

Speaking Up for the Mentally Disabled

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A slight hissing sound, some static, and suddenly the video takes us inside an Armenian "orphanage." The rooms look barren and cold; a few teddy bears hang on a wall, out of any child's reach.

Here some 170 children live, many of them since birth. They have been brought here with problems such as mental retardation, left by families who can't afford their care or cope with their disabilities. Most are eerily quiet. One boy with beautiful dark eyes plays with a plastic bag, slowly twisting it again and again. No one bounces a ball, or giggles, or flips the pages of a book.

One child, sitting in his own waste, breaks the silence with a wail--a horrible, desperate shriek.

This is international human rights activist Eric Rosenthal's video, and for the last seven years, documenting such conditions has been his life. And for anyone who will sit long enough to listen, this is the point of it all: "People with disabilities have a life, a past, they have strengths. But instead of building on those strengths, they're allowed to degenerate."

Rosenthal, a Georgetown University-trained lawyer, by no means believes that mental health care in the United States is ideal. But he's chosen to focus abroad on places where, despite the efforts of activists in their home countries, people with mental disabilities too often are consigned to neglect, isolation and a lifetime of institutionalization.

As executive director of Mental Disability Rights International (MDRI), he's distinguished himself as one of the few full-time advocates on the world stage for the rights of people with mental disabilities. He's based in a downtown office in Northwest Washington, but since he started MDRI--which includes one assistant and an advisory board--he's traveled to 12 countries and more than 50 institutions.

Some four months out of the year he jumps into a grueling travel schedule, moving from one country to the next, recording human rights abuses and advocating for reform.

In Hungary he saw a woman beating her bloodied head against a metal-caged bed. In Russia he saw five or six infants crowded into one vinyl-lined metal crib. In Mexico--where he just finished a major report to be released next month--he saw flies crawling into a child's mouth and no one offering any help.

The children's wards, he says, are the hardest.

"Kids run up to you. They hold you, they hug you. They think you are their daddy. They ask you to take them home."

Rosenthal wants the world to formally recognize the human rights of children and adults with mental disabilities with an international treaty. He wants deinstitutionalization, or as he calls it, community integration, the opportunity for people with mental disabilities to have full participation in every aspect of society, from education to jobs to politics.

He believes long-term institutions are vacuums that can devour a person's soul. "If you're in an institution for years, you get nothingness, the horror of a lifetime of nothingness."

Despite such conditions, even major international human rights organizations have neglected the issue, he says.

"I would read reports by human rights workers who would go into a psychiatric institution and describe horrible conditions, the use of drugs with agonizing side effects, massive overcrowding, filth. And they would cry foul that three political dissidents were being held there," Rosenthal says. "But they would not mention one word about the hundreds of other people in the same horrible conditions."

Rosenthal's efforts are paying off. He's helped push through legal changes in Hungary, aided family advocacy groups in Russia and trained hundreds of activists. Now he's helping to draw an international media spotlight on some abysmal institutions in Mexico. Officials there have already made some reforms, but Rosenthal says there's still far to go.

The Advocate as a Young Man

For a man who spends much of his time in hard-to-imagine places, Eric Rosenthal's apartment is disarmingly warm. A big-hipped statue made years ago in his high school art class is the embodiment of his cheerful personality.

At 36, he still has a boyish face and a head full of brown hair, and is a little roundish in the middle. He is a man who's always in a bit of a hurry.

His line of work doesn't make having a relationship easy, but he and his girlfriend of six months have managed--they spend a lot of time talking on the phone and e-mailing.

With his oval glasses, suspenders and green-speckled tie, Rosenthal looks more the small-town lawyer than the impassioned activist.

"Eric Rosenthal was an extraordinarily talented law student," says Philip G. Schrag, one of his former professors. "He could have made a fortune in law or business, but he chose to apply his great entrepreneurial talents to public service."

Rosenthal's international efforts in the mental health field were sparked seven years ago when he was on a mission to Chihuahua, Mexico, for Minnesota Advocates for Human Rights,

investigating allegations of military abuses. Before heading home, he accepted an offer to visit a psychiatric institution. It was "one of the most horrifying experiences of my life," he says now.

"Filth, squalor, the most horrible conditions. I remember it vividly. . . . The lack of human dignity was amazing, even to me, though I had been to many [U.S.] psychiatric hospitals."

