

HOTEL DEADLINE APPROACHING: If you plan to attend VOR's Annual Meeting and Initiative, or if you are still thinking about it, make your hotel reservations TODAY. The deadline to be part of VOR's block rate is May 12. See <http://vor.net/2008AnnualMeetingandInitiative.htm> for the hotel details, number, rate, etc.

Join Us! Help Commemorate VOR's 25th Anniversary!!
VOR will host its Annual Meeting, Washington Initiative, Special Anniversary Celebration, and the 2nd Annual Capitol Hill reception, beginning June 13, 2008 in Washington, D.C. Visit <http://vor.net/2008AnnualMeetingandInitiative.htm> for more information on the Annual Meeting and Initiative.

Be a Sponsor / Get a Sponsor: Select a sponsorship category you would like to support! Help with the Capitol Hill Reception expenses, support the 25th Anniversary Reception, help fund the successful day-long Annual Meeting, including breakfast, lunch, speaker sessions, participant handouts, help with the expenses for the critically important Washington Initiative, and more! See <http://vor.net/2008Sponsorship.htm> for details. Questions? Contact Tamie at Tamie327@hotmail.com or 605-399-1624.

VOR Weekly E-Mail Update
May 9, 2008

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STATE NEWS

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- Coming Up: May 16: Focus on the Arizona Training Center at Coolidge - "The only home some developmentally disabled people have known" AND May 23: Focus on Aging Crisis (Texas, Nationa): "When Crisis Hits the Disabled - Limited Options for Support and Housing Exist for Aging Caregivers and Their Children"

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1. MASSACHUSETTS: VOR and COFAR in fight for Fernald

Summary: In support of keeping Fernald an option for current residents, VOR and the Massachusetts Coalition of Families and Advocates for the Retarded (COFAR, VOR's Massachusetts affiliate) on April 29 submitted a 'friend of the court' brief, which can be filed by those who are not party to the actual court case. Their brief claims that Judge Tauro's ruling in Ricci, which requires Fernald remain an option for current residents, was in line with the Olmstead Supreme Court decision. The groups claim while the "Olmstead" decision dealt with two women whose conditions improved enough to be placed in community homes, it also made clear that there are individuals for whom community placement is not appropriate. "The remaining residents of Fernald, are, for the most part, exactly such individuals," the brief said. "They are profoundly retarded individuals who not only will not benefit from community placement, but who will suffer there."

Advocacy groups in fight for Fernald
By Richard Conn
Daily News Tribune
May 05, 2008

WALTHAM - National and statewide advocacy groups for the developmentally disabled filed a joint brief earlier this week in the U.S. Court of Appeals supporting a federal judge's decision to keep Fernald Developmental Center open as an option for its residents.

In August 2007, U.S. District Court Judge Joseph Tauro ruled Fernald must remain an option for its current residents. The state, which has long planned to close Fernald, appealed that decision in March.

The state and the Fernald League, a group of guardians fighting to keep Fernald open, have been locked in a legal battle since 2003, when the state announced its intention to close the state institution.

The Voice of the Retarded and the Massachusetts Coalition of Families and Advocates for the Retarded on April 29 submitted a 'friend of the court' brief, which can be filed by those who are not party to the actual court case.

"It's definitely in support of keeping the facility open," said Marilyn Meagher, president of the Fernald League of the brief filed by the two organizations.

Both sides in the Fernald case have cited a 1999 U.S. Supreme Court decision *Olmstead vs. Zimring*, which said that the state of Georgia did not have the right to keep two women with developmental disabilities in a state mental hospital when it had been recommended that they be transferred to a community care facility.

The brief filed last week by the Voice of the Retarded and the Coalition of Families and Advocates for the Retarded, claims that Tauro's ruling was in line with the earlier Supreme Court decision. The groups claim while the "Olmstead" decision dealt with two women whose conditions improved enough to be placed in community homes, it also made clear that there are individuals for whom community placement is not appropriate.

"The remaining residents of Fernald, are, for the most part, exactly such individuals," the brief said. "They are profoundly retarded individuals who not only will not benefit from community placement, but who will suffer there."

State officials say the 196-acre Fernald campus is too costly to keep open and that closing Fernald would be in line with a switch nationally from institutional care to community living for the developmentally disabled.

Members of the Fernald League have argued that the facility's residents - many of whom have lived there for about 50 years - should be given the option of staying.

