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May 25, 2012

VOR Weekly News Update

News and views for VOR advocates

VOR's Weekly News Update is taking a break! Next issue will be Friday, June 22, 2012. Details are below.

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VOR and You

1. Coming Up: VOR Annual Conference and Initiative (June 9 -13), VOR Action Alert (June 8) and next Weekly News Update (June 22)

Due to preparation for and participation in VOR's 2012 Annual Conference and Initiative in Washington, D.C. from June 9 – 13, the *VOR Weekly News Update* will be taking a break. Look for the next issue on Friday, June 22.

An Action Alert will be distributed on or about June 8 to provide VOR members "back home" to support the meetings VOR Initiative participant will be having the week of June 11 with Members of Congress and their staff. Your calls, emails and faxes really reinforce and support the message VOR Initiative participants are delivering in person. Thank you in advance for your participation.

2. William Choslovsky, attorney for choice in *Ligas* case, honored for efforts on behalf of people with developmental disabilities

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Neal, Gerber, & Eisenberg LLP * May 7, 2012

CHICAGO (May 7, 2012) – The U.S. District Court for the Northern District of Illinois, Eastern Division, in conjunction with the Federal Bar Association's Chicago Chapter, will recognize **William Choslovsky**, a partner at Neal Gerber Eisenberg, as a recipient of one of its Awards for Excellence in Pro Bono Service. Choslovsky is being honored for his work in *Ligas v. Hamos*, a 2011 decision that protected and expanded living arrangements for the developmentally disabled in Illinois. The final settlement in *Ligas v. Hamos*, handed down by Chief Judge James F. Holderman, allows for expanded living arrangements for the state's developmentally disabled population, giving them the choice of either remaining in their state-supported intermediate-care facilities, seeking accommodations in smaller community-based settings, or living at home with relatives while receiving community-based services. Neal Gerber Eisenberg's pro bono representation, led by Choslovsky, helped bring the six-year-long heated battle to closure.

"The settlement protects all developmentally disabled people and their living arrangement choices, whatever they may be," said Choslovsky, who represented a group of developmentally disabled people and their families who objected to an initial settlement proposed in 2009. Choslovsky has a personal connection to the case: His sister has resided for 25 years at the Misericordia Home in Chicago, a large intermediate-care facility where he said she has received "world class" care.

Read Full Release

3. Who Speaks for the Disabled? Editorial by Bill Choslovsky, featuring Rita Burke's story

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***Chicago Tribune* (Editorial) * May 25, 2012**

[*Editor's Note*: **William Choslovsky**, a Chicago lawyer, is on Misericordia Home's advisory board. His sister, Stacie, has profound intellectual disabilities and resides at Misericordia, a private ICF/MR. Working pro bono, Bill represented Misercordia families in Ligas v. Hamos (see related article, above). **Rita Burke**, featured in this editorial, is the President of the Illinois League of Advocates for the Developmentally Disabled and is VOR's Illinois State Coordinator. **VOR members are encouraged to support this excellent editorial with Letters to the Editors of their own. Send to ctc-tribletter@tribune.com, as soon as possible. Your letters should *briefly* share your story and express how and why large facilities are "homes."]**

"No one knows better than I do what is best for my son."

So began my conversation with Rita Burke, who along with her husband, Kevin, has raised seven kids. One is an assistant U.S. attorney. Another a nurse. Another a federal agent. Another a teacher. Another a physical therapist. Another a battalion commander who has served tours of duty in Afghanistan and Iraq.

And then there is Brian, their second child, now 42, who Rita, of Makanda, Ill., said is "our real hero, who forged our family into steel."

Shortly after birth, Brian suffered a severe brain injury. The clinicians say he has "pervasive developmental disorder," which Rita says means "his obsessive-compulsive behaviors can become extremely dangerous to himself and others." For years he swallowed objects like pens and pencils, a disorder called pica, which led to emergency surgeries.

"In a structured setting, he can function quite well," Rita explains, "but out of that structure his behaviors completely disintegrate and he becomes like another person." Simply stated, he needs round-the-clock care. "Without it, he will end up dead or in jail," Rita says soberly.

When schools could not serve him, Rita home-schooled Brian, even teaching him "how to read words he does not completely understand." But when Brian's behaviors became too much, the family looked for help. They tried many placements in the "community," because as Rita says, "we wanted Brian to live as independent a life as possible."

But they all failed. "However hard they tried, all the places eventually kicked Brian out because private facilities do not have to keep difficult residents with extreme needs. And Brian was extreme," Rita says.

