

Last Rights

As a human-rights issue, treatment of the mentally disabled routinely gets ignored around the globe. Eric Rosenthal, AB'85, works to make governments see—and address—the problem.

ON A GRAY MORNING IN JUNE, Eric Rosenthal's taxi pulls up in front of a drab two-story building on a quiet side street in Braila, Romania, a small industrial city about 100 miles northeast of Bucharest. With its pale concrete exterior, the building looks like countless others in Eastern Europe, except that bars cover its windows. A sign above the entrance identifies it as a ward for chronically ill children, a part of St. Pantelimon Psychiatric Hospital. Rosenthal presses the entrance buzzer and waits, listening to the cries of children in the still morning air.

Rosenthal, AB'85, is the founder and executive director of Mental Disability Rights International ([MDRI](#)), a Washington-based group devoted to helping the mentally disabled around the world. An earnest and energetic 41-year-old lawyer, Rosenthal started MDRI in 1993 after concluding that the major human-rights organizations were ignoring the plight of people with mental illness and retardation. Since then he has worked in 23 countries, investigating abuses, training activists, and lobbying governments. He has become a forceful advocate for the mentally disabled and a leader in the growing movement to view their treatment not only as a social problem but also as a human-rights issue.



Rosenthal has worked in Romania since the mid-1990s, but this weeklong trip comes at a critical moment. With Romania preparing to enter the European Union in 2007, the government is under pressure to institute reforms in many areas, including human rights. Romania's psychiatric institutions have aroused particular concern. In January and February 2004, a scandal broke out when, according to an Amnesty International report, 18 patients died of hypothermia and malnutrition at a hospital in Poiana Mare. But Rosenthal wants the government to do more than improve the living conditions in psychiatric institutions; he wants it to ensure humane, effective treatment, to prevent people from being committed against their will, and, ultimately, to remove patients from the isolation of institutions and integrate them back into their communities.

Rosenthal is slightly plump and still boyish, with wire-rimmed glasses and suspenders. He carries a small video camera in his pants pocket, where he can retrieve it quickly and, if necessary, surreptitiously. He learned long ago that images of abused patients are more effective than reports at shaming governments and arousing public indignation. With him are Ivan Fiser, a Serbian-born lawyer and human-rights expert with an insider's understanding of Eastern Europe; Robert Okin, AB'64, MD'67, head of psychiatry at San Francisco General Hospital and a leader in U.S. mental-health reform; and Georgiana Pascu, a young activist from the Center for Legal Research, a Romanian organization that monitors psychiatric institutions.

Rosenthal and his colleagues have shown up unannounced: it's the only way they can hope to get a true picture of an institution. On a surprise visit to St. Pantelimon several months earlier, Pascu found almost all the children confined to their cribs. A letter of complaint to the national child-protection agency, she says, brought no response.

Finally the door creaks open and a balding, middle-aged man in a short-sleeved shirt invites them in. He is Stefan Bobosescu, the resident psychiatrist. When they describe their mission and produce a letter of support from the Ministry of Health, he ushers them into a small room off the lobby and says nervously that he must call the hospital's director. Then he disappears, leaving them sitting in battered chairs, sipping mineral water from tiny plastic cups and feeling thwarted. "So much for the element of surprise," Okin says.

"I'm very sorry," the doctor apologizes when he returns, now changed into a white lab coat. "We are in a very big cleaning—the beds, the walls. I don't know how to say in English. It's not very pleasant." He sits down and begins to talk. The ward houses 46 children, he says, most suffering from cerebral palsy and severe mental retardation. Some have other afflictions, including epilepsy. But changes lie ahead, he says. The building is to be transformed into a ward for the acutely ill, and almost half the patients will be placed in the care of the child-protection agency and perhaps moved to foster homes. The rest will receive medical treatment elsewhere.

Rosenthal is skeptical. "How many children here have psychiatric problems?" he asks. One concern of MDRI is that many children—and adults—in psychiatric institutions lack problems that justify long-term confinement.

"Because they stay all their life in institutions, all of them have intense problems," Bobosescu says frankly. "Even if a normal person were to stay here a month, they would have problems. This is the situation here. What can I say?"