Tauro said his decision was not meant to stop the state's plans to close Fernald. Instead, his ruling intended to give residents the choice to stay there as long as the facility stays open.

However, the state, in its appeal of Tauro's decision filed in March, said the order "effectively constituted an unlawful command" that Fernald be kept open. The Fernald League was given 30 days to file a response to the state's appeal, but asked the court for an extension until June - which has been granted, George Mavridis, plaintiff representative for the Fernald League said Friday.

2. TENNESSEE: State Retaliates Against Advocacy Group by Eliminating Contract

Press Release:
Leanne Boyce
People First of TN, Inc.
April 11, 2008

After taking a stand against funding cuts in programs supporting Tennessee's most vulnerable citizens, People First of Tennessee received a letter from the TN Division of Mental Retardation that its self-advocacy contract will not be renewed. The funding cuts have been a major source of contention during this spring's budget hearings with provider agencies being forced to absorb a 6.1% reduction in payments as well as other overall efforts to reduce community services. At a loss to stem the harmful effects of these unilateral actions, People First took action by filing a motion for contempt in their lawsuit against the Arlington Developmental Center, alleging that the current course of action taken by the DMRS puts Arlington lawsuit class members' health and safety in jeopardy. In response, this week the organization received notice that its contract to provide training in advocacy to DMRS recipients would not be renewed.

"We feel that this is retaliation for our actions regarding the budget cuts," says Leanne Boyce, Executive Director. "DMRS tried to cancel our contract when we first filed our case against the Arlington Developmental Center in 1991. We feel there is a definite pattern of unlawful retaliation on DMR's part."

People First has had its self-advocacy contract with the state since 1987. Funding from this grant has been used to assist individuals with developmental disabilities learn how to speak up and become contributing citizens in their local communities.

"Having this contract eliminated now," explained Ms. Boyce, "when the need to educate service recipients about their rights with regard to the funding cuts, only increases the likelihood that service reductions will proceed without due recourse being taken by those affected."

3. MISSOURI: Community standards bill continues to move through the legislature

Missouri VOR Newsletter

April 29, 2008

Senator Nolder's and Senator Green's SB 1081 which strengthens quality assurance and safety in community residential settings passed the Senate this week and is in the House. It looks like it finally has a good chance of passing.

4. More from MISSOURI: Parents of autistic man seek help from state

Summary: This article sums up exactly the bureaucracy, confusion, waiting and sometimes lies that thousands and thousands of families across the country whose children are on waiting lists for services.

By Bill McClellan

ST. LOUIS POST-DISPATCH

Bill McClellan

05/04/2008

Brent Schnurman is 23 years old, autistic and essentially nonverbal. He sometimes speaks, but most often just repeats the last word he has heard. You can imagine the confusion. "Do you want to go for a walk, Brent, or take a ride?" "Ride." "Do you want to go for a ride, Brent, or take a walk?" "Walk."

Perhaps this should have prepared his parents, Richard and Donna Schnurman, for their journey into the rabbit hole of the Missouri mental health system where nothing is quite as it seems. About a month ago, I wrote about the first part of their journey. It began when Brent left the Special School District of St. Louis County and got into a program for adults with disabilities. The program was not a good fit. It didn't provide

adequate supervision. In mental health parlance, Brent is an eloper. A runner. An out-the-door-and-just-take-off sort of runner. In December, Brent was dropped from the program. Donna has been his full-time caregiver ever since.

It is hard to imagine how exhausting that job is. Brent is a strapping young man. He paces with nervous energy. Donna is with him every moment. Touching him, holding his arm. She loves him fiercely, but she is tired. Bruised, too. He likes to squeeze, and he sometimes squeezes his mother's arm. There is no intent to hurt, but still, the squeezing takes its toll.

The Schnurmans finally found a program that seemed like a perfect fit. It's the Community Integration Program run by St. Louis Arc. But unlike the program that dropped Brent in December, the Arc program does not take Medicaid, and at about \$26,000 a year, it is well beyond the Schnurmans' means. Fortunately, federal and state governments are prepared for just this sort of problem and handle it through something called a Medicaid Waiver. In Missouri, the Department of Mental Health buys the services from Arc through the Medicaid Waiver program. But because the state picks up 40 percent of the cost, it limits the number of waivers.

Are any available, and could Brent get one?

