
VOR Weekly E-Mail Update

August 29, 2008

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Contents

1. DD Act Proposed Regs - Electronic Submissions Update

**STATE
NEWS**

2. OREGON: Abuse and Neglect Reports Shows Higher Numbers

3. OREGON: State Reviews Fairview Transition

4. CALIFORNIA: Budget cuts gut disabled worker bill

5. NEW MEXICO: Suit Now 21; Taxpayers' Bill \$4M a year

6. NEBRASKA: Committee hears testimony about Beatrice center

7. KENTUCKY: State Seeks Medicaid Funds for Oakwood

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1. DD Act Proposed Regs - Electronic Submissions Update

In last week's update, we shared with members the opportunity to submit comments in response to proposed DD Act regulations.

Here is an update on how to submit your comments electronically:
<http://www.regulations.acf.hhs.gov>.

Good luck and thank you.

2. OREGON: Abuse and Neglect Reports Shows Higher Numbers

Source: Perspectives -MR/DD Advocacy

Date: August 2008

Editor: Sid Stuller, Oregon VOR Coordinator

The OIT (Office of Investigations and Training) annual abuse/neglect report document for the year 2007 was released in June. It revealed that abuse and neglect increased in volume in the past year. In 2006, 1583 incidents of abuse were alleged and 682 of these were proven for a rate of 43.1%. In 2007, the number of incidents increased to 1857, of which 790 incidents of abuse were proven for a rate of 43%.

Chief among the types of abuse was neglect, which resulted in the deaths of two persons with MRDD, followed by financial abuse, and physical abuse. Other types of abuse reported included sexual abuse, restraint, restriction, and verbal abuse. Most of the abusers were care-givers, who are charged with protecting the vulnerable residents, according to previous reports.

What about EOTC - the only ICF/MR left in Oregon? In some categories of abuse, none was reported. In all categories, EOTC has an average of five confirmed abuse cases per year for the past five years. In 2007, there were eight confirmed abuse cases, but the least of any type of residential category about which OIT reports.

What about improvements to the system? The OIT worked with the MFCU (Medicaid Fraud Control Unit) of the Oregon Dept. of Justice, which

secured a restitution of \$72 000 in one case and a 12 month jail sentence in another case. Those convicted can no longer be employed as caregivers for elderly or disabled persons.

A full copy of the OIT 2007 Abuse/neglect report may be obtained on-line at <http://egov.oregon.gov/DHS/data>

3. OREGON: State Reviews Fairview Transition

Source: Perspectives -MR/DD Advocacy

Date: August 2008

Editor: Sid Stuller, Oregon VOR Coordinator

A workgroup designed to further the MFP program (Money Follows the Person) has been reviewing the way folks were moved out of Fairview [State Operated Center], and a document now is available online detailing what worked and what didn't work.

The document says what didn't work was that managers relied on direct care staff for critical information. There was "no provision for staff turnover nor how to train newly hired staff."

There was nothing about the lack of group home supervision or administration on weekends, no mention either of the lack of unannounced "drop-in visits" to see if the lowly trained staffs were doing their jobs.

Not one word was mentioned about the results, which the Oregonian published last November, and which detailed that one out of every five persons in state licensed care has suffered abuse. The purpose of all this reviewing is ??? Speculation has it that they want to do a better

job of forced removal of residents from Eastern Oregon Training Center in a few years.

See: <http://www.oregon.gov/dhs/spd/mfp/dd/index/shtml> (Follow links to DD workgroup)

4. CALIFORNIA: Budget cuts gut disabled worker bill

Summary: California Assembly Bill (AB) 2424 which sought to bring many more people with developmental disabilities into the work force has failed citing the state's budget concerns. But cost was only one issue. Another concern voiced by "choice" advocates was the bill's presumption that an individual wants to live and work in ordinary settings among the general population. Critics said no one should presume where people want to live and work, calling that a choice for the individuals, their families and conservators to make. "People with developmental disabilities have a whole range of desires and wants and needs and likes and dislikes," said Theresa DeBell, president of California Association of State Hospital Parent Councils for the Retarded, a group of relatives and friends of residents in the state-run institutions known as developmental centers. The California Association of Psychiatric Technicians, which represents 3,000 workers in the developmental centers, also has objected.

By Kathleen Wilson

Monday, August 4, 2008

Ventura County Star

A bill seeking to bring many more developmentally disabled adults into the work force has been cut back in the face of budget concerns.

The bill, which goes to a key hearing today before the Senate Appropriations Committee, had called for major new efforts to bring California adults with developmental disabilities into regular jobs.

But at a cost of \$2 million and a state budget in crisis, the bill had to be rolled back, officials said Friday.

