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VOR Weekly E-Mail Update
February 27, 2009

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BREAKING VOR NEWS

1. VOR Files Amicus in Fernald case

On February 25, 2009, VOR filed an Amicus Curiae ("friend of the court") brief, in support of the Fernald League's Petition to the U.S. Supreme Court.
Consistent with the Fernald League's petition, VOR called on the Supreme Court to review the First Circuit decision in the Ricci class action, pointing to the significant divide among federal appellate courts with regard to an appropriate standard of review. VOR argued that the District Court should have been afforded far more deference given the District Court Judge's active management of the case for more than 35 years. VOR also argued that "the policy concerns influencing the decision below rest upon an erroneous reading of this Court's decision in Olmstead."

STATE NEWS

2. TEXAS: This is where my daughter lives

About the author: Jacque Beavers of China Spring is a retired Realtor. [She is also a VOR member].

By Jacque Beavers, Guest Column
Waco Tribune
Sunday, February 08, 2009

It was 1992. A six-mile long caravan of 6,000 supporters traveled on 38 Greyhound buses and in private vehicles to Austin to protest the possible closure of Mexia State School.

We'd collected almost \$38,000 in three weeks to provide expenses for those traveling - families and friends who believed the Mexia State School was necessary.

As the Parents Association President for the Mexia school, I was one of 12 people who spoke on the State Capitol grounds on a windy day in April.

The event captured the attention of the national media. Our group was too large to be allowed in the Capitol building. The tension was high. The stakes were higher.

Our retarded family members were about to lose their home and school. We had no place for our children to live.

Gov. Ann Richards wanted to convert Mexia State School to an alcohol rehabilitation center. She left Austin before the caravan arrived for a too-convenient obligation in California.

She explained later that she had "pressing business" there. I think we were the pressing business she wanted to avoid.

We won our battle to keep the school open. Now we are girding up for another battle, with certain groups calling for the dismantling of state schools and certain elected officials receptive to the idea.

Again, we are going to fight it.

Mexia State School is an intermediate care facility for the mentally retarded, established in 1946. The 215-acre campus has 1,400 dedicated employees caring for more than 500 clients.

Some groups believe that community homes are the best solution for caring for the retarded and that state schools should be closed.

This approach disregards the various levels of mental retardation addressed by schools such as where my daughter lives.

About 80 percent of the approximately 4,700 residents living in state schools in Texas are severely to profoundly retarded (between the IQs of 34 and zero).

They can't care for themselves.

Right now the guardian of a retarded individual can choose between state schools and community homes. If the state schools were closed, where could I place my child?

My husband and I agree that community homes should be the No. 1 option for the retarded person who is able to provide most of the care for him or herself and does not need 24/7 care.

To those who have severe to profound retardation and need constant supervision, add the population that is less mentally retarded but has mental health problems.

My daughter Julie, who is 44, is profoundly retarded. She has an IQ of 17. She was born a normal baby, but was severely disabled at 10 months by an adverse reaction to a smallpox injection. In addition to her retardation, she has developed an inoperable brain tumor.

Having her condition doesn't mean being left in bed all day. She is dressed, bathed, fed, and schooled in special programs geared to her abilities, as are other profoundly retarded clients.

She must be lifted in and out of her wheelchair with a special harness and mechanical lift device every time she needs to be transferred from one activity to another such as being bathed, having physical therapy in a pool and getting in and out of bed.

Most of the wheelchairs for people like my daughter have special features for handling them. Some are two times larger than the standard wheelchair. The rooms and hallways in a community-based residence would need to be sized to accommodate the larger wheelchairs and the special lifting equipment.

As for less mentally retarded individuals who have mental health problems, they should not be placed in community homes because of safety concerns for the other home residents.

Caregivers for these individuals are given special training. The Legislature directed state schools to care for the retarded with mental health problems on a 24/7 basis.

Care for retarded persons presents issues and problems that only a family member or a state employee fully understands.

Concerns have been raised about the welfare of residents at state schools. I can vouch for my own daughter that she is in the best of hands.

