Click to view this email in a browser

Speaking out for people with intellectual & developmental disabilities

www.vor.net

/VOR

@VOR_NET

info@vor.net

Reminders: Help VOR Grow!

Make a Lasting Impact with a Will Bequest

July 5, 2013

VOR Weekly News Update

News and views for VOR Advocates

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!

Table of Contents

VOR.net:
Your one-stop
advocacy
resource

Calendar Reminders

Coming Up: State of the States in Background Checks

VOR and You

1. Reminder: SAVE THE DATE: VOR SOCIAL MEDIA WEBINAR: An overview of Twitter and Facebook, Wednesday, July 17, 2013 - 12:00 pm central / 1:00 pm eastern

----

Mark your calendars! Registration details coming very soon.

2. New Blog! The Real Choices in Care Blog has been launched

David Kassel has launched "The Real Choices in Care Blog" - a project in conjunction with the VOR and the Massachusetts Coalition of Families and Advocates (COFAR, Inc.).

The blogsite reports on issues affecting people with developmental disabilities around the country.

"I hope to bring a critical perspective and investigative scrutiny to the ongoing closures of developmental centers and the privatization of services nationwide," said Kassel. "I also hope to report on success stories regarding the preservation of the continuum of care."

Comments to posts on the blogsite and suggestions for future research and posts are greatly appreciated. You can also click on the "Follow" link on the home page to receive notifications of future posts.

"I hope readers will find this site interesting and helpful," said Kassel.

VOR, a national advocacy organization, and COFAR both support a full continuum of care, from community-based to state-operated services. Kassel is a former journalist and analyst with the Massachusetts Inspector General's Office. He is currently a

Reminders:

Help VOR Grow!

Make a Lasting Impact with a Will Bequest

VOR.net: Your one-stop advocacy resource

communications and policy consultant to COFAR and other nonprofit organizations. He is the author of “Managing Public Sector Projects,” published by CRC Press.

Visit the blog at http://realcarechoices.com/

Great Story Submission

3. Washington State: Our Son Forrest

Rebecca Sargent * May 2013

Our son is at Fircrest, an Residential Habilitation Center (RHC; ICF/IID). Our son’s life was literally saved by Fircrest. Our story is one you should listen to, because there are thousands of people like our son who are entering the system and many of them will need the services that the RHCs offer which cannot be met ‘in the community’.

A year ago our son, Forrest, was 18 years old and 6’2” we were getting attacked more and more as were his teachers and group home staff. He was scratching and biting intensely.

He sent 3 people to the emergency room.

Read more

State News

4. Massachusetts: At Nation's Oldest Institution for the Disabled, 13 Lives in Limbo

----

***Wall Street Journal* (Clare Ansberry) * June 28, 2013**

WALTHAM, Mass.—Michael Martin is 51 years old, but because of brain damage he lives his days like a very young and anxious child, prone to violent outbursts. He is learning to fold towels.

Yet his abilities tower over a longtime neighbor, Teresa Kacinski, who can't walk, talk, see, feed herself or change positions. With help, she can strike a key on a toy piano.

They are among the 13 remaining residents of the Fernald Developmental Center, the oldest state-run institution in the U.S. for people with developmental and intellectual disabilities. Fernald once housed thousands of men, women and children who have since joined the slow exodus from large public institutions that advocates of those with disabilities initiated decades ago.

Massachusetts wants to move the last residents from Fernald and sell the 186-acre property. But their families want them to stay, saying Fernald's experienced caregivers and familiar surroundings are irreplaceable. The matter has gone to court.

About 30,000 people remain in 160 state-operated facilities in the U.S., including many who face similar dislocations. Like those at Fernald, they tend to be older, with complex physical and psychological needs. Many require one-on-one care.

Families say uprooting people with such limited coping skills is too traumatic. State authorities say smaller settings are better than larger public facilities; they cite thousands of successful transfers.

What is different about Fernald is that its residents have legal rights others don't. In a class-action suit, they were awarded in 1993 a guaranteed level of care, regardless of cost, to compensate for decades of abuse and neglect.

Read more

Related article: Spending on the Disabled Falls for First Time in Decades (*Wall Street Journal*, June 28, 2013)

5. California: Task Force deciding fate of developmental centers; Process feels rushed to some

---

***The Kenwood Press* * July 1, 2013**

The state’s Task Force on the Future of Developmental Centers has held its first meeting since its formation was announced on May 22. Members learned at the all-day convocation that there will be three more meetings and that they will be expected to provide a complete outline for the state to continue care for residents displaced when the remaining centers catering to the developmentally disabled are shuttered.

The Task Force numbers 21 people from organizations and institutions affected by the closures, including parents of clients, consumers, consumer advocates, regional centers, community center advocates, members of the legislature, and staff from the Department of Developmental Services, a division of the state health department that directly oversees developmental centers.

