

## The Global Willowbrook

**Humane treatment for the mentally ill is the newest goal of human rights activists, whose current target is Mexico's decrepit institutions. By MICHAEL WINERIP**

There were 10 people traveling with the international human rights delegation, several of them Americans who looked extremely gringo and spoke no Spanish. They were in a Dodge Ram van that was almost as big as a city bus, and so it seemed a safe bet that their plan to sneak into the state mental hospital in Hidalgo was preposterous. Their hope was to document conditions at this mental institution, considered one of Mexico's snake pits, before the hospital director discovered what they were up to.

They had one thing in their favor. Guiding the international entourage that chilly fall morning was Virginia Gonzalez, the Dorothea Dix of Mexico, that nation's leading advocate for the mentally ill and the country's No. 1 expert on sneaking into mental hospitals. In the previous decade, Virginia Gonzalez had wormed her way into most of the public mental institutions around Mexico, spending three nights posing as a patient at a women's hospital and smuggling a Mexico City mayor into a men's hospital late one night to view horrid conditions there.

At Hidalgo, she believed, the staff was so lax that the investigators might get lucky and walk right in. "I think we can do it," she told Eric Rosenthal, the lead investigator, as they neared the hospital. "We'll see. Nothing is sure." More than once she was beaten up at institutions when she was discovered inside. The last time she tried in Hidalgo, the year before, a guard with a rifle at the front gate turned her away.

This time, the guard booth was empty, the gate unlocked, and at 7:30 a.m. on Nov. 16, 1999, they drove the big van straight down the private road to the hospital. The institution was majestic, an enormous beige and cream-colored hacienda with two bell towers rising four stories above the desert, a place that had the look of a child's castle and once -- long ago, before it was a mental hospital -- belonged to a wealthy Spanish landowner.

"Hurry, hurry," Gonzalez whispered, leading the group through an archway and down a corridor that ended at a closed gate. One push from Gonzalez and it swung open. For an instant, they froze. This is how it must have felt to the ancient Greek soldiers when they unlatched the trap door on the Trojan horse. "Come, we're in," Gonzalez whispered. "You will have your report."

Half rushed off to the men's ward, where two wooden doors were secured with a lock and chain. One of the human rights members, acting as if this were all very routine, vaguely explained that they were a group taking an official tour, and the attendant, assuming his boss had forgotten to notify him, unchained the doors.

Inside, one long room was filled with beds closely packed together, 10 to a row, dorm style. A single nurse was watching the 110 men. Spotting the visitors, several patients crowded around, and one man, naked from the waist down, was suddenly slammed to the floor by another patient trying to squeeze closer. Though some patients had been there 30 years, there were no lockers, night tables or any personal items. Most had already been herded to their usual morning spot, a

walled-off section at the far end of the ward, perhaps 60 feet long by 15 feet wide, where they milled about or huddled together for warmth.

Several were naked. Many were only partly dressed. Few had shoes, though the floor was puddled with urine and scattered with piles of men's feces. The men do not have their own clothes and each morning picked through stacks from the laundry. Unfortunately, the clothes were not carefully sorted, and one man ended up with women's black buckled shoes; a second wore a flowered blouse; a third had on a skirt. As Rosenthal videotaped them, several patients reached their arms over the wall, shook hands and with toothless smiles wished the investigators good health and long life. Juan Martinez Sanchez, an articulate man of 37, explained that he was schizophrenic, had been there three years and wanted desperately to leave. "My family won't come," he said. "They say I'm crazy. And I don't know where else to go."

The nurse on duty, Irma Lopez, who has worked at Hidalgo 28 years, politely answered questions put to her in Spanish by the team. "No," she said, "practically no one ever leaves." She explained that while this was a psychiatric hospital, half the patients were not even mentally ill; they were mentally retarded. The hospital doctors estimate as many as 80 percent could be discharged, but there is not one government-financed group home or apartment program in all of Mexico.

Why, an investigator asked, were so many naked?

