

There will be no Weekly Update on Friday, November 27.

Happy Thanksgiving!

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VOR Weekly E-Mail Update
November 20, 2009

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VOR Membership and Contribution Form
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STATE NEWS

1. VOR's Abuse and Neglect document updated

See, <http://vor.net/get-help/toolkit-for-families/quality-of-care-abuse-and-neglect-in-community-settings> (November 19, 2009)

VOR's Abuse and Neglect in Community Settings document provides a bibliography of investigative media series, state audits and peer-reviewed research in more than half the states that detail systemic concerns with regard to quality of care in community-based settings for persons with developmental disabilities. Tragedies range from physical, emotional, and financial abuse, neglect and even death. Many of these outcomes are associated with a zest to move to a "community for all" vision people with developmental disabilities without adequately considering the ramifications of separating vulnerable people from specialized care and then

doing away with a critical safety net (a/k/a deinstitutionalization). The lessons learned from more than 25 states should cause policymakers and lawmakers to take pause and recognize that a range of needs requires a range of service options.

2. NEBRASKA: Beatrice report draws fire

Related News/ Breaking News: According to a Nebraska Radio Network report on November 18, 2009, a 10th person has died from among the 47 "medically fragile" residents who were moved from the Beatrice State Developmental Center last February. Brady Kruse, 35 years old, is the latest victim. He had resided at Beatrice for 33 years before he was moved.

Beatrice Report Draws Fire Lincoln Journal-Star (NE) 10/23/2009

The third report from an independent expert on progress at the Beatrice State Developmental Center drew strong criticism from the state's top administrator for developmental disabilities. The report by John McGee, required by a court settlement, contains inaccurate statistics and information, said Jodi Fenner, director of the state Department of Health and Human Services' Division of Developmental Disabilities.

In the 42-page report, McGee praises some progress made at BSDC but is critical of the center's continued use of restraints, the high death rate of former residents and the use of nursing homes.

Fenner said some of the criticism is unfair and not based on accurate information.

"I don't know if the man can read," she said in a telephone interview Thursday. "We are dealing with consistent inaccuracies, and I'm a little fed up."

McGee criticized the state's progress in reducing the use of restraints at BSDC, although staff members have reduced their use by more than 50 percent, Fenner said.

Statistical information on the death of BSDC residents also is incorrect, she said, even though staff members have worked with McGee to correct data on his spreadsheet.

Staff members repeatedly have given McGee correct information, she said.

"I don't know what else to do."

McGee, an expert in developmental disabilities from Omaha, did not respond to a request for comment.

He is required to report quarterly on progress at BSDC under a 2008 settlement between the state and the U.S. Department of Justice over inadequate care at the institution for people with developmental disabilities.

The settlement requires improved care at BSDC and that more people be moved from the institution into local communities.

Fenner took exception with some of McGee's comments about efforts to move people into programs provided by local communities.

McGee's description of a specific case -- placement of a BSDC resident in a private home -- was not accurate and unfairly blamed the BSDC transition staff for problems the family had, Fenner said.

"It was heartbreaking. We worked very, very hard to put all the protections in place," she said.

McGee's description of the family as "caring and well intended" and his assessment that the state was to blame "is inaccurate," she said.

The family received training but did not live up to its contract, she said.

Instead, they dropped off the former BSDC client at a local hospital, she said.

The report "was not respectful of my staff, who worked very hard to make sure this individual had options," she said.

Fenner said McGee also violated the settlement agreement because he did not provide Health and Human Services with a draft of the report so the state could point out inaccuracies before he gave the final report to the court, Fenner said.

Health and Human Services has reported its concerns to the judge handling the BSDC settlement and will provide the court and the public with its own report to correct inaccuracies, Fenner said.

The state has sent \$294,434.48 to the court for payment to McGee, who uses a team of experts to follow progress at the institution and of people moved into the community.

"This is a lot of taxpayers' money to spend," Fenner said. "We don't want to waste taxpayers' money for information that isn't accurate."

BSDC staff members have received valuable information from experts on McGee's team, particularly on the community transition process, she said. But a "significant amount of the report is grossly inaccurate," she said.

In addition to the criticism, McGee's report also praised progress at BSDC, including:

- * State support of a campaign to recruit pro-active guardians.
- * State leadership in getting special group homes built to serve people with serious medical issues.

* Initial steps to increase support for people in nursing homes.

3. NEBRASKA: Care providers claim state hypocrisy

By NATE JENKINS (AP)
November 9, 2009

LINCOLN, Neb. - Pay at some state-funded programs where people with mental disabilities are cared for in Nebraska is so low that McDonald's workers make a higher hourly wage.

"Why would you work here?" said Linda Redfern, director of the Scottsbluff-based Region I Office of Human Development. Overseen by elected county officials, the office provides day and round-the-clock residential services to 190 people in 11 Panhandle counties.

Redfern and others across the state who help people with developmental disabilities likely won't have a better answer to that question again next year if Gov. Dave Heineman's budget-cutting plan is approved by lawmakers. Those who care for the developmentally disabled say his plan to ax previously approved, state-funded pay hikes next year for people who care for people with mental disabilities could keep them from expanding at the same time state officials say they want to move more people out of institutions and into the programs.