They listen impatiently and with growing concern. Rosenthal has been turned away from institutions he visits, but rarely. At last, half an hour later, the hospital's medical director appears. Heavy-set and stern, she holds a long conversation in Romanian with Pascu before agreeing to let them see the ward. She forbids photography. Rosenthal's camera remains in his pocket as Bobosescu leads the group next door.

In a sparsely furnished room nine children sit at tables. All have short-cropped hair, making it hard to tell boys from girls. Coloring books lie unused in front of them. There are no toys. Often, Rosenthal says, an institution's staff will force children into chairs to impress visitors. When the children see the newcomers, some grow excited. One leaps up, grinning wildly, and clutches Fiser. Two others rock back and forth in their seats, oblivious. Another strikes himself on the head with both palms. Rosenthal scribbles in his notebook. "Self-abuse is a sign of neglect," he whispers. "They lack stimulation, so they self-stimulate." Two women minding the children struggle to keep order.

In the next room stand rows of white iron cribs. Only one is occupied, by a girl who lies covered with a sheet and blanket. She stares at the visitors, mouth agape. Bobosescu says she is 12 years old, but she looks no more than four or five. When the group moves away she begins to moan.

“It’s very difficult,” Bobosescu says. “You are from the USA. Maybe 100 years ago it was like this.”

“No, very recently—30 to 40 years ago,” says Okin. Indeed, the conditions in many of the institutions MDRI investigates are not far different from those that until recently prevailed in some large psychiatric hospitals in the United States. Okin, who headed state mental-health departments in Vermont and Massachusetts, has devoted much of his career to providing effective community services for people with mental disabilities.

“It’s not possible,” the doctor insists, shaking his head. “I can’t believe that. We’re saying that we have these problems because of communism. But in the USA, the first country in the world? It’s not possible. To us, USA is another planet!”

Rosenthal, who has a three-year-old daughter at home in Washington, approaches the girl, bends down, and smiles. “Hello! Hello!” he says cheerily. “See! That’s a smile.” With effort she lifts her head. She seems to be trying to get up, but this small movement is all she can manage.

The meager furnishings, the lack of toys, the small staff, the boredom and inactivity—all point to an environment of neglect and despair. The ward, Bobosescu says, has not employed a physical therapist for two years. And Rosenthal notes subtler signs of neglect. Strips of white cloth on a crib-room table are physical restraints, a device restricted by international convention but often overused, especially where staffing is low. A bench’s legs have been chewed, a sign of a child’s boredom.

They climb to the next floor and a large room where half a dozen children sit on a red pad; a television flickers on the wall. Off to one side, a child furiously rides a small rocking elephant. An emaciated boy of 14 sits with his bony hands clenched over his face.

Rosenthal hangs back, taking notes, while Okin crouches and plays with the children. Their actions reflect both a difference in temperament and a division of labor. While Rosenthal documents the visit for his reports, Okin judges the patients’ physical and psychological states, balancing MDRI’s legalistic approach with consideration of the patients’ medical needs. He lifts one small boy to his feet. “Good! Good!” he says as the boy stands. Legs trembling, he kisses Okin on the nose. Okin is not simply showing kindness; he also is gauging the boy’s fitness and development, his strength and range of motion, his willingness to make eye contact, his capacity for touch. Abused children often shrink from a stranger’s approach. But the staff here, whatever its deficiencies, seems kindly, and many of the children yearn for human contact.



In two adjoining rooms, rows of cribs hold children in far worse shape. Okin and Rosenthal stand over a boy swaddled like an infant, arms and legs bound. A nurse tells the visitors he is seven

years old. It's hard to believe, his body is so shrunken. But his black eyes shine. "Will this child have to spend all his life bound like this?" Okin asks.

"We don't know," Bobosescu says. He explains that unless the boy has someone with him all the time he will chew on his fingers. "But we do not have enough staff. It is very difficult."

Okin suggests gloves. "There has got to be another way," he murmurs. He reaches down and feels the strips of cloth that bind the boy's legs: "This is unbelievably tight." He asks if the strips can be removed. A nurse unties them and unwinds the sheets. The boy's skeletal body is naked except for a rag that serves as a diaper. Sores fester on his legs. He has gnawed several fingers to red, swollen stumps.