So in 1990, when Brian was 20, they placed him at the state-operated Clyde L. Choate Mental Health and Developmental Center in downstate Anna. "It's been a godsend. No other place could address all of Brian's complex needs," Rita says. She adds, "Brian functions at his maximum potential at Choate, has an on-campus job, enjoys his music, interacts with friends — has a real community life."

Choate, with 158 residents, is one of eight large facilities the state of Illinois still operates where Brian and 2,000 others live. But the state, along with many self-proclaimed "advocates," wants to close the facilities, which they call "institutions." As Tony Paulauski, director of the disability group Arc of Illinois recently wrote, "It is imperative that state institutions be closed in Illinois."

Advocates like Paulauski and state bureaucrats make for strange bedfellows. The advocates are motivated by dogma, believing all disabled people can and should live in the "community," while state officials see a way to save money in tough economic times.

"But nobody sees Brian," Rita says. "Choate is not an institution, it is his home in the best sense of the word."

Read Full Editorial

State News

4. Georgia: Lax enforcement in personal care homes

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***The Atlanta Journal-Constitution* * May 22, 2012**

[*Editor's Note*: A Justice Department and Georgia Settlement Agreement call for the displacement of 1,000 residents with profound intellectual and developmental disabilities from Georgia's ICFs/MR by 2015. The Agreement also calls for "community" placement for 10,000 people with mental illness. The Justice Department has hailed Georgia's agreement as the "model." The Court's Independent Reviewer's one-year implementation report and the article below tells a different, but predictable, story].

Deficiencies in care, living conditions and record-keeping have piled up in scores of Georgia personal care homes, with the state rarely shutting down violators or levying heavy fines, The *Atlanta Journal-Constitution* has found.

An analysis of five years' worth of inspections, violations and enforcement actions revealed that many frequent violators have faced nothing more than a fine of a few hundred dollars.

The *Atlanta Journal-Constitution's* investigation found numerous troubling instances — from live cockroaches in the kitchen of one home to another in which eight residents were out of medication.

About half of the state's 2,000 licensed personal care homes are in metro Atlanta, and they provide more than 12,000 beds for some of the region's most fragile residents — those who are disabled, elderly or mentally ill.

Such weak enforcement, advocates say, creates a culture in which unscrupulous operators believe they can game the system.

Read Full Story Here

5. Illinois: Leaving Homes: Plans to close developmental centers provoke fears; "home care workers" recruited on Craigslist

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***Illinois Times* * May 24, 2012 (Excerpts)**

The state wants to close Jacksonville Developmental Center by autumn, the first step in shutting down four of the state's eight institutions for the developmentally disabled during the next three years

"WE ARE IN SEARCH OF PEOPLE WHO WANT TO MAKE A DIFFERENCE IN SOMEONE'S LIFE!" screams a Springfield Craigslist advertisement placed by a company in search of "home care providers" willing to take in developmentally disabled adults and assist with hygiene, cooking, transportation and "life skills" in return for tax-free annual stipends. "We will provide all necessary training and support."

The notion that state employees at institutions could be replaced by care providers recruited on Craigslist frightens some families. "Without melo-dramatizing it, this will mean deaths and imprisonment and homelessness and so on," says Kevin Burke, a member of the Illinois League of Advocates for the Developmentally Disabled, which opposes closing the institutions where folks like his son Brian live. "This plan is reckless. It cannot be emphasized enough how truly radical this is." Four tries at living in the community didn't work for their son, Brian (42), according to Burke and his wife, **Rita Burke [VOR's Illinois State Coordinator]**. He lives at the Choate Developmental Center in Anna

"He would run across the room and break a window, afterward he would say 'Why did I do that?'" Kevin Burke says. "Our son, if you put him in a home like the one behind you across the street, one of these days, he's going to walk out the door and punch someone in the mouth."

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Read Related (Great!) Letter to the Editor Here

6. Virginia families battling Justice Department closure of state institutions for disabled are monitoring funding woes for Fairfax services

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***Washington Post* * May 23, 2012**

"You're going to tell us that the state, which has a historically poor record on funding, is going to move people out into the community? It just isn't credible," said **Peter Kinzler [Chair, VOR Legislative Committee].** He said deepening financial troubles with Fairfax County's Community Services Board only reinforces the argument that people with disabilities could be turned out into a community whose resources for care are inadequate.

