
VOR Weekly E-Mail Update
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1. California: Finding a place for the state's severely mentally
ill / The policy of clearing California's institutions is nearing the
end. Left are the cases that are most difficult to relocate.

By Garrett Therolf
Los Angeles Times Staff Writer
March 6, 2008

Jim Grivich had always known that one day the letter would arrive.
He'd worried about what to do if it came, discussing it with his wife
over dinner and with his mother as she lay in bed, dying.

Still, when he got the letter in 2006 informing him that his brother
Bobby would have to leave the state institution where he had lived for
more than three decades, he was dismayed. Grivich scrutinized it,
looking for a way out. His only chance to fight, the letter said,
would be a hearing at a mental health court in Los Angeles.

At stake was the future of a severely developmentally disabled man
with extraordinary needs. Now 60, Bobby still smears feces on the
wall, hits people when he is around large or noisy groups, shouts "no"
when his schedule is disrupted. He also has a sweet side, smiling when
someone takes the time to play peekaboo with him.

For four decades, California has been trying to place
developmentally disabled people like Bobby in less restrictive
facilities, moving them out of large state hospitals and into
community care.

Now, as the state nears the end of the deinstitutionalization process, it is faced with finding new homes for its toughest cases. And it is coming up against increasing resistance from families.

From the time he was in his 20s, when his mother realized she could no longer accommodate his needs, Bobby has lived at Lanterman Developmental Center in Pomona. He sleeps in a dorm-like room with two other men, spends much of his day in group activities and eats well-rounded meals that have been approved by nutritionists. Grivich believes his brother is content and well cared for; his simple needs always met.

Grivich, of West Covina, promised his mother before she died of colon cancer that he would look after Bobby and worried that his brother would die if he had to move.

Grivich and others joined the resistance movement: fighting to save what remains of some of the state's most-disquieting institutions.

The policy affects the future of 2,761 mentally retarded, severely autistic, or brain damaged Californians, the system's eldest, frailest and neediest who have highly trained caretakers always at their sides.

When Bobby Grivich arrived at Lanterman Developmental Center in Pomona, the facility was the oldest institution in the state for the developmentally disabled. At the time, more than 13,000 people lived in the 12 publicly funded institutions statewide. Lanterman alone housed more than 2,800 at its peak.

Since 1969, five institutions have closed and another is slated to shutter this year. At Lanterman, 498 people remain, sharing 320 acres, 1,382 paid staff members, 86 buildings and a \$111.8-million budget.

In this spacious world, Bobby moves haltingly through the mission-style buildings. He stops and plays with a rattle, or sometimes a tambourine. More often than not, he sits in the corner, a lip pressed against his nose.

Caregivers roam about the day room, playing guitar and singing long-ago songs like the Beatles "Yellow Submarine." Bobby has not lived in the outside world since the song was a radio favorite.

Some of the attendants know Bobby so well they understand the gentle gestures, such as a hand on the shoulder, that work best to move him peacefully from one place to the next. And when he strays from the group, as he likes to do, the wide open space and slow moving cars allow him to walk unharmed.

At lunch, one of his usual attendants quietly separates him from the rest of the group so that he can sit at a table alone with soft foods. No risk of fighting over food that way.

Community settings, however, have been widely accepted as an

improvement for the vast majority of developmentally disabled people, in part because hospitals had earned a reputation as purveyors of lobotomies and shock treatments. Some supporters of community settings say the freedom found on the outside gives developmentally disabled people "the dignity of risk."

But the Griviches and a growing number of other families say that risk threatens too much.

"It's a matter of life and death," said Terry DeBell, president of the private organization for families of developmentally disabled people in California institutions.

Since Bobby's arrival at Lanterman in 1969, staff reports always concluded that the barriers separating him from the outside world were insurmountable. Doctors said his IQ is eight, and that he never will develop past the level of an average 18-month-old. He lacks strength in his bones, chokes on food and wanders away without any sense of danger.

Jim Grivich's reasons for keeping Bobby at Lanterman were manifold: staff at the institution have more demanding credentials; he believed more safeguards were in place to prevent Bobby from harming himself or others; no one was making a profit off Bobby's care; and his mother insisted on it as her dying wish.

