The PEERS Social Club: A qualitative study of an emerging peer support network.

by

Peter Stastny, Dorinda Welle, and Celia Brown

Introduction

This chapter describes the process of organizing the PEERS social club, the final phase of the Peer Specialist Project. In this federally funded project former psychiatric patients were hired and trained to work as peer specialists in partnership with intensive case managers. The aim of the project was to ascertain whether and in what way the assignment of peer specialists contributed to a better outcome for intensive case management clients. The study showed that consumers who were served by the ICM-team that had peer specialists attached to it reported a significantly better quality of life, as compared to those that had paraprofessionals or no additional staff. [1] As originally hypothesized in the demonstration grant, peer specialists were expected to organize and maintain a self-help group composed of those ICM-clients they had worked with most actively. This occured through the formation of a social club, the "PEERS Club" in the latter part of the three-year demonstration project.

This report examines how peer specialists defined and implemented the goal of supporting ICM clients to become empowered through participation in self-help. It also considers how the social club was sustained not only by a common vision but also by differences in professional, peer specialist and ICM client/participant understandings of empowerment and self-help. This study also examines changes in degrees and qualities of participation, types of activities pursued, the very name and focus of the club, the needs of peer specialists and ICM clients, and the meaning of this particular social club within the broader context of the local mental health system.

Qualitative Design and Methodology

The qualitative research component was seen by the peer specialists as "a way to tell our story." It generated three unpublished reports co-authored by the qualitative researcher, the project director and the facilitators.[2] This component of the project was basically seen as a positive addition, "because no one else was willing to tell the peer specialists' story.". But it became complicated in the course of the project. For one, it became difficult to distinguish between what peer specialist thought should be kept confidential and what they wanted to be known. Also, it was difficult to draw a line between personal issues relating to their backgrounds and psychiatric histories. This was especially true about any personal problems a peer specialist might be encountering during the project. Peer specialists, especially the project facilitators, wanted to have a measure of control over where to draw this line. On the one hand, there was an expectation that the qualitative research, in contrast to the quantitative interviews, "would bring us to the forefront rather than just presenting us as numbers or percentages." This led to an openness and a close working relationship to the qualitative researcher ("participant observer - p.o."), which in turn fostered a kind of insecurity about which kind of information should be shared with the project administrators and the "outside world." Overall, it was felt that the information presented in the qualitative reports was more authentic and true to the experiences of the peer specialists than the quantitative results. In the end, it was worth taking the risk of exposing onelf in order to have the peer specialists' experience represented.

The study design was formulated to establish the nature and extent of client networks with ICMs, peer specialists, and with other ICM clients. A combination of client interviews, network

mapping, and participant-observation at club activities was employed as the elements of data collection. The design called for a one-hour long unpaid interview with each of the twelve or so clients who formed the core participants of the social club, and intended to inquire into clients' views on self-help, their interest in the social club, and aspects of their own life histories.

A number of difficulties arose in implementing the original design and methodology, and a different approach had to be established. For one, the client interview questions proved too demanding of clients' time and interest. Clients involved in the social club who already participated for two years in the quantitative evaluation interviews had strong reactions to being interviewed for the qualitative study. Clients were surprised by the difference between the qualitative and quantitative interviews, and took the qualitative interview as an opportunity to discuss their experiences with the quantitative evaluation, and their questions about its purposes and uses. This, of course, raised questions about who evaluates the evaluative process in mental health research, and how such voices---the voices of the researched---ought to be considered beyond the confines of research questions.

Clients insisted upon speaking at length about the quantitative evaluation, the ICM program, and about the peer specialist program. In addition, clients wanted to talk at length with someone who made no demands of them, but who would listen and respond. Familiar with the qualitative evaluator who had met them when accompanying "their" peer specialists in the field, clients at the qualitative interviews brought in paintings and poems, delved into their favorite stories, and without hesitation stated that they were not interested in answering the interview questions, but rather in raising their own questions about self-help and its organizing elements.

While this experience proved challenging for the qualitative evaluator, it also spoke of the

confidence which clients had developed in their encounters with other research interviewers, and the initiative and caution which they asserted. One client commented that he had participated in several interviews already, and that he had yet to see any research results "from the data I gave you people." Another client agreed to the interview, but first noted that he was volunteering his time. Yet another client asked her peer specialist to attend the interview with her, "because he's my advocate with professionals." Thus the difficulties encountered in implementing the original design provided evidence of client empowerment in dealing with professionals, and indicated the information gap that divides researchers and research subjects.

After extensive discussion of these issues with the program facilitator and director, the focus shifted from formal interviews with clients to participant-observation at club activities. Client-ICM-peer specialist network maps were compiled at the beginning of the study to reveal the complicated social organization in which the social club was developing. The evaluator attended nearly every social club activity and related meetings during the ten months of this study (October 1991 to July 1992). Although formal interviews with social club participants were halted, the topics outlined in that interview were nevertheless discussed with participants, albeit in a less systematic way. Some clients agreed to the formal interview, and the information from them is included in this chapter.

Whenever possible, the evaluator supported the development of the social club. Interviews turned into conversations; questions posed to clients became questions clients and interviewer posed to society, or to the mental health system; and the search for information about clients became a research-based effort to help support the social club, its organizers and participants, in the club's formative and vibrant months.

Social Club Development and Participation

Three distinct "moments," representing three aspects of the club organizing process, emerged within the lifespan of the PEERS social club. These "moments" include: the psychosocial club months; the PEERS club months; and the replication months.

