Voices From An Invisible Movement: Mental Health Consumer/Survivor/Ex-Patient Activism

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This narrative is the result of the author's long standing interest in the mental health consumer/survivor movement and its implications for social work practice. Her primary purpose is to raise awareness on the part of human service professionals about this movement by giving voice to the experiences and perspectives of consumer/survivors. A number of narratives are woven together, based on in-depth interviews with movement leaders and participants. Implications for social work practice are identified.

Introduction

There is a hidden movement, unknown to most social workers and other mental health professionals. The movement and its participants have gone by a number of names, the most common of which are mental health consumers, psychiatric survivors, and ex-patients, often referred to collectively as C/S/X. The primary purpose of this paper is to raise awareness on the part of non-consumer professionals about this movement and give voice to the experiences and perspectives of some of its participants. For more than 30 years, there has been a network of activists in the U.S. who have rejected the subjugated role of "mental patient" that professionals have thrust upon them. Emerging from the atmosphere of political action and social change of the 1960s, the early movement, beginning around 1970, was organized against involuntary hospitalization, electro-shock treatment (ECT), psychosurgery, and forced medication. The potential for self-help alternatives to professionally controlled services is detailed in Judi Chamberlin's (1978) seminal book *On Our Own: Patient Controlled Alternatives to the Mental Health System.* Chamberlin identified three types of alternative models:

• In the *partnership* model, professionals and nonprofessionals work together to provide services. The recipients of services are told that they , too, are partners in the service. However, the distinction between those who give help and those who receive it remain clearly defined. I consider services based on this model to be alternatives in name only.

• In the *supportive* model, membership is open to all people who want to use the service for mutual support. Non-patients and ex-patients are seen as equals, since everyone has problems at one time or another, and all are capable of helping one another. Professionals are excluded from this model (except in external roles, such as writing letters of support).

• In the *separatist* model, ex-patients provide support for one another and run the service…All non-patients and professionals are excluded because they interfere with consciousness raising and usually have mentalist attitudes.

Indeed, while there has always been a wide range of perspectives among different C/S/X groups regarding the role of non-consumers, the movement during much of the 1970s tended to be characterized by a separatist view, in which the inclusion of non-consumer social workers and other professionals was seen as undermining the efforts of psychiatric survivors to value their own expertise and claim control over their lives. Beginning in the 1980s, with the support

and funding of the Community Support Program (CSP) of the National Institute of Mental Health (NIMH), non-consumer professionals, genuinely interested in forging partnerships, have worked with C/S/X activists on policy-making committees, advisory boards, and other aspects of mental health advocacy (McLean,1995). These professionals were trusted by many psychiatric survivors in a context where the professionals were able to provide political access and assistance in obtaining funding for C/S/X projects without seeking to control them.

This exploration of the history, goals, and current strategies of the C/S/X movement will be explored through narratives culled from in-depth, open-ended interviews with movement leaders and other participants.

Terminology

As stated above, participants in this movement have gone by a number of names. The terms "consumer," "psychiatric survivor," "ex-patient," and "ex-inmate" suggest ideological differences. There have been many debates within movement groups as to which descriptor is most appropriate. The term consumer is used by most consumer advocates as well as state mental health officials. Many movement activists object to this term, primarily because it implies a freedom of choice in consumption that survivor/ex-patients do not have. The term has also been rejected because of its association with a market economy, which obfuscates the relationship of the users of these services to the providers. Audrey, an advocate with ties to the movement's leadership, explained the differences in terminology this way:

"When I was studying the movement, twelve different terms came up, but no one wanted to call themselves consumers. That was really a Department of Mental Health term. My personal favorite is psychiatric survivor...Judi Chamberlin used 'ex-inmate' in the '70s, but almost no one uses it now. 'Ex-patients' denies the subordinate relationship, and the whole medical model paradigm..."

The term "survivor" speaks to an individual's strengths and capacity for recovery as well as to the self-help aspects of the movement. "Ex-inmate" emphasizes the element of incarceration in prison-like hospital environments. So, while it may appear that these terms are being used interchangeably in this paper as they vary from narrative to narrative, they contain different nuances and implications. Certainly the incarcerated inmate whose freedom has been denied connotes a very different image from the mental health consumer choosing freely among a range of voluntary services. Disagreements about terminology have been divisive at times despite attempts to compromise with more inclusive, if cumbersome, terms such as "consumer/ survivor/ex-patient" or C/S/X, which reflect commonality among different groups and their ideological perspectives.