State schools are tightly supervised by the Department of Aging and Disabilities, as well as the federal government.

Community-based residences, by contrast, are not so closely overseen. Hence, incidents that might not get reported at those venues would draw major scrutiny at state schools.

That's why you will never read the abuse, neglect and deaths of mentally retarded clients in community homes as you do about state schools.

Severely and profoundly retarded clients are medically fragile. Most cannot describe symptoms to medical personnel. Inaccurate diagnoses can lead to possible death.

Julie has lived at Mexia State School since 1976. Someone must diaper, bathe, dress, feed, and care for her every need.

Julie must be moved by two employees using a harness and mechanical lift device from her bed to the bath, dining room, and to her very large wheelchair many times daily.

Could you care for a person in this condition? I cared for Julie for 12 years. The task got so overwhelming I could no longer do it.

The best place for my daughter is the place where she now resides. Send your letters in support of the state schools to Jacque Beavers, 264 Emily Lane, Waco 76708.

Our helpless citizens need your support.

3. NEBRASKA: Our view: You can't hide a black eye (address the problems, save the center)

Related update: 47 medically fragile Beatrice residents were hastily removed from Beatrice Developmental Center and taken to hospitals earlier this month after Nebraska's chief medical officer deemed the Beatrice home unable to care for its neediest residents. Since these forcible transfers, two former residents have died, and another is in intensive care. Patty McGill Smith of Omaha, past president of the Arc of Nebraska, said that the way the move was done puts residents at greater risk of dying and is creating unnecessary stress for families. "Change is very difficult for people with developmental disabilities," she said. "It isn't fair to move people so fast. The state could have made a better plan, and they could have acted earlier." But the state official who ordered the transfers stood by the state's handling of the moves, saying they were necessary for the safety of residents with serious health complications. Dr. Joann Schaefer, Nebraska's chief medical officer, said a transferred resident who died Saturday at BryanLGH Medical Center West was in the right place to get the best medical care. "A death does not mean anything was done wrong but underlines the importance of why residents need to be in the proper placement to deal with a complication," Schaefer said. (Source: Omaha World Herald, Feb. 24, 2009).

Our view: You can't hide a black eye (address the problems, save the center)

Beatrice Daily Sun
Editorial
Tuesday, Feb. 24, 2009

This past week saw more allegations of neglect made against the troubled Beatrice State Developmental Center.

Make no mistake, the center is troubled.

Hundreds of allegations of abuse and neglect have been reported at the center over the last few years, it has repeatedly run afoul of federal standards, and is expected to lose about \$29 million in annual, federal funding.

That fact isn't an indictment of all BSDC employees, who have unfortunately become collateral damage amid a whirlwind of chaotic developments.

Now, just two weeks after state officials ordered 45 "medically fragile" people moved out of the center, the inevitable flood of lawsuits has started. Three such cases are now in motion.

If nothing else, the lawsuits will surely result in a number of additional media reports, be it on TV, radio and in newspapers.

While we understand many in the community would rather not see those reports, they are justified, necessary and real.

Ignoring the problem will not make it go away.

In the Beatrice Daily Sun alone, dozens of stories relating to BSDC have been published in the past couple months. The stories have resulted in a variety of calls and letters, from those wishing to see more coverage, those appalled that we continue publishing "negative" stories about BSDC and several from BSDC employees who refuse to leave their names for fear of retaliation, but assure us that the majority of BSDC staff does truly care for residents of the center.

Caring for the state's most severely developmentally disabled is no easy task, but employees at the Beatrice center have done it for many decades. And up until recently, the center has been nothing short of a Godsend for many residents who call the center home, and their family members who can rest easy at night knowing their loved ones are cared for by compassionate and knowledgeable professionals.

Talk to most BSDC employees and you'll quickly realize the compassion remains, despite the center's well documented problems.

And most of the employees who have called or written to us have the right attitude. They realize there is no changing or making light of the recent allegations and obvious failures at BSDC.

All that can be done now is to move forward.

