

# Challenging Assumptions: Psychiatric Disabilities and Grassroots Development

*By Eduardo Rodríguez-Frías*



Miguel Sayago

Among individuals with disabilities, those with psychiatric conditions are perhaps the least understood. Many suffer in silence, fearful of the ostracism, confinement, isolation and wardship associated with being labeled mentally ill. For years, treatment itself has been the subject of controversy and exposés. The social activism of the 1960s included the emergence of an anti-psychiatric movement that decried hospital conditions, involuntary commitments and coercive methods and, in its more extreme manifestation, questioned the validity of psychiatry and its diagnoses.

The IAF has interpreted its mission as calling for the inclusion of the disabled in the development process, and in 1972, within a year of launching its grant program, it made its first such award, funding a conference on disability rights. Since then, grants have supported efforts throughout Latin America and the Caribbean to rehabilitate people with physical, sensory and cognitive disabilities, train them, encourage their enterprises and educate the public in their abilities and challenges. But examples of grants for people with psychiatric or psychosocial disabilities are much rarer. Poring over four decades of files some years ago, I found one documenting the work of Fundación Granja Taller de Asistencia Colombiana (FUNGRATA), a 1987 grantee that provided an alternative to psychiatric hospitals for indigent Colombians with schizophrenia, which I set aside on my shelf where it remained for some years awaiting further research. Then, in 2006, when IAF funded Asociación Pro Derechos Humanos (APRODEH), which proposed to organize Peruvians with psychosocial disabilities, I decided to learn more about how grassroots development relates to such individuals.

### Deconstructing a gilded cage

Dr. Alberto Fergusson is a Colombian psychiatrist who founded FUNGRATA. In November 2009, I sat down with him in his home in Bogota to hear the story of this singular organization. More than 27 years ago, FUNGRATA began to work with the homeless *locos de la calle* who scavenge garbage and beg on Bogota's streets and sidewalks. FUNGRATA's staff and volunteers would engage these potential patients in conversation, evaluate them and encourage them to enter a facility that provided therapy, job training,

employment and recreation toward achieving the maximum possible degree of autonomy. Often several sessions were required to overcome fear of institutionalization, which many believed would leave them languishing in the black hole of state hospitals. The "street beat" staff promised that anyone seeking treatment in FUNGRATA's facility could come and go at will. Some 80 percent chose to stay in the infinitely more comfortable conditions than those offered by the streets of the Colombian capital.

To inform the public of its work, FUNGRATA commissioned a video summarizing its mission and methods. Accustomed to today's digital formats, Dr. Fergusson took a few minutes to figure out how to play the antiquated VHS tape for me. After listening to a younger Dr. Ferguson discuss FUNGRATA on the video, my grayer host enthusiastically explained how the organization was born. Disillusioned with existing treatments, he and several colleagues posited that art and work could be therapeutic for schizophrenics, an idea supported by scientific research of the day and, he insisted, dating back to antiquity. Ancient Egyptians believed physical labor aided in healing mental illness, according to archeological evidence, he said. In 1982, funded by a low-interest loan from the Banco de la República de Colombia, these young psychiatrists purchased a 90-acre farm outside the capital and began using agriculture as occupational therapy. When asked, Dr. Fergusson flatly denied that his negative views of conventional treatment were anti-psychiatric, clarifying that he was "only against certain types of psychiatry."

The IAF was at first reluctant to support a project focused on such a "narrow segment of the population" and questioned its feasibility, but this skepticism was overcome. "The IAF bet on us when it was risky," Dr. Fergusson recalled. "We didn't really have a track record then, only an idea." When FUNGRATA received its IAF grant, only two facilities in the United States offered a similarly enlightened approach to psychiatric treatment. FUNGRATA referred to those in treatment as "students." IAF funding allowed it to include in its occupational therapy a bakery and a laundry staffed by students paid the minimum wage. As workers, they learned to manage their finances and to interact with individuals outside the circle of therapists and other students. Some regularly left the facility to dine out

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with friends or go to the movies, further preparation for taking charge of their own life.