The plan is part of his wide-ranging proposal to shave \$334 million from the two-year state budget over the next couple weeks during a special legislative session called to respond to drooping state revenues.

"It's such an ironic set of circumstances. If we weren't in the middle of it all, it would be unbelievable," said Alan Zavodny, CEO of Northstar Services, which provides services to about 300 developmentally disabled people in 22 northeastern Nebraska counties.

"At the same time community-based programs are falling behind, we're talking about increasing the number of people in the community." Northstar now serves about 300 people and he said it's likely fewer will be served next year.

Zavodny, president of a state association of organizations that serve the mentally disabled, predicted some would go out of business if Heineman's plan is approved.

State officials strongly disagree and say they expect capacity at the programs will actually increase even if providers like Zavodny don't get an increase in state funds next year to boost employee pay. State-funded pay hikes that went into effect this year and that Heineman's proposal won't change allowed Redfern, for example, to increase starting wages to \$9 an hour from \$8.30 an hour.

"I'm not buying that at all," Jodi Fenner, director of the state's developmental disabilities division, said of claims that nixing the previously planned pay increases for next year would shutter some organizations. "I agree it's a financial hardship, but am I afraid we'll lose capacity? I don't think so."

Fenner said that the stream of money that follows mentally disabled people into community-based programs where they get job training and more interaction with the general public is not being disrupted under Heineman's plan. Flat funding for employee pay, she said, may narrow the profit margins of businesses such as Zavodny's, but shouldn't limit their ability to expand. Also, Heineman's plan doesn't attempt to take any of the \$10 million lawmakers set aside early this year to help reduce a waiting list of mentally disabled people wanting services.

Lawmakers set aside the money after attempts to improve the Beatrice State Developmental Center, where hundreds of cases of alleged abuse and neglect of mentally disabled residents were reported in 2006 and 2007, drew attention to the waiting list of about 2,000 people.

As of Nov. 6, 1,717 people were on the waiting list. State officials say some people on the list are already receiving services but have requested additional services.

4. MASSACHUSETTS: Was Disabled Man Abused At Group Home?

Kathy Curran
I-Team WBZ (Boston)
November 13, 2009

Several state agencies and the Middlesex District Attorney's office are investigating disturbing allegations of abuse and neglect at a group home.

Danny Butler was found with bruises all over his body, black eyes and broken bones while in the care of a group home licensed by the state.

"He has down syndrome, he's lovable, he never had an enemy in the world until this," said brother Ed Butler.

But what happened and who's responsible are still unanswered questions that haunt Danny Butler's family.

The 61-year old was living at a group home in Dracut, a home managed by the Mental Health Association of Greater Lowell and licensed by the former Department of Mental Retardation.

On July 23rd, Danny was rushed to Lowell General Hospital because he was in respiratory distress.

Dracut Police weren't notified about Daniel Butler's injuries until he began having difficulty breathing and ended up in the hospital. That's when doctors and family members discovered all of the bruises and broken bones and called police.

Medical records show Danny Butler had multiple bruises, facial injuries, emotional trauma and possible sexual abuse.

Nancy Alterio, the head of the Disabled Persons Protection Commission says her agency had four allegations of abuse with this one victim.

According to reports obtained by the I-Team, one person at the group home said Danny fell out of bed, another said he pulled some dresser drawers onto his face.

One major problem with this investigation is that Danny Butler has been silenced by the trauma. Ed Butler says right now Danny can't communicate beyond yes or no, and as soon as the sun goes down he gets agitated and restless and he's very afraid.

Nancy Alterio said a lot of things can make it difficult to prove a case. When you don't have forensic evidence or testimony from victims or witnesses it's difficult to determine what actually did or didn't happen.

The Middlesex District Attorney's Office issued this statement:

"The victim in this case was in a vulnerable situation and suffered highly disturbing injuries. We are conducting an active investigation into what caused these injuries, who may be responsible and whether crimes were committed."

"It's tearing me apart. I don't know how many times I've cried up there watching him lay in bed. I don't want to see him hurt again and I don't want to see anyone hurt again," said Ed Butler.

All of the people involved in Danny's care and the residents at the group home are part of this investigation.

Danny Butler is currently at Tewksbury State Hospital recovering from his injuries.

A spokesperson for the Department of Developmental Services, formerly known as the Department of Mental Retardation, tells us the department has zero tolerance for abuse and if a case of abuse is found at a group home, the license is reviewed and steps are taken to make sure it doesn't happen again.

The head of the Mental Health Association of Greater Lowell said his organization is cooperating with the investigation.

5. KANSAS: Legislators wary of KNI closure

The Topeka Capital-Journal
November 12, 2009

Three House Republicans questioned Thursday whether the state would save money by closing Kansas Neurological Institute in Topeka and moving disabled residents of the facility to community housing or a state hospital in Parsons.

Reps. Lana Gordon and Joe Patton, both of Topeka, and Rep. Rocky Fund, R-Hoyt, met with staff and residents in response to a recommendation by the Kansas Facilities Closure and

Realignment Commission to shut down the Topeka complex and transfer the 150 residents to smaller living units or Parsons State Hospital.