"Some want to be naked," Lopez said. "We cannot force them." It was 45 degrees that morning. The hospital has no heat and more than one window on the ward was broken. Investigators wore heavy coats. Lopez lowered her eyes. "So many patients," she said softly. "And so little help."

The team moved on to the women's ward. Just as we walked in, 15 naked women were being marched toward us, and we backed away, to give them privacy. But the naked women paraded past, to a hallway where a male attendant stood beside the shower room. There, as hospital workers came and went in the hall, the 15 naked women squatted, shivering, their arms folded over their breasts for warmth, waiting to shower. Standing nearby, the ward nurse, Oliveria Garcia, explained, "Most days, we may have two towels for 98 women."

Soon, doctors and administrators in white coats began to appear. The always troublesome Virginia Gonzalez had been detected in their midst, and now they were attempting damage control. Cleaners arrived to mop up the urine and feces. Naked patients were rounded up and dressed.

The hospital doctors were angry, but they had decided to act civilly while getting the troublemakers out. Politely yet firmly they escorted Rosenthal and his people away from the patients, to a handsome meeting room that looked as if it might have been the library in the old days of the hacienda. Dr. Victor Vazquez was collegial as we left the wards, though he was also agitated with the investigators. "We don't know," he explained, "if they have the proper permits for such a visit." As he said this, an attendant walked by, escorting a naked man. Vazquez glanced at me to see if I'd noticed, and I said nothing, continuing our civil conversation, although a patient so naked is hard to overlook.

The site visit that morning was one of a hundred this group has conducted at mental institutions worldwide in recent years as it labors to establish treatment of the mentally ill and mentally retarded as a new human right. In Hungary, the investigators documented the barbaric use of bed cages (a bed covered by a padlocked cage). In Armenia, they visited institutions where they were told the annual mortality rate had been as high as 30 percent. In Ukraine, they toured freezing, crowded facilities short of medicine. And practically everywhere they go -- Uruguay, Argentina, Azerbaijan, Romania, Russia -- they see disabled men, women and children who could live in the community, left to rot in remote asylums that are worse than most prisons.

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Known as Mental Disability Rights International, the small organization is based in Washington and financed by George Soros's Open Society Institute. It was founded in 1993 by Rosenthal, who was just 29 at the time and fresh out of Georgetown Law School. The group's ambitious goal is to add a new criterion -- a nation's treatment of its mentally disabled citizens -- to the list of human rights used when judging whether a country should be a member in good standing of the world community. The hope is that eventually, when the United States, the European nations, the United Nations and the World Bank make their foreign aid and trade decisions, they will consider a nation's care of its mental patients along with such well-established human rights as political and religious freedom, torture and prison conditions, slave and child labor and protections afforded refugees.

Already the group has had an impact, even in countries of limited wealth like Mexico. Since Rosenthal's first visits, places that were once as vile as Hidalgo now separate the mentally ill from the retarded, have rehabilitation and vocational programs, teach toilet-training and grooming and take care to see that patients are clothed. Robert Goldman, president of the Organization of American States' human rights commission, says complaints involving care in Latin America are on the rise thanks to the group. "This is pioneering work," says Goldman. "It's slow, incremental, but you're seeing the beginning."

Rosenthal does this all with one other staff person, a few dozen consultants and a \$400,000 annual budget. It helps that he is single, works all the time and zips around like the planet's busiest human. In Mexico, he and his investigators usually started before dawn and finished past midnight. The following month he flew to Lithuania, Hungary, Hong Kong, China.

He believes this is a historic moment for the mentally disabled. Indeed, seeing a place like Hidalgo from the inside is like being transported back in time, to the year 1972, to Staten Island, when a young Geraldo Rivera sneaked his TV camera into Willowbrook, a state institution for the retarded, and filmed the wards crowded with disabled children, their feces smeared on walls. So horrid were conditions, the American public was moved. It helped set off deinstitutionalization in the United States.