He had a powerful ally. Richard Schnurman read a newspaper story about state Rep. Dwight Scharnhorst, the majority deputy whip. He had an autistic grandson who died of an epileptic seizure at the age of 6. Although the Schnurmans do not live in his district, Richard wrote him a letter. He came to the Schnurman house. I was there that day, too.

"I'm going to try to help them get some kind of funding," he said.

That was a little more than a month ago. Shortly after the story appeared in the paper, I received an e-mail from John Hutchings. "I read your article with great interest. I have a handicapped, autistic 27-year-old son," he wrote. "In 2002, when I applied for a Medicaid Waiver slot for my son, I was informed that no waiver slots or money were available. Both were lies. Please take a look at the two attached appellate court decisions regarding my son. ..."

Hutchings successfully sued the Division of Social Services and the Department of Mental Health. His son was awarded a waiver, and the state had to reimburse him for his legal fees. I called Hutchings. He said his son was still receiving services through the waiver. But Hutchings was not pleased with the state. "I've been lied to so many times I don't trust anybody in state government. The Department of Mental Health should be my son's advocate, not his adversary," he said. With Hutching's permission, I forwarded his e-mail to the Schnurmans.

Meanwhile, Scharnhorst seemed to be plugging away. He suggested the Schnurmans also contact their state senator, Mike Gibbons. Richard called the senator's office. The person he spoke with was pleasant, but noncommittal.

Richard continued calling people, trying to learn if any waivers were available. It seemed impossible to find out. The Department of Social Services has the contract with Medicaid, but the Department of Mental Health administers the waiver program.

Richard's calls bounced from office to office.

Finally, somebody from the Missouri Health Net in the Department of Social Services called and left some numbers on the answering machine. The state had approved 7,775 comprehensive waivers for this fiscal year and had assigned 7,534 of them. But 75 were reserved for people leaving institutional care and 190 were reserved for people in crisis. The numbers didn't quite add up. Richard was perplexed, but thrilled. Mostly thrilled.

There were 190 reserved for people in crisis? Wouldn't Brent's case qualify for crisis?

I called the Department of Mental Health. Bob Bax, the director of public affairs, arranged for a teleconference with Kay Green, director of federal programs for the Division of Mental Retardation and Developmental Disabilities, and Jeff Grosvenor, the deputy director for administration of that same division. I asked about the numbers from Missouri Health Net.

"Missouri Health Net got those numbers from me," said Green, "but that was as of April 22nd."

"I think the situation we're talking about is the individual is eligible, but there aren't funds available," Grosvenor said.

"Jeff is correct," Green said. "Those are targets and we're on target based on available funding. ..."

The conversation went on like that for several minutes. I was talking to the right people, and they apparently were trying to explain things to me, but I understood nothing.

Later, I spoke with Bax and we exchanged e-mails. What about the waivers for people in crisis? These people are in crisis.

"Brent and his family are one of 140 families across the state with the same level of crisis and we do not have the resources to serve them," Bax stated in an e-mail. "When persons leave waiver services we take any funds available and apply to persons in crisis. Unfortunately there is no funding currently and we can't predict when persons might leave waiver services. Our hearts go out to Brent and his family as well as the other families in this situation. We will continue to look for ways to support Brent and other individuals and families."

I visited the Schnurmans one evening last week. Richard was walking with Brent as I approached the house. Brent is a nice-looking young man, but locked in his own world. Richard and Donna are solicitous of him, loving, watchful. But tired, too, and desperate for help. It does not speak well of Missouri that we have no help to give. Other than Hutchings, that is. At least he has advice.

5. KENTUCKY: CMS Agrees to Continue Funding for Oakwood ICF/MR Through May 15

Summary: Following an administrative law judge's appeal ruling on April 15, 2008, federal funding was lost as a result of the investigation of two incidents, one of which involved a death, in August and September 2005. The investigation and report identified "an immediate and serious threat to the clients' health and safety." CMS allowed funding to continue during the duration of the Cabinet's appeal. In September 2006, CHFS contracted with the Bluegrass Regional Mental Health-Mental Retardation Board to assume full management responsibility for the facility. Bluegrass has made significant progress in improving the safety of the residents.

Source: Kentucky Cabinet for Health and Family Services (CHFS) press release May 1, 2008

The Cabinet for Health and Family Services (CHFS) is aggressively pursuing recertification and federal funding from the Centers for Medicare and Medicaid Services (CMS) for the Bluegrass Communities at Oakwood in Somerset.

