

# AGENCY OF THE MONTH

## Clubhouse of Suffolk: Poetry and PROS

Clubs are all about belonging, that special feeling of warmth and safety that comes through supportive friendships, common purpose and a shared sense of ownership. For individuals with mental illness -- stigmatized and often living in isolation -- this sense of belonging can be especially hard to find. Since 1990, Clubhouse of Suffolk has served as an oasis of physical and emotional security for Long Islanders struggling with mental illness.

"I have been coming to clubhouse since 1993," says Dale. "If it wasn't for Clubhouse, I would probably be in a mental institution today."

The Clubhouse community of caring friends and supportive staff stands in stark contrast to an earlier life many members describe. "I used to live in my house with all the shades pulled down," says Elizabeth. "I wouldn't talk to anyone except my animals."

"I was isolated and depressed," says Cathy, whose long term condition became overwhelming after her three children grew up and left home.

While members often receive clinical treatment through other mental health programs, they find a home and hope for rebuilding their lives at Clubhouse programs like Clubhouse of Suffolk.

"At its inception, Clubhouse of Suffolk grew out of a sense of dissatisfaction among a group of family members with the range of services that were available," says Michael Stoltz who has served as Executive Director at Clubhouse of Suffolk since its inception. "Family members had adult children who, prior to the onset of mental illness, had been brilliant and successful and wanted to overcome the effects of their illness to return to productive roles."

The Clubhouse model, which was first developed in 1948 at Fountain House in New York City, is built upon the assumption that people with mental illness can recover, can learn to manage their illness, and can live healthy and productive lives.

Just as important, clubhouses assume that people with mental illness can and must play an active role in their own recovery. Consumers are members, not patients. Membership is voluntary and not subject to time limits. Members choose the ways in which they utilize the clubhouse and the particular staff with whom they work. While members develop a personal plan to meet their chosen goals,

there are no written contracts or agreements which enforce participation in club activities.

Clubhouse of Suffolk was formed in 1990 by family members who had come together through local support and advocacy groups, particularly the Suffolk Chapter of the National Alliance for the Mentally Ill. Dr. Davis Pollak, a founder and still President of the Clubhouse of Suffolk Board, had been involved with the earlier, pioneering efforts of Fountain House and Venture House.

"Both Fountain House and Venture House helped us a great deal in formulating our two clubhouses," says Stoltz. "Fountain House is the grandfather of the clubhouse model and part of their mission has been to help promote clubhouse model programs all over the world."

Clubhouse of Suffolk spent its first year in borrowed space at Kings Park Psychiatric Center before finding its current main location in Ronkonkoma. "We are geographically right in the center of Suffolk," says Stoltz. After starting with 5,000 sq. ft. in the one-story building, the Clubhouse and its programs gradually expanded to fill the full 13,000 square foot structure. In 1997, it secured sufficient funding to acquire the building.

In response to increasing demand for its services from eastern Suffolk, Clubhouse of Suffolk opened a second facility, Synergy Center, in Riverhead in 1995.

Approximately, 290 members actively participate in the Ronkonkoma Clubhouse at any one time while 100 more utilize Synergy Center, says Stoltz. In all, Clubhouse of Suffolk serves more than 1,200 individuals annually through the two Clubhouses with their associated programs and a separate Case Management Program.

For members, the clubhouse is one place where they can escape the stigma which so often is attached to mental illness.

"I don't feel different here," says Cathy. "The people here have the same illnesses or similar ones. It is one big family, even the staff. They have classes where we learn coping skills."

"This is the only place I know where I feel safe and comfortable," says Frances. "My own family doesn't understand."

In addition to the overarching culture of recovery, there are several sets of programs which are fundamental to the clubhouse model:

- Work Ordered Day
- Supported Employment
- Evening and Weekend Services

### WORK ORDERED DAY

Members do the work necessary to make the club function. Staff participate on an equal footing, but accreditation standards for clubhouse programs actually require that the

number of paid staff be insufficient to handle all club activities.

"Work-Ordered Day is the foundation of a club," explains Stoltz. "Units -- teams of members and staff -- work to accomplish all the operations of the club." A Clerical Unit maintains a database of club members, handles all communications, puts out a newsletter, sets up calendars of activities and sends out birthday cards. The Membership Unit tracks attendance and activities, does outreach at psychiatric hospitals and clinics, offers tours and encouragement for potential new members, checks in with existing members who may have missed clubhouse sessions, etc. The Kitchen Unit takes care of all the tasks associated with preparing and serving two meals a day for up to 75 clubhouse members -- menu planning, purchasing, cooking and clean-up.

For members, the Work-Ordered Day offers structure and purpose. It integrates individuals who may have become isolated through their illness into functioning teams which provide their own clubhouse services. Members refresh and develop new communication and social skills required to accomplish the task at hand. In the process, they rebuild confidence in their own abilities and develop new friendships with fellow club members.