IAF's grant, according to Dr. Fergusson, was the vote of confidence FUNGRATA needed to obtain the support from the Inter-American Development Bank and other donors, which allowed it to operate for many years. An independent study of FUNGRATA's methods undertaken by researchers from Yale University in the early 1990s confirmed the value of this treatment for schizophrenia. It didn't cure the students but it helped them to adapt to their condition. Eventually Colombia's lawmakers

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passed legislation citing FUNGRATA's treatment as the model to be applied in psychiatric institutions. Unfortunately this legislation was never enforced.

FUNGRATA's laundry and bakery generated sufficient revenue to cover operating costs but not the cost of replacing equipment purchased with IAF funds. Nominal deductions from the students' salaries did not nearly cover their housing and treatment. The shortfall was a factor in a re-evaluation of FUNGRATA's methods. By 2002, Dr. Fergusson and his colleagues had once again begun to question medical assumptions, this time their own. They saw the students as too dependent and FUNGRATA as just another institution, better than a psychiatric ward, but nonetheless a gilded cage.

As difficulties and doubts mounted, they decided to close the facility, liquidate its assets and invest the funds in a new organization, Instituto de Autorehabilitacion Acompañada (IAA). The disappointing outcome of the legislation passed earlier had caused FUNGRATA to all but give up on influencing national policies. Instead, during its transition years, it focused on local authorities. Sopó, the location of FUNGRATA's first farm, is a town of 20,000 inhabitants about 50 kilometers from Bogota. To apply his new vision for treatment, Dr. Ferguson persuaded Sopó's mayor and other municipal officials that people with psychosocial disabilities could, with some help, *autorehabilitarse*, or "rehabilitate themselves," by participating in community life. The entire town of Sopó now serves as a "facility" for more than 300 IAA students, mostly schizophrenics. IAA helps residents understand the importance of integrating the students into their community; students find employers willing to accept them; a team of 20 volunteers provides psychiatric support. IAA is also advising the Colombian government on how to assist individuals traumatized as a result of the violent civil conflict. As FUNGRATA's heir, the new institute continues work begun over two decades ago, but in a contemporary setting that its professionals hope will prove effective in making Colombians with psychosocial disabilities contributing members of their communities.

### Laying the foundation for Henry's halfway house

The IAF's history with disability rights in Peru includes its support in 1981 for the *Primer Congreso Peruano por los Derechos del Minusválido*. Considered by Peruvian activists a watershed event, it counted President Fernando Belaunde Terry in attendance. At the time, said the organizers, who had sought funding from Peruvian and international donors, "[O]nly the Inter-American Foundation understood the task we had set before us, committing to financial support and giving us its trust."

Henry, a young Peruvian who lives in San Martín de Porres, a low-income district of Lima, is very likely schizophrenic and he also suffers from bouts of depression. I met him last year at a session for the 20 members of Asociación de Usuarios de Salud Mental (ASUMEN), a grassroots organization for people with psychosocial disabilities formed with support from APRODEH, one of Peru's oldest and most respected human rights organizations. Peruvians seeking treatment have no alternatives to psychiatric wards, but through APRODEH, Henry learned of a halfway house in Buenos Aires and ever since has wanted a simi-

lar facility for Peru. Raised in a family of artists, he has sketched an idyllic place offering employment and recreational opportunities that would include field trips and even a swimming pool. He hopes that ASUMEN will make this a reality.

The IAF became aware of APRODEH's work with people with psychosocial disabilities thanks to Mental Disability Rights International (MDRI), which is based in Washington, D.C. I had connected with MDRI's executive director Eric Rosenthal and Alison Hillman, its coordinator for Latin America, at disability-rights conferences in Washington and New York. MDRI exposes human rights abuses in psychiatric institutions around the world, by documenting on video and in photographs harrowing conditions that include horrific sanitation, gross idleness, overcrowding and misuse of restraints, medication and electroconvulsive therapy. MDRI's 2004 report on Peru's mental hospitals was drafted in collaboration with APRODEH.

APRODEH's application to the IAF for the 2005 grant cycle proposed to address a universe of problems faced by people with psychosocial disabilities, for which it requested significant funding. Given



APRODEH's inexperience with people with disabilities, the IAF suggested it resubmit something more manageable for consideration during the next cycle. The leaner project focused on human rights and the development of new and incipient organizations of users of mental health services in four provinces, which APRODEH envisioned could benefit from the decentralized budget process that gives Peruvians more say over how community resources are used. This revised proposal allowed APRODEH to vaunt its sterling reputation in human rights, specifically as a participant in the Truth and Reconciliation Commission's examination of the conflict that had pitted Peru's armed forces against the Shining Path and Movimiento Revolucionario Tupac Amaru.