A nurse lifts him gently in her arms. Talking soothingly, she carries the child to a sink and begins to bathe him.

At last the medical director relents and says photographs are OK. Rosenthal pulls out his camcorder and moves from crib to crib, relentless and thorough. The rooms offer a grim montage. A 12-year-old-girl named Joana, with short hair and huge eyes, scratches her head compulsively. Okin unwinds the covering sheets and examines her pale, shrunken form. Two nurses give her a bath, redo the swaddling, and return her to the crib. Flies swarm around a girl named Adina, who is 15 but looks four or five. A 12-year-old boy named Costel wears a jagged smile that is half grin, half grimace with several teeth missing. He is bound in an awkward position, feet up over his head and held in place by a red sweater. A free hand clutches the bars of his crib.

"It's hard to know what they would be like today if they had had early intervention," Okin says. Merely living in a hospital, without emotional attachment or regular physical exercise, can cause enormous physical, psychological, intellectual, and emotional damage. "I've never seen anything like this before," Okin continues softly. "It's terrible. These poor children."

Bobosescu is clearly embarrassed. "I'm sorry for the situation," he says. "I hope you'll take away not only the bad aspects. Next year these children will be other places. It will not be a problem."

Later, as they ride away in taxis, heading toward an adult ward of the same hospital, Rosenthal and Okin compare St. Pantelimon to other places they've visited over the past decade. "I'd say it's worse than Azerbaijan," says Rosenthal, recalling a particularly bad orphanage. "I've never seen so many kids tied down. Those kids were literally wrapped from head to toe. I've never seen so many kids like that."

"The bottom line is, no kid should be left in an institution," he says a few minutes later. "That's an international convention. Children with disabilities have a right to treatment and care to maximize their social integration. These children are not getting close to maximizing their social integration. Quite the opposite." The images will haunt him for days.

THE NOTION OF FUNDAMENTAL HUMAN RIGHTS is an old one. Sophocles's Antigone invokes a kind of human right when she defies Creon's order to leave her slain brother

unburied, arguing that she is obeying the unchanging laws of the gods. Eighteenth-century revolutionaries appealed unambiguously to the idea of universal rights, such as life, liberty, and the pursuit of happiness. Modern human rights grew out of the Second World War and the crimes of Nazi Germany. At Nuremberg, German officials faced charges of crimes against humanity, even when their actions had been permitted by local laws. In 1948 the United Nations General Assembly adopted the Universal Declaration of Human Rights, a fundamental document that called for, among other things, freedom from cruel, inhumane, or degrading treatment or punishment.

The human-rights movement flowered in the 1980s and '90s as Europe and the Americas adopted regional conventions, Europe and Latin America established human-rights courts, and international tribunals sprang up to judge accused war criminals in places like the former Yugoslavia. More groups received the protection of human-rights conventions, including children, migrant laborers, and women. Yet those with mental disabilities were overlooked. Kenneth Roth, executive director of Human Rights Watch, wrote in 2002 that “people with disabilities are among the human rights community’s most neglected victims.”

Rosenthal had discovered this neglect years earlier. Mental illness had touched his own family—his grandmother suffered from manic depression—and he came to the University hoping to become a psychiatrist. “I wanted to be a professional,” he says. “I wanted to help people. I was interested in mental health. I thought being a psychiatrist would be one way to do that.”

First-year chemistry persuaded him that that his future lay elsewhere than medicine. He ended up taking a special major in politics, economics, rhetoric, and law, writing a senior thesis on the insanity defense. He took courses in clinical psychology along the way and spent the summer before his senior year researching thought disorders and schizophrenia at Michael Reese Hospital on the South Side. It was the first of many unpleasant experiences: “I found it deeply, deeply impersonal,” he recalls. “People were in crisis, and we were studying them. It felt so dehumanizing to be in this institution at all. I had this gut feeling that something was wrong. I knew I didn’t want to be a mental-health professional.”

The troubled feeling persisted. After graduation he joined the peace movement in Israel and spent two years living near the West Bank, where he herded sheep and thought about next steps. “I decided that to bring about peace and justice you have to protect human rights,” he says. He returned to the States determined to become a human-rights lawyer. While studying for the LSAT he worked as a paralegal at the Mental Health Law Project in Washington, fielding calls. Most callers were patients in psychiatric institutions who wanted out. “It was an unbelievable education,” he says. “It taught me that the system has a capacity for incredible abuse and that people had almost no protection.”