My Interest and Methodology

I first met some of the C/S/X advocates in the Boston area in the late 1970s. I was a social worker who later went on to work with people labeled "homeless mentally ill" and the memory of these radical activists stayed with me. I had identified with their political resistance and was intrigued with their view that there could and should be patient-controlled alternatives to the mental health system (Chamberlin, 1978). The homeless, mental health program I supervised was voluntary, but it was professionally controlled with limited avenues for consumer input into programmatic decision making and information control. Chamberlin's critique of "alternative" mental health programs based

on an unequal partnership model rang uncomfortably true:

"…It is clear that true partnership is not possible because the partners are not equal. The staff… keep records on members, consult with others about members, and make decisions members have to abide by. Members, on the other hand, can participate in only the most limited kinds of decision making. They can vote to schedule a bowling night instead of a swimming night, but they cannot vote to fire the executive director…." (1978, p. 92).

Chamberlin's critique raised disquieting questions for me, but I did not pursue these at the time, choosing instead to focus on research concerning homelessness. Many years later, I moved to New England and became involved in a consumer-run, mental health, peer-support center. This particular center is run by a Board of Directors elected by the center's membership, and composed of twelve center members plus a maximum of four "community" members appointed annually by the Board. These distinctions become blurred, as most of the appointed community Board members can also be identified as consumers to one degree or another. They differ from other Board members in that they are not center members, have been appointed because of a particular areas of expertise and cannot run for any of the Board offices. There are clear distinctions drawn between center members and paid staff. The current director is a non-consumer social worker who plays a coordinating role as well as being instrumental in obtaining funding. However, the hiring of the director, like that of all staff, is the responsibility of the Board, which also evaluates the director on an annual basis, and has the power to terminate his employment.

In 1997, I was appointed to one of the center's community seats. My continued involvement in this capacity served to rekindle my early interest in the C/S/X movement. In the late 1990s, I conducted a study of the perceptions of power differentials in the client/worker relationship in more conventional mental health programs (Cohen, 1998). More recently, I conducted a narrative-based study with twelve individuals active in the C/S/X movement. The people I interviewed included three national leaders of the C/S/X movement, four consumer advocates with ties to the movement, four members of the Board of Directors of the above-mentioned peer-support center, and its director. All but the center's director identified as mental health consumers, psychiatric survivors, and/or ex-patients. Participants in these interviews were de-identified for purposes of confidentiality, with the exception of the three national leaders who have been movement spokespersons for many years. They are Judi Chamberlain, Jay Mahler, and Pat Deegan, all of whom readily consented to the use of their names.

Narratives of a Hidden Movement: The Personal Meets the Political

It seems worth commenting that, although each interview began with a very general statement ("I am interested in hearing a bit about your own experiences with advocacy for mental health consumers and survivors"), the majority of people interviewed immediately responded with a recounting of their personal histories in the mental health system as a prelude to their becoming involved in mental health activism:

Pat Deegan, a public spokesperson and author of numerous publications related to C/S/X, responded as follows:

"My experiences with it, with the consumer/survivor/movement, began while I was in the early years of being incarcerated in mental hospitals. I was a teenager in the 1970s and I was in a mental hospital in Boston that overlooks Brookline Avenue, which isn't
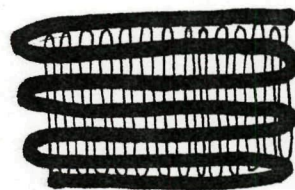
far from Mass Mental Health Center. I think it was maybe only my second or third time in and I think I was 18 by then and looking down the street and actually seeing a demonstration go by...I mean I didn't know what it was. It was a ragtag group, not terribly big, but they were marching on Mass Mental Health Center and holding signs like, 'Lobotomize Shrinks' and 'Shrinks are Nazis.' I just remember catching a glimpse of that and at the same time there was a paper in Boston called the *Phoenix,* and I remember reading about it and that's how I put it together what it was that I had seen, you know...So, that was really my first exposure to it but I didn't really connect at the time. I was very much just trying to survive, but the seed had been planted. At least I knew that there was this group of people out there and that they were somewhere in the Boston area."