He found people strewn lifelessly on the home's fields and others lying naked on concrete floors. "The indigenous people in [Chihuahua] were poor and abused by their government," he says. "But when you live in your own village, have your own family, there's a certain human dignity you can maintain. People in a psychiatric hospital have none of that."

That was it, the emotional turning point. "I said to myself, 'You know, Eric, you really have to do this.'"

He had been eyeing a job at Human Rights Watch, but after what he'd witnessed in Mexico decided not even to apply. "If I didn't do the [Human Rights Watch] job, it would get done, but if I didn't do human rights work for people in psychiatric institutions, no one else would do it," he says.

So Rosenthal landed a fellowship that paid \$25,000 "for people with an idea" and founded MDRI.

He will tell you that he stumbled into this work. But look at his life, and it's clear that he has been headed in this direction for a long time.

His father's career with the United States Agency for International Development gave Rosenthal his international perspective. His family lived in Tunisia, Italy and the Ivory Coast before he was 12.

The roots of his interest in mental health are not so easy to pin down.

"I'd say my neurotic family is probably no more or less neurotic than any other middle-class American Jewish family," Rosenthal laughs. His maternal grandmother was diagnosed with manic depression, but he plays down the effect it might have had on his own life. "If you scratch the surface, most people have someone with a diagnosis of something in their family."

In any case, he went on to merge an interest in human rights with an interest in mental health. As an undergraduate at the University of Chicago, he worked on a psychiatric ward. His first job after college involved helping U.S. psychiatric patients get legal assistance. And as a law student, he co-authored an article arguing that the U.N. Principles for the Protection of Persons with Mental Illness--which are not legally binding--could be used to interpret treaties that are. The work may be a turning point for the rights of people with mental disabilities.

A Healthy Distance

His work comes with its own price.

"I used to get psychosomatic asthma attacks when I walked into an institution because it felt so horrible," Rosenthal says. He survived by learning to withdraw as much as possible. He has become, he says, the investigator, taking notes rather than taking hold of every extended hand, interviewing staff and patients about conditions, rather than learning too much about any one person.

"It is very, very easy to dehumanize people," he says. "I've been dehumanized, too. . . . It frightens me the extent to which I can emotionally disengage."

And yet: "I go into an institution and I see possibilities, how things can be better. If you view people with disabilities as pathetic souls, then you can feel all is lost. But if you see that their lives can be better, then you see hope."

On visits, he's been awed as fellow activists connect with patients. "People who look like they are living so horribly that they are gone from the family of humanity" have stories, feelings, thoughts that are overpowering, he says.

The successes help sustain him. Four years ago, one of his missions visited a facility in Mexico where people with retardation and mental illness were kept in the same ward--a troubling situation in and of itself--and where patients' bodies and clothes were covered with filth. "We met the head of the ward on a pathway up to the hospital," recalls Rosenthal, and demanded, "why do you let people live like this?"

Two years later, Rosenthal and an MDRI mission returned. The patients had been cleaned up, and they had been separated into appropriate groups.

"To this day," says Rosenthal, "I wonder, what is the value of walking into an institution in some remote part of the world and confronting some poor director. . . . Does that matter? I can't know for sure, but I felt like in that case it made a difference. He was looking for us to come back someday to show us what he had done."

Haunting Images

Of course, not everyone says Rosenthal's work is flawless.

Istvan Bitter, president of the Hungarian Psychiatric Association, thinks the activist doesn't appreciate the financial constraints on a country such as Hungary.

And James Birley, chairman of the Geneva Initiative on Psychiatry, an international group that works to improve psychiatric care, argues, "People don't respond very well to being told compulsorily that they have to behave humanely. It's just not very effective."

Rosenthal is not focused only on "effectiveness" but on doing what he believes is right.

There are images that he cannot shake, memories that play like videos in his mind.

Rosenthal recounts visiting a women's ward in Armenia in 1997. The patients looked dried out and old, as if a dark screen had been draped over them. But one woman had been admitted just a week before. She was nicely dressed. She had lipstick on. She was beautiful and young, an almost surreal hint of color in an otherwise ashy place. "And she looked," Rosenthal recalls, "like she was going to break down into tears."

"I was just haunted by her," he says.

A year later he went back. The woman was still there. But now she looked like everyone else.