California Health and Human Services (CHHS) Secretary Diana Dooley announced the formation of a task force on the future of developmental centers – including Sonoma Developmental Center – in May. The task force is charged with producing a “written master plan that addresses (1) the effective and efficient delivery of integrated services to meet the specialty needs of developmental center residents; and (2) the fiscal implications of developmental center operations, including the cost of resident care and services, maintenance of aging infrastructure, and utilization of existing resources.”

Just how this large group will accomplish all this by Nov. 14, still isn’t clear, according to some task force members.

“The concern I expressed to Secretary Dooley is what we can accomplish in four meetings,” Kathleen Miller said. “There are people on both sides of the fence who won’t necessarily agree. I don’t feel like that question has been answered.”

Miller, whose son has been an SDC resident for many years, is president of the Parent Hospital Association and is a strong advocate for keeping at least some parts of the developmental center functioning to serve the most severely disabled residents.

Task force members were provided some data and a copy of a 2002 report on possible alternatives to developmental centers. While the report suggests many options, it does not resolve issues raised by often conflicting ideas.

Connie Lapin of Northridge has a 45-year-old son who has extreme autism, but who is able to live on his own with support from various community and state programs, something Connie and her husband fought for many years to achieve. An outspoken champion of community living for developmentally disabled, she has questions about the best way to manage the most severely disabled.

"I used to say 'No, developmental centers aren't useful.' Many of the individuals still in developmental centers could be in the community, but others I can't speak for with authority any more. I don't know what to do with the forensic and duly diagnosed," Lapin said, referring to people with major mental illnesses.

"I know families, developmental center parents and siblings," Lapin said. "We both want the same thing and I don't want us pitted against each other."

Read more

The information provided to task force members is available **online**, including the 2002 report on alternatives to developmental centers and other useful information.

6. New Jersey: Battle on to keep state from shutting center for disabled

---

***Observer-Tribune* (Mendham, NJ) * June 28, 2013**

Peter Banos of Ironia Road is struggling against the state government to make sure his disabled sister, Joyce, and hundreds of other disabled New Jerseyans do not get displaced from the center many of them have called home for decades.

Banos is a member of the Woodbridge Developmental Center Parents Association, the group that speaks for the roughly 330 disabled Woodbridge residents who can not speak for themselves.

Banos's sister, Joyce, is one of the residents. At 54, she has lived at the Woodbridge center since she was 14, and she has neither spoken nor stood up in years. Now, 40 years after she first moved to Woodbridge, Peter Banos and several others are standing up for her.

Mr. Banos and the families of the residents of the Woodbridge and North Jersey Developmental Centers have filed a lawsuit against the state insisting that the state reverse its decision to close the centers within the next two years in order to lower state spending.

The suit alleges that the task force dedicated to assessing the centers under Gov. Chris Christie was biased and its study was rushed and illegitimate.

Read more

Related News: Billboard posted opposing developmental disabilities centers' closures (*PolitickerNJ* * June 27, 2013). **Click here for a picture of the Billboard.**

Special Education Legal Update

7. Doug C. v. Hawaii: Critical Questions Answered about Parent Involvement in IEP Meetings

---

***WrightsLaw* * July 1, 2013**

The Court held it was not reasonable for the Department of Education to prioritize strict deadline compliance over parent participation at the Individual Education Plan (IEP) meeting. Parent attendance at the IEP meeting must take priority over the attendance of others.

Read the Analysis of Doug C. v Hawaii by Pete and Pam Wright.

Federal Update

8. The Long-Term Care Commission's First Meeting

Capitol Insider * July 1, 2013

The Long-Term Care Commission had its first meeting on Thursday, June 27. The Chair, Bruce Chernof of the SCAN Foundation, said that the commission would send recommendations to Congress by the end of September on a long-term-care system overhaul. The 15-member group was created by the American Taxpayer Relief Act of 2012, which repealed the CLASS Act program for a voluntary long term services and supports insurance program supported by premium payments. Chairman Chernof said that the Commission would launch a website soon because the Commission wants its deliberations to be transparent.

==================================

Calendar Reminders:

***SAVE THE DATE: VOR SOCIAL MEDIA WEBINAR:An overview of Twitter and Facebook, Wednesday, July 17, 2013 - 12:00 pm central / 1:00 pm eastern. Cost: Free. Registration details coming soon.**

*** Recorded - Listen Here. Tuesday, April 23, 2013 - 12:00 pm central / 1:00 pm eastern**

FREE WEBINAR: How Congress Works: The Basics. Hosted by Peter Kinzler and Larry Innis.

*** Sunday, June 9, 2013**

VOR Annual Conference * Washington, D.C. Registration 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.

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

JOIN VOR. DONATE TO VOR. MAKE A DIFFERENCE

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