The psychosocial club months, from June 1991 to November 1991, involved a series of discussions and planning meetings in which peer specialists defined the nature of their self-help project. Peer specialists first took their direction from suggestions provided by the project management team. These suggestions reflected the intent of the grant proposal to encourage networking among ICM-clients. In the early discussions of the self-help project, an ICM-coordinator raised the possibility of organizing a psychosocial club. Although none of the members of the management team had any experience in organizing psychosocial clubs, this idea took. The ICM-coordinator offered both concrete suggestions and personal assistance to support the organizing efforts of the peer specialists. Other management team members offered information on funding sources or grant writing. They did not, however, offer extensive assistance in helping the peer specialists define their project.

Over time, the idea of a psychosocial club gained general acceptance. Some peer specialists had successful experiences with psychosocial clubs in the past. In addition, peer specialists and paraprofessionals had fond memories of their "social club days" in the Bronx, when churches, neighborhoods or youth groups would organize weekend parties, dances, and other events for the community and specifically for young people.

Professionals on the management team came to see the psychosocial club as a model intervention for clients. ICM-program staff saw client participation in the club as having specific value in the management and treatment of clients, whom they saw as by and large idle and lacking structured activities. In early discussions of the club, ICM program staff looked forward to "prescribing" participation in the club for certain clients or "referring" them to the club as a kind of social service. Having a psychosocial club available expanded the range of services ICMs could offer clients, and also allowed them to utilize peer specialist services in new ways.

During the psychosocial club phase a swell of consumers (as well as a handful of ICMs and family member-advocates) participated in planning meetings headed by peer specialists. A core of approximately twenty consumers contributed to the initial effort, either in a large group or in committees. Peer specialists and other consumers elaborated on the various elements they wanted to go into a psychosocial club run as a self-help project. Committees on education, socialization, recreation, advocacy, vocational and cultural issues were formed. During planning meetings, ideas on each topic were written down and turned in to the peer specialists. Networks formed between currently and formerly hospitalized advocates, and a great deal of momentum developed for the psychosocial club project.

The months of organizing the psychosocial club concluded with a most memorable event: The 1991 Christmas Party, which drew over 40 people and, according to those who attended, displayed the most festive atmosphere in recent hospital memory. Held on the same day that one of the paraprofessionals gave birth to a healthy baby, the Christmas Party drew members of the planning committee, peer specialists, ICM-clients, and ICMs. Peer specialists, paraprofessionals, and the qualitative researcher contributed large dishes of homemade pastas, salad, chicken, rice,

fruit salad, and deserts. "Project money" supplied the refreshments table and its bold, colorful decorations: green paper tablecloths, red plastic cups, red and green plates, red and black baloons, and black napkins. Around a small plastic tree blinking with lights, peer specialists had set wrapped gifts for ICM-clients. In one corner, members of the planning committee played DJ, selecting tapes from their collection from a supermarket grocery cart. In another corner, a men's card game formed. Across from the card table, a group of women sat at their own table and watched their children play with each other. The center of the room sometimes turned into a dance floor. Nearly everybody danced to the first song of the night. "I'd never hurt nobody; never wanna hurt someone. My love's not dangerous."

The months of January through June 1992 marked the "PEERS Club" months. The peer specialists planned and hosted activities, trips, and skills trainings. During this time the psychosocial club idea faded and was replaced by the vision and logistics of the PEERS social club. In January 1992, peer specialists and psychosocial club supporters realized they simply did not have adequate time or resources to secure funding in a timely manner. They also were alarmed by the the fact that another highly successful local consumer-run initiative was not refunded, and were leery to take the leap into starting another organization in need of separate funding. As a result, peer specialists resolved to begin the club on a smaller scale by organizing activities for ICM-clients without the input of the planning committees. They identified activities which could start immediately by using project funds. From late winter to early summer participants and peer specialists held card-game parties, skills training workshops, recreational trips to the circus, kite flying, the movies, handball and other sports , a Chinese raffle party, a trip to the Bronx Zoo, and a party in a park on hospital grounds to acknowledge the end of the project.

In contrast to the organizing meetings and the Christmas Party, planning committee members and ICMs did not attend club events during these months. The meetings and activities during these months drew anywhere from two to twelve participants. Participants fell into three groups: those who attended consistently throughout the duration of the social club; those who joined at the beginning and participated intermittently until the end of the project; and those who joined after the club got started and then attended only one or two times. All of the intermittent participants attended the end-of-the-project party in August. At a time when the continuation of the project was very uncertain, participants demonstrated their personal interest in the project and in the future of the peer specialists.

During the summer of 1992 the PEERS social club was promoted as a model for other agencies to replicate. It was presented as an effective and unique rehabilitation model based on self-help and reconceptualized as a service component that could fit into the existing array of community-based services. Patterns of participation began to change during the time when the PEERS club started to be seen as a replicable model. In April 1992 one peer specialist stated that "we have to market ourselves now," and discussions followed as to how the group would maintain a triple focus: on their individual ICM clients, on their social club responsibilities, and on promoting the club as a model. In anticipation of the expiration of grant funding, the project leaders began meeting with representatives of various social service agencies in an effort to "transplant" the social club into "the community." The "model club" period culminated in late August 1992, when the federal grant ended and a local provider agency agreed to develop a new variant of the social club.

From Psychosocial Club to the PEERS Club

> Participant: What is the name of this club? If you ask me, I would say this name "Psychosocial" sounds rather sinister.
> Peer: My idea was to call it PEERS Club. PEERS stands for People Educating and Empowering Each other to Realize Self-help.
> (Much discussion. People like how it sounds. "Nice and simple." "Sounds complicated, like me." "Do you spell that PEERS or PIERS?" In all, people like how it sounds, what it stands for.)
> Peer: So can we call it the PEERS Club? Sounds good to everybody?
> (People agree. Everybody claps. Somebody opens the soda and we all start eating the food on the tables.)