In 1989 he entered Georgetown University’s law school. While researching a paper on the rights of the mentally ill, he discovered that little had been written on the subject. The exceptions were cases involving political dissidents in Soviet psychiatric institutions. The descriptions of these institutions recalled what he had heard from the patients calling the Mental Health Law Project. And yet the human-rights groups seemed concerned only for the dissidents.

Following law school he worked at the Minnesota Advocates for Human Rights, documenting abuses against indigenous people in Mexico. When a Mexican activist took him to a psychiatric hospital, he found “a horrifying scene. Naked and scantily clad people covered by their own urine and feces. Barbed wire.” Returning home, he used a \$25,000 fellowship from the Echoing Green Foundation to launch MDRI. Its director and sole employee, he worked out of office space donated by American University’s College of Law.

People who know Rosenthal say he is driven by a passion for social justice. He is also persistent. As a law student interning at Human Rights Watch in New York, he once followed the group’s executive director, Aryeh Neier, into an elevator. Between floors they talked about the mentally disabled. When Neier moved to the Open Society Institute, which funds projects in Eastern Europe, Rosenthal asked for funding. He got it.

Psychiatrist Judit Harangozo, who worked with Rosenthal in Hungary, admires his dedication. “He wanted to give 100 percent,” says Harangozo, secretary of the Awakenings Foundation, a mental-health advocacy group. “He had a kind of empathy. He really wanted to know what was here—not just to bring the truth from somewhere else, but to cooperate and communicate.”

Indignation pervades Rosenthal’s writing and sustains him on five or six missions a year and visits to scores of psychiatric institutions. “When you see the suffering and hear all the stories, there’s a certain outrage,” he says. “But it’s not all about outrage. It’s also about inspiration. There are some amazingly inspiring activists.”

Today MDRI has nine employees and satellite offices in London and Kosovo. Rosenthal has become a well-known expert on mental-health policy and on applying human-rights law to the mentally disabled, advising the World Health Organization and the United Nations. He collaborated with Senator Tom Harkin of Iowa, a longtime advocate for the disabled, on legislation that requires a portion of U.S. foreign aid to be earmarked for people with disabilities.

Working mainly in Eastern Europe and Latin America, MDRI has two broad aims. One is to persuade governments and other organizations, including international donors, to protect the mentally disabled from such abuses as involuntary hospitalization, excessive use of restraints, and other inhumane conditions. The organization also promotes deinstitutionalization—allowing people with mental disabilities to live in ordinary community settings. Nothing annoys Rosenthal more than the suggestion that the way to correct abuses in a psychiatric institution is to build a better hospital. In addition to assembling teams of lawyers, psychiatrists, and local experts to visit mental institutions and to lobby officials, MDRI trains local activists to monitor institutions and to exert pressure for reform. Harangozo, who is one such activist, says she had little appreciation for the scale of abuse in her country until MDRI investigated it.

Often governments—Romania is a good example—embrace reform in theory but do little to carry it out. When Rosenthal began MDRI he assumed that “holding up a mirror” to abuses would shame governments into change. “We quickly learned that we had to put an enormous amount of effort into training activities and staying in a country until something got done.” Finding and cultivating local allies has been critical. He made little progress in Romania until

MDRI teamed up with the Center for Legal Research, a group with experienced staff and political connections.

A harder lesson Rosenthal has learned is that MDRI can't do everything. In 1996 it joined with an organization in Sibiu, Romania, to create community services for about 400 institutionalized mentally retarded people. It trained a group of activists, bringing them to the United States on a study tour. The goal was to take the people out of the institution and, by providing supportive working and living environments, help them live in society. But the project failed to receive funding, and MDRI had to pull out. "We raised hopes and couldn't follow through," Rosenthal admits. Afterward he resolved to stick to advocacy and monitoring and leave other groups to provide services.