An interim CEO has been named while a nationwide search continues for a new permanent leader. Gov. Dave Heineman has vowed to do all he can to keep the center open, even if it means using state funding for two years until BSDC can be recertified to win back its federal funding.

That's good news, and we can only hope the legislature will follow suit and realize the center's importance.

With the proper leadership, training and resources, we remain positive there is hope for BSDC.

The problems are severe, and we don't condone or make light of the recent allegations.

At the same time, we remain optimistic that BSDC, and our entire community, can recover and remain the very best option for the state's developmentally disabled.

The path to betterment may be long and arduous. There will likely be more setbacks along the way, but we refuse to give up on BSDC.

If for no other reason, we continue to support BSDC on behalf of its approximately 200 clients who have no better place to go.

To them, it's not the "troubled Beatrice State Developmental Center," it's simply home.

And we hope it stays that way for many years to come.

4. NEW JERSEY: Funds lacking, operator of group homes leaves

APP.Com
By ZACH PATBERG
STAFF WRITER
February 24, 2009

Outside a ranch house in Howell, Tom Prendeville jiggled the loose railing of a sloping weather-bruised deck that had been condemned since January. Inside, he pointed to dents in the unpainted hallway wall probably made by someone's forehead a year ago. Then he introduced George Nyangena, the group home's assistant manager, who revealed a warped kitchen floor that had caused the cabinets under the sink to split from the counter and expose the plumbing.

"We're supposed to teach them how to wash dishes and wash their hands, but we're afraid because (the area) is unstable. How can you take care of them if things are falling apart?" Nyangena said, referring to the five severely handicapped residents in the house.

Soon Prendeville, then-contractor for DSNJ, moved on. He was determined to show that the state, through funding shortages, had allowed these 11 homes for the disabled, in Ocean and Monmouth counties, to languish, and in doing so forced their caretaker, Developmental Services of New Jersey, to quit.

There was a living room in Long Branch with no furniture, a hole in the wallboard from a leaking roof in Manalapan and bathrooms and doorways in the homes waiting for years to be made handicapped accessible.

Whether the fundraising advocate for the 60 residents and their families proved his case - that such sub-par conditions should spur the state to boost DSNJ's budget - is open to debate. Along with their inadequacies, the homes have merit in their quiet streets, big back yards, leather sofas and flat-screen televisions.

But at this point, the effort is more about principle than self-preservation. Within two months of DSNJ announcing it would stop operations March 7 after 37 years because of "archaic, inequitable and inconsistent" reimbursements, the state Division of Developmental Disabilities solicited four other agencies to take its place. DSNJ later suggested it could stay for another \$235,000 on top of its \$5.3 million annual budget, but it was too late. So, the agency in its last days, has decided to expose the consequence of inadequate funding.

"We could've struggled on, but the reason we're doing this is because, frankly, just keeping quiet and letting it go on year after year isn't going to change things," Martin Lampner, DSNJ's chief administrative officer, said in a recent interview. "This is a form of advocacy to get it out there that this is a system teetering on collapse."

Other advocates for the disabled agree the group-home network is cash-starved. But blame, they say, stretches beyond the Division of Developmental Disabilities, which has seen substantial cuts to its \$1.35 billion budget.

Some see the answer in eliminating most of New Jersey's seven developmental institutions and redirecting that funding - roughly \$223,000 a year per resident - toward group homes, where the cost is slashed by almost half.

Assemblyman Louis Greenwald, D-Camden, who recently introduced a bill to close five of the institutions, said there are enough group homes to accommodate the additional 2,800 residents as long as the state makes an effort to rotate out those able to live independently.

"But there's no fire in the belly for anybody to go in that direction," Greenwald said. "If the departments will not do it on their own, I think legislation is needed to force them."

As it stands, residential agencies like DSNJ say they are steering more toward creative income alternatives such as private fundraising and grants to keep some 950 group homes statewide afloat while the economic crisis eats away at government subsidies. If overhauls aren't made, agency departures could become a trend, Greenwald said.

