of Developmental Disabilities (DDD) claimed that there were no resources for him (even though he was on a Home and Community Based Services (HCBS) waiver). Before his admission to Fircrest, DDD suggested that for the next crisis we would just have to call the police.

Since moving to Fircrest, he has not had to be hospitalized once and has been stable. He is so happy in his home. It has also allowed our family to regroup since our family disintegrated and my health also became life threatening in efforts to manage Thomas at home. We have also had to file for bankruptcy. Moving him to the RHC has enabled us to work and become productive members of our community and also be advocates for other families who are in the shoes we were in and are in.

When Thomas was 14 years old and living at home, I recorded him during a typical manic/psychotic episode – typical for Thomas; typical for others dealing with this. During such episodes, everything becomes intense and all-consuming for the caregiver to maintain the health and safety of the child. During the episode I taped I was trying to get Thomas to go to the bathroom prior to leaving for the day camp, which he really loves. You'll hear screaming, disorganized thought patterns, and Thomas hitting and biting himself during this taping. I hope this audio helps people (citizens, advocates, legislators and policymakers) to hear what life is like for many of us when our child is home.

The audio was also in response to a question by the Executive Director of an Arc chapter who asked me, "If RHCs are so great, why we don't see people in Olympia testifying how much they LOVE living there?"

This comment alone tells me that The Arc advocates do not understand the issue of the ICF/MR residents at all. Many of our residents are mostly non-verbal, may not tolerate the trip to Olympia, may not tolerate crowds, may not be able to maintain appropriate behavior skills for very long or may be too medically fragile to travel.

Thomas has taught me a lot in our journey together. I'm motivated to maintain the good, compassionate home he now has at Fircrest.. I'm motivated to help others. I founded "Because We Care – Beyond Inclusion" as one way to help.

State News

5. Alabama closes its last public ICF/MR

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The Tuscaloosa News * December 29, 2011

The W.D. Partlow Developmental Center, which was home for thousands of intellectually disabled residents, closed Wednesday after 88 years in operation in Tuscaloosa.

Partlow, opened in 1923, was the state's sole remaining facility for the intellectually disabled. Its closure was determined by the trend to move residents to community-based housing and by state budget shortages.

The department originally planned to close Partlow on Sept. 30, but Gov. Robert Bentley pushed the date back to Nov. 30 because lawsuits and other issues arose.

At least two lawsuits were filed by relatives of Partlow residents claiming the state had no legal right to close Partlow and claiming their loved ones wouldn't be in a better environment if moved. The lawsuits were unsuccessful.

Tuscaloosa Mayor Walt Maddox and local legislators opposed Partlow's closing because of the perceived impact on the economy, jobs, residents and the financial impact on local, non-state government services.

"I believe their decision was driven by funding," Maddox said. "Every piece of evidence I've seen, every conversation I've had with parents and guardians of consumers, leads me to believe this decision was based on downsizing instead. I hope everyone comes together and provides what is best for mental health consumers and not the bottom line."

ADAP]the Alabama Protection & Advocacy system] attorney James Tucker said Alabama set a standard in becoming the first state in the

Southeast to close institutions like Partlow.

"In closing its last state-run institution that segregated persons with developmental disabilities, Alabama continues to improve the quality of services provided to persons with disabilities," he said. "Our experience has been consistently that once family members see improvements for their loved ones in the quality of life in the community, their objections dissipate."

However, Tucker warned about state funding that has been cut over several years, endangering community services to ADAP clients who face more harm than just violation of their civil rights.

"Because the DMH budget already has been slashed, and will likely be slashed again in FY13, there is a significant risk that services to persons in community placements will not have their needs met," he said. "I am gravely concerned about the ability of DMH to provide needed services to my clients in fiscal year 2013 if DMH is not level funded, or better."

Curtis James is vice-chairman of the advisory board of trustees to the Department of Mental Health. At the last board meeting members approved a letter to Bentley asking him to at least provide level funding to the department next year.

"We also request that you deem the Department of Mental Health an essential function of state government," the letter said.

In a telephone interview, James said he supports Baugh's decision to close Partlow and advises that more cuts will endanger services to consumers.

*[**VOR Editor's note** : If ADAP and the state are "gravely concerned" about the ability of the state to provide/fund community-based services, why did they support the forced displacement of Partlow residents? Shouldn't the "community" be adequately funded first?]*

6. Wisconsin: Jury awards $1.5 million in group home death

Journal Sentinel (Milwaukee, WI) * January 7, 2012

Jurors in Washington County awarded more than $1.5 million Friday to the mother of 56-year-old woman who died after choking while in the care of a group home in Germantown.

Vicky Anderson died on March 3, 2009, after an incident on Feb. 27 of that year, according to her attorney, in which staff of the group home failed to properly purée her food.

As a result she choked on her meal, causing brain damage and eventually her death, attorney Jeff Pitman said.

Anderson was developmentally disabled, blind and had difficulty swallowing her food. She lived at a group home in Germantown operated by Countryview Group Homes.

Pitman said that while researching the case, he discovered Countryview was operating the day of the incident without a required manager and had recently cut staffing levels.

Jurors awarded the woman's estate nearly $1.52 million for burial expenses, pain and suffering, loss of companionship for Vicky's mother, Evelyn, and punitive damages.

Michael Yelin, administrator of Countryview, said in a statement: "Countryview disputes any evidence of inappropriate staff cuts and (is) considering an appeal on that issue. Countryview took responsibility from the beginning because its employee made a mistake."

7. Massachusetts: Alleged assaulter of disabled man is a no-show on trial date

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COFAR blog * January 10, 2012

Sheila Paquette's long-running quest to bring the man who allegedly assaulted her intellectually disabled brother to justice took yet another turn this week.

After months of delay, Monday, January 9, marked the date for the trial of John Saunders, a former care worker in the group home in which Paquette's brother, John Burns, lives.

The bad news is Saunders was a no-show at Falmouth District Court, to which Paquette and five witnesses in the case had traveled from their homes in western Massachusetts. But Paquette was not deterred or defeated. The good news is that the judge in the case ruled that Saunders had defaulted on his bail and should not be released prior to trial if he is picked up on a violation of any kind.

Saunders allegedly hit John Burns in the face while toileting him, causing two black eyes and other injuries. The alleged incident occurred in June 2010, during an outing on Cape Cod on which Burns and other residents of his West Springfield-based group home had been taken. Burns was subsequently fired by the group home, which is operated by the Center for Human Development, Inc.

The assault charges were filed in July 2010 by Burns' sister and co-guardian, Sheila Paquette, after she became frustrated with the slow pace of state and law enforcement authorities in investigating the alleged assault. Saunders, who is represented by a public defender, has previously denied the charges.

Read more and comment.

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