How well has he succeeded? In a dozen years MDRI has published major reports on human-rights abuses in seven countries: Peru, Uruguay, Mexico, Kosovo, Russia, Hungary, and, most recently, Turkey. Nowhere, however, has it produced broad-scale reform. Working more than a decade in Hungary, MDRI exposed glaring abuses, including the use of cages to restrain patients. It managed to end some of the worst practices—the government finally banned cages in 2004. Hungary has been equally slow in carrying out deinstitutionalization; a system of community services remains in its infancy. Hungarian psychiatrists also resisted MDRI's efforts, spreading rumors it was linked to Scientology, says Harangozo, who suffered professionally for her association with the group. Yet she calls MDRI's work "revolutionary" for making abuses a human-rights issue. "It did not change the system immediately," she says. "But it sped up the process."

Michelle Funk, a World Health Organization official who works with governments on mental-health legislation, says MDRI has done important work in calling attention to human-rights violations around the world. But success with this approach, she says, creates its own obstacles: "Once a government has been blamed and exposed in public, it's unlikely that it wants to work with the group who has blamed them. It makes it more difficult for them to develop a more cooperative working relationship to change things."

Where MDRI has achieved its quickest results has been in battles over individual institutions. In 2000 the Mexican government closed a hospital in Hidalgo after MDRI publicized the bleak conditions there, moving patients to group homes. Last February the Paraguayan government agreed to close the state psychiatric hospital in Asunción within five years after MDRI and another organization complained to the Intra-American Commission on Human Rights about patient treatment. Cesar Escobar, the hospital's medical director, says MDRI's intervention put enormous pressure on the staff but conceded that its complaints were just.

Rosenthal hopes successes like these will lead to broader deinstitutionalization. Often government officials resist the change, either because they assume people living in large institutions can't function on the outside or because they believe providing services will cost too much. Counterexamples are crucial, Rosenthal says, yet hard to come by. In Mexico, he says, the government made closing the Hidalgo hospital a model for other parts of the country: "It hasn't been followed, ostensibly for lack of funding, but really for lack of pressure." Because the mentally disabled remain among society's weakest and most vulnerable members, he says,

governments still find it easy to ignore them. The numbers of local activists, often parents of the mentally disabled, are growing, but too often, he says, they are still “a voice in the wilderness.”

It’s not only governments that Rosenthal grapples with. In a 2002 report, MDRI revealed inhumane conditions at a psychiatric hospital in Kosovo, a province of Serbia under NATO and United Nations control since 1999. Rosenthal was optimistic about reform: the UN was in charge and foreign aid was pouring in. Yet the UN, ethnic Albanian officials, and international donors hesitated to carry out MDRI’s recommendations. Rather than close the guilty hospital, they used foreign aid to refurbish it—a waste of money, Rosenthal says. When group homes finally opened, some were in locations so remote and inaccessible that the residents were no less isolated than before.

In Kosovo and elsewhere, international organizations have lagged in viewing the treatment of the mentally disabled as a pressing human-rights issue. Only within the past three years has the World Bank, a major funder of reforms in developing countries, begun to devote a portion of its loans to people with disabilities. “It’s still a relatively new area for the bank,” says Jeanine Braithwaite, the bank’s disability coordinator for Europe and central Asia. Last summer one major sponsor of human-rights work—Rosenthal would not say which—declined to award MDRI a grant, saying that the war on terror had made other human-rights issues a greater priority.

“There are always other priorities,” Rosenthal grumbles. “Mental disabilities are never a priority.”

Leaving the children’s ward of St. Pantelimon, Rosenthal and the others ride several miles to a four-story building that houses 132 men and women deemed to have chronic psychiatric problems. Although it is early afternoon, they find most patients lying or sitting on their beds. The patients stare at them dully. There seems to be little to do—the ward lacks even a day room. As the group goes from room to room it encounters the same listlessness, the same vacant looks.

“Think of what keeps people sitting in bed like this all day,” Rosenthal whispers. “It’s either high levels of medicine or extremely long stays that take the life out of people.” Afterward they travel to the main hospital and pay a visit to its director, an urbane, dark-suited man who tells them, “One of the reasons the situation is so dramatic is the lack of money.” It’s a complaint they hear often.