"Any bill with money in it this year is in danger of dying," said Jordan Lindsey, director of public policy for Arc of California, a state advocacy group for developmentally disabled people.

At issue was not only the cost of AB 2424 but also the presumption that an individual wants to live and work in ordinary settings among the general population.

About 70 percent of adults with developmental disabilities are unemployed and many have said they want to work in the community, not sheltered workshops.

In hearings held over a year and a half on the state's system for the developmentally disabled, gainful employment was the No. 1 issue, Lindsey said.

"People said we want to work, we can work, we are good workers," he said.

But critics said no one should presume where people want to live and work, calling that a choice for the individuals, their families and conservators to make.

"People with developmental disabilities have a whole range of desires and wants and needs and likes and dislikes," said Theresa DeBell, president of California Association of State Hospital Parent

Councils for the Retarded, a group of relatives and friends of residents in the state-run institutions known as developmental centers.

The California Association of Psychiatric Technicians, which represents 3,000 workers in the developmental centers, also has objected.

A variety of groups representing disabled people and special education groups, though, supported it.

The bill would have established an Employment First Policy, required the state to implement it, and established a startup fund.

But that has been rolled back into what's being called an employment opportunity initiative.

"It's now a much more modest bill," said Eric Gelber, chief consultant to the Assembly Human Services Committee chaired by the bill sponsor, Assemblyman Jim Beall Jr.

Gelber said the current version would establish priorities for employing the developmentally disabled and require information to be collected showing their representation in the work force and the barriers they face.

"We see this as setting the groundwork for other things in future," Gelber said.

The bill is intended to update the Lanterman Act, a nearly 40-year-old law focusing on people with disabilities such as mental retardation, cerebral palsy, autism, epilepsy and traumatic brain injury. About 110,000 adults receive services.

5. NEW MEXICO: Suit Now 21; Taxpayers' Bill \$4M a year

Sunday, July 20, 2008

By Mike Gallagher

Albuquerque Journal

The federal civil rights lawsuit that led to the closure of two state hospitals for developmentally disabled people more than a decade ago entered its 21st year this month. Nobody held a birthday party.

The case, which at times has been acrimonious, is costing the state more than \$4 million a year in legal fees, compliance monitoring and administrative expenses.

Earlier this year, Senior U.S. District Judge James Parker appointed an expert to report to the court on what progress is being made on the remaining issues.

The expert's budget for the first three months of the year: nearly \$90,000.

State officials can't say how much has been spent on legal and administrative costs since the case began. They did come up with a number since 2003. That amount is about \$19 million.

These costs don't include any expenses related to direct care of the developmentally disabled.

The lawsuit was filed in 1987 over living conditions and lack of treatment of developmentally disabled people at the state hospital and training schools in Los Lunas and Fort Stanton. The state fought the case but lost at every turn until 1997 when state officials agreed to a stipulated judgment and plan to care for the hospital patients in community settings.

Parker didn't order the two institutions to shut their doors. The state decided to close them after so many clients were transferred to community settings that the facilities were no longer economically viable.

Despite its costs, the litigation known as Jackson V. Fort Stanton et. al. , is a lawsuit where courtroom activity is sporadic. The issues are dealt with mostly in audit reports, memoranda and meetings among the parties.

Changing standards

Dr. Alfredo Vigil, secretary of the Department of Health, said the state has faced a challenge in complying because the standard of care for the developmentally disabled has changed over the years.

"Care for the developmentally disabled has evolved very rapidly," Vigil said. "The complexity of that care and the standard of that care moves quickly."

Translated to lay terms, that generally means care that might have been acceptable 10 years ago no longer is.

Vigil has been secretary of the Department of Health for about a year and has tried to change the tone of the case. A new attorney, Jerry Walz, has been hired to bring the case to a resolution.

Over the last 11 years, in fits and starts, the state has managed to meet about 64 percent of the goals laid out in the 1997 agreement and plan to end court oversight.

Vigil said the state at one point reached a plateau where there was little movement in reaching the goals laid out in the agreement.

Others said the state was almost "frozen" for several years in its ability to move forward on meeting the goals outlined in the agreement

One attorney for disabled clients, Maureen Sanders, said turnover at the top levels of the Department of Health has led to each new administration having a learning curve.

During an interview with the Journal, Vigil made it clear he is committed to moving forward to a successful conclusion of the case.

Steps outlined in the agreement cover everything from staff training to oversight of contract providers who actually do the daily work to systems for uncovering and reporting abuse.

"When it started there was a fairly confined scope from a technical point of view," Vigil said. "Make sure they are not abused or neglected. Make sure their nutrition has been maximized. A few things were clear goals.

"The goals have now expanded hugely and to a great degree appropriately."

One attorney representing developmentally disabled clients says the state's argument about moving targets would have more credence if it had met even the original goals.

