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## Peer Programs Across Disability Groups: A Partnership for Human Rights

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# Peer Programs Across Disability Groups: A Partnership for Human Rights

In looking at the approach taken by three different articles that deal with mental illness, the author finds peer-to-peer support to be a common thread among all three.

by Sam Nickels [ Center for Health and Human Development ]

Peer-to-peer support provides effective coping strategies across disability groups—from helping landmine survivors to those with mental-health issues. My personal experiences and work with mental-health services in El Salvador highlight the success of peer education and support programs for those with mental illnesses. I was impressed with three articles in issue 15.2 of *The Journal of ERW and Mine Action* (Summer 2011) that exemplify effective peer-to-peer support for landmine survivors. These articles provide a good platform for discussion of peer-to-peer support groups for those dealing with mental illness. “Survivor Heroes Heal Lives and Landscapes Throughout the World” by Ken Rutherford outlined the impressive stories of landmine and traumatic-accident victims as they rose from personal tragedy to becoming peer advocates on a global scale.<sup>1</sup> “Peer Support and Recovery From Limb Loss in Post-conflict Settings” by Cameron Macauley, et.al., reviewed a recent study on peer-support services for survivors, showing significant benefits “for trauma survivors, their families and their communities.”<sup>2</sup> The third article, “Art Therapy and Sport Activities Enhance Psychosocial Rehabilitation” by Reykhan Muminova, described how survivors improved their emotional and relational needs through a summer program of peer-to-peer support in Tajikistan.<sup>3</sup>

What moved me in these articles was the common thread of peers serving peers. I am not a survivor. No one in my family suffered the trauma of mines or explosive remnants of war, but I understand this program. I know exactly how the dynamics of peer and family support bring about healing. I understand the importance of peers working with peers, because I am part of a family that deals with a disabling condition too—mental illness.

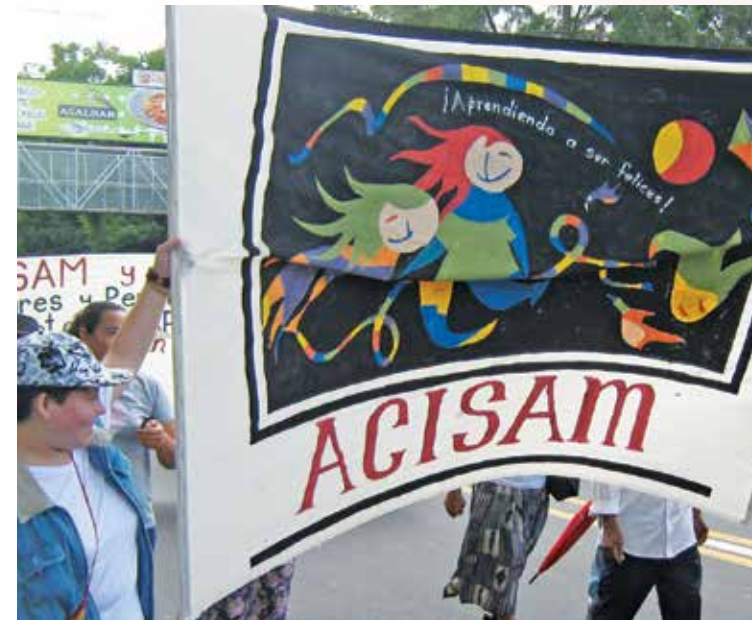
Thirty years ago my brother was diagnosed with schizophrenia. For 15 years our family struggled with depression, anger, misunderstanding, stigma and social

isolation. Then in 1992, two things happened. My brother received a new medication that helped control the worst symptoms of his schizophrenia, and my family entered the National Alliance on Mental Illness, a peer education and support program. My parents were so appreciative of this program that they became peer instructors in NAMI’s Virginia group, working with other families for the next 15 years. I remember listening to my mother answer call after call and talk for hours with other families who had a child or a spouse who was recently diagnosed with schizophrenia, bipolar disorder or had attempted suicide because of major depression. Of everyone in our family, my mother was the most deeply affected by my brother’s illness. She mourned the loss of his intellectual abilities, but she is my hero because she responded with courage, never gave up and reached out to others in need.

## Peer Support

This is what peer programs are about. Family reaching out to family, survivor reaching out to survivor, or—as we call people with mental illness in the United States’ peer movement—consumer reaching out to consumer (consumers are people with severe mental illnesses who consume mental-health services). The goals of survivor and consumer peer programs are the same—to end discrimination, empower individuals to find healing and recovery and become advocates for change.