At every hospital Rosenthal's human rights investigators toured in Mexico, they heard the same thing: thanks to antipsychotic medications, as many as 80 percent of patients could live in the community if there were supervised housing programs. Mexican government officials

interviewed talked about new plans to begin deinstitutionalization. But can Mexico do it without dumping these patients into the streets? Will such a move create a homeless mentally ill problem that would be as devastating as the problem they're trying to solve? "What you hope," says Rosenthal, "is you can help prevent countries like Mexico from making the same mistakes we did in the U.S. You want to catch them at this crucial moment."

But what you fear is that, like some character in a young-adult adventure novel, Rosenthal has been transported back in time to that crucial night on the Titanic, but no one believes his warnings, history prevails, the ship sinks, the mentally ill become homeless.

For all Rosenthal's efforts, his cause is still barely a blip. Holly Burkhalter, a Washington-based human rights advocate for 20 years, says the group has had "little if any impact" on agencies like Human Rights Watch and Amnesty International, which shape the world's human rights agenda. "Right now, Mental Disability Rights International is not on their radar," she says. "It's a poor reflection on the well-funded human rights community that these issues have been invisible to us."

Until now, the main human rights focus involving mental patients has been the misuse of psychiatry to institutionalize political dissidents in Communist countries. That work was very important, says Rosenthal, but what it overlooked "were the horrid conditions in those hospitals for the thousands of Russian psychiatric patients who *were* mentally ill." Soviet mental hospitals routinely employed orderlies with criminal backgrounds who beat patients, denied them access to bathrooms unless a bribe was paid and stole food sent by their families. There was often no individual psychotherapy or group therapy, no recreational time or vocational training. Some hospitals literally were prisons. At the Chernyakhovsk Special Psychiatric Hospital, which had been converted in the 1960's from a maximum security prison to a hospital, the 446 mentally ill patients were "locked in their rooms" and had to "ask permission to go to the bathroom by turning on a light outside the door of the cell,à}|

The question is, How *do* you make the world see? How do you establish a brand new international human right? The mental disabilities group is working on two fronts. First, it is trying to carve out a body of international law. Ultimately this would involve a United Nations treaty guaranteeing the rights and protections of the mentally disabled, similar to the 1987 convention against torture or the conventions in the 1980's on the rights of women and children. That, however, is not likely to happen soon. Nations are wary of creating new rights, especially ones that cost money. As anyone who has walked New York City's streets knows, not even rich Western nations can be proud of their care of the mentally ill.

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And so, in much the way that an activist American lawyer tries to squeeze a civil rights or labor precedent from the Supreme Court, Mental Disability Rights is trying to squeeze human rights precedents from existing international law. For this they have relied on a mix of U.N. resolutions, including the International Covenant on Civil and Political Rights. That treaty provides in Article 7 that "no one shall be subjected to torture or cruel, inhuman or degrading treatment." When

Rosenthal sees naked, shivering women at Hidalgo, he writes in his report that it is a violation of Article 7 of I.C.C.P.R: "cruel, inhuman or degrading treatment."

And when Dr. Juan deDios Uribe at the Hidalgo hospital tells him that 80 percent of patients could live in the community if the government financed group homes, Rosenthal writes that this is a violation of the 1991 U.N. General Assembly Resolution 119, Principles for Protection of People with Mental Illness: "Every person with mental illness shall have the right to live and work, as far as possible, in the community."

There is good reason for grounding the work in international law. "We are sending a message," says Rosenthal, "that this is not about comparing Mexico to Western standards: this is about the violation of universal law."

Unfortunately, a million violations mean nothing without world opinion on your side, and that is the second, more important -- and far more difficult -- change that must take place to establish a new human right. "Basically," says Rosenthal, "you have to shame the world."