There are between 360 and 370 people in the state system who were original members of the lawsuit, which is called the Jackson Case after the lead plaintiff Walter Stephen Jackson. But the state provides the same level of care for all 3,700 people in the system at a cost of more than \$70,000 a year per person. The total, much of it federal money, exceeds \$250 million a year.

Despite that, another 3,700 people with developmental disabilities are on a waiting list for services from the department - a practice advocates are challenging in court. They argue the people on the list are entitled to services now.

State officials said they would prefer that the money being spent on the Jackson lawsuit be directed to providing services to those on the waiting list.

'Moving target'

In the past there has been debate over whether the attorneys who brought the suit are creating a "moving target" or setting the goals the state must attain at an unreasonably high level.

One of the only attorneys not getting paid by the state is Sanders, who represents an intervenor in the lawsuit, The ARC of New Mexico, the guardian for about 70 members of the Jackson class of plaintiffs.

"They can complain about moving targets all they want," Sanders said. "They haven't come close to hitting the original target."

Vigil said it is the job of those representing the developmentally disabled to challenge the department, and he expects them to raise the bar on the quality of care their clients receive.

He says the goals for people in state care evolve because advances in medicine and technology have meant improved and more meaningful lives for people with even the most profound developmental disabilities.

One area of debate surrounds the issue that each person in the state's care have a "meaningful day." In some instances that may mean the person goes to a job. For others it may mean pet therapy.

The definition of "meaningful day" is different for each individual and is not dictated by the state but the individual and the treatment team. It is the subject of constant discussion.

But the state is running into some more concrete problems beyond its control.

"We have a shortage of primary care physicians and dentists in the state," Vigil said. "And not every dentist or primary care physician that might be available feels capable of treating people with severe disabilities."

That makes reaching the goal of having access to dental and medical care difficult.

Others say the department acts quickly when informed of problems with individual clients, but the system of identifying those problems is an area the state needs to improve.

Vigil and Walz said they are committed to bringing the lawsuit to an end within two years.

Sanders says that's close but not quite possible.

"If they made a concerted effort," she said, "they could get out from the case in about three years."

6. NEBRASKA: Committee hears testimony about Beatrice center

Summary:

About a dozen parents and siblings of people living at Beatrice State Developmental Center got their chance to defend the place their loved ones call home during the daylong legislative public hearing. State senators on the committee also heard from some who want the center closed.

Here is a good blog comment posted in response to this story:

" We spend so much time on BSDC versus community-based services that we prevent ourselves from completing a reliable root cause analysis of the statewide system of services. The problem is gaps in service quality and there are examples in both BSDC and community-based services. The discussion should be about the best design for a continuum of services. Just as acute medical hospitals provide a different level of care than out-patient clinics, BSDC's level of care is different community-based level of care. Some people need BSDC, some need transition services and some need community-based services. Some people need the ability to move back and forth as needed. I expect that system redesign may sound too much like something that may cost more so we will bury the idea and keep the focus on which is better, BSDC or community-based. Too bad, there may be some design efficiencies out there that would actually make both services less expensive and more appropriate to meeting the needs of Nebraskans with developmental disabilities. "

By NANCY HICKS

Lincoln Journal Star

Thursday, Aug 21, 2008

Sandra Ham's teenage son Ian started running away when he lived in Lincoln group homes.

Once he caused a ruckus at a convenience store late at night, his mother said. The police who responded thought he was on drugs. They stepped on his bare feet while handcuffing him. Then they noticed his medic alert bracelet.

The officers returned Ian to his group home, where the staff member responsible for watching the clients was asleep.

It was just one example Ham presented Thursday to a Legislative committee of how the Beatrice State Developmental Center is the best place for her son and others like him.

About a dozen parents and siblings of people living at BSDC got their chance to defend the place their loved ones call home during the daylong legislative public hearing. State senators on the committee also heard from some who want the center closed.

Ham told the committee of another time when Ian left at night, in the dead of winter. He was located after an intensive search - with help from police and the local TV station - miles from his home.

Then there was the day a group home staff member was stopped for drunk driving, with Ian in the car. This was the same staff member who was responsible for Ian's blood testing, his insulin dosage and his meal preparation, Ham said.

After three years of living in group homes run by two different community agencies, Ham finally got Ian into BSDC - where there is always staff on duty, where there is a nurse on call, where there is constant oversight, she said.

"He now has the care that group homes could not or would not provide," she told the committee.

It is the safest place for her son and others with more demanding medical needs and who exhibit at-risk behaviors, she said.

Other supporters praised the state institution, the long-term loving staff members who watch over adults with the capabilities of a toddler, the special program for teens and adults with serious behavior issues, the community atmosphere where everything from the doctor to the swimming pool is just a short walk away.