On Tuesday, the Fairfax County Board of Supervisors grilled George Braunstein, the Community Services Board’s executive director, over a budget gap projected to widen to nearly $9.5 million in fiscal 2013, which begins July 1.

On May 9, Judge Gibney agreed to allow the families to intervene in the legal case between Virginia and the Justice Department.

The families have also been pushing on the political front. In a March 27 letter to U.S. Attorney General Eric Holder, U.S. Reps. James P. Moran (D-Va.) and Robert W. Goodlatte (R-Va) cited the families’ concerns in objecting to the proposed legal settlement.

Read Full Story Here

7. Pennsylvania: Wilkes-Barre nonprofit group home faces wrongful death suit

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Citizen’s Voice *** May 18, 2012**

The staff at the home - operated by the Wilkes-Barre nonprofit Step-by-Step Inc. - "knew full well" of Popple's habit of forcing large amounts of food into his mouth, his history of choking, and his propensity to "wander aimlessly" without supervision, according to a lawsuit his brother filed Thursday in Luzerne County Court.

Yet, despite those warning signs, the staff at the facility failed to take the required steps to ensure Popple's "health, safety and welfare" - to ensure that his habit wouldn't kill him - the lawsuit says.

Read Full Story Here

8. New York: Reform efforts continue

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According to the Governor’s website supporting his reform proposal: “The Justice Center for the Protection of People with Special Needs will transform how our state protects over one million New Yorkers under the care or jurisdiction of six state agencies.”

9. South Carolina: 'Client H' death investigation raises more troubling questions for South Carolina’s Disabilities and Special Needs Division

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Did Disabilities and Special Needs violations contribute to the death of a Greenville group home resident?

Greenville County Disabilities and Special Needs has been cited by state officials for violating the standard of care in the Feb. 11 death of Heather Dawn Worchester Lemon, 36, a resident at one

of the agency's group homes.
Read More.

10. Massachusetts: Saving the Glavin Center comes down to one man

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COFAR Blog (by David Kassel) * May 21, 2012

The Dumonts are desperate to keep Glavin open for their self-injurous son, Stephen. No community-based group home would keep or accept him as a resident. The fate of Glavin center rests with one man — State Senator Stephen Brewer of Barre.

Under the Legislature's current budget process, it is totally up to Brewer whether to approve a state budget amendment that would require an independent cost analysis before the Department of Developmental Services can move more people out of Glavin and subsequently close the center.

Read Full Story

11. Connecticut: Southbury Training School Fulfills a role

***Republican American* (Editorial) * May 17, 2012**

Over the last several decades, an ideology that emphasizes privatizing services for intellectually disabled citizens has taken hold in Connecticut. Gov. Dannel P. Malloy appears inclined to keep this trend alive.

Soon after taking office last year, he nominated Terrence Macy, a longtime privatization champion, to be commissioner of the Department of Developmental Services. The administration's zeal for privatization could spell disaster for Southbury Training School (STS) residents and their families.

One problem with this approach, as noted in our Jan. 5 editorial "Privatization: Don't be hasty," is that many STS residents have lived there for decades. Total privatization would be extremely disruptive to them and their families, and many would not receive the services they need outside the state system.

The Southbury Training School Home and School Association, founded in 1949 to ensure STS residents have the best possible quality of life, agrees. In a Dec. 6, 2011 letter to members of the PRI Committee, David Kassel, the association's communications director, said it would be difficult for STS residents to obtain the same level of care in a private setting that they have come to expect at the training school. Also, in concluding STS is more expensive than private facilities, the committee relied on an incomplete comparison of services, he said.

May 7, Mr. Kassel reiterated these points to the *Republican-American's* editorial board. He was accompanied by **Hugo**

Dwyer [VOR State Coordinator] and Barb Hirsch, family members of two of the 404 STS residents.

They affirmed that their loved ones, longtime STS residents, receive excellent care at the facility and enjoy a good quality of life.

In tough fiscal times, it’s imperative that state government review the cost and efficiency of longtime practices like the training-school operation. Still, state leaders should not act without assurance that changes would elicit real savings. Also, disrupting the lives of Connecticut’s most vulnerable citizens would be heartless, even cruel.

Prudence and compassion therefore demand that the training school remain open for the foreseeable future.

Read Full Editorial

REMINDER:

Next Weekly News Update: Friday, June 22, 2012

Tel: (605) 399-1624
Toll Free: (877) 399-4867
Fax: (605) 399-1631
Email: info@vor.net

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VOR
836 S. Arlington Heights Rd.
#351
Elk Grove Village, Illinois 60007
US