Jim took responsibility for Bobby when his mother died in 2003. Years had passed since he had driven down the long tree-lined driveway at Lanterman, and he barely remembered the 80-year-old expanse of mission-style buildings, nor the tawny hills that surround it.

On the surface, Lanterman resembled the college campus his mother once had hoped Bobby would attend. New patients trickle in -- five in 2007, whose conditions were so severe there was no other place for them -- but far more are holdovers from long-ago decades. The average tenure for residents living at Lanterman is 43 years. The oldest is 84.

Almost all of Jim's memories of his brother were formed before Bobby turned 21, when his mother still woke to the sight and odor of his bedroom covered with feces. At that age, she finally agreed to institutionalize him. "She did not want to chain him up or lock him up," Jim said.

When Jim became Bobby's conservator, he found that his brother had become an old man. He had the same long nose, but his hair had grayed and his cheeks had hollowed.

Socially, he was still an outcast. He avoided others, often sitting in the corner with his chin in his hand. "He's a little bit of a loner type," said Monica Lopez, a Lanterman staff member.

He rarely spoke, and when he did, it was with the disposition of a toddler. He recoiled when others try to touch him. Jim doesn't try anymore.

"He doesn't know who I am," Jim said.

The institution was the first of its kind in California when it opened in 1917 as the Pacific Colony for the "insane", "feeble-minded" and "high-grade imbeciles."

Some of the first residents had been stowed in attics by shame-stricken families. The state's approach was not entirely different. The Pacific Colony, for instance, was far from existing railroad lines, and it was difficult to reach.

But it tapped into an overflowing need. By 1949, the 1,925 residents at Lanterman outstripped the institution's capacity.

In those early decades, some residents were sterilized, others were restrained for days. When patients displayed excessive anger, lobotomies were performed.

Longtime figures in the mental health field remember public opinion rising up against the institutions as stories of atrocities leaked out. When "One Flew Over The Cuckoo's Nest" was published in 1962 -- a hallmark novel about a fictional insane asylum in Oregon -- it helped cement the public perception that mental institutions were barbaric places.

In 1963, a reporter for what was then the Santa Ana Register wrote an expose after visiting a state institution for the developmentally disabled in Costa Mesa, finding the conditions to be filthy and the residents to be ill fed and unwashed.

Vivian Walter, the mother of a developmentally disabled person and a prominent advocate with the Assn. for Retarded Citizens, criticized the system during testimony in Sacramento.

"There were sights there that will haunt me for the rest of my life," Walter later recounted in a documentary before her 2002 death.

The Legislature upended the system with the passage of the Lanterman Act in 1969, named for Frank D. Lanterman, the assemblyman who sponsored the bill. For the first time, a law laid down a definitive preference for community placements over institutional commitments for every developmentally disabled person in the state.

It placed an emphasis on the rights of the developmentally disabled to make basic life choices, even if those came with the risks of living in the outside world. In 1979, Bobby's home was renamed after Lanterman.

In five decades, people at the Pomona institution and others like it had been officially recognized as "inmates," then "patients", and finally "consumers." A "consumers bill of rights" is posted throughout the grounds at Lanterman, emphasizing the right of residents to live the most self-directed lives possible.

Still, the facility is bedeviled by occasional claims of abuse.

Last year, the U.S. Department of Justice wrote to Gov. Arnold Schwarzenegger that, "we find that residents of Lanterman suffer significant harm and risk of harm from the facility's failure to: keep them safe; provide them with adequate training and associated behavioral and mental health services; and provide them with adequate healthcare."

The most serious charge, investigators said, involved a man who was found stomped to death in his room in 2002. Suspicion pointed mostly to his roommate, but the Justice Department said a Lanterman staff member could not be eliminated as a suspect. In any case, the investigators said the institution should have prevented the death.

The investigators also alleged that Lanterman staffers have not always adhered to stringent reporting requirements when a resident has to be restrained by force or chemicals.

Family members, however, took the report as an encouraging sign, not an alarm to rescue loved ones.

"We take these allegations seriously and made sure they were addressed, but this sort of report is exactly why we like Lanterman. Every organization has its bad apples. This type of scrutiny of their actions never would have taken place in the community," said Robert Hazard, who leads the family group at Lanterman and whose sister lives there.

"I'm not worried," Jim Grivich said.