Some told horror stories about community programs where staff members slept while their children wandered the streets, or watched TV rather than watch over the residents. Where there was not enough staff to give high-need clients one-on-one supervision, where staff weren't able to handle people with serious behavior or medical problems.

And they suggested community programs should have the same scrutiny that occurs at Beatrice, where investigators from several federal agencies have spent weeks observing life at the center.

The reports from those agencies citing serious, specific instances of abuse, neglect and staffing shortages at BSDC led to creation of the special committee, with Omaha Sen. Steve Lathrop as its chairman.

The state faces the loss of about \$28.6 million a year in federal funds for the center, which currently cares for 263 Nebraskans with

serious developmental disabilities. The center is also being monitored under a federal court order.

Senators also heard Thursday from some who want BSDC closed.

Beatrice is an "outmoded, outdated institution" that "violates the rights of people living there," said Mary Angus, lobbyist for the ARC of Nebraska, an advocacy group for people with disabilities and their families and friends.

"We believe the reasons BSDC has remained opened are political. ... Because it is best for the community, not because it is best for the residents," she said.

People with severe disabilities also live successfully in local community programs, she said. Sixty percent of the adult Nebraskans with profound mental retardation are served by such programs, she noted.

BSDC uses up 18 percent of the state's funding for developmental disability services, but serves only 6 percent of the people getting services, she said. It "misuses scarce resources."

Chairman Lathrop commented on the obvious philosophical split between Beatrice center supporters - who want to make certain an institutional choice exists - and groups like ARC of Nebraska - that would like to see the Beatrice campus eventually closed and its \$52 million in state and federal funding used for community programs.

"It seems to me this is not a black and white issue. That there is room for both (community programs and institutional programs)," Lathrop said.

Angus gave another option. Everyone could be served in community programs if the state increased the quality and the breadth of community services, she said.

7. KENTUCKY: State Seeks Medicaid Funds for Oakwood

By Sarah Vos and Beth Musgrave

Lexington Herald-Leader

August 29, 2008

The state has applied to receive Medicaid funding for Oakwood, the historically troubled state facility for mentally disabled people in Somerset.

Oakwood lost its Medicaid funding in May, and the state began paying the full cost to run the facility, about \$6.5 million a month.

Janie Miller, secretary of the Cabinet for Health and Family Services, announced Thursday that the state had submitted an application for recertification by the federal government.

"The application begins the formal recertification process, which includes two unannounced surveys," Miller said in a statement.

The first inspection by the federal Centers for Medicaid and Medicare can happen any time after the application is filed. The second survey occurs 30 to 120 days later.

The state needs federal money to help pay its bills.

The state has budgeted \$78 million for Oakwood; about \$70 million of that money goes to directly to Bluegrass Regional Mental Health-Mental Retardation Board, which has a contract to manage the facility. But the state will be out of money for Oakwood sometime before the next fiscal year, which begins July 1, Miller said

Miller said that, once the money runs out, it is unclear what will happen to the state-run facility, where 214 people with mental and physical disabilities live. "I do think at some point ... we're going to be out of money to pay the bills; that issue will have to be addressed at that time. This is just one issue in a very challenging budget this year."

It is unclear how quickly the federal government will make its decision. Don Putnam, president of the parents and relative organization at Oakwood, said he hopes the federal government will approve Medicaid funding for the facility before the state's money runs out.

"I have confidence that the cabinet and the legislature and the Health and Welfare Committee will work something out," Putnam said. "Oakwood needs to be there."

Miller said Thursday she thinks the state and Bluegrass Mental Health have worked hard to make sure that it will be ready for the survey. Putnam agreed, adding that many parents have seen positive changes at Oakwood since Bluegrass took over in November 2006.

"We've had no Type As (the most serious violation) during 2008," Miller said. "I feel really good about where we are."

Oakwood lost its Medicaid certification in September 2005, after an unsupervised resident drowned in a bathtub. It was not a good era for the facility: In 2005 and 2006, Oakwood received 24 Type A citations, the most serious kind, for failing to keep residents safe.

Tamie Hopp

REFERRAL/MEMBERSHIP/CONTRIBUTION FORM

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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!

You may pay by credit card or check.

TO REFER SOMEONE TO VOR: Use the form below, including the additional sections for referrals.

Mail the completed form (if joining or contributing) with payment to:

Voice of the Retarded
836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007
847-253-0675 fax (for referrals or credit card payments)
Tamie327@hotmail.com (for referrals or credit card payments)

FOR REFERRALS: _____ The contact information provided is for someone I think would consider membership with VOR.

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

Name

Address (if paying by credit card, use billing address). All forms must include complete address including zip code)

City St Zip

Phone Fax

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