The four agencies replacing DSNJ, for instance, will work with virtually the same slim budget.

"It's going to be close," said Thomas Baffuto, executive director of the Arc of New Jersey, whose Ocean County arm is adding four of the homes to the 13 it already manages. "But with a bigger agency, we might be able to better spread out those funds."

The Arc and the others are seeking, on top of the annual allotment, a one-time payment as high as \$100,000 per house in order to bring the conditions up to standard. State DDD spokeswoman Pam Ronan said discussions for repair money are still under way.

Yet such talk has left Prendeville wondering why more money wasn't just given to DSNJ to avoid a potentially disruptive transition.

On Thursday, he sent a letter to state Sen. Robert W. Singer, R-Ocean, asking for immediate assistance in "saving such a valuable resource." Singer forwarded the letter to Department of Human Services Commissioner Jennifer Velez.

Sharon Pipero, whose 38-year-old nonverbal and autistic son Michael has lived in a DSNJ group home in Lakewood and Brick for 16 years, also wished things would stay the same.

"I want him in the same house with the same staff because change is very difficult for him," she said.

According to DSNJ, most of its some 130 care providers will remain where they are.

Yet at least one relative of a resident said she felt DSNJ was abandoning his 46-year-old sister at her Brick group home with too little warning.

"I felt they had absolutely no concern for the individuals," said Kenneth Heim, who received notice 60 days before DSNJ's departure. "Now my mom, who's in her 80s, has got one last worry before she leaves this earth of whether her daughter is going to be OK or not."

Additional Facts AT A GLANCE

Lakewood-based Developmental Services of New Jersey, part of the largely East Coast nonprofit company Chimes, will give up its 11 group homes for the disabled March 7 in a dispute over state funding. It has liens on some of the state-owned homes totaling about \$1 million, which is about the sum of the agency's deficit, DSNJ officials said.

Four other agencies are slated to take over the homes and a day program:

Arc, Ocean County Chapter, Lakewood, four homes.

SERV Achievement Centers, Ewing, four homes.

Opportunity Knocks, Englishtown, three homes.

N.J. Institute for Disabilities, day program in Lakewood.

5. MICHIGAN: Closure of Mt. Pleasant Center is Heartless

Michigan AFSCME News Release LANSING, Michigan Feb. 18 /PRNewswire-USNewswire

Albert Garrett, President of Michigan Council 25 of the American Federation of State, County and Municipal Employees (AFSCME), AFL-CIO, issued the following statement:

"I am reading from a report prepared by the Michigan Department of Community Health: 'The Mt. Pleasant Center is the last remaining state-operated facility for persons with developmental disabilities. It is also the last Medicaid Certified "Intermediate Care Facility for Persons with Mental Retardation" (ICF-MR) in this state,'" began Garrett. "The State's current budget plan calls for the closure of the Mt. Pleasant Center on October 10, 2009.

"A closure coordinator is on site in Mt. Pleasant now. These Michigan citizens with developmental disabilities will be 'placed in the community,' as the current jargon expresses it," continued Garrett. "We have already seen, repeatedly, the impact of this 'community placement' strategy: these citizens are placed in privately operated facilities which are often ill-equipped to meet their needs, and which exist for the purpose of making a profit on the care of these people. Many of these citizens in need will become entangled in our correctional systems, because they are not equipped to function in the community.

"We long ago passed the point of diminishing returns in 'community placement.' For some time we have been

engaged in dumping these residents with little regard for the quality of care they will receive. With the closure of the Mt. Pleasant Center, our state will abandon these hapless citizens completely," concluded Garrett. "These 160 individuals will lose the care they need, and the Mt. Pleasant area will lose 400 good jobs. These are difficult times, but this is a singularly heartless approach to the State's budgetary problems."

Albert Garrett also serves as Vice President of AFSCME International. Michigan AFSCME Council 25 represents more than 90,000 public workers across Michigan, including 271 workers at the Mt. Pleasant Center. AFSCME International represents 1.4 million public workers nationwide.

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