Every year, court hearings are scheduled in a Los Angeles mental health court for each person at Lanterman to determine what is blocking their transfer to the outside world. The presumption is that each person's goal is to live beyond the walls, in the community. If the reason for staying isn't good enough, a judge orders them out.

In some cases, advocates allege that the urge to push residents into the community is so single-minded that innocuous or meaningless acts are interpreted as evidence the person wants to leave.

One man packed his radio to take with him whenever he went anywhere, an action that was interpreted as meaning he wanted to pack up and leave the developmental center. Advocates pointed out that he died a year after he was moved out.

Terri Delgadillo, director of the California Department of Developmental Services, defended the system. "When decisions are made," she said, "that decision is an extremely comprehensive decision, and it involves an extremely comprehensive process. If a person has nonverbal communication, that might be one piece, but it is not the whole piece."

In Bobby's case, furtive signals weren't the issue. A placement team led by case worker Rhoda Tong in January 2006 determined that his needs and desires were the same as always. And, she determined, there was a new group home that would finally meet those needs.

Jim and his wife, Ann, took Bobby for a visit to the San Gabriel Valley location. Jim took out his notepad and camera and -- leaning on his experience as a college administrator -- documented a list of violations, including exposed electrical wiring and a bedroom with no direct door or window leading outside. Jim reported the violations to the city, which issued citations.

At least on this day, the Griviches felt they had won, if only the promise of more time in limbo for Bobby.

Tong, Bobby's case worker, has since been asked to prepare a report every few months on what barriers remain to moving Bobby to a different group home.

2. The rest of the story: California couple spends \$30,000 in fight to keep brother at Lanterman / Jim and Ann Grivich call for improved IPPs, community safety

California Association of Psychiatric Technicians
Posted on the CAPT website
www.psychtechs.net
May 21, 2007

When Jim and Ann Grivich inspected the community facility that was scheduled to start housing Jim's brother Bobby, the couple couldn't believe what they saw and heard.

The home that was supposed to be a safe place for Bobby to live was anything but.

So the Griviches stood up and fought to keep their brother at Lanterman: a battle that cost them \$30,000 and untold amounts of heartache and headaches as they battled state bureaucracy and policy agendas that called for community placement-- no matter what the human cost.

ABOUT BOBBY

Bobby has lived at Lanterman for nearly 40 years. He is considered profoundly disabled, with numerous medical and psychological concerns, including severe osteoporosis, walking problems, choking and a tendency to wander.

Bobby and Jim's mother placed Bobby in Lanterman after it became clear that the family just wasn't able to care for him at home anymore, most especially with the danger presented by the busy street out front.

"It was clear he was going to either kill himself or someone else," said Jim Grivich.

Jim Grivich believes that, with its specialized staff and singular purpose, Lanterman was the right choice for Bobby.

"Community placement is appropriate for the category of people who need less help, such as some people who have Down's Syndrome," said Jim. "But there has been a push towards community placement for everyone by people who have no idea that there are others much more disabled -- people like my brother.

"LDC provides a certain level of services for the profoundly disabled, with professionals who are knowledgeable about medical services, psychological services and medications. And my brother isn't alone."

BATTLING FOR A BROTHER'S SAFETY

Although Bobby continued to do well at Lanterman, others began taking it upon themselves to place him in the community.

As Bobby's legal conservators, the Griviches were shocked when -- in September 2005 -- the annual HOP hearing was held without anyone even telling them about it. Although the hearing held that Bobby was "appropriately placed" as a Lanterman resident, the public defender took the ball and ran with it, insisting on an additional "barriers to community placement" hearing.

Next came a "special meeting" with a regional project staffer who oversees clients' community placements. The staffer said Bobby didn't have enough barriers to placement, so he would be placed in a pre-selected community home.

And the couple soon discovered that the staffer would be passing off this "no barriers" report to a court as an Individual Program Plan, which is an official document outlining client care. At this suspicious meeting, there were only a few people present -- far from the dozen or more usually required. Nor was Bobby present, as required by law.

"We were just told, 'He'll be placed,'" said Ann Grivich. "So we called for our own, real IPP meeting with all of the required stakeholders. We went over his needs as outlined in the official document and our desire he stay at LDC with the professional staff, only to be told by the regional project manager, 'Those requirements aren't a problem; we'll just change the IPP to fit community placement.' We couldn't believe it."

