

Advocacy

By consumers, for consumers: Peer run programs

By Karen Farber

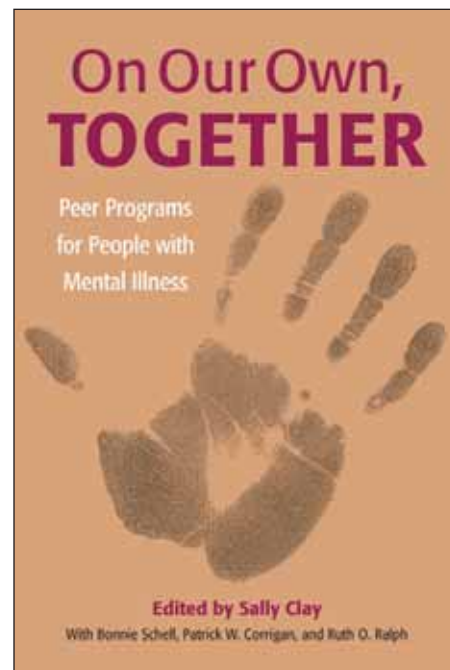
Maine's Portland Coalition for the Psychiatrically Labeled (PCPL) is one of eight peer-run programs for adults diagnosed with mental illness profiled in an upcoming book. The book, titled "On Our Own, Together: Peer Programs for People with Mental Illness," from Vanderbilt University Press, is edited by Sally Clay, PCPL's first executive director from 1981 to 1985.

By and for consumers

It is fitting that a book about peer support is in fact written by participants in these programs. The volume rises above the purely clinical because it is, in large part, written by these consumers — adults with mental illness. Some may be recovered and some may not, but each knows the feeling that Clay describes as the shock of finding oneself within a few weeks or hours transformed from a promising young 'something' to a black sheep or outcast following that first encounter with the mental health system.

"On Our Own" examines the inner workings of consumer-operated services at drop-in centers, educational programs, and services based on peer support and mentoring. Despite the eight

recovering from mental illness are survivors of a mental health system that tends to objectify and coerce us. We have alternately been demonized and treated as wayward children, and until very recently, had no say in the treatment formed 'about us' but chosen 'without us.'



South African movement inspires

Peer-run programs are a response to this situation and inspired by the South African disability movement whose motto, "Nothing about us without us," is reflected in the title of this book.

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— Sally Clay

programs' many differences, they share essential characteristics revolving around being peer operated and peer-governed organizations. Each emphasizes equality, mutuality, empowerment, recovery, belonging, and hope, according to the publisher.

Been there

Sally Clay and her fellow writers and editors have been there, so to speak, and this very fact gives authenticity to the book's prescriptions. Clay's episodic manic periods began at the age of 20 while she was enrolled at Sarah Lawrence College. These continue, though with less frequency, today.

In the preface to "On Our Own," Clay writes, "...we as persons

Asked why the South African movement in particular was so important, Clay said it is because the disability movement became part of the actual liberation movement in that country.

Six years of labor

Clay said that the book took six years to pull together — longer than she originally expected. The goal was to get the information out about these peer-run projects as quickly as possible so others could be aware of what was going on around the country. Many involved wanted to inspire other consumers. Many of the researchers involved wanted to appeal to the clinicians. In the end, the book is for both.

Asked whether she has ideas for

another book, Clay said, "This is the culmination of my career as a peer advocate. I consider myself now retired. Though I guess one never really retires; I'll always talk to people."

Lack of national voice disappointing

One of Clay's disappointments regarding the peer advocacy movement has been the lack of a national voice, a policy influencing movement— something like what the National Alliance for the Mentally Ill is but for the peer-run program movement. She sees more than one reason for this. "Most of us with psychological illnesses are at the bottom of the socio-economic ladder. There is the stigma (of mental illness). But poverty is a bigger problem — the real problem is poverty." The third difficulty the movement has had is infighting that is probably true in any grass roots advocacy movement.

Clay's next project is editing for the publishing arm of a Buddhist monastery with which she has been involved for a number of years.

Today, physical disability keeps her housebound much of the time. An avid computer user, technology gives Clay a steady link to the outside world. Asked if there are differences in how others relate to physical disability compared to psychological disability, Clay chuckled. "It's a lot easier to explain (physical disability) than mental illness. You receive more obvious sympathy and there's no fear of it."

Looking to the future

"I don't mind being home. I have a lovely house and yard and my computer. An agency brings food by and a friend drops in three times a week to help with the household." The last three hurricanes have certainly created a more complicated life if only because it is nearly impossible to find a carpenter with time to make needed adaptations to her bathroom. "I'm doing okay but I'm a little scared about the future," Clay concluded. ■

To learn more about Sally Clay, visit www.sallyclay.net. For information about "On Our Own," visit www.vanderbilt.edu/vupress/clay.html.

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