That is when it helps to have a national activist like Virginia Gonzalez and an international one like Rosenthal, who feed off each other. Rosenthal learned this early on from Gonzalez, a maestro at orchestrating press coverage. In 1992, when Mental Disability Rights was still in the planning phase, he was in Mexico on another matter and called Gonzalez about meeting for coffee the next morning before he headed to the airport. He wanted to tell her about the new human rights group he was planning. Gonzalez took him to Ramirez Moreno, then the most notorious mental institution in Mexico City. "She gets me into Ramirez Moreno," he recalls. "We tour the place, and as we walk out, there's a radio reporter waiting for us -- Virginia had arranged it. And the reporter says, 'Tell me, what do you think of conditions?'" At that moment, even before he had an organization, Rosenthal gave his first interview on mental disability rights.

Much of the change in Mexico's public mental health system in the last decade has come thanks to Mexicans, primarily the 50-year-old Gonzalez and her allies both in the government and at various hospitals. But she has also needed help along the way from the international community. She has received financing from international foundations and has been given a platform to denounce Mexican policies at international conferences. She is also likely to get a boost later this month, when Rosenthal releases his report on Mexico, the product of three years' work.

Doing human rights advocacy for 25 years in a country of limited wealth on behalf of people usually dismissed as less than human is a long, hard, often solitary haul, and there have been stretches when Gonzalez has felt as if she has been rolling a Mayan pyramid uphill. But she is rich, politically connected and has never had to hold a paying job, allowing her to make activism

her full-time work. The family wealth comes from a national chain of pharmacies founded by her great-grandfather. Virginia Gonzalez Torres was one of eight children who grew up in a mansion in the upscale Polanco section of Mexico City. Her brother Enrique, a priest, is president of the country's biggest Catholic university; another brother has run (unsuccessfully) for Mexico's presidency; two others own competing pharmacy chains.

After high school, she studied interior decorating, married a businessman and had children -- all that was expected from a woman of her social class. Then in 1973, a sister, Margarita, received a diagnosis of manic depression, and during visits to the private hospital, Virginia found a cause. "I used to sneak patients out in my car, four at a time, with their heads ducked down. We'd go for coffee, see the city, then I'd sneak them back at the end of the day. To me, it was the best therapy." The hospital psychiatrist who uncovered her car therapy sessions suggested a greater cause might be starting a volunteer program at one of the city's public hospitals, Sayago, a women's facility.

In the early 1980's, the Sayago director, since deceased, was not interested in having outsiders come inside to witness the bedlam, but Gonzalez persisted. "Finally, I paid him a bribe," she says. "I said some rich English people wanted to give the hospital money -- it wasn't true; it was my money. Every month I paid him \$400. He wanted it in American dollars -- this was corruption." But it allowed her to get 15 workers doing rehabilitation training at Sayago, her first foothold in the system.

In 1992, she helped make Ramírez Moreno, the men's hospital, as notorious in Mexico as Willowbrook was in the United States. This was a violent place, where you still see patients whose ears were bitten off by other patients. Gonzalez sneaked in with a video camera hidden under her blouse, and the footage made all Mexico's major TV news reports. The administration countered by posting signs on the front gate banning her, but she and a radio reporter sneaked back in anyway. When the director, Salvador Ortiz Freyre, found them inside, he was enraged and went to punch the reporter, who ducked. Instead, he hit Gonzalez. "It was my first hit," she says. But not the last. After confronting workers at the Sayago institution a few years later, she was shoved to the ground, and the day after, wearing a neck brace and lying in a hospital bed surrounded by reporters, she merrily granted interview after interview.

In 1992, Gonzalez filed a legal complaint against the director of Ramirez Moreno and won: Ortiz was removed and banned from government work for a year. By Gonzalez's count, more than a dozen hospital directors and government officials she has done battle with in the years since have lost their jobs. It has made her feared, loathed and respected by those in power.

Ramírez Moreno was a turning point. Gonzalez wanted to establish a citizens' committee at the hospital, to serve an ombudsman function, but the administration refused. So she and her brother, Father Enrique, now the president of Universidad Iberoamericana, visited the secretary of health and persuaded him in 1993 to authorize a citizens' committee at the hospital, a first for Mexico.

In 1995, Virginia Gonzalez was part of a group that drafted a new national mental health law, providing for citizens' committees at every public psychiatric hospital, opening them to scrutiny.