The Griviches finally helped create a very detailed IPP outlining everything Bobby required, including licensed staff 24/7 and care equal to or better than what's provided at Lanterman.

But even this wasn't enough to keep community advocates from trying to place him.

"The public defender made the regional center search the entire state for a home meeting Bobby's needs, even though the IPP requirement is that the home must be within 10 miles of ours so that we can easily visit and be able to supervise Bobby's care," said Jim. "The search turned up nothing, but it cost us thousands of dollars in legal fees. They appear to want to bankrupt families who dare to stand up and fight. Luckily, my mother left me the money to fight for Bobby."

RED FLAGS

The chosen community home was further than the 10-mile radius required in Bobby's final IPP, but in the Griviches' general area. Not only did the home not meet Bobby's many IPP requirements, but dangers also lurked around every corner.

Upon visiting the home, Jim and Ann were stunned by what they found out. Numerous issues presented an immediate danger to Bobby and other clients who were scheduled to move in that very day, including major electrical work in progress done by an unlicensed employee (without a permit) that resulted in an exposed electrical panel, as well as live wires dangling from a wall in a bedroom (also built without a permit); an illegally constructed bedroom for Bobby that had no outside exits, as required by fire code; and a nighttime employee who would sleep in an additional illegal bedroom in the garage, far away from clients in need of help.

And with the house offering a "home-like" atmosphere, clients were free to come and go as they chose and to help themselves to food in the kitchen. With Bobby's choking and wandering issues, this "home-like" facility put him directly at risk.

"Just the bowl of fruit on the kitchen counter could kill him," said Ann.

And as for the employees and owner, "They didn't even understand what we were talking about when we mentioned Bobby's IPP," said Jim.

When they asked if employees were licensed, they found out that those caring for Bobby and his many physical and psychological needs would be high-school graduates with just two weeks of training.

"You need to be educated to state standards and licensed by the state to paint fingernails or trim hair, but I guess you don't even need that to take care of Bobby," Ann said bitterly.

"They told us, 'Well, the facility's got a license, so it must be OK, right?'" said Jim.

RED TAPE

Even with all of these problems, the facility indeed had a license. But how did it get and maintain one? That's what the Griviches want to find out, but have yet to hear a clear answer from anyone.

The couple contacted the licensing office, the city building department and the fire marshall. Their complaints were substantiated, and the city even found many more deficiencies.

Although the judge in the Griviches' case eventually refused to allow Bobby to be placed in the prospective home because of the many safety concerns and the needs reflected in his IPP, the home has remained licensed to this day. Despite the safety hazards -- many of which still exist more than a year later -- three other clients have been placed in the home and the license remains intact. What's more, construction work continues with clients still in the home.

With Bobby still safe (for now) at Lanterman, the couple's concern for these other clients has led them to continue their fight against unsafe conditions, which various agencies say have "been taken care of," although many haven't been.

"In spite of our substantiated complaints, the licensing office refused to suspend the license until the necessary corrective work was completed," said Jim Grivich. "These clients are in danger."

URGENT CHANGES NEEDED

To help clients and families in situations like theirs, the Griviches are pushing to improve IPPs and ensure that licensed community homes are safe.

On IPPs, they recommend making sure that they are accurate, detailed and correct. For instance, Bobby's initial IPP included very broad statements, such as "all supports must be in place." But this vague language provides lots of wiggle room for those insisting on types of care that may not be in the client's best interests.

"These statements can let people get away with no supports for clients," said Ann. "The judges -- like our judge -- pay attention to the IPPs. When documents come out of Lanterman, they have to be right."

And on community home licensure, the couple is calling on the Department of Developmental Services, the regional centers and the licensing agencies to stop the finger-pointing and ball-dropping.

"Licensing must make sure these facilities are safe, period." said Jim Grivich.

Can Psych Techs do to anything to help?

"Specifically, Psych Techs can insist that every IPP requires that every prospective home has passed fire, safety and code inspections to state standards by licensed inspectors, and has licensed Psych Techs and/or RNs 24/7 where appropriate (and other specific needs of the client) spelled out in the 'preferred future section' of the IPP," said Ann Grivich. "And in general, Psych Techs can help by watching out for our family members."

Tamie Hopp

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