Audrey is a psychiatric and trauma survivor with a master's degree in social work who has been employed in a consumer advocacy role in two different state mental health departments. Like Pat, Audrey began our interview by sharing some of her personal experiences:

"I always had a leaning toward activism but never did too well trying stay connected to it. When I was in and out of hospitals in the 1970s, I was aware that there was some critique of the mental health system going on. I read *The Politics of Experience* by R.D. Laing so I knew that there was at least somebody out there who thought that things should be done differently and that was important to me...I was aware in some vague way that what happened to me was more harmful than helpful, but since I kept sort of ending up back in the hospital, I also had the belief that I probably just wasn't the right kind of patient. Meanwhile, it's the '70s and I'm missing the feminist movement. But, I was too busy being a mental patient...Of course nobody was

doing anything about trauma then. So I was also one of the many abuse survivors who wasn't even questioned about abuse, and then even when I told people about that part of my life, it was not contextualized at all as sexual abuse...On the unit, they were sending my roommate out for shock treatment...I could see that there was this disgusting, inherent coercion happening that just pissed me off, but I was someone who didn't get angry. I got depressed instead of angry. So when I finally got out of the hospital, I had to figure it out, I had to sort of let go all the stuff about what I would have wanted to do globally and just really focus on what I was gonna do with my life."

Jay Mahler's story further highlights the interconnection between the personal and the political:

"I was active in the Free Speech movement at Berkeley around 1964...Around the same time I had a 'nervous breakdown.' So, I was an activist who became a mental patient, who became a mental health activist. This was in the early days when the movement was more militant. My involvement was focused on the rights of psychiatric inmates, especially the right to be free of involuntary hospitalization, ECT, forced medication. For about ten years I was incarcerated in state hospitals, subjected to shock treatment...But, on and off, I was able to get back to school. In 1972, I was back at Berkeley as an undergraduate. I was active in the movement and also had the opportunity to have a consumer advisory role in a county-level mental health committee. In this role, I went to statewide meetings of county mental health officials, some of whom were progressive and who saw the importance of mental health consumers having a role in designing mental health service policies and the provision of services...In 1976, I helped organize Mental Health Consumer Concerns (MHCC), a

mental health advocacy group which advocated for patients' rights to refuse treatment and to get treatment in the least restrictive setting possible. We looked to political activism and began to make connections with activist groups from other parts of the country...We founded the Coalition Against Forced Treatment (CAFT), which engaged in political protest against the use of a medical model in mental health and gave testimony against its worst abuses. We had all been traumatized by the mental health system; we got support from each other and from fighting back; we were political activists and survivors. There were other groups like CAFT around the country which had been organizing national Conferences for Human Rights and Against Psychiatric Oppression since 1972. These annual conferences were initially open to non-consumer professionals, but the leadership role of patients and ex-patients was always acknowledged. In 1976, they threw the radical shrinks out...The separatism in the movement continued for most of the 1970s, and, in fact, in some groups it remains. But there was a move back to partnering with non-consumers, professionals by the late 1970s because there was federal money available through the Community Support Program (CSP) for community mental health programs that had consumer involvement. This provided some opportunities for consumers to have a voice in policy and service planning. At that time, there were some progressive non-consumers with power in the public arena at state and federal levels, so partnerships and alliances were formed. This was how I ended up having some voice in the system...."

Perspectives from the Ground Level

Jay's narrative provided rich historical information about the C/S/X movement in California, where it was particularly strong, as well as the early development of the more loosely woven national movement. My discussion

with Judi Chamberlin provides a view from a movement leader on the opposite coast:

"It's interesting because it's gone through so many changes. When it first got started, it was very clearly a civil rights movement, analogous to the women's movement, the black movement, the gay movement. It's about people who are systematically deprived of their rights and their voice. And then over time we kind of got away from the idea that it's about rights. I don't think I ever got away from those ideas but as a group...of organizations that work somewhat in concert with one another, it became much more focused on alternatives and improving treatment and working within the system and all of that...It has been two steps forward and one back, surprising gains in one area and beating yourself against a stone wall in another. The establishment of Offices of Consumer Affairs in the state mental health departments is a good example. Some of them are a total joke but others have done some pretty interesting things, empowering direct users and exposing them to things they wouldn't have been exposed to otherwise. So, there have been incremental changes in that respect...I mean if you look at the organizational charts of how different states have done it, some Directors of Office of Consumer Affairs are in direct line of command and they're really part of senior management, and in other states the same people are stuck off in a cul-de-sac...But we are still fighting against forced treatment, that is still the key. We are legally second-class citizens in that you can do stuff to us that you can't do to anybody else. There is a whole lot less long-term hospitalization than there used to be, although not because of us. There are many more community based housing arrangements and drop-in centers of various kinds, although very few are really integrated...but that confirms the essential truth, that if we get sidetracked into a reformist agenda, we just get put on a treadmill...We

need to get back to challenging the real problem which is power distribution and civil rights."

The ex-patients employed as consumer advocates within state mental health bureaucracies generally shared the overarching goals expressed by the movement leadership. However, unlike the national leaders, they were more inclined to emphasize increasing C/S/X voice in the options available to psychiatric survivors within the mental health system, as well as in seeking alternatives. A related goal was having the expertise of patients and ex-patients respected and incorporated into planning by professionals and public officials. Their energies tended to be directed on the immediate concerns before them, which involved ensuring consumer input on specific policies and proposals. While others emphasized the importance of working from outside the system and creating alternatives to it, these individuals put most of their efforts into changing the system from within. This is less of a dichotomy than it may appear. As Pat Deegan commented:

"Right now there are about 35 states that have ex-patients as part of their management structures. That group now has organized themselves nationally and have a president, treasurer, and a little bit of a budget and that in itself becomes powerful...Incremental changes and symbols are important...I think that the people in these positions have recognized that they're going to try to work the system from within, but they need the heat to remain turned on by activists on the outside and, secretly, the people in power, the commissioners, they don't know this, we worked strategically at times with these insiders. They helped us figure out how high to turn that heat, how much the system could handle, what had to be done by outside agitators...I think that when viewed as a whole, at the alliances forged between people who are working it

from the inside and working it and agitating it from the outside… then some cool things can start to happen, so long as we can maintain some solidarity. Now the danger becomes if that leadership becomes so entrenched in their position and isolated from the outsiders and begins to view us as unwanted agitators who bust into their meetings and make their job hard, that's when it breaks down and then that's when you have the possibility of co-optation. But I see people working in very creative and good ways."

Lily, employed as a consumer representative within a state mental health department, described the specific goals of the movement as varying widely from group to group. Much of her emphasis was on a strengths-based, peer-oriented approach to recovery, which assumes that survivors and not professionals are experts and can help each other. She also identified as a high priority the goal of increased opportunities for consumer voice in state mental health department decision making:

"I think a lot of folks would say that a couple of goals of the consumer movement would be helping folks move forward in recovery and having opportunities for recovery…You would really have that infusion of recovery and that availability to grow peer support. You never know. It means different things to different people … peer support is very powerful in that recovery process, that's what we're trying to tap into and that's what we're trying to help people utilize. The other obvious goal is to increase consumer voice, to have consumers be directive, to have their say in the programs they have a stake in. In a nutshell, my job is to bring consumer voice to the department on matters of program development, policy, contract, and to work to increase consumer involvement."

Asked about her perception of encouragement and/or or limitations in her job, Lily responded:

"There is encouragement for what I do because the state needs to show it has consumer input into mental health services. There are federal mandates and the former state commissioner was an ally to consumers. I really haven't felt co-opted in this job, but there have been times recently when I have felt my power to do my job was being undermined. I was in senior management, my position was supposed to be a senior management position. But then the reporting structure changed in a way which diminished my ability to serve as an effective consumer voice."