Later in the week they drive north through the Carpathian Mountains to the village of Vulcan, to see another psychiatric institution for the chronically ill. Set on a hill near the edge of the village and girded by a concrete wall, the ward is more isolated— and yet livelier—than the adult ward in Braila. Patients wander the halls, watch television, bum cigarettes. A couple lies in bed together—one of three or four couples with long relationships, the staff says. “You don’t have the sense that there is an oppressive regime here,” says Fiser. Yet the staffing is low, the building old, the patients cut off from ordinary life, shut away with nothing to do. Even the few freedoms patients enjoy conjure up darker possibilities. When Fiser and the others ask about sexual violence, the staff assures them the men are mostly impotent.

They drive on to the medieval city of Brasov to see a hospital for acute cases, where patients stay for shorter periods. Although some human-rights investigators think visiting in a group is a mistake, Rosenthal believes it offers tactical advantages. Wherever they go, after a while one or two of them lag behind or wander off unnoticed, searching for whatever the staff does not want them to see. Rosenthal makes a point of looking into the bathrooms. He videotapes water on the floor, broken fixtures, any kind of filth. In Vulcan he videotapes one patient carrying another man, who cannot move on his own, to the toilet. Okin sometimes asks to look at patient files to see what medicines and dosages have been prescribed. Fiser, who speaks Romanian, regularly slips away to talk to patients and listen to their stories, looking for cases that might be brought to the European Court on Human Rights to challenge commitment procedures. Often families commit relatives against their will because they are too difficult to care for. In Braila a 40-year-old woman says she wants to go home but can't. "If her sister wants her out, she can go out," the medical director explains. "If not, she will stay here." In Brasov Fiser meets a woman who says her family has threatened to send her to Vulcan if she makes trouble. He gives her his card and invites her to call.

Amid the bleak conditions, the visits reveal moments of humanity. In Vulcan a woman in her 50s with amputated legs perches on a wooden dolly and gazes raptly at a television broadcast of folk dancers. She smiles broadly and poses for a picture. Outside, Okin photographs a patient with his digital camera. When he sees his image, the man cries out with delight and demands to see it again and again. In Brasov the team has a long conversation with a middle-aged psychiatrist who seems to be doing her best despite the conditions. Rosenthal and the others seldom blame the staff for the problems they find. Often, they say, the employees are as much victims of official neglect as the patients. "Thank you," Okin tells the director as they say goodbye. The woman beams.

Between hospital visits they meet with government and aid officials, including a representative of USAID, the foreign-aid arm of the United States. A meeting with high-level Romanian officials convinces them that the government may establish a commission to protect the rights of the mentally disabled. The World Bank has been talking with Romanian officials about lending the government millions of dollars to help the disabled, including those with mental disabilities. Rosenthal thinks MDRI can persuade USAID to spend \$500,000 on training advocates. But what excites him most is the hope that they can pressure the government to rescue the children in Braila. "It's a breakthrough issue," he says, pacing back and forth outside a hotel in the mountains, where they have assembled in the open air for a final strategy session. "It's something everyone understands. It's an issue that can generate publicity and fire and drive—'The Kids of Braila!'"

THE WEEKS AND MONTHS THAT FOLLOW yield mixed results. The government commission never materializes. The American government bestows no aid. The loan from the World Bank is delayed. Yet by late summer Romania has begun to transfer some of the Braila children to institutions where they can receive better treatment. "They start to eat and to walk," says Georgiana Pascu by phone from her office in Bucharest. "They have another kind of life." Meanwhile, another American psychiatrist evaluates the remaining children, the most difficult cases. The government promises to work through a private charity to move them to group homes.

It's a small step, but to Rosenthal it's deeply gratifying. It falls well short of the wider change he strives for, but then almost everything does. Without a broad vision, he might never have gotten started. To him MDRI stands at the vanguard of the human-rights movement, pricking the global conscience. Someday, he says, "the public is going to understand that this is one of the most serious human-rights issues in the world."

For now, small steps like helping the children of Braila keep him going, and he's proud of the progress he's made: "For a long time I was living on the edge. Now I'm up to a staff of nine people. We're really as an organization starting to turn the corner." One day he would like MDRI to have a global reach, with experts everywhere. "This is a worldwide problem," he says. "It demands a worldwide response. That's my goal." In the meantime he keeps pushing—one visit at a time.