But her most important accomplishment came in the late 1980's, when she used family money -- she estimates they've donated \$2 million -- to open a 12-bed group home and an apartment program that houses another 12. It is the only supervised community housing for the mentally ill in this city of nearly 20 million. By comparison, New York State, with 18 million people, finances about 22,000 community beds for the mentally ill, and even that is insufficient.

"When we invite people to see the program and they come -- they cry," says Gonzalez. "They were all expected to live in a psychiatric hospital forever. It was written in their charts." This was the case with 22-year-old Francisco Fermin. He had been held in Hidalgo for two years, placed there by his mother, when a member of Gonzalez's citizens' committee discovered him during a visit. "Could you get me out?" Fermin begged. "This is for people with mental illness. I am not sick." He wasn't: he is a high-functioning mentally retarded man, nearly in the normal I.Q. range. "I escaped once," he said, "but they brought me back."

Gonzalez pressed Fermin's case with Hidalgo's director. "They said he can't be released; his mother wants him here," said Gonzalez. "But we kept pushing." Two years ago, Fermin moved into her group home. Each day now, he rides the subway to work. "It is excellent," he said, "excellent, excellent. I am free."

Westerners hear of Mexican mental hospitals and assume that every place is like Hidalgo. In fact, during their inspections, investigators were impressed with Mexico City's main short-term public hospital, Fray Bernardino, as well as the children's hospital, Navarro. Even some long-term public hospitals, like Ramírez Moreno, have made much progress. During a 1996 inspection, Rosenthal's team recommended that the hospital separate the mentally ill from the retarded, increase rehabilitation and establish vocational workshops, and all had been done by this visit.

This time, there was hope even on Ramírez Moreno's toughest wards. Dr. Saul Bustillos works with men so profoundly retarded they do not talk; they grunt. He has developed a detailed training chart, which he showed investigators. "Routine is everything," he explained. "You see, here they go to the toilet three times a day, the same time, every day. They spend three or four minutes in the toilet; they do it all by themselves. Same thing, they practice dressing -- 29 of 31 can dress themselves."

At lunch, the human rights team saw men who used to eat like dogs, their faces shoved into their plates, using forks and spoons.

Bustillos showed the visitors a music therapy session. Patients sat in a circle, staring at a tape player in the center. "They need to see where the music comes from," said the doctor. "Otherwise they look around; they don't concentrate; they think it's magic." He has experimented with several types of music. "They like Jamaican music -- steel drums, a lot of percussion. And certain classical music like Ravel's 'Bolero.' They like Johann Strauss waltzes."

One morning before dawn, the human rights team flew an hour from the capital to Guadalajara, the nation's second-largest city, to visit a state psychiatric hospital there. Like most of these

places, it was located way out in the countryside, invisible to the public, far from the historic city center where strolling mariachis in sombreros entertain tourists.

The doctors explained that the psychiatric hospital is divided into two sections, adult and children. But as the human rights team toured the children's facility, it quickly became apparent that this was neither a children's hospital nor a psychiatric hospital; it was an institution for the retarded inside the larger mental hospital, where children as young as 8 mix with adults.

The ward for the profoundly retarded had been built in a pentagon shape with a nurse's station in the center surrounded by five locked, barred rooms. The nurse's station was empty -- the hospital has just six ward aides for the 58 retarded patients, and the aides spend all day either feeding them or cleaning them. The only furniture in the rooms, which were tiled from floor to ceiling and had steel grates over the windows, were metal beds, half a dozen to a room. There were no couches, chairs, toys, sports equipment, TV, radio or music. There was not a single decoration, stuffed animal or rubber ball. "We stopped putting in toys," Dr. Enrique Madrigal explained. "They just hurt themselves." No one on the staff had time to play with them, teach toilet training, grooming or eating skills.

One boy's hands were tied together; another boy was tied at one ankle to his bed; a third was tied by the stump of his leg -- he had no foot -- to the window grate. In these rooms, they spent their entire days. While there was a grassy courtyard outside, the doctors explained that too many got bug bites and rashes from the grass and could not be left alone. "We know these kids will die here for sure," said Dr. Armando Rodriguez.