"I got involved in the kitchen," says Dale. "We serve two meals a day and I take care of evening meals for about 25 or 30 members." Dale credits her successful experience with the Kitchen Unit for giving her the confidence to try Supported Employment.

### SUPPORTED EMPLOYMENT

Supported Employment is another cornerstone of the clubhouse model, explains Stoltz. Services range from intensive Transitional Employment (TE) to simple, behind the scenes coaching on job searches and interview techniques for individuals with histories of mental illness.

"Transitional Employment is the most highly supported form of supported employment," says Stoltz. "It is for people who need an extended period of side-by-side job coaching, people who have built up a lot of rust in terms of workplace experience or who may never have worked. They need to learn about the world of work -- how to report to work, do a job, get a paycheck. We go with the member every day for a couple of weeks and then fade out. The employer knows the person is from the clubhouse and that they have a serious illness. The employer gets trained in how to be supportive."

Clubhouse of Suffolk has developed working relationships with a broad range of employers on Long Island. Members have held positions with for profit firms such as Bed, Bath and Beyond, Computer Associates, BJ's Wholesale Warehouse, Sears, Minute Man Press and Ronkonkoma Printing. Local nonprofits, including the Animal Rescue Fund, Big Brothers/Big Sisters and Hands Across



Michael Stoltz, Executive Director

Long Island, also provide employment opportunities for members. Participating employers receive considerable support, including guarantees of coverage for entry level positions held by members.

"At the other end, we have members who are fairly capable," says Stoltz. "We have people who have worked in warehouses as well as teachers, lawyers and MBAs." Here, the focus is on how members can find, get and keep a job -- how to explain that gap in the resume, how to deal with co-workers or productivity issues. "Once a week we have a dinner just to deal with workplace issues," says Stoltz. "We can have anywhere from 5-25 members on a Thursday night." The Clubhouse provides employment-related support for approximately 80 members from Ronkonkoma and another 20 at Synergy Center in Riverhead.

Similar support is available for members seeking to continue their education. "We have people going to college or who have never been to college but want to resume their education," says Stoltz who notes that onset of mental illness often occurs between the ages of 16 and 24, thereby disrupting high school and college plans. "We have a relationship with Suffolk Community College and a couple of the other colleges that have offices of disability services. We help connect a member with the support services they need -- financial, remedial, help in picking a beginning course or a major." Approximately 20 members at both Ronkonkoma and Riverhead now attend college.

### EVENING SERVICES

Members develop their own personal plan for using the clubhouse activities to meet their own recovery goals. A significant segment of members already work or attend school and use the Clubhouse to address specific issues. "They know they have serious mental illness and that they need to learn how to manage it better," explains Stoltz. "They need assistance in getting a job or going back to school. They know what they are looking for. They come in, get what they need and go on."

Other regular and long term members have psychiatric disabilities which have prevented them from working or attending school. For these, the clubhouse is an important place of respite and a critical link to the outside world. They come frequently over long periods as they work towards recovery.

"I come every day," says Elizabeth. "I am so happy I have a place to come.



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My life is nothing like it was before. I have mental illness, but I still have a life."

In order to serve both these groups, Clubhouse and Synergy Center operate daily, including evening hours until 8:30 p.m. on Tuesdays through Fridays.

Both clubhouses are also open and available to members on most holidays, periods which can be particularly stressful for members. "A lot of people here don't have families," says Cathy. "They can come here and feel welcome."

The clubhouses are not open on weekends at present, although staff and members help facilitate opportunities for members to get together on the weekends. "We would like to be open," says Stoltz. However, most of the Clubhouse's contracts have not been adjusted to reflect the real and rising costs of utilities, rent, insurance, salaries and benefits for over 10 years and can no longer cover the extended hours.



Synergy Center is Clubhouse of Suffolk's satellite facility in Riverhead.

## PROS

Clubhouse of Suffolk is not alone in these financial difficulties. Clubhouses and other rehabilitation programs throughout the state have suffered with stagnant funding for many years. In an effort to provide additional funding – and shift a greater share of costs to the Federal government – New York State OMH has been working for more than two years on a radical restructuring of the way clubhouses and other rehabilitation programs are funded: PROS.

Personalized Rehabilitation Oriented Services (PROS) will be the latest in a long line of services which OMH has converted to Medicaid-based funding streams. PROS collapses a wide range of rehabilitation programs, each with its own regulations and unique contract structure, into a new series of program licenses. The goal is to integrate treatment, support, and rehabilitation in a manner that facilitates the individual's recovery.

PROS will include services under three broad umbrellas:

- Community Rehabilitation and Support (CRS) designed to assist individuals in managing their illness and restoring skills and supports necessary to live successfully in the community;
- Intensive Rehabilitation (IR) de-



Members do the work necessary to make the club function, such as preparing and serving two meals daily.

signed to assist individuals in attaining specific goals such as employment, education or housing, and;

- Ongoing Rehabilitation and Support (ORS) to support individuals in managing their symptoms in the competitive workplace.