In his article, Rutherford uses phrases that apply equally to landmine survivors and mental health consumers. He writes “victims often experience extended separations from family members.”<sup>1</sup> Persons in psychiatric crisis can spend months or years in psychiatric hospitals. This often means being far removed from family. Rutherford writes that victims face “decreased employment opportunities ... tasks that were once easy to complete can become Herculean chores ... many [victims]



Consumer advocates participate in a march for affordable medications while holding ACISAM sign in El Salvador, September 2010.

All photos courtesy of *Asociacion de Capacitacion e Investigacion Para la Salud Mental (ACISAM)*.

can no longer find work ... survivors are often ostracized and are denied proper medical care ...”<sup>1</sup> Persons with mental illness often experience the same things.

Rutherford praises the courageous response of survivors, as they have become “leaders and productive community members by devoting their lives to helping other victims ... Survivors’ peer skills are in many cases essential in helping other survivors recover.”<sup>1</sup> This is true also in mental health peer programs.

According to People, Inc., a New York nonprofit supporting people with disabilities, “In the peer community of people with the lived experience of psychiatric or emotional issues, it is well known that there is a connection to the relationship among peers and wellness. For some people, developing a peer-to-peer relationship has long been more healing than traditional treatment. Peer-to-peer engagement has often provided efficient and effective outcomes that traditional services cannot or do not provide due in part to limited or poor engagement between the provider and person and/or barriers to trust between the provider and person in need.”<sup>4</sup>

The U.S. has used mental health peer services for several decades. Studies on the effectiveness of consumer-operated service programs began in the early 1980s, and their effectiveness became more apparent in recent years. Peer-run self-help programs are shown to “lessen feelings of isolation, increase practical knowledge [about mental

illness and self-care] ... enhance coping ... [replace] self-defeating thoughts and actions with wellness-promoting activities ... improve employment involvement ... [improve] social support and shared problem solving ... increase empowerment, and realistic hope for the future.” Importantly, participants in such groups are shown to have “fewer symptoms and fewer hospitalizations.”<sup>5</sup> A report by the U.S. Surgeon General cites a study comparing peer-case managers with professional-case managers that found “clients assigned to either case management program fared equally well in clinical, social and quality of life outcomes.”<sup>5</sup>

## Peer Support in El Salvador

The study of survivor peer services discussed in Macauley’s article shows impressive results of peer-support programs in six countries. The positive outcomes remind me of the Family Education and Support Program I helped start 10 years ago in El Salvador in partnership with the nongovernmental organization *Asociacion de Capacitacion e Investigacion para la Salud Mental* (The Association for Training and Research on Mental Health). The Family Education and Support Program’s facilitators train family members to be instructors and the program provides a support structure that allows them to carry out peer education and support. This program aims to provide an educational mental health curriculum and empowering activities that train family members and consumer leaders to take on the fight for policies and funding related to mental-health services in El Salvador. Five years ago, it expanded to include a psychosocial group for severely mentally ill consumers.

Myrna Rojas, a psychiatrist who volunteers with the Family Education and Support Program in El Salvador, noted five goals and the program’s subsequent achievements, as well as several recommendations to improve effectiveness (listed below).

### Goals:

1. The consumer becomes involved in psychoeducation and self-help.
2. Family members experience positive changes in perception toward their loved ones with mental illness.
3. Consumers learn of their rights to improved services.
4. Participants act at the national level regarding policies that affect consumers.
5. Family members and consumers participate in a growing national and regional network.



Disabled persons, including those with mental illness and their families, participate in a march for human rights in El Salvador, September 2010.

#### Achievements:

- The legalization in 2010 of the family group as a nonprofit entity under Salvadoran law (a difficult process in El Salvador that can take years to accomplish)
- Participation on the *Mesa Redonda Permanente por la Defensa de los Derechos Humanos de Personas con Discapacidades* (National Permanent Council for the Defense of Human Rights of Disabled Persons)
- Participation on the *Consejo Nacional de Atención Integral a la Persona con Discapacidad* (National Council for Integrated Attention to Disabled Persons)
- Participation as an association partner with two citizens' national health-care advocacy coalitions—the *Fundación Maquilishuatl* (Citizens Alliance Against the Privatization of Health) and the *Foro Nacional de Salud* (National Health Forum)

#### Recommendations:

- At the national level, extend assistance to these types of programs in order to achieve greater national advances for mental-health improvement.
- At the Ministry of Public Health level, collaborate with these types of organizations to develop partnerships that increase the reach of mental

health services; identify suitable leaders within these organizations to collaborate with to establish intervention strategies for community-level development; demystify psychiatry and permit the development of community based psychiatry.