The proposal is designed to save money and conform with a philosophy of placing people in the "least restrictive" environment. Gov. Mark Parkinson hasn't spoken publicly about his view on KNI other than to express deference to work of state commissions.

Patton said he wasn't convinced the state would save money by locking the doors at KNI following a two- or three-year transition.

"It looks like it may not be a cost savings as much as a cost shifting," Patton said.

In addition, he said, there was no guarantee services provided people with disabilities at KNI could be replicated elsewhere. State officials say 90 percent of KNI residents have profound intellectual disabilities. Two-thirds cannot walk, while four of five cannot speak.

Patton said more than 130 residents at KNI are employed part-time on the Topeka campus and all have access to specialized technical and medical assistance.

"That would, I think, be very hard to duplicate," he said.

Democrats in the Topeka legislative delegation have also expressed reservations about the commission's recommendation regarding KNI.

6. WASHINGTON DC: District Suspends Referrals To Nonprofit's Group Homes; City Took Agency to Court This Week Over Safety Concerns

By Henri E. Cauvin and Nikita Stewart
Washington Post Staff Writers
Thursday, October 8, 2009

The District is halting new referrals to all group homes operated by a nonprofit organization that the city took to court this week over health and safety concerns at two of its homes for the mentally disabled.

The nonprofit organization, Individual Development Inc., operates 11 facilities in the District. The city's latest move is a sign that its concerns go beyond the two homes that the city has petitioned to be taken over by a court-appointed receiver.

Laura L. Nuss, head of the city's Developmental Disabilities Administration, delivered the news in a letter sent Tuesday to IDI's president and chairman, David W. Wilmot.

"DDA takes this action as a result of on-going concerns related to the systemic problems experienced by IDI in delivering adequate health care services and ensuring persons are protected from harm," Nuss wrote.

Wilmot is an influential figure in D.C. politics, as are two other members of the IDI board, Frederick D. Cooke Jr. and A. Scott Bolden.

"We received the letter. We're reviewing it, and we will respond accordingly to the city's concerns," said Bolden, who is serving as the nonprofit group's counsel.

Bolden has said that IDI provided nothing less than high-quality care to its clients and that it was not responsible for any abuse or neglect.

Advocates for the mentally disabled, health inspectors for the District and the federal court monitor in a class-action lawsuit have been raising questions for years about the quality of care at IDI facilities.

After one woman recently lost 26 pounds in a month, the advocacy group University Legal Services expressed concern, and the court monitor urged the District to seek a receiver for IDI's group homes on 53rd Street SE and Edson Place NE.

The District did that in a filing Monday in D.C. Superior Court, and in an accompanying report, the court monitor, Elizabeth Jones, catalogued a pattern of problems at the two homes, which are licensed to care for up to 16 residents.

In the report, which was filed under seal but summarized in the government's complaint, the monitor cites three deaths at the 53rd Street and Edson Place homes as among her concerns.

Independent investigations of two of the deaths by a consultant found significant deficiencies in the health care provided to two women at the IDI homes. The investigation of the third death is underway.

One case involved a 57-year-old woman who died in November of a urine-related infection and pneumonia, according to the investigation report, which was obtained under the Freedom of Information Act.

Investigators wrote that although "it would difficult to determine whether this death was preventable, problems were identified related to the decedent's health care management. Overall, health care did not appear to be comprehensive and coordinated, especially in regard to the decedent's history of recurrent urinary tract infections and psychotropic medication usage."

The other case involved a 57-year-old woman who had a misplaced feeding tube and died in January 2007, apparently of an infection, according to a report. The death was not preventable, the report says, but "it appeared that the misplaced feeding tube may have been a factor in the development of this scenario and her subsequent demise."

Bolden said Wednesday night that the deaths in questions were natural and that the D.C. government cannot now try to "rewrite history."

7. RESEARCH: First National Study on Crime Against Persons with Disabilities

Young and middle-age persons with disabilities experienced violence at nearly twice the rate as persons of the same age without a disability concluded a study released by the U.S. Department of Justice. Yet, the rate of violence did not differ by disability status for persons age 50 or older and persons age 65 or older, with or without a disability, had the lowest rates of violent crime, the study concludes. (DOJ, October 2009).

VOR and YOU

8. Give the Gift of a VOR Membership this Season!

A VOR membership make a great Holiday Gift. Membership is only \$25 per year. See <http://www.vor.net/giving/join/online-membership-form> for details and a membership form.

VOR is the only national advocacy organization that expressly opposes efforts to eliminate the facility option while also supporting expansion of quality community programs.

VOR advocates that final determination of what is appropriate depends on the unique abilities, needs and desires of each individual, with the input of family guardians where necessary and appropriate.

Editor: Tamie Hopp, VOR Director of Government Relations & Advocacy

THANK YOU FOR YOUR SUPPORT!

TO JOIN OR CONTRIBUTE: \$25 per individual, \$150 per family organization, or \$200 per provider/professional organization. Extra donations are welcome!

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