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In some ways, it was harder at the other end of the children's hospital, where the high functioning were kept. Antonio Ruiz Cabañas is 24 now. He has been at the children's hospital since coming from an orphanage at age 8. His real last name is not Ruiz Cabañas; he was abandoned as a baby, and like others at the children's hospital was given the family name of the orphanage priest. Among Antonio Ruiz Cabañas's mates on the ward are Gustavo Ruiz Cabañas and Leopoldo Ruiz Cabañas.

"Antonio has independent skills," Rodriguez tells the human rights team. "He can wash, shave, shower. He works at a craft program at the hospital and makes 21 pesos a day" (about \$2). Antonio takes them to see his bed, which he has made. There are even a few possessions arranged neatly on a night table.

So why is he institutionalized? "There are many hospitalized patients -- they don't need to be here," says Rodriguez. "He would like to travel to the city to work, but it is far and he has no practice taking buses." As with many of the high functioning, his biggest problem is that his retardation makes him too naive and trusting -- simple" is the old-fashioned word. On his own, he would be an easy mark for the world's supposedly normal people.

The hospital directors have discussed opening a group home for the mentally retarded and one for the mentally ill, but do not have money. Antonio Ruiz has heard the plans. "I'd like to be in that house," he says. Once he knows the city, he says, "I won't have fear. I like to work."

Dr. Daniel Ojeda, the hospital director, says for six years he tried to raise funds. "The federal government should give support to do this program," he says, "but doesn't."

"This is a psychiatric hospital. The mentally retarded should not be here. But there's no place for them. This hospital is doing something it is not qualified to do and shouldn't be doing. People like Antonio are here because they've been rejected by their families, and the only place that accepted them is the psychiatric hospital."

At the end of each tour, the human rights team gathered with the hospital directors to review the visit. These meetings started out tense. The two sides sat across from each other, staring, whispering.

Human rights members were repulsed by what they had seen, yet at the same time exhilarated to have captured so much incriminating footage on their video cameras for the report.

Hospital directors were angry at being judged by these naive people who would come and go in a day and not realize how limited the resources are, how little the public cares, how thankless the task.

But as the meetings progressed, there invariably would be a warming of relations. As people spoke, it began to sink in that the two sides had much in common: they were among a tiny minority who cared about such things. Both sides were trying to pry loose more resources for this population. After an hour, the hospital director actually thanked Virginia Gonzalez. "The attention you give the mentally ill has improved things in our country," Ojeda said. "Societies don't want to see these institutions, and now it's changing a little and that will help the mentally ill."

Rosenthal mentioned that it was the goal of Mexico's federal government to reduce the institutional population. In an interview earlier that week, the federal mental health director, Dr. Carlos Gamez, had told Rosenthal that he hoped to see the nation's hospital census cut 30 percent in the next year.

Ojeda, the Guadalajara hospital director, looked stunned when Rosenthal mentioned this. "Where will they go?" he asked.

Where will they go? That is the question, not just in Mexico but also in Latin America, eastern Europe and Russia when the inevitable happens. Gamez, the federal official, says he has requested funds for community housing, but he acknowledged nothing had been budgeted yet.

In this respect, there was disturbing news, too, at Ramírez Moreno, the men's institution in Mexico City. While explaining the hospital's improvements, the director there, Dr. Jose Sanchez,

talked about efforts to reduce its size. "We have been able to cut the hospital population," he said proudly, from 500 to 300 patients in four years.

Where did they go? he was asked

"Back to their families," Sanchez said. After discharge, he said, the hospital set up a plan to keep in touch by calling them on the phone or having them contact the hospital.

Did it work?

"Most didn't call," he said. "We lost contact."

Did he think these families were equipped to take care of patients who had been hospitalized so long?

"Most can't," he said. "They're poor and not much education."

Where do you think they are?

"We don't know."

The streets?

He nodded. "It is possible," he said.