Audrey, who has strong ties to movement leaders and considerable experiences in consumer advocacy roles in two different state mental health bureaucracies, pointed out several obstacles to meaningful input by psychiatric survivors:

"There has definitely been an attempt to co-opt and limit the movement...They do it in different ways. Some state mental health authorities think they've got it now, like they know what it's about and so therefore they don't have to have consumers at the table anymore or they think it doesn't make any difference who's a consumer and who isn't, because they've taken care of stigma...They don't get why we have to be out of the closet as ex-patients. They say why we shouldn't just assume that everybody is a consumer...or they wouldn't be speaking their mind...So that aids and abets the marginalization of direct consumer voices...it's amazing what discussions aren't even on the table anymore. The other thing that has aided and abetted this marginalization is the state budget situation...There's a way in which these budget crises have given people in authority li-

cense to say we don't have time to include people...you know there's this whole thing about what's too much trouble also costs too much, whether that is a realistic assessment or not."

Jay, while aware of his positive impact on the state level also talked about what he sees as the inevitability of co-optation. As he put it:

"I have met the enemy and it is me. I am an advocate but I am also a consumer representative on the county mental health management team. Sometimes I find it hard to sustain the identity and values of a consumer. It is hard for me and others in positions like mine not to begin to identify with management. This is true co-optation, when you identify with the oppressor...I feel co-opted *all the time* in my job as consumer representative for the county...I go to meeting after meeting where nothing is accomplished, where I am a token member of the mental health of management team. This is a contradiction I have really struggled with, whether I am making any kind of a difference in this role."

The Board members of the consumer-run peer support center described above tended to view the movement and its goals in very local terms. Several saw advocacy for consumers and survivors mostly in terms of lobbying the state government for funding for the center. Sylvia is a Board member whose view is local but less parochial than many of the others:

"I think the consumer/survivor movement may be stronger in other states; here it is still trying to be born. I know I've watched some of the projects start to come together and unite, but for whatever reason, they don't seem to be working.... while they may be doing it, they're not being listened to by the

people in power and so the system doesn't change. I know that our center is trying very hard not just to change the system, but to create a different system…and then, we will need to figure out how the new system relates to the state mental health system and if it doesn't, then money is the major question. And if it does relate to the state system, then a whole bunch of other potential problems come into play…But, the biggest problem is money. You know the state holds the purse strings and they want us to jump through certain hoops in order to get funded and they don't necessarily want to fund consumer initiatives because then they'd lose power. You know, it's like, first we had to get out of the mental institution. Well, now we've gotten out of the mental institutions, but we're stuck in the mental health system and the question is, how do we get out of the system, how do we get what we need?"

Activists working on the ground level have far more than theory and terminology with which to contend. They have to deal with day-to-day issues, compromises, repercussions, and choices of which battles to fight. The concept of being a "consumer representative" is a tricky one as it can become easy to lose sight of which constituency one represents.

The Movement Today

The consensus among most of those interviewed seemed to be that the national C/S/X movement needs to reach out to a broader constituency and find common goals, while overcoming ideological differences. Pat Deegan sees the movement as internally polarized:

"My opinion is that there are these ideological differences and a failure to identify a common ground that we can work together on…The movement is still very polarized. You know, you now have people who proudly call

themselves consumers, which means they believe that mental illness really does exist and that psychiatry is okay. Sometimes it's helpful and it's okay to take meds and then there is sort of this other much more clearly anti-psychiatry, pro-choice group that believes that psychiatry is not a legitimate discipline but rather a tool of social oppression…These two groups are really polarized…The one area where I think we are doing very important work, and I'm very pleased with it, is in our cross-disability collaboration and building of partnerships. I think this has been extremely fruitful…For me, that's a natural connection and it really is working out, really well and I think we have a lot to learn from our co-conspirators who are, who come from the other parts of the disability movement."

Judi Chamberlin echoed Pat's excitement about working collaboratively with groups of people with physical and developmental disabilities and agrees that this is an important future direction for the movement:

"For me, in the last five or ten years, the movement has become a lot more focused on cross-disability work and that's where we got back into the rights arena, because the cross-disability aspect of things has focused a lot of ideas, you know, of hey, it's not just us. I guess it began coming together on getting the A.D.A. implemented; we really saw our commonalties. People with disabilities are systematically mistreated and ignored and medicalized and kept out of the mainstream and have their voices taken away and right now, one of my main focuses is working on an international level on this, the U.N. Convention On Human Rights Of People With Disabilities. And that brings it squarely back, this is a human rights issue…There is a history of fighting for fundamental justice for people who are perceived in one way or another as different and defective and not fitting in, and it's really just a joy to do cross-

disability work, because people's experiences are different. You know, the particular needs of somebody who uses a wheelchair or somebody who's deaf or somebody who's blind or somebody with a developmental disability or somebody with a psychiatric disability, their particular needs are different in some ways, but the experience of being the outsider, of having other people think they know what's best for you, it's such a powerful commonality."