The project facilitator came up with the PEERS name one afternoon. It happened after she had a confrontational meeting with some ICMs who felt the peer specialists should "just concentrate on their usual work." She explained her philosophy behind the name:

> For one thing, you have to appreciate that the first word is PEOPLE, not any other word that you could use, like PATIENTS, PROFESSIONALS, or PROVIDERS. We want to call ourselves PEOPLE more than anything. Then comes EDUCATING. You have to educate before you can empower. Educate yourself, educate others. Then comes the EMPOWERING. You should appreciate, it's people doing these things for EACH other, in a mutual way. That means the peers learn from the clients, and they learn from us and from each other. Now, the word REALIZING. That means you don't just start doing self-help; it comes gradually to you, and you have to come into it through aware-

ness. That way, self-help is both the goal and the process. I think [the qualitative] part of the research has taught me that you have to appreciate both. For most clients, they're only supposed to look at the end result, the goals. Nobody cares about what process they go through, or what they realize in the process. It's interesting that SELF-HELP comes last. That's because you don't start out with the method or the structure; you have to start out with the people. That's what it means to be a peer.

One of the club participants liked the play on words afforded by the term "PIER." Accordingly, club members designed a logo of a boat full of people taking off from a pier and waving back at those who remained on shore. "The PIER idea is to emphasize us taking the trips we go on." The participant also said he wanted to have an alternate logo of a clown. "People want to call us these serious names. Let's just be clowns!" Another possible logo sketch showed cut-out paper dolls sticking their heads out of a jeans pocket. "That one is more vast. It's to symbolize us coming out of the dark into the light of day. You know, it's good to be vast with people and let them imaginate [sic]."

The peer specialists and participants all felt that a strength of the club was that it didn't have to stand for any one thing, but could change as people wanted to pursue different activities.

Participant A: What is the agenda for the spring for this program?
Peer A: It's up to us, what we want to do. Next meeting is for travel skills. After that, it's up to us.
Participant A: I don't have any ideas.
Peer A (to a woman participant who earlier had protested being left out of the socializing because she was the only female client there): Do you have any ideas?
Participant B: Yeah. Some outdoor activities. Let's go to a park and play some handball.

Peer B: Yeah, we could play some sports. Basketball, volleyball.
Participant C: I don't know how to play those. I play handball.
Peer B: So you can show us handball, in a park where there's a court.
Peer C: Yeah, so you can teach us how to play handball.
Peer B: Yeah, and (n) plays handball, too. We should invite them along.
Peer A: But they're a para(professional). It won't work. Remember?
Peer B: Oh, damn. And they got access to some great courts near the stadium.

Club organizers encouraged participants to confront other barriers to implementing their ideas. One of these barriers included the internalized beliefs from hospitalization experiences.

(In one club meeting, flying kites was suggested. People discuss whether to make kites or buy them.)
Participant: Look. We're not in the hospital now. We don't have to make that shit anymore.
Peer: No kidding. Let's buy some cheap kites and take them to the park.

Another barrier included the language and expectations learned through participation in mental health and rehabilitation programs after being discharged from the hospital.

Participant A: I think we should learn about travel skills. And grooming skills are most important.
Participant B: But you look very nice. You look natural. You hair's a little windblown, but you really look fine. I don't think you have a problem with grooming.
Participant A: Well, that's fine for some days. I look fine, but that's just for today. Maybe I won't look so good like this tomorrow. I need it for everyday.
(Then one peer asks the participant what they exactly want to learn about grooming.)
Participant A: How to bathe.

Peer: Okay, we can work on that. Maybe (the client's peer specialist) can also help you.
Participant A: That would be nice.

Thus participants and peer specialists worked to strengthen the personhood of all individuals, while clarifying what practical concerns participants had for themselves. Individual help was provided by the club organizers in their role as peer specialists. Thus peer specialists could focus on club activities or fall back on their one-on-one relationships outside the club. At other times, participants raised "traditional" mental health concerns at the club meetings.

Participant A: How do I forget my mental problems?
Peer A: I don't know what they are.
Participant A: I'm afraid around lots of people. I feel like everybody's looking. Paranoid.
Peer A: I've observed you hanging out here very comfortably. Playing cards. Playing Pokeeno. Talking with (client). Getting to know (peer). You already know (your peer specialist), and I'm getting to know you.
Peer B: Why not try some activity?
Peer C: Like baseball, sports.
Participant: Talk to your friends.
Peer (who works with this person): Meet with your therapist. Go to your groups or program. Take your medication. Be consistent.
Peer A: Talk to your friends. Bring your ideas here.
Peer C: Like on the streets, people are always scoping each other out. You know how people scope each other out on the streets?
Participant A: Yeah.
Peer C: Self-help is like that. It's people scoping each other out, but in a positive way, so you help people get to know each other.

People encouraged one another to focus on activities that would expand their competence in social situations. Sometimes this meant confronting obstacles that had nothing to do with mental health experiences.

Female participant: We need to socialize with each other more. Why isn't anybody talking to me today? The guys are just talking to themselves. This is my last time here. There's nobody to talk to.
Reactions: That's just how men are.
Everybody's trying to get comfortable with coming here. It takes time. It doesn't have anything to do with you.
Peer A: There's (two peers and the evaluator) here. We talk to you. We're all equal, right?
Female participant: But there's no other women here like me. To really talk to.
Peer B: (Lists the female clients who couldn't make it today. As she names each one out loud, people ask "how's she doing," etc.) We need to make an effort to invite more women so you'll be in good company.

Outside of group discussions, peer specialists and participants shared their concerns. When the meeting was over, people turned the music up and started to chat. One peer specialist made her way over to the woman and encouraged her to come to the next meeting. She complimented her on her ideas for the group, and for getting the group to invite more women. One at a time, several people went up to the client concerned about feeling afraid around people. They encouraged him to come back, "glad you came to the meeting." The client and their peer specialist got ready to take the subway back to the client's apartment nearly an hour away. One peer specialist said to the participant, "I'm not even going to ask you to come back. I simply expect to see you at the next meeting." The person smiled and nodded "okay."