Those credentials notwithstanding, APRODEH's first foray into disability rights did not go smoothly. Most Peruvian groups advocating for those with psychosocial disabilities are led by relatives and were formed by psychiatric hospitals applying a medi-

cal model that often conflicts with a human-rights approach. These potential partners expected the grantee to finance medication and, while well-meaning, they projected paternalism or condescension toward *los enfermitos*. Some individuals in participating communities and hospitals considered the notion of organizing schizophrenics, manic depressives and people with bipolar disorders irresponsible and even dangerous, akin to handing them fire arms. Detractors accused APRODEH of being part of a radical anti-psychiatry movement. The organization, not as adept as Dr. Fergusson, failed to quickly dismiss this claim.

Slowly, APRODEH learned from its mistakes. It hired Ana Núñez, a social worker who aptly transferred her experience with individuals with physical disabilities to those with psychosocial conditions. APRODEH patiently pushed families to allow those diagnosed with a disability to attend its meetings unaccompanied, a goal that took more than two years to reach in Huancayo. It hired community organiz-



Henry's drawing created in an APRODEH workshop with ASUMEN.

ers in each geographic area that it served, something not originally envisioned. Of APRODEH's groups, ASUMEN, in Lima, is the most advanced. I witnessed the challenges Ana faces moderating one weekly meeting that included art, dance, team-building exercises and conversation. For the first half of the session, Henry was unresponsive and slouched in his chair, but he cheered up and participated when he was given a chance to describe his halfway house. Others shared their experiences and hopes—for a global organization promoting their rights or simply for a steady job.

Two weeks before I visited, three ASUMEN members had met with representatives of the Disability Rights Fund (DRF), a Boston-based donor that provides grants of up to \$100,000 for the promotion of the rights enumerated in the United Nations Convention on the Rights of Persons with Disabilities. Most applications that DRF receives come from groups representing those with physical or sensory disabilities. At the time ASUMEN was the only applicant from Latin America representing people with psychosocial disabilities and DRF was prepared to take a chance on the new organization. DRF's grant will finance training to improve ASUMEN's management and materials for workshops to raise awareness of the needs of Peruvians with psychosocial disabilities.

As DRF's grantee, ASUMEN was invited to send representatives to a gathering of Peruvians with disabilities in Miraflores, only a 30-minute drive from San Martín de Porres. For ASUMEN's three representatives, the meeting in Miraflores would be an important first opportunity to advocate for their organization. Initially, relatives objected to their traveling alone—even that short distance—and staying overnight, citing potentially dangerous scenarios. But DRF's invitation was restricted to disabled people and, moreover, the donor wanted to encourage independence. None of their relatives' fears materialized during the short stay and no further objections were raised when ASUMEN's leadership attended a follow-up meeting with DRF, which resulted in a second grant. APRODEH is promoting ASUMEN as a model for Peru. Meanwhile APRODEH itself recently began addressing discrimination against Peruvians with physical disabilities in the area of employment. The Colegio de Abogados del Peru, the Peruvian bar asso-

Courtesy DRF



*ASUMEN members welcome Catalina Devandas (front row, left) of the Disability Rights Fund.*

ciation, has approached APRODEH for guidance on disability rights.

The accomplishments of FUNGRATA and APRODEH exemplify the potential of grassroots initiatives on behalf of people with psychosocial disabilities. FUNGRATA helped nearly 4,000 Colombians over almost two decades and a generation of volunteer psychiatrists and social workers learned the benefit of a dignified approach to treatment. Dr. Fergusson was honored with an Ashoka fellowship and he frequently shares FUNGRATA's experience in lectures at universities and professional forums. He currently advises the government of the District of Columbia on how to address the mental health issues of Washington's indigent residents. His point of departure is the approach he developed with the support of the IAF, which is based in the D.C. metro area, completing a circle begun in 1987. His experiment in Colombia continues to evolve to meet new challenges, the hallmark of a successful grassroots experience. Perhaps APRODEH and ASUMEN will one day boast such a track record.

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