Following an administrative law judge's appeal ruling on April 15, 2008, federal funding was lost as a result of the investigation of two incidents, one of which involved a death, in August and September 2005. The investigation and report identified "an immediate and serious threat to the clients' health and safety." CMS allowed funding to continue during the duration of the Cabinet's appeal.

According to a letter from CMS, funding will continue for 30 days from April 15, provided CMS is assured that CHFS is protecting the well-being, safety and health of Oakwood residents, and that appropriate transitional efforts are under way.

"The Cabinet has directed the Bluegrass Regional Mental Health-Mental Retardation Board, the facility's manager, to focus all of its efforts toward that goal," said CHFS Secretary Janie Miller. "A Cabinet team is on-site at Oakwood, assisting Bluegrass. We are working diligently to assure that the residents continue to receive appropriate care in a safe environment, and to assess Oakwood's readiness for reinstatement in the Medicaid program."

CHFS also plans to identify an independent team to assist in finalizing preparations for the surveys required by CMS for reinstatement.

"Recognizing that we may experience a gap in federal funding, the Cabinet will explore,

in cooperation with families of the Oakwood residents and providers, opportunities for transition to community placements or alternative settings," Miller said.

Toward that end, CHFS plans to meet with parents, guardians and other constituent groups to discuss the loss of federal funding and to explore transition opportunities. The Cabinet also plans to work with the Division of Protection and Advocacy to ensure additional assistance from advocacy organizations and with community providers with proven histories of successful support of individuals similar to Oakwood residents. CHFS continues to consult with CMS and the Department of Justice throughout this process.

Following the investigations in the fall of 2005 that resulted in termination, the facility underwent several management changes, and the facility continued to receive Type A citations, the most serious violation issued by the Office of Inspector General.

In September 2006, CHFS contracted with the Bluegrass Regional Mental Health-Mental Retardation Board to assume full management responsibility for the facility. In the contract, Bluegrass agreed to operate Oakwood in compliance with all requirements, and has made significant progress in improving the safety of the residents.

Oakwood's current annual budget is approximately \$78 million, of which roughly \$60 million comes from the Medicaid program.

Oakwood currently serves 224 people with mental retardation, 24 of whom are in the process of already being transitioned to community placements.

6. Florida: Law could cut \$120 million for services to disabled

Pensacola News Journal

By Jamie Page

April 28, 2008

The Florida Legislature is proposing a change in the law that would cut more than \$120 million from the budget for services for people with developmental disabilities.

A coalition of at least six local nonprofits that assist disabled residents, along with advocates and families, are calling for the legislature to reconsider the cuts, which would leave some disabled residents homeless, said Donna Fassett, executive director of ARC Gateway.

The news was announced today at the Pollak Training Center at ARC Gateway in Pensacola.

"There are so many things they (legislature) don't understand," said Dave Miller, CEO of Horizons of Okaloosa County. "We are afraid many people are going to have their services cut and we're not sure what's going to happen to those people."

The legislature is looking at moving to a tier funding system for those with disabilities. Depending on which tier they fall in, based on their needs, the cuts will be significant in three of the four categories.

Ruth Brassow of Pensacola has a 29-year-old son, Paul, who has a developmental disability. He lives in a group home with five other men who are like family to him, she said. Paul also attends an adult day training program, where he learns jobs skills and earns some money of his own.

Under the cuts, Paul would be \$7,000 short of covering the costs of his basic services, not including medical supplies or dental care. However, during the past year, Paul has had to have extensive dental work.

"In the future, he will have to choose between his home, his job and dental care," Ruth Brassow said. "The choices we face leave us with no easy answers, and in some cases with no answers or solutions at all."

Recently, a House and Senate committee agreed on an additional 5.5 percent reduction to funding to these organizations, on top of the \$120 million cut, said Sherry White, CEO of UCP of Northwest Florida.

"The combination of the tiers and the rate reduction will have ramifications that we've only begun to determine," White said. "We do understand that this is a very difficult

financial year and that we are not the only group facing challenges, but we have endured many years of rate reductions."
White said the proposed cuts would leave no choice but to discontinue certain services.

Tamie Hopp

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836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007
847-258-5273 fax (for referrals or credit card payments)
kluck146@comcast.net (for referrals or credit card payments)

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FOR REFERRALS: ___ You may use my name in any correspondence with this individual. My name is _____.

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