Another peer specialist and the evaluator took the woman client to the clothing rack, which had been established through donations solicited by the project team, and helped her pick out some clothes. The woman's ICM came into the room, and complimented the client on her new clothes and how good they looked on her. Meanwhile, another peer started to clean up the food and put the desks back in place, all the time chatting with people as they got ready to leave.

Another peer sat down for a minute---"just a breather, okay?"---to study a grant proposal from a consumer group, and prepared for an evening meeting at the hospital.

All of the interactions cited in this section occurred during one meeting of the PEERS club. In the course of a single meeting, people articulated a wide range of concerns, plans, feelings and ideas, in such a way that mental health concerns did not dominate the flow of the meeting, yet could be addressed in the social atmosphere of the club.

The role of peer specialists as intermediary between clients and ICMs became apparent at the end of the PEERS club meetings, when ICMs took the opportunity to approach clients individually. At these moments, peer specialists tended to socialize with both client and ICM, attempting to facilitate ICM-client relations and at the same time almost "protect" clients from the their ICMs. Sometimes clients would send out a warning to the group, when an ICM approached a club meeting. "It makes me feel proud," one club participant explained to the qualitative researcher over lunch one day, "because my peer specialist knows when to be a peer and when to be herself and when to be an authority, you know, a professional. Not very many people get to be so many people to me."

Meeting in the Community

Peer specialists favored holding events and meetings outside of the hospital, but had difficulty securing a site for social club meetings. The transportation skills meeting, for example, was held at Bronx Independent Living Services (BILS), several miles north of the hospital. The unfamiliarity of most clients with the BILS location required them to use public transportation in new neighborhoods.

"Arrive at Gun Hill Road. The announcement board in the token booth reads "Today is Feb 24 Monday. That Which Hurts, Instructs." After asking some people, I find my way to the meeting place. I buzz the door, and a woman lets me in. "They're in the back." We walk past lounges, bathrooms, desks, and the boiler room, to a small yellow conference room with no windows. A peer greets me, "Isn't this great?!! Our own place to meet!" I say hi to people sitting around the conference table, not talking to each other yet, and ask whether people arrived by train or the van. "We're here under the auspices of the State of New York," one client said. So, they took the hospital van driven by a former patient.

Two peers are out getting food. People are laughing about my getting lost to a transportation skills meeting, as a peer gives me my own travel skills folder. Another peer takes out the game we played at the last meeting. Everybody starts smoking. I put out the tokens I have left, for prizes. A peer writes up on the board, "WELCOME PEERS CLUB!" A peer won the first game, and seized a token from the center of the table. Another peer thought it was funny that a peer would take a prize, but the winner said, "Prizes aren't just for clients." One client won't play; says he's bored. He's unshaven today, looks down. People just let him be, occasionally encouraging him to play.

The assistant director of Bronx Independent Living Center comes in; she's in a motorized wheelchair, speaks to the group with great effort and determination. She asked people to introduce themselves. One client introduced himself as a consumer. The others followed suit, even one client who says he hates the word. ("Consumer makes it sound like I sit around eating chips all day.")

People are always hungry at these meetings. Somebody muttered to themselves, "This isn't going to be enough; I'm so starving." Nobody had knives to cut up the fruit, so each person took a whole piece of fruit, and then offered bites to other people around the table. Because time is limited for using the room, the peers hurry people to finish eating so the training can start.

For the training session, the project facilitator distributed folders with bus and train maps of the Bronx and Manhattan, flyers about how to avoid getting mugged, and information about fare reductions. Each participant received a folder with their name hand-written on the front cover. A peer specialist opened the meeting.

> Peer A: The trains are interesting. (Tells story about seeing a woman with a mink coat riding the subway.}
> Participant A: Trains are too crowded, people are too pushy.
> Participant B: Like the trains, especially when they go too fast. Buses are too slow; take forever to get you there.
> Participant C: People object to being squeezed chest to chest, side to side.
> Participant D: On the buses you can look all around. Good feature.
> Peer B: Used to get paranoid on the trains. But I take them everyday now.
> Visitor A: I took trains all my life. The bus I learned about in grammar school.
> Researcher: Didn't take trains my first year in New York; only buses.
> Participant D: Mostly I wish I could drive.
> Visitor B: I prefer the buses. They're safer.
> Peer C: I used to feel trapped on the train, so many people hanging out.
> Visitor A: (Tells story of getting mugged at a train station.)
> Peer D: I'm a bus fan. Take buses sometimes just to discover where they go. Like the Bronx 29 to City Island. (Writes it up on the board.)
> Everybody discusses the Bx21 bus to Bronx State (Psychiatric Center).
> Peer B: Remember when transfers went for all day?
> Visitor B: Or when the subway was a nickel?
> All reminisce. People handing each other pieces of fruit, pizza.
> Participant C: Too bad transfers only work North-South to East-West.
> Peer B: No, there's ways to get past that rule. (Explains how you can transfer from the Bx31 to Bx41 and get back to the hospital for free.)
> Peer B: Then there's the Metro North. It's "always on time." That means it don't

wait for nobody.
Peer A: Explains how Medicaid card lets you take city buses for half-fare.
Peer B: Explains how 2 picture IDs and a letter from your doctor gets you half-fare on MetroNorth.
Participant D: Half-fare? That's motivation!

At the end of the meeting, people stood outside on the sidewalk, discussing the best ways to get themselves back home. They were also congratulating each other for having a good meeting. People debated over which subway line comes closest to whose apartment, to which residence, or to the hospital. Debate over which bus runs on time at this hour of the evening, especially since it was starting to snow, and traffic would get backed up soon. Each person argued about their own neighborhood, their own train or bus. Those who were being taken home by the van argued about which streets the driver should take, etc. "Enough already!" somebody said. "Let's just GO!"

At this club meeting, several "firsts" occured for both peer specialists and participants. For one, a peer specialist who had never spoken before in a public setting opened the training discussion with a first-hand story that set the tone for a free-flowing group discussion about transportation. Two clients who had never spoken during social club discussions offered their comments. The ways in which such new experiences were organized and introduced through social club activities and meetings enabled people to take risks without worry of "being put on the spot." Each risk received an acknowledgement from one person or another in the course of conversations after the meetings finished. Both peer specialists and participants took up the responsibility of encouraging the potential in the group members. In this way, people most reached out to each other.

Participant Views of Self-Help

The social club grew from a network of ICM clients aiming to establish self-help group activities. Therefore the participants' understanding of self-help was most relevant to the development of the social club. When asked about their views of self-help, participants did not use concepts and terminology espoused by the mental health consumer advocacy movement. One participant discussed his participation in anonymous-type groups (AA, NA). Others associated self-help with the admonition to "help yourself." Some participants criticized this "bootstrapping" view of self-help by pointing at social and economic barriers to individual success.

The core participants of the social club brought their own views of self-help into the group. These views were informed by participation in other self-help groups and derived from personal perspectives. In describing self-help, clients called upon experiences of creativity, spirituality, and their personal philosophies of life. Clients spoke of two kinds of self-help: the kind in which peers or friends help each other to become stronger, more resourceful, more comfortable in themselves; and the kind of "self-help" which instructs clients to find individual solutions to their problems without considering their personal networks and society at large. When clients discussed the "pick yourself up by the bootstraps" version of self-help, their words resonated with feelings of inadequacy and anger at having to meet the challenge alone.

> I feel bad I have to depend on my peer and ICM.
> I should be more manly than that. But I have friends,
> I have phone numbers. I can call people.
>
> If you can't help yourself, you can't help others. My

> ICM helps me out once in a while, but mostly I have to help myself. That makes it hard.

Clients in the social club often explained "the alone kind of self-help" as a result of excessive demands, which leades to inadequate attention by mental health providers.

> I recently received a new ICM worker. I guess I have mixed feelings. I wonder if there might be people you can feel a rapport with, but who may not be in your corner.
>
> Sometimes I say even my peer specialist only has time for paperwork and her work-friends. Sometimes I've said to hell with this place! But I have to give her credit. It's not her fault, what I go through.

Clients also acknowledged the economic and bureaucratic restraints the mental health and entitlements systems place on clients' ability to "help themselves."

> What other choice do I have? Being in a residence, I come to the hospital and make some money here, a couple of dollars to spend for the week. (When hospitalized) I used to work seven days a week; I was taking home $32 a week back then. Now I make $2.50 an hour. They call it recreation work. I call it trying to get by.
> I want to start a new life. But for that, I need money and paperwork. Believe me, a lot of paperwork. I think more paperwork than money.
> The only thing I asked for, was to go out there and make it on my own. Everybody's struggling, little by little. I want to have the same things other people have. A room, the most I can afford is maybe $250 a month. I only get $508 from the outside.

Sometimes clients felt restrained by doubts expressed by mental health providers regarding their potential to progress.

> I've been to so many programs at the hospital and in the so-called community, and I've never figured out what they wanted of me. I would think big, and I'd think small. And I never could figure it out, what they wanted of me.

This client continued to describe providers' limited vision of what is needed---and what is possible---in a person's life.

> Once you get independent, in every sense, you can move into the collective consciousness. That's my goal. Although it's not one I put forward to the ICM worker. I just emphasize the need for housing. Most people never tie into the collective consciousness; they are too self-focused.

Thus "the alone kind of self-help" was seen as actually holding people back from a more meaningful, wider-reaching participation and relationship with others. This model of self-help also placed most of the burden on clients for not "making it" on their own, or for not knowing what they "should" be capable of, a blame which clients in the social club struggled against constantly.

In contrast to the "bootstrap" perspective, participants offered many ways to conceptualize self-help by describing a vision of a practical, meaningful life experienced in a holistic way.

> Based on my knowledge and experience of the past thirty years, self-help is part of practical consciousness, which is one of the sources of language. Yet, like all other words, it holds mysteries that only life can reveal to you. Some terms are scientific, and are explained that way. Other terms, you just take them as they come. Words are like formulas. Take "BPC," for example. Now, that stands for Bronx Psychiatric Center. But having that formula doesn't help you decode BPC and its mysteries.

> Only living at BPC, you come to understand how the words and the codes are related to the mystery. And then, when you understand how the words and the codes are related to the mystery, it's not a mystery any more, and that's when you should take up another problem in life. Like this place, it's really no longer a mystery to me. Get my my own place, so I can move on. That's what I keep telling the ICM.

Another client described self-help as a way to get the "benefits" in life that he needs, but which are not generally available to him or others. In absence of tactics available to him previously as a worker, the client described self-help as a way to provide for himself.

> Well, self-help is a step up from Medicaid. I have to pay half for the doctor; I might as well cut my own toenails. The way benefits go, it doesn't cover me, so how do I cover the rest? That's just one point. When I was working (as a machinist), we didn't have a Martin Luther King Day. We had a strike to get it. That's how I got the benefits when I was working. Like when we wanted holiday pay, we had another strike. Okay. Next self-help example. At Yankee Stadium, I used to sell ices. You get the ice block, the syrup, your cart and bottles. Maybe $50 to get started. But you can make four times your money. But the cops, you have to be sophisticated when they tell you to move. "Move on to another corner, there are important people here." "But Sir, important people want ices, too!" You get good benefits over a long time. Like being your own boss. I had dreams like that. I really did.

Self-help also provides inspiration from "real people,"a way to somehow live the pain from the past, and sustain visions for the future. Discussing his participation in AA meetings over the last few years, a client explained:

> I been to a few self-help groups. I met some decent
> people there I haven't met before in my whole life.
> One girl, she had stabbed herself in the stomach,
> because she hated herself, being 250 pounds. I would
> believe you would die, but she's still alive. She
> must have some incredible scars...
> I don't get along with my family; they never cared about me,
> never wanted to help me. My sister, we don't get along.
> I want to meet real people. At the meetings,
> I see real people. I want to get a girlfriend and live
> with her, maybe get married.

Another person noted that she did not have the means to put her past behind. The client envisioned her own "self-help program" in which everyone would be able to put the past behind and experience a new sense of self.

> I can't wait to get out of here, and get a room in a
> small apartment where I can have a desk, a chair,
> some paper and a pen. Then I'd have people come
> in, people who are feeling troubled, and let them
> write down on paper what they consider to be all
> their sins. Once they do that, they could either
> give them to someone to read and discuss them
> Or they could have the pleasure of putting
> the paper through one of those paper shredders,
> and watch all of that grief disintegrate. If people
> like Ollie North can put the past and its shame
> behind, cover their tracks, so can we.

None of the clients kept their descriptions of self-help within a contained model or a unified concept. In sometimes very emotional discussions of self-help, clients spoke in terms that addressed "what is really deep in life." They discussed communication, love, prejudice, loneliness, and enjoying "the important things in life," like a good cup of coffee, a conversation with somebody "real," or a moment of inspiration. These experiences also raised the possibility of tapping sources of personal creativity.

> I read this article in Essence magazine, (about) these stars who leave their old friends behind. Even though they're getting fan mail that says "okay, man, let's get together," people say they can't look back or they'll slip. Sometimes it's good to be alone; it lets you be more cosmic. How do they say? "Cosmic-politan." I don't just follow---you know, like follow my race. That's all good, but we need to be open as we can. Some say, "That's just for Puerto Ricans." "Only the Chinese are into that." But not me. Because that's what being an artist is about. since I'm an artist, I can practice not being prejudiced. I'll try a culture, or how it feels, and if somebody hurts me, well, I'll learn from that. But don't generalize too much or it's prejudice. But moving on is hard. Like you move to a new block, and there's a gorgeous new girl, and there's the park, but you just want to run back to your old stoop and that old Loretta!
>
> Let's talk about communication now. Very few people understand the physicality of their voice, and the sacredness of voice. Communication involves how you speak, how you convey yourself, not just the words. Now, medication is one way to mess up people's experience of their voice.

All clients described themselves as very social people who enjoyed sharing food and conversation with others.

> I like to be around people, talk with people, male or female, maybe go out for lunch.
>
> I've been to one social club that was most progressive, because they had free coffee. At the socializing hour, you can sit around talking and sipping the evil brew all day long if you like.

The significance of small enjoyments cannot be underestimated in the context of a life under constant supervision and economic restraints.

> We sit down in the residence dining room, and put two chairs down from the table. A worker comes over, wearing surgical green shirt and pants, and tells us we can't sit here. "I can't trust you here unsupervised." I got up, but (the client) said to the worker, "Hey, we'll put the rest of the chairs down at this table, and then you can set the table where there's empty places." We took the rest of the chairs down, and sat back down. The fellow came back, sprayed the table with Windex, and wiped the table for us. We thanked him, and continued the interview. "I think we need us a cup of coffee after that, don't you?" the client asked me. When he brought cups of coffee and milk back from the kitchen, we held onto them like they were precious.

Over the same windexed table, the client continued the discussion...

> I once knew this older artist at the hospital, someone who was never really recognized except by me. He had been experiencing a creative block, and hadn't produced a satisfying work in months. So one day I took the change I had in my room, and collected a few small debts, and went and bought him a fresh canvas, a really big one, and I told him, "You are going to stand in front of this blank canvas until you paint something you can live with." He started painting a scene from outer space, but it was so disconnected. I said, "Bring something into the foreground! Pull everything towards you!" Then the completed the scene, by putting in the planets spinning so that YOU became part of the whole universe there on the canvas. YOU became part of it all. Life has to be that way. You can't just be out there on the edge all the time, or just be in the position of the viewer, or the rest of the world isn't right somehow.

Such experiences enabled social club participants to go beyond previously accepted limits.

Participants responded to questions about "what is self-help" with narratives about courage,

economic and personal independence, love, and other pleasures of social life.

> Bold moves aren't encouraged by psychiatrists,
> but they are necessary in any creative process.
>
> You can do a lot when you're independent.
> Get a job, play sports, have friends, feel okay about life.
>
> When I get money, I get a shirt this week,
> socks another week. But I'm planning to get
> a radio that costs $41, a little more than that with tax.
>
> The only thing I ever wanted to do in life
> was to do things right. It's hard out there,
> but I have to go out there sooner or later.
>
> I won't give up on trying to discover what love is.
> Love is people passionately caring for each other.
> When I write love poems,
> I write them as love statements to the collective "you."
>
> Let's organize a party that's got nothing to do
> with attire. Not even mention sneakers.
> Everybody just come in peace. Good security,
> good food, nice drinks. $2 for gents, $1 for ladies.

Social club participants, then, used their own language and developed concepts from their experiences outside of the mental health system. They built personal philosophies akin to self-help or mutual support. Many emphasized the positive outcomes of self-help participation. Social club participants described the processes of creativity and the enjoyment of social life as central to any experience of self-help. They emphasized economic and personal empowerment (rather than recovery from mental illness, for example) as desired outcomes of mutual help.

Peer Specialist Views of Self-Help

Peer specialists also distinguished different types of self-help. Whereas clients distinguished individualistic from collective kinds of self-help, peer specialists distinguished self-help programs tailored by providers and carried out in an institutional setting, from those created by and for participants. Peer specialists had varied views and experiences with self-help organization or participation. All had participated in self-help groups and social clubs, and nearly all had experience in organizing a self-help group. Because of these experiences, peer specialists had formulated their own views of how self-help should work, and how groups should be formed.

Peer specialists were often wary of professional understandings of self-help. They wished to establish their own model of self-help in the Bronx. This desire was consistent with their self-help approaches with ICM clients. They emphasized social activity rather than "talking" or "therapy" as the organizing element. Whereas professionals would refer to "self-help" as a general term, peer specialists refered consistently to "self-help in the Bronx." This was a way of noting that, when applying a general model with clients, specific local conditions have to be taken into account. When asked, peer specialists understood "self-help in the Bronx" in terms of a region of multicultural relations: a community.

Peer specialists recognized that "their" self-help efforts were occuring within a research project. That demanded certain guidelines for organizing and participation. Only the peer specialists were designated to organize a group (and only ICM clients assigned to the peer specialist were eligible to join. This was aimed to preventing contamination effects between the experimental and comparison groups). One peer specialist explained how these guidelines

established a different consciousness of self-help.

> Self-help, when it's not in a function, like being in a self-help project, comes from a commitment that is individually made. Then there's more conviction in the realm of action. On the job, there's not that freedom of the individual. What you do pertains to the job function. You can't perform in a free-flowing, in-and-out fashion. Outside, you don't tell people they can't come, like in our project. But then, our project is self-help that's being adapted to the system.

Because organizing a self-help group was taken as a "job function," peer specialists it as an "exercise in organizing " They interacted with ICM clients under the rules of the project.

> With our project, there's a master plan. The employees are only as good as each other in self-help, but that doesn't mean you're held to be as good as your employer. In the end, you always have to come back to them .

In other words, peer specialists felt that employee-employer relations complicated the peer/self-help relations, in contrast to their previous participation in "independent" self-help initiatives .

Besides conferring with each other to make significant decisions about the social club, peer specialists also had to seek the approval of ---or at least consult with--- management team members when faced with important decisions.

> Clients are subject to change, not to my control. I like the social club aspects, enjoy participating in different things, stretching who I am. I wouldn't put a limit on the boundary lines. If you bound a group to one area you might only get a few active members. It all depends on being open to the community of mental health.

The combination of being a consumer and being a provider sometimes proved challenging for peer specialists working on the social club. Whereas peer specialists had to look to their employer for certain kinds of guidance with the social club, clients looked to peer specialists as providers as well as peers. These hierarchical relations posed problems and opportunities for peer specialists.

> As a consumer, more or less it's expressing one's
> opinion or ideas, something you felt would make
> a change. As a provider, there's a different type of outlook.
> Presentations to make that are for the job.
> As a consumer, it's all individualized, with indi-
> vidual reasons for presenting, personal reasons.
> As a provider, presenting and organizing are my job functions.
> My views as a consumer go beyond the outlook of the project.
> And that gets confusing.

> You have to create from what is needed for it to
> really be empowering. You can teach that there is
> a way, but you have to create the action. Teaching versus creating.
> It can come down from providers or come equally from a peer.
> But who knows best than the fisherman at sea?

In addition, peer specialists contended that permanent or consistent client participation in the social club may or may not be a measure of self-help success.

> In my experience, everyone got to the point in
> their lives where they felt comfortable, emotionally and financially.
> So then they could move on.
> Fullfilment has been met so they move on.

Peer specialists argued that the use of one's experience and the expansion of personal creativity and resourcefulness were important elements of success with the social club. In other words, peer specialists measured the successes of the club against themselves, and not just against objective oucome variables, such as the number of clients participating.

> Self-help is satisfying. Something you have to want, and then you do it, and then it's real accomplishment, giving praise to oneself, and to others.
>
> My mind is focused on helping others, but through myself. I use the experience when needed, and it comes as needed. Already stored in me. If there is the need for a creative plan, it comes up automatically. I'm creative in a lot of ways. To keep it, you have to give it away. That's when you know it well enough, so you can pass it on, and another person can grow.

Mutual Support

Over time, participants and peer specialists developed ways of supporting each other through their involvement in social club activities. According to both groups, the formation of mutually beneficial and meaningful relationships was one of the best indicators of social club success.

Two social club events represented the ways in which peers and participants extended and reciprocated support. An afternoon spent flying kites is an example of how peers created a supportive, open environment for clients to talk about issues and simply enjoy themselves. A trip to the Bronx Zoo gives evidence for how participants supported peer specialists at critical moments. It is important to note through these two examples that reciprocity did not occur immediately, or within the context of a single interaction, but was established over time.

Just as peers had to initially learn about the needs of ICM clients and ways to address them, so the social club participants gradually learned about the peers' needs and extended themselves in return. In a fluid response to differing needs and pressures experienced by peers

and participants, mutually supportive and encouraging relationships were established through the social club activities.

In the spring 1992, the social club planned an afternoon of kite flying on the lawns behind one of the hospital buildings. Because some participants were not interested in attending the event and others had schedule conflicts, only two participants joined the peers and the researcher that day. While conversing in the office before going out, people ate the fried chicken wings one of the peers had made the previous night at home. Sitting around the peers' desks, one peer, one participant, and the researcher played a card game while another peer and participant talked at another desk. During the ensuing afternoon of kite flying, one peer's kite kept coming down; another peer's kite kept getting stuck in a particular tree no matter which direction the wind was blowing; and another peer acknowledged that they had never flown a kite. Participants that day had their own troubles keeping kites in the air or bringing them down without a tangle, but such circumstances became secondary to, or simply part of the process of, everyone enjoying the afternoon together.

Near the end of the project, peer specialists were especially concerned about their prospects for future employment, their relationships with ICM clients, and the resultant pressure which seemed to build with each passing week of the summer. During the social club trip to the Bronx Zoo in July, participants took it upon themselves to cheer the peer specialists. Offering a cigarette, placing a hand on someone's slumped shoulder, giving advice on where to look for work, and pledging to remain friends beyond the duration of the project, participants encouraged peer specialists to look beyond the confines of immediate circumstances to the broader (and more hopeful) picture of ongoing friendships and enjoyable times to come. Looking back to previous

social club events, participants asked peer specialists to remember some of the good times as a way to get through more difficult times. "Remember when we were flying kites? Maybe you'll feel like a kite in the sky when you finish up here. You'll be flying. You'll be up there like never before."

At the zoo, participants also took the lead in deciding which exhibits and areas to visit. Taking some of the "pressure of leadership" off of the peer specialists, they obtained maps, found serene places to sit and relax, and insisted upon buying sodas for the peers: a reversal of the usual practice of peer specialists spending "project money" to buy snacks for participants.

Social club events gave participants an opportunity to step aside from "the downside of being an ICM client" and provide something equally meaningful and necessary as that which the peer specialists had provided them. Even during "ordinary times," participants seemed to sense that peer specialists sometimes needed a break from their complicated roles and from the expectations placed upon them by their co-workers and by ICM clients. Yet, because peer specialists never blamed clients for these burdens of expectation, responsibility, and "the work of being a pioneer," social club participants could offer their support without feeling that they were personally responsible for the pressures the peer specialists experienced. Providing an atmosphere of acceptance and tolerance at times when peer specialists found it difficult to "just give and give and give," social club participants reciprocated the support the peer specialists had been offering ICM clients at the individual level.

The social club was valued by participants because "good times bring you around to yourself." "Being with a good group brings out the best in people." "It's a way to make life worth living." "I like being around everybody, even if I just hang out with myself." Peers found

social club events enjoyable as an alternative and an enhancement to their one-on-one relationships with ICM clients, and as a haven which "felt separate from the peer specialist project and the ICM project; like it was just ours."

Peers also appreciated organizing something which they themselves could also enjoy. One peer stated: "Helping should be like this more often. I think usually professionals don't get to really enjoy their work. Instead they have to wait and hope for some good effects either for themselves or for clients, at some later date." Reflecting on their experiences with social club participants, peer specialists raised questions about why professional work with clients is depicted as difficult to enjoy.

In one sense, the trip to the zoo seemed disappointing. Only two participants joined in this final event of the social club. There were twice the number of staff than participants at this outing. Instead of being a manifestation of strength in numbers, the trip to the Bronx Zoo allowed an appreciation for the types and the quality of relationships that emerged from the PEERS club. Participants of social club events did not merely ettend to be counted, but to contribute in increasingly confident and reciprocal ways.

It is also significant that those who participated in the club until the conclusion of the project were ICM clients with whom many professionals were reluctant to work. Sustaining these individuals' participation in the social club until the project's conclusion was an accomplishment which brought the peer specialists much pride, not because these were "difficult clients," but because the peer specialists had created an accepting and supportive environment for people who they felt had been denied acceptance and support.

Through the relationships developed with these loyal social club participants, peer specialists created a safe social space for participants and for themselves, times to retreat from ordinary social and professional pressures, and the basis for mutual support over time. This speaks not only to the peer specialists' competence as providers and organizers, but to their openness to to being affected by the very processes they had initiated with social club participants. "It goes back to the phrase 'each other' in the PEERS club name. That was a vision that came true; we really did help each other. It wasn't just a one-way thing."

Conclusions:

The PEER Social Club was an example of a small, emergent self-help organization. It developed as an intended outcome of a federally funded research demonstration project and was carried out by a team of trained consumer advocates (peer specialists). While there are a number of reports on self-help groups and activities that occur as appendages of mental health programs, the PEERS Social Club offers unique insights in the processes that underly such developments (Refs.) In bringing together a variety of stake-holders with different goals and perspectives, the PEERS Club illustrates the potential and the limits of such experiments. A "progressive" group of mental health researchers and officials coverged on a more traditional system of service providers (ICMs) by introducing former patients as a new type of mental health worker. The group that stood to benefit most from this complex social experiment were the ICM clients, who were recruited from among those for whom more conventional services (i.e. clinics, case management, day treatment) have not worked. Through individual contacts with peer specialists, and in

particular through the formation of a social network, these relatively disenfranchized individuals were brought in contact with the values and activities of self-help and empowerment. Organized self-help, which has been promoted by a rapidly growing group of activists, has yet to reach the considerably larger number of individuals receiving psychiatric services. In this project we can see the interface between these groups in action, resulting in a mutual support network based on the principles of self-help. It became clear that the imposition of values, be they rehabilitation-oriented or stemming from a codified self-help practice, does not necessarily take into account the definitions and expectations of consumers. To what extent these developments can lead to lasting friendships of people who are generally lacking reciprocal relationships cannot be established from this exploratory work. However, it is clear, that with the right levels of ongoing support from outside, be that through funding, technical assistance or both, relatively autonomous networks can emerge and provide evidence of a new "culture" which is both separate from and a part of the "mental health system."

References

1. Felton, Stastny, et al Hospital and Community Psychiatry

2. Welle, D., Stastny, P. And Gelman, R. The "Mod Squad" of Mental Health: A Case Study of the Development of the Peer Specialist Program. Unpublished Manuscript, 1992.
Welle, D., Stastny, P. And Brown, C. A Qualitative Field-Based Study of Peer Specialist and Paraprofessional Work and Relationship with ICMs and Clients. Unpublished Manuscript, 1992.
Welle, D., Stastny, P. and Brown, C. People Educating and Empowering each other to Realize Self-Help: A Qualitative Study of the PEERS Social Club. Unpublished Manzuscript, 1992.