Providers can apply for a Com-

prehensive PROS license requiring all three sets of services (CRS, IR and ORS) or a Limited PROS license which would allow only ORS and IR. In addition, Comprehensive PROS licenses may also apply to provide Clinical Treatment services.

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Mental health providers have spent much of the past two years attempting to discern exactly what a transition to PROS will mean for rehabilitation programs whose culture and operations are steeped in the philosophy of recovery.

Clubhouse of Suffolk will be among the very first providers in New York State to find out. OMH is rolling out the new PROS licenses in several counties, including Suffolk, and Stoltz anticipates approval of the Clubhouse' application effective this Spring. (The State's first PROS license application was approved for Behavioral Health Services North in Clinton County on January 3rd.)

"The challenge is how do we retain the culture that we have created and meet the PROS environment of regulation and billing," says Stoltz. PROS takes programs with a decidedly non-medical approach to service delivery and converts them to a Medicaid funding stream, complete with rate-based, billable units of service in the form of face-to-face contacts. "We feel positive about the expansion in services that come with PROS but it will require a big upgrade in administration," he says.

However, despite wide-spread fears among consumers and rehab advocates about the possibility of an upcoming culture clash, Stoltz believes Clubhouse of Suffolk's transition to PROS can be mostly transparent to individual members. In part, this is because the Clubhouse's programs are al-

ready built on a firm rehabilitation and recovery base.

"For the past five years, we have incorporated the Psychiatric Rehabilitation Approach (PRA) as a platform for all of our services," explains Stoltz. "While the clubhouse model is the framework for how programs happen, PRA is the process that staff use to help people in recovery reach their goals." The Clubhouse has had a collaboration with Boston University Center for Psychiatric Rehabilitation which has provided training and consultation.

Stoltz believes that this existing relationship between clubhouse programs and PRA theory will allow an easier transition to the world of PROS. "A lot of what we are doing is cross-walking the models, translating PRA and the Clubhouse model into the framework of the PROS provider."

Clubhouse of Suffolk also plans to add clinical services to its array of programming through its new PROS licenses. "We will have psychiatrists and nurse practitioners," says Stoltz.

## IPRT & CASE MANAGEMENT

Clubhouse of Suffolk and Synergy have strived to meet members' needs through Pathways, its IPRT (Intensive Psychiatric Rehabilitative Treatment) program. "IPRT is an aggressive way of working with people who have a pretty clear idea on the needs they have," says Stoltz. The Clubhouse has also applied PRA as a foundation for

the IPRT program. The IPRT will "fold-in" to the PROS programs.

"It includes a lot of education about illness and recovery," says Stoltz. "If you think of any other illness, such as diabetes, there are many ways to get information about the illness. You can go online for research, see a dietitian, visit local hospitals, attend supports groups and generally learn about the importance of a healthy lifestyle. For people with mental illness, this information is just as important. What is my diagnosis? What does it mean? What do I need to ask my doctor about treatments and how they will affect my life? What are the side effects and are they permanent? How about my relationships with friends? Should I talk about my illness or shouldn't I. How about with my employer? How can I compensate? Our programs are a response to people saying that they need help with managing aspects of their illness."

Clubhouse has also developed specific tracks for individuals with different levels of impairments and with co-occurring disabilities. "We found we had a lot of people with learning and cognitive impairments," says Stoltz. "We have a cohort of people who are over 65. They are often reconciling losses and struggles with families, still wanting to be productive and facing financial issues in terms of life planning. There are a whole set of issues with that group that we need to learn about and respond to."

In 2001, Clubhouse of Suffolk began providing case management services for consumers on the East End of Long Island. "We took over programs that had been run by two other providers," says Stoltz. "When we started, there were 65 clients and now we serve 350. The two clubhouses help to anchor the case management programs."

## LOOKING AHEAD

The transition to PROS -- with its addition of clinical treatment services -- is certain to keep the Clubhouse's administrative plate full for the near term. However, Stoltz believes that Clubhouse will always need to adapt its services to meet the evolving needs of members' experiences with mental illnesses. "The cohort of people we serve has really changed over the past ten years," he explains. "There are larger proportions of people who have had contacts with the criminal justice system and the homeless shelter systems." Stoltz would also like to expand services to younger clients, particularly in the 15-20 age range which so often marks the onset of mental illness. "Although we do have a cohort of 18-25 year olds, we now only serve adults," he says. "Earlier intervention is everything in health care and that is no different in mental health."

For information on Clubhouse of Suffolk and its programs, call 631-471-7242 or visit [www.clubhouseof-suffolk.org](http://www.clubhouseof-suffolk.org).

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