- At the level of nonprofit organizations, encourage a culture of research and studies on the evidence regarding the impact of these programs.

- At the level of family and consumer associations, establish partnerships that will achieve the defense of patient rights.

Recently, Rojas completed a descriptive case study of family and consumer programs, which showed many results similar to the survivor study noted above.<sup>6</sup> Rojas' study reflected the same peer support results as reported by Macauley, showing improved self-perceived mental health, improved social

functioning and improved role-taking due to improved emotional stability.<sup>2,6,7</sup>

To my knowledge, Rojas' study is one of the most detailed of any family or peer mental health program in Latin America. Indeed, even the U.S. has only one randomized controlled study of family mental health education programs. The study, "Outcomes of a Randomized Study of a Peer-Taught Family-to-Family Education Program for Mental Illness," published in 2011 by the American Psychiatric Association, showed that families experienced a significantly greater ability to cope with problems, increased knowledge of the illness, greater ability to cope emotionally, greater acceptance of the mentally ill loved one and reduced stress.<sup>8</sup> The study's authors believe their data is sufficient to consider family-driven educational programs as evidence-based practice.

#### Art Therapy

The third article in *The Journal*, "Art Therapy and Sport Activities Enhance Psychosocial Rehabilitation," reminded me of the Family Education and Support Program's art therapy and psychosocial education for consumers in El Salvador. Recently, one of our family-member leaders turned on the radio and began to dance. Almost immediately, nearly everyone in the group was



Family members march in support of affordable medications in San Salvador, El Salvador.

dancing! Perhaps we should rename our group "Art Therapy with Rumba Dancing Breaks." This therapy group is based upon the same concepts as the art therapy and sports activities camp in Tajikistan. People on psychotropic medications struggle with side effects, many of which include lethargy and obesity. Physical activity is essential to their health.

Unlike the program in Tajikistan, the El Salvador art-therapy program evolved into a supported employment setting. Consumers learn artistic and production skills and apply them to make candles, hammocks, cards and other items. When sold, after deducting the cost of materials, profits are distributed to the consumers. Everyone smiles when the small paychecks are given out.

#### Comprehensive Disability Services

How do mental health and survivor support efforts align? An example is an advocacy gathering held by multiple Salvadoran NGOs I attended in a large central park on a sunny day in San Salvador, El Salvador's capital. The event's purpose was to hear speeches about the need for a new law that would provide affordable access to medications for people with various kinds of disabilities—a

huge need in the mental health community. It also concerns people with special needs in many sectors, since the cost of medications is very high in El Salvador. Our family and consumer group set up early—chairs and microphones for the speakers and display tables for the arts and crafts our group would sell. Soon people began to arrive—dignitaries from the Ministry of Health and the national assembly. Then a large truck pulled up, an electric ramp was extended to the back of the truck and the truck's back door slid up. I could hardly believe my eyes; 30 or so people in wheelchairs with their families and friends filed out and were lowered on the electric ramp. Soon the speeches began, followed by a march through the park and down the street. Banners were unfurled, and people walked/wheeled with pride—people with mental illness, people without limbs, wheelchair users and blind people. I was deeply moved to see them all working together and advocating in public for their rights and needs.

We are not alone. Disability Rights International states "there are 650 million children and adults with disabilities worldwide—most still segregated from society in abusive institutions, living in poverty, or left without educational and economic opportunity."<sup>9</sup> Each type of disability brings its challenges, and yet we are united. We may be different, but we are equal. We may be misunderstood, but we will take our rightful place in society. We may face more challenges than other people, but we will empower one another to overcome those challenges. 🌐

See endnotes page 66



Sam Nickels has worked in the nonprofit sector for 25 years. He is a trained instructor in the Family-to-Family peer program run by the National Alliance on Mental Illness. His nonprofit Center for Health and Human Development seeks to support social entrepreneurial efforts in developing countries. He is a doctoral candidate in the School of Strategic Leadership Studies at James Madison University.

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