Jay also saw the future of the movement in broadening its scope:

"...into the community, to form alliances with other groups but, at the same time we don't even really have our own national group. We have information clearing houses, yearly conferences, publications, ... but it is still very regional. We need a stronger national identity, an organization, visibility, a presence. We have done a lot of work at the state level in allying with physical disabilities. I wish we were more a part of the larger disability rights movements, of the various civil rights movements, and really unite all the other disadvantaged and stigmatized groups, groups of poor people for example, under a "rainbow coalition" – unifying all of these groups that have been discriminated against."
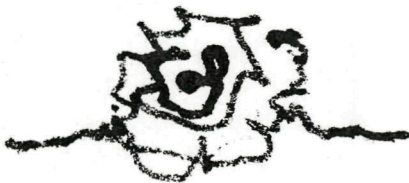
Partnership and Implications for Social Work Practice

Judy, Jay, Audrey, Pat, and many of the other movement participants interviewed were in strong consensus that the C/S/X movement needs to be understood first and foremost as a human rights movement, em-phasizing an awareness of their commonality with other oppressed groups. This view has important implications for working in partnership with social workers and other human service professionals. In Judi's words:

"We can all work together if all of our expertise is valued. We come from a society that doesn't recognize the value of experiential knowledge. If you've got a Ph.D. in it, you must know something about it...If you've lived it, what the hell do you know, you know, whether it's mental health or anything else?"

Jay expressed his view of partnership with professionals as follows:

"Partnering is necessary. Consumer/survivors just don't have the power to make needed changes in the system alone. They need allies who do have the power even though this frustrates me. I have the experience but not the professional training. As a consumer, my power lies in my ability to influence non-consumer professional allies to advocate for change."

While the traditional worker/client role does not lend itself to the paradigm of the C/S/X movement, there are important practice roles and resources that social workers can offer the movement to help advance its objectives of social justice and self-determination. These are goals which resonate strongly with social work values. Some of the professional roles and skills that social work allies can offer are consultation, assistance with grant writing, linkages to other groups, and concrete and mutual support. We can also provide assistance by publicly allying with the C/S/X movement using our professional legitimacy and power in support of consumer/survivor/ex-patients' rights. Social work educators can play a role by introducing the C/S/X perspective in the classroom, exposing stu-

dents to C/S/X literature and to guest speakers active in the movement.

Professionals have knowledge and access to resources that can contribute to social change in the mental health system. The strengths perspective in social work (Saleeby, 2002) overlaps with the concept of recovery which many ex-patients see as integral to their work in the movement. A focus on individual and collective strengths makes working for change more humane and provides a bulwark against social oppression.

Two psychiatric survivors, Mead and Copeland (2000), see a potential for infusing treatment-oriented relationships with mutuality and respect for self-determination. In their words:

"We believe that the need for mutual support extends into clinical settings. Though clinical relationships may never truly be mutual or without some assumptions, we can all work to change our roles with each other in order to discard the kinds of paternalistic relationships some of us have experienced in the past" (p. 318).

The major caveat in the partnering of non-consumer social workers with consumer/survivor/ex-patients is that social workers must remain humble about the expertise that we bring to programs and projects. While professionals have many important contributions to make, it is essential that we not attempt to impose our own solutions when called on by ex-patients to provide assistance. In this context, acting in partnership means making our many skills available, not substituting our professional knowledge for what psychiatric survivors have learned through lived experience.

I believe that one of the challenges for social workers *and* consumer/survivor/ex-patients is transcending the "us" and "them" dichotomy within the context of our different roles. My impression is that most social work-

ers have had some experience as consumers of mental health services. We fall somewhere on a continuum which stretches from involuntary hospitalization and/or outpatient treatment, to voluntary hospitalization and medication, to various forms of voluntary outpatient treatment.

At some point during the course of this research, I found myself identifying with the consumer/survivor/ex-patients, relating to them as "we." In the process of writing this article, I found myself slipping back into my professional voice. In point of fact, while I have not experienced hospitalization or involuntary treatment, I have been a mental health consumer at various points in my life. Since taking part in these interviews, I find myself straddling both identities. I suspect that this kind of potential boundary blurring may account for the hesitation on the part of many social workers to focus on their commonalities with consumer/survivor/ex-patients. There are risks associated with social workers revealing their own experiences in the mental health system. I have seen such disclosure lead to decisions against hiring, to a demotion from a management position following a colleague's hospitalization, and, in my own case, to extreme scrutiny of my job performance following my disclosure that I was being treated for depression. The stigma associated with "mental illness" is powerful, perhaps as much within the social work profession as without. Many of us hesitate to join with psychiatrically labeled people out of fear of risking professional stature and credibility among our peers and employers.

Hesitation exists on both sides. Unless, as social workers, we are fully identified as members of the C/S/X community, we must build our relationships with consumer/survivors carefully through trust and respect, acknowledging and exploring our similarities and differences. Not surprisingly, this parallels how we can work most effectively with members of other oppressed populations, seeing them

as experts in their own lives and confident about their abilities and strengths (Breton, 1994; Cohen, 1998; Saleeby, 2002). We need to trust consumer/survivor/ex-patients to be able to choose their own goals and tap into our skills and expertise where necessary. People who have been psychiatrically labeled have experienced great harm from mental health professionals, and we need to take the time for them to experience us differently, thus helping to close the "us" and "them" gap.

My own experiences working as an ally in this movement have been very positive. I have become part of the community at the consumer-run mental health center, and feel honored by this. The participants in the C/S/X movement whom I approached to participate in this narrative project agreed readily, presumably trusting my motives in wanting to give voice to their stories. My earlier experiences talking with homeless and other poor people was very similar (Cohen, 1998). Oppressed people seem to have a keen ability to distinguish between those whose interests lie in equal partnerships and those whose perspectives are clouded by motives of power and control; their survival depends on it.

Closing Thoughts

A few themes begin to emerge from these narratives, including the dehumanizing effects of involuntary treatment and the importance of self-determination. There is a close parallel between the C/S/X movement and other contemporary social movements that emphasize social justice and the civil rights of marginalized groups (Chamberlin, 1995). Historically, as the militancy of the 1960s and 1970s began to ebb, some of the more incremental demands of these movements were met, at the potential cost of co-opting or absorbing the movements' more radical demands.

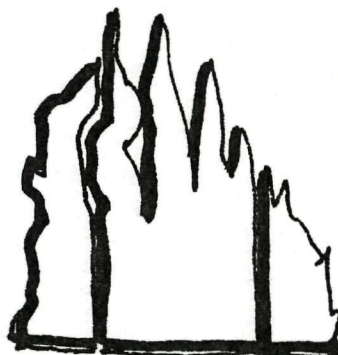Most states have some infrastructure for consumer input into mental health services, but this voice has tended to be a muted one. The C/S/X movement has had its impact, at least at the local level, in states that took the mandate to include consumer input seriously. There are still pockets of political resistance in areas where campaigns against the use of restraints, seclusion, and the lack of informed consent continue. The sometimes fragmented and hidden nature of the movement should not mislead us into thinking that this movement is small or easily dismissed. There is a network in the United States, and internationally, that connects many of these regional pockets, however loosely. Support Coalition International, for example, is an international umbrella group with over a hundred sponsors and thousands of members, including many social work allies (*Mind Freedom Journal*, 2003). It publicizes mental health abuses and civil disobedience responses via its website (*Mind Freedom* website), extensive email lists, and the *Mind Freedom Journal*. Moreover, although even the broader disabilities movement has been described as relatively invisible (Shapiro, 1994), the potential for cross-disability organizing and work with professional and non-professional allies seem promising. As a number of the individuals interviewed noted, we may not have changed the system, but the system now knows we are here and we will continue to